EXPLORING THE ETHICAL DIMENSIONS OF HOSPICE CARE
IN NURSING HOMES

BY

TIMOTHY M CORBETT

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Approved By:

John C Moskop, PhD, Advisor

Nancy M P King, JD, Chair

Laura C Hanson, MD

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ABSTRACT

Each year in the United States approximately a quarter to a third of the deaths of older adults occur in nursing homes (US Census Bureau, 2010). These statistics indicate that nursing homes are vitally important in providing end-of-life care to our oldest frail adults in their final days. Hospice care is seen as the gold standard of end-of-life care in many settings, and studies support its benefits for nursing home residents as well. Available evidence suggests, however, that many nursing homes are not meeting even basic needs of their residents or expectations of residents' families at the end of life (Munn et al., 2006; Murphy et al., 1997).

In this thesis, I will argue that the problem of poor end-of-life care for nursing home residents is rooted in a fundamental difference between the philosophies of hospice care and nursing home care. To present and defend my position, I will examine three essential questions:

1. What are the philosophies of both hospice care and nursing home care?
2. Should these two philosophies of care work together, and if so, why?
3. How should these two philosophies of care become more harmonious?

CHAPTER 1

INTRODUCTION

Each year in the United States approximately a quarter of the deaths of older

adults occur in nursing homes, and in some states up to a third occur there (US Census

Bureau, 2010; Miller, Tino, & Mor, 2004). Moreover, mortality rates range from 34% in

the first year of residence in a nursing home, to 24% thereafter (Kiely & Flacker, 2003).

Altogether, approximately a third of older adults who enter a nursing home will die there

(Hanson, Henderson, & Rogman, 1999). These rates are even higher for people with

dementia; 67% of cognitively impaired older adults will die in a long-term care setting

(Mitchell, Morris, Parks, & Fries, 2004; Mitchell, Teno, Miller, & Mor, 2005).

Before I proceed, I believe some clarification of the definitions of key terms is

warranted. Additionally, a word of caution is necessary since there does not appear to be

any formal consensus regarding these definitions, and therefore the terms are often used

interchangeably. For the purposes of this thesis, however, when I refer to long-term care

I am referring to care that is provide in either an assisted living facility or a nursing home.

Assisted living facilities provide care for those who require assistance with their

instrumental activities of daily living (iADLs), which include managing finances,

transportation, taking medications, meal preparation, housework, shopping, and

communication. Nursing homes provide care for those who require assistance with their

activities of daily living (ADLs), which include ambulation, toileting, bathing, dressing,

grooming, and feeding. Nursing homes are further subdivided into nursing facilities

(NFs) and skilled nursing facilities (SNFs). Nursing facilities provide only custodial care

that includes assistance with ADLs. Skilled nursing facilities also provide skilled care.

Skilled care refers to health care provided by a registered nurse (RN) and therapy staff to treat, manage, observe and evaluate the resident's care. For example, administering intravenous injections of medications and providing physical therapy would both be skilled care. I have decided to focus on residents in nursing homes because they are the most frail and therefore the most likely to require hospice care.

As surprising as the mortality rate in nursing homes is today, it is expected to increase significantly as the number of older adults in the United States doubles by the year 2030. Furthermore, by 2050 the number of US residents over 65 will have increased five-fold to 88.5 million. Within this older adult population, the fastest growing segment are those 85 years of age and older (US Census Bureau, 2010). Coincidentally, this is the group most likely to require nursing home care. These statistics indicate that nursing homes are and will continue to be vitally important in providing end-of-life care to our oldest frail adults in their final days (Munn et al., 2008).

Hospice care is seen as the gold standard of end-of-life care in many settings, and studies support its benefits for nursing home residents. However, collaboration between hospice and nursing home providers varies substantially. Moreover, some evidence suggests that many nursing homes are not meeting even basic needs of their residents or expectations of residents' families at the end of life. For example, it has been reported that many residents die with inadequate symptom management, personal hygiene, and emotional and spiritual care (Munn, Hanson, Zimmerman, Sloane, & Mitchell, 2006; Murphy, Hanrahan, & Luchins, 1997).

In this thesis, I will argue that the problem of poor end-of-life care for nursing home residents is rooted in a fundamental difference between the philosophies of hospice care and nursing home care. To present and defend my position, I will examine three essential questions:

1. What are the philosophies of both hospice care and nursing home care? How are these philosophies of care similar and different?

2. Should these two philosophies of care work together and if so, why?

3. How should these two philosophies of care become more harmonious?

In chapter 1 of my thesis, I will delve deeply into both of these philosophies of care, and I will explore their similarities and differences. In what is perhaps her clearest and most direct writing on the philosophy of hospice care, Dame Cicely Saunders outlined thirteen general principles (Saunders, 1978; Saunders, 1979). These can be further condensed into four philosophical concepts: (1) dying is an experience filled with meaning; (2) care of dying patients should be family-centered; (3) relief of total suffering should be paramount; and (4) maximizing patient integrity and sense of self is essential to finding and creating meaning until the last moment of death (Kirk & Jennings, 2014).

Nursing homes represent the most institutional and highly regulated long-term care setting. As a result of this history, a nursing home philosophy of care can be drawn from regulations implemented under both the Social Security Act and the Omnibus Budget Reconciliation Act (OBRA). OBRA and the Department of Health and Human Services (DHHS) intended to improve the quality of care and quality of life of nursing home residents by maximizing their independence and function, concurrent with focusing

on curative and restorative models of medical care (Department of Health and Human Services, 1989). Therefore, the primary goals and defining elements of the moral practice of nursing home care, as I interpret them, are: (1) maximizing functional independence and quality of life via preventive, curative, and restorative models of care; and (2) providing care of residents in a home-like setting in order to foster autonomy and privacy. In this chapter, I will argue that the primary goals of these two types of care are different, but that there are also significant areas of overlap.

In chapter 2, I will contend that these philosophies should be more congruent and explain why. While there is less research on dying in nursing homes than in acute care hospitals or at home, some studies do exist. Studies of nursing homes that do not recognize hospice care reveal poor care provided by untrained staff, resulting in unrelieved pain, family dissatisfaction, and unnecessary hospitalizations (Miller et al., 2004). Furthermore, evidence also indicates that individuals who receive hospice care while dying in nursing homes have better outcomes (Hallenbeck, Hickey, Czarnowski, Lehner, & Periyakoil, 2007). I will explore these and other studies, both empirical and theoretical, to make the case for a shared model of care based on an integrated philosophy of care.

In chapter 3, I will assert that the philosophies of hospice care and of nursing home care can become more harmonious and begin to explore ways in which this can occur. The new nursing home philosophy of care that I will propose has the following four guiding principles:

1. Optimizing functional independence and quality of life via preventive, curative, restorative, and palliative components of comprehensive care along the continuum of the resident's life should be paramount.

2. Care of the frail elderly should be provided in a home-like setting in order to foster autonomy and privacy.

3. Maximizing patient integrity and sense of self is essential to finding and creating meaning while aging until death.

4. Care of frail elderly should be both patient and family-centered.

The remaining question I will examine is how nursing homes can effectively implement an integrated philosophy of care and address moral issues they will confront in doing so. In this final chapter, I will explore ways in which this should occur. I will begin by outlining some main areas of potential ethical conflict between the two philosophies of care. Then, I will propose a model of ethical support and consultation that might mitigate these ethical issues and so achieve the goal of better care for residents in nursing homes at the end of life.

I believe that this thesis will serve as a platform for launching further scholarly examination of the relationship of hospice care and nursing home care. The goal of these efforts is to improve substantially the quality of care of older adults nearing the end of their lives in the nursing home setting.

CHAPTER 2

HOSPICE CARE AND NURSING HOME CARE: HISTORY AND

PHILOSOPHY

Introduction

I maintain that the core issue with poor end-of-life care in nursing homes stems

from the inherent difference in its philosophy of care from that of hospice services. The

philosophies of these two kinds of health care facilities also have some similarities, but

their similarities are easily overshadowed by their differences. As a result, it is pertinent

to spend some time analyzing both hospice and nursing home philosophies of care. In

doing so, I will begin with a discussion of the concept of a moral practice followed by a

review of the historical evolution of hospice and nursing home care, which has essentially

shaped their core values and subsequent philosophies. Lastly, I will explore the

similarities and differences in their care philosophies.

Moral Practice

I assert that both hospice care and nursing home care are types of moral practice

with well-defined goals and values internal to themselves. Both types of care are also

situated in a larger society, and therefore their internal values interact with a broader set

of social values. What I will employ here is the special sense of 'practice' that

philosopher Alasdair MacIntyre has proposed. He defines it as follows:

By a practice I am going to mean a coherent and complex form of socially

established cooperative human activity through which human goods internal to

that form of activity are realized in the course of trying to achieve those standards

of excellence which are appropriate to, and definitive of, that form of activity,

with the result that human powers to achieve excellence, and human conceptions

of the ends and goods involved, are systematically extended. (MacIntyre, 1981,

p. 30)

In other words, a moral practice is an activity in which people work together using specific skills and methods toward a shared goal. Furthermore, the goal itself is good for both those who achieve it and for society at large. Additionally, the habits and character traits one develops in working to achieve the goal are also considered good for both the practice and the society at large (MacIntyre, 1981).

For example, we often speak of medicine as a practice. While we may not have Macintyre's formal sense of 'practice' in mind when we do so, medicine does fit his formal definition. It is a cooperative endeavor that requires the development of specialized skills and the development of certain character traits to engage patients therapeutically and to deliver quality care. It has a set of "internal goods" (abilities, values, and goals) required to achieve and measure "good" medical care. Additionally, that set of internal goods is consistent with, and contributes to, a set of "external goods" in society at large. The habits and traits one develops in becoming a good physician are consistent with being a good person in general, and the goals of medicine (maintenance and restoration of health, engaging patients in self-care, teaching preventive practices that promote wellness, and so on) promote the larger goals of a thriving society. To know which values, character traits, actions, and decisions constitute "good" medicine, one must have a solid understanding of the defining core philosophical concepts of medicine

as a practice. Practices that are consistent with its philosophy are considered "good" or "right." Those inconsistent with, or that violate its philosophy, are "poor" or "wrong" (Sellman, 2011). In the rest of this chapter, I will describe the historical evolution and the core philosophical concepts of the practices of nursing home care and hospice care to reveal their differences and similarities.

<u>History of Hospice Care</u>

Hospice derives from the Latin word *hospes*, referring to both guests and hosts. In the early 14th century, the order of the Knights Hospitaller of St. John of Jerusalem opened the first hospice in Rhodes. It was meant to provide refuge for travelers and care for the ill and dying. Hospices thrived throughout the Middle Ages, but declined around 1500 until their revival in the 17th century in by the Daughters of Charity of Saint Vincent de Paul in France (Connor, 1998; Robbins, 1983). While France continued to see development in the hospice field during the 1800s, other nations, including the United Kingdom, also began to give attention to the needs of the terminally ill. In response to reports pointing to the need for good care and sanitary conditions for the impoverished terminally ill, the English government took steps to remedy inadequate facilities (Lewis, 2007).

Dame Cicely Saunders is acknowledged as the founder of the modern international hospice movement. Her commitment to the care of the terminally ill evolved from her work at St. Luke's Home for the Dying Poor and St. Joseph's Hospice, initially as a registered nurse, then as a social worker, and finally as a physician. She was the first to identify the interaction of physical, psychosocial and spiritual suffering in the

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dying. This concept of total pain and total suffering challenged the dualism of body and mind underlying medicine at that time. Moreover, her philosophy challenged several aspects of the then-current hospice philosophy. That philosophy had evolved out of Christianity during medieval times; it emphasized spiritual support, devoted physical care on the part of the staff, and stoicism on the part of the patient (Kerr, 1993; Lamberton, 1980). As a result, hospices at that time functioned outside of the regular health system with very little medical input. Saunders believed that her concept of hospice care, which had evolved through her experience and research, would allow symptom-free patients the ability to pursue the meaning of their terminal situation and ultimately come to terms with their approaching death.

In the late 1950s, Saunders began corresponding with American leaders in cancer care about the "cancer problem" in the United States. This "cancer problem" referred to the suboptimal care of cancer patients, which eventually led to their poor end-of-life care and subsequent painful death. Several studies revealed that more than 60% of deaths in the United States were caused by cancer (Backer, Hannon, & Russell 1982; Lerner, 1970). Even more troubling was that additional research showed that communication about prognosis was virtually nonexistent and patients often died in an isolated room, in pain and alone (Duff & Hollingshead, 1968; Glaser & Strauss, 1965). These practices took a heavy toll on patients. In one study, more than 50% of hospitalized patients expressed fear and anxiety related to the lack of response from physicians and nurses to their concerns. Furthermore, patients reported overhearing staff talking in the halls about other patients, often with graphic detail regarding the horrors of disease (Duff & Hollingshead, 1968). As a result of this correspondence, in 1963, Saunders made her

first visit to the United States to give lectures at the Yale School of Nursing describing her work at St. Joseph's Hospice (Saunders, 1966). Florence Wald, who was then the dean of the Yale School of Nursing, was herself an idealist, and she found Saunders' hospice concept very appealing. In 1968, Wald stepped down as dean in order to commit her efforts to transplanting Saunders's vision of hospice in America, and she founded Hospice Inc. in 1971 (Wald, 1986).

While Wald and Hospice Inc.'s collective idealism fueled their efforts, pragmatic issues such as funding and structure soon became paramount. They needed to describe hospice more specifically as a patient care model that was distinctly different from care in nursing homes and hospitals, so they would not be seen as duplicating services or competing with existing programs. This lead to the development of four principles of hospice care. First, hospice would be a "total community" that included staff, patients, and their families. Care would be directed by the expressed desires of the patient and family. Second, the hospice facility would be physically structured to maximize socialization and community while respecting privacy and autonomy. Third, professional roles would be blurred to facilitate team interdependence. Nurses would serve as the hub since they were to be omnipresent and be ultimately responsible for coordinating patient care. Fourth, spirituality would play a key role in hospice care, whether implicit or explicit (Hospice, Inc., 1971).

Over the next 10 years, hospices were funded via various grants, but it soon became clear that stable reimbursement streams would be critical to the viability of the hospice movement. In July 1982, despite intense lobbying by hospitals, home health organizations, nursing homes, and insurance companies that opposed the bill, Congress

enacted the Medicare hospice benefit. The benefit set capitated payment rates for hospice services and imposed eligibility criteria that required patients to be in the last 6 months of life, to abandon all intensive treatment, and to forfeit traditional Medicare benefits. While many celebrated, the Medicare hospice benefit was not the panacea some had hoped for. It did increase access and enrolment, but regulations, such as capitated payments and eligibility criteria, essentially required patients to forgo curative treatment and accept their impending death. This resulted in later hospice referral and decreased length of stay in hospice care. Furthermore, it left the physician with the difficult task of predicting accurately that death would occur within 6 months.

As hospice leaders advocated for increased per diem reimbursement rates and liberalization of benefit eligibility criteria, divisions emerged regarding hospice care. On the one hand, there were advocates, mostly clinicians, of less rigid eligibility criteria, coverage for treatment of coexisting conditions, and higher capitation rates. On the other hand, there were advocates, mostly politicians, of the exact opposite, in order to limit the cost of hospice care. This division coincided with the rapid emergence of the professional specialty organizations in hospice and palliative care medicine and nursing, in an effort to balance the power within the political arena and redirect hospice philosophy towards Saunders' original doctrine. (Buck, 2007a; Buck, 2007b; Buck, 2010).

<u>Hospice Care Philosophy</u>

In what is likely her most refined writing on the philosophy of hospice care, Dame Cicely Saunders outlined three general principles that should guide hospice care: (1) understanding control of the common symptoms of terminal disease, especially pain

in all its aspects; (2) recognition of the patient and family as the unit of care; and (3) commitment to and search for meaning (Saunders, 1978; Saunders, 1979). These are statements regarding the nature and moral significance of personhood, suffering, and dying. Kirk asserts, and I agree, that these general principles can be derived from four core philosophical claims: (1) relief of total suffering should be paramount; (2) care of dying patients should be family-centered; (3) dying is an experience filled with meaning; and (4) maximizing patient integrity and sense of self is essential to finding and creating meaning until death (Kirk & Jennings, 2014).

Similar to how the experience of dying affects the whole person, pain and suffering is equally holistic. In Saunders's concept of total pain and suffering, her intent was to describe not only a bodily phenomenon, but one that also has emotional, spiritual, psychological, relational, and intellectual effects (Saunders, 1978; Saunders, 1979). Ultimately, Saunders observes, pain and suffering can permeate the totality of one's existence. Addressing such total pain and suffering effectively meant finding ways to intervene in patients' lives that diminished the overall level of suffering experienced by the patient. In order to accomplish this, clinicians must engage patients as experiencing persons, not just as medically complex physiologic organisms. Only by engaging patients at this level of experience, where they interact with others, experience meaning, and develop feelings about their world, can clinicians relieve total suffering and pain (Clark, 2000).

Hospice care emphasizes that dying is not just a biological process, but rather an experience involving all the different elements of an individual's personhood, including emotional life, spiritual life, professional life, and many others. Additionally, the dying

experience is a meaningful one both for individuals and their loved ones. For example, the focus in hospice care of dying in one's home or a home-like environment, surrounded by loved ones, rather than isolated in the hospital, enables dying to be a shared experience. Being surrounded by loved ones in a familiar and comfortable environment can enable the dying person to create and find meaning at the end of life. Furthermore, since our identity as individuals emerges and develops in the context of personal relationships with loved ones, those relationships enable us to create and discover meaning throughout our lives. Therefore, it makes sense that hospice care would seek to encourage and support relationships with loved ones during the dying process. Just as the home gives individuals the benefit of leaning on their familiar surroundings, so does allowing care to be delivered through an already existing family structure promote support through personal relationships that have already been established (Kirk & Jennings, 2014).

The final core philosophical concept informing hospice care lies in delivering care that supports patients so they can live with the integrity and sense of self required to find and create meaning until death. Saunders conceptualized this as preserving moral agency: supporting patients so that they can continue to explore and express who they are and to live in a manner that honors what they hold most valuable and meaningful until death. Saunders believed it was possible for medical treatment to impede and violate a patient's sense of self, thereby compromising his or her moral agency. Saunders speaks directly to supporting moral agency and honoring patient preferences in the following passage:

Continuity of care for people suffering from persistent cancer aims to ensure that
throughout the whole course of the disease they receive treatment appropriate to
each stage and that, as far as possible, this is carried out in the place that accords
best with their own way of life and its commitments. We owe our patients the
attempt to decide when our management has finally turned into care for their
dying, even though this may be a difficult moment to identify. We define it as
occurring when all active treatments only hold out diminishing returns coupled
with increasing morbidity, when the incidence of side effects or the management
required by the treatment itself serve only to isolate the patient from those around
him and hinder him from completing life in his way. (Saunders, 1979, p. 636)

Here, then, are the goals and defining elements of the moral practice of hospice
care that create the space in which normative value takes shape and concrete ethical
values can become clearer. Intentions, decisions, and actions that embrace and promote
these core components of hospice philosophy are then ethically sound. It is under these
conditions that good hospice practice thrives. Conversely, those that inhibit the
actualization of the goals and values of hospice care are morally suspect, and in such
conditions good hospice practice fails to thrive. Consistent with the idea of "practice"
explained earlier, Saunders believed that the defining elements of good hospice care,
which constitute the hospice philosophy, were embedded in a larger vision of the good
life in general.

History of Nursing Home Care

The first nursing homes appeared around 324-337 A.D., when Emperor Constantine's wife Helena developed a series of homes, referred to as gerocomeia, to take care of the infirm elderly. From these beginnings, care for the infirm and the elderly were predominantly provided by the Catholic Church and associated with monasteries. In England, after the split of the Roman Catholic and Anglican Churches, the care of the poor, sick, and aged became the responsibility of parishes under the English Poor Law of 1601. This led to the building of poorhouses and almshouses that eventually evolved into nursing homes. For several centuries in Europe and the United States, if you were elderly and in need but did not have children or independent wealth, the poorhouse was your only refuge (Morley, 2013).

In the early 1850s, both Catholic nuns and the Jewish community also began to develop almshouses or poorhouses. By the early 1900s, reports surfaced within the United States describing poorhouses as unfit housing where the elderly died untended, received inadequate nutrition and care, and contracted tuberculosis from uncontrolled contagion. In 1935, with the passage of the Social Security Act, the United States joined Europe in creating a national pension system, hoping this would end poorhouses. However, the number of elderly in poorhouses did not decrease. It turned out that the reason older people ended up in poorhouses was not just financial. Most were there because they were too frail to take care of themselves and had nowhere else to turn (Haber & Gratton, 1993; Illinois, 1912; Virginia, 1909).

When hospitals emerged in the early 1950s as a major venue for the provision of health care, they became an attractive place for care of the frail and ultimately led to the emptying out of poorhouses. However, hospitals soon realized they could not cure the

debilities of chronic illness and old age, and they began to fill up with elderly who had nowhere else to turn. In 1954, Congress enacted the Hill-Burton Act (also known as the Hospital Survey and Construction Act). This law provided federal funding for community hospital construction and allowed hospitals to include custodial care as one of their services for patients requiring an extended period of recovery. This ultimately led to the birth of the modern day nursing home. The initial intent was not to provide a place of care for the elderly debilitated patient, but rather to empty hospital beds, which is why they were called nursing homes.

After their establishment in 1965, the Medicare and Medicaid health insurance programs paid for nursing home care in facilities that met basic health and safety standards. However, policy makers began to fear that hospital-managed nursing homes might begin to turn away Medicare patients. As a result, the Bureau of Heath Insurance invented the concept of substantial compliance. It asserted that if the nursing home came close to meeting the standards and aimed to improve, it would be approved. This led to an explosion of new nursing homes. All claimed substantial compliance, but most did not meet even minimum federal standards. Eventually, reports of neglect and mistreatment erupted across the country (Chung, 2012; Vladeck, 1980).

In 1987, President Reagan signed into law the Omnibus Reconciliation Act of 1987 (OBRA '87), which included the first major revision of federal standards for nursing home care since the 1965 creation of both Medicare and Medicaid. This landmark legislation forever changed society's legal expectations of nursing homes and their care. Under the new federal standards, nursing home facilities receiving Medicare or Medicaid funding were required to provide services so that each resident could attain

and maintain his or her highest practicable level of physical, mental, and psychosocial well-being. It created a set of national minimum standards of care and rights for individuals living in certified nursing facilities. These minimum federal health care requirements for nursing homes were to be delivered through adoption of a variety of established protocols within nursing homes. Nursing home Ombudsmen were to view OBRA standards as a baseline that should be built upon to reach not only resident well-being, but also happiness and fulfillment.

The changes that OBRA '87 brought to nursing home care were immense. Some of the most important provisions included:

- Emphasis on residents' quality of life as well as quality of care;

- Maintaining or improving each resident's ability to walk, bathe, and perform other activities of daily living absent medical reasons;

- Resident assessment and development of an individualized care plan;

- Right to organize and participate in a resident or family council;

- Right to be free of unnecessary and inappropriate physical and chemical restraints;

Although there is nothing in the literature that explicitly delineates core principles of nursing home care, these provisions provide important clues about its central values and goals of care. I suggest that those central values and goals are twofold: (1) maximizing functional independence and quality of life via preventive, curative, and restorative models of care should be paramount; and (2) care of the frail should be provided in a home-like setting in order to foster autonomy and privacy.

In summary, OBRA '87 expressed the intent of Congress, which authorized the Department of Health and Human Services (DHHS) to develop enabling regulations. The intent was to improve the quality of care and quality of life of nursing home residents by maximizing their independence and function, focusing on curative and restorative models of medical care (Department of Health and Human Services, 1989). OBRA '87 authorized federal protocols that require screening assessments and care plans to determine provision of services within nursing homes. The Minimum Data Set (MDS) is such an assessment tool that contains indicators for maintaining and improving resident function. Furthermore, the MDS is used to determine quality of care and to enable nursing homes to qualify for Medicare reimbursement (Centers for Medicare and Medicaid Services, 2010). Unfortunately, these indicators focus on maintaining and improving function, which are not good indicators for optimal end-of-life care. The newest version, MDS 3.0, introduced in 2011, includes some items relevant to hospice care (i.e. pain and shortness of breath), but these items are limited in scope (Centers for Medicare and Medicaid Services, 2011).

<center>Nursing Home Care Philosophy</center>

The current nursing home philosophy of care has been drawn from both the Social Security Act and the Omnibus Budget Reconciliation Act (OBRA). As such, it should come as no surprise that nursing homes are criticized for their governmental and institutional-provider-driven philosophy of care. As a result of specific regulatory standards, nursing home administration is consumed with matters like avoiding weight loss, falls, infection, use of psychoactive medications, and bedsores. These are certainly important healthcare goals, but are only means, not ends. For these reasons, controversy

continues in nursing homes over the priorities and values by which staff are supposed to practice, especially for residents with serious life-limiting illness. However, it would be too easy to place total blame on government regulations. The philosophy and goals of nursing home care are also products of our age-defying and death-denying culture. We live in a society that confronts the final phase of life by either trying to ignore it or doing everything possible to halt its progression. As such, we now have nursing homes that exist predominantly to address multiple societal goals, such as decreasing hospital readmissions and lengths of stay.

Here, again, are the primary goals and defining elements of the moral practice of nursing home care, as I see them: (1) maximizing functional independence and quality of life via preventive, curative, and restorative models of care should be paramount; and (2) care of the frail should be provided in a home-like setting in order to foster autonomy and privacy. Like the defining elements of the practice of hospice care, these also create the space in which normative value takes shape and concrete ethical values are clarified. These nursing home values and goals, and the practices that promote them, are morally defensible for some residents, but not for others. In particular, they are ill-suited for terminally ill nursing home residents for whom prevention or cure of their illnesses, functional independence, autonomous decision-making, and physical privacy are no longer realistic.

Nursing home residents in the final phase of their lives have different clinical and psychological needs than do other nursing home residents. As a result, nursing homes fall short in addressing what truly matters to a significant number of the people residing in them: how to make life worth living when they are frail and at the end of their lives.

Rather than focus on restoration or on prevention of physiologic decline, optimal care of terminally ill nursing home residents requires a focus on palliation – on the management of their terminal decline and associated symptoms (Keay et al., 1994; Rutman, 1992). To provide appropriate care for these nursing home patients, facility leaders bear moral responsibility to depart from the predominant model of nursing home care to encourage decisions and actions that address care needs at the end of life.

<u>Similarities and Differences in Care Philosophy</u>

In conclusion, the four core philosophical claims of hospice care include: (1) relief of total suffering should be paramount; (2) care of dying patients should be family-centered; (3) dying is an experience filled with meaning; and (4) maximizing patient integrity and sense of self is essential to finding and creating meaning until death. These concepts are derived from beliefs about the nature and moral significance of personhood, suffering, and dying. The two core philosophical claims of nursing home care include: (1) maximizing functional independence and quality of life via preventive, curative, and restorative models of care should be paramount; and (2) care of the frail should be provided in a home-like setting in order to foster autonomy and privacy. These concepts are derived from different beliefs about the nature and moral significance of personhood and aging. Both types of care assert the importance of these concepts and in so doing build their respective goals of care around them, ultimately constituting their philosophy of care. While these hospice care and nursing home care philosophies overlap with respect to promoting autonomy and moral agency, they remain very different at their core. Ultimately, hospice care aims to provide optimal end-of-life care while nursing home care aims to provide optimal preventive, curative, and restorative care.

I realize that given the historical evolution of nursing homes from a place where the poor and sick were often abandoned to die, there exists a justified fear that recommending palliative care and forgoing life-prolonging measures may be perceived as imposing a duty to die. I also understand that laws and regulations are in place to protect this vulnerable population from neglect, and that may be the reason why nursing homes emphasize preventive, curative, and restorative care. I adamantly disagree, however, that this fear justifies the exclusion of palliative care from nursing homes. In fact, I find that continuing to provide certain kinds of preventive, curative, and restorative care, while ignoring opportunities for palliative care, often directly undermines the integrity and sense of self required to find and create meaning until the final moment of life. I contend that it is at this crossroads where most ethical issues and moral distress surface when providing hospice care within the nursing home.

Therefore, in order to mitigate these ethical issues, in the subsequent chapters of this thesis I will propose a revised philosophy of nursing home care that incorporates the core philosophical concepts of hospice care. I will argue that the new nursing home philosophy of care should include: (1) optimizing functional independence and quality of life via preventive, curative, restorative, and palliative components of comprehensive care along the continuum of the resident's life should be paramount; (2) care of the frail elderly should be provided in a home-like setting in order to foster autonomy and privacy; (3) maximizing patient integrity and sense of self is essential to finding and creating meaning while aging until death; and (4) care of frail elderly should be both patient and family-centered. In the following chapters I will explain why key elements of

hospice care philosophy should be integrated within nursing home care philosophy and then finally, how this integration should occur.

CHAPTER 3

THE CASE FOR AN INTEGRATED PHILOSOPHY OF CARE

<u>Narrative</u>

Mr. Boyd was a 94-year old-gentleman with Myelodysplastic Syndrome (MDS), a malignancy characterized by dysplastic and ineffective blood cell production with variable risk of transformation to acute leukemia. Patients with MDS have both a quantitative and qualitative defect in red blood cells and platelets. These abnormalities often result in a variety of systemic consequences, including anemia, bleeding, and an increased risk of infection. MDS occurs most commonly in older adults with a median age at diagnosis in most series of ≥65 years and a male predominance. The precise incidence of MDS is not known; conservative estimates from cancer databases suggest that there are approximately 10,000 new cases diagnosed annually in the United States. Anemia is the most common presenting symptom and can manifest as fatigue, weakness, exercise intolerance, angina, dizziness, cognitive impairment, or an altered sense of well-being. Often these patients become transfusion dependent, leaving families with the distressing decision of when to discontinue transfusions.

Mr. Boyd was diagnosed with MDS several years prior to our meeting. By the time I assumed his care he had exhausted all chemotherapy options and was receiving blood transfusions approximately every two months. This was usually frequent enough to prevent symptoms of fatigue, shortness of breath, and chest pain. Over the next eight months, however, his frequency of transfusions increased to monthly, followed by every other week, and then finally weekly. Over this time period Mr. Boyd required multiple hospitalizations and became very frail. During the weeks to months leading up to his

death, hospice services could have been instrumental in his care. They could have assisted with communication, spiritual support, and pain and symptom management. Unfortunately, however, they were not involved.

Early one morning in the winter of 2014, Mr. Boyd had a fall while alone in his apartment at Homeridge Village, the assisted living facility where he has resided for seven years. He was not found until many hours later when he failed to join others for breakfast at a dining room in the facility. He was later discovered laid out beside his leather recliner, nearly unconscious and very confused. His son was contacted and EMS was immediately called for transport to the local hospital. There the medical team gave him intravenous fluids and a series of tests and X-rays. They found no broken bones or head injury, but they noted an alarmingly low hemoglobin. After receiving several units of blood, he returned to Homeridge Village in a wheelchair, where he was strongly encouraged to move to their skilled nursing unit. Despite his strong resistance, both staff and family felt this to be best option for him, and he grudgingly complied with their wishes.

Mr. Boyd, unfortunately, now required assistance with all of his everyday activities – using the toilet, bathing, and dressing. The hope was that with physical therapy, he would be able to walk again and then return to his apartment, but he never did. Over the next several months he sustained repeated falls and infections resulting in recurrent hospitalizations. Each time he returned to Homeridge Village more frail than the last. Eventually, Mr. Boyd was confined to either a bed or a chair due to progression of his weakness and fatigue. One day when his son Tim visited, Mr. Boyd leaned toward him and uttered four words. "I'm ready to go," he said. They looked at each other as

tears streamed down Tim's cheeks. "Okay, Dad," Tim said. Although heartbroken, he understood. He was ready to die. Afterward we all three sat together and completed a Medical Order for Scope of Treatment form to be put on record at the nursing home. If his heart or breathing stopped, the nursing home staff would not attempt to restart them. We would not do chest compressions, shock him, or put a breathing tube down his throat. We would not put him on artificial nutrition or hydration. Furthermore, we would no longer use antibiotics to treat infection, or transfer him to the hospital. We would keep him comfortable and let him go.

Several months passed, during which time Mr. Boyd became completely bedbound and developed pressure wounds resulting in pain. As he became more anemic he experienced worsening shortness of breath and confusion. Tim, worried about his father's progressive decline, inquired about hospice services. Sue, the nursing home director, replied, "We don't have a contract with any of the local hospices because we can provide just as good if not better care for our residents at the end of life." Over the next several weeks, Mr. Boyd continued to suffer from uncontrolled pain, shortness of breath, and anxiety. One evening Tim and I were at his bedside. His body tense, fists clinched tight, with labored breathing and furrowed brow he whimpered, "Help me." Tim was beside himself, and although both he and his father had strong spiritual beliefs and practices, we had no chaplain or counseling services to offer at Homeridge Village. Over the next several days we did the best we could to keep Mr. Boyd comfortable and to support Tim. Late one October night, with no family present, a bed alarm sounded and a nurse ran to his room. Mr. Boyd was found lying on the floor pulseless and breathless. He had died.

After receiving a call from one of the nurses notifying me of Mr. Boyd's death, I proceeded to call his son Tim. Needless to say, Tim was devastated. As he began to process this overwhelming information he yelled over the phone, "I don't understand." "Why was he on the floor?" "Was he still in pain?" "Why wasn't I called earlier?" "Did anyone know it was this close?" I apologized to Tim wholeheartedly and offered my condolences.

<div align="center">Introduction</div>

The above case narrative from my practice experience is just one example of a failure to provide effective palliative care to a nursing home resident near the end of life. Available evidence, however, suggests that this is not an isolated phenomenon. Each year in the United States approximately a quarter of the deaths of older adults occur in nursing homes, and in some states up to a third occur there (Miller et al., 2004; US Census Bureau, 2010). Moreover, mortality rates range from 34% in the first year of residence in a nursing home, to 24% thereafter (Kiely & Flacker, 2003). Altogether, approximately a third of older adults who enter a nursing home will die there (Hanson et al., 1999). These rates are even higher for people with dementia; 67% of cognitively impaired older adults will die in the nursing home setting (Mitchell et al., 2004; Mitchell et al., 2005). Furthermore, hospice utilization among nursing home residents is increasing. Rates of nursing home hospice use more than doubled from 14% of US nursing homes in 1999 to 33.1% in 2006 (Miller et al., 2010). Lastly, the majority of hospice care is provided in the place the patient calls "home". In 2014, 58.9% of all US hospice patients received care at home; for 14.5% of those patients, the "home" in which they received care was a nursing home (NHPCO, 2015).

As surprising as these numbers are, the overall number of nursing home residents and deaths among nursing home residents are expected to increase drastically, primarily because the number of older adults in the United States is projected to double between 2010 and 2030. Furthermore, between 2010 and 2050 the number of US residents over 65 will increase five-fold, to 88.5 million. Within this older adult population, the fastest growing segment is those 85 years of age and older (US Census Bureau, 2010). This is the group most likely to require nursing home care. These statistics indicate that nursing homes are and will continue to be vitally important in providing end-of-life care to our oldest and frailest adults in their final days (Munn et al., 2008).

Hospice care is seen as the gold standard of end-of-life care in many settings, but does evidence exist to support its benefits in the nursing home setting? Studies of nursing home environments that do not utilize hospice care reveal that residents who are near the end of life receive poor care provided by untrained staff, resulting in unrelieved pain, family dissatisfaction, and unnecessary hospitalizations (Miller et al., 2004). Moreover, some evidence suggests that many nursing homes are not meeting even basic needs of their residents or expectations of residents' families at the end of life. For example, it has been reported that many residents die with inadequate symptom management, personal hygiene, and emotional and spiritual care (Hanson et al., 2008; Munn et al., 2006; Murphy et al., 1997). Evidence also indicates that individuals who receive hospice care while dying in nursing homes have better outcomes (Baer and Hanson, 2000; Hallenbeck et al., 2007; Miller et al., 2004; Munn et al., 2006; Murphy et al., 1997). Therefore, in this chapter I plan to highlight the elements that are most important to patients, their families, and their health care team at the end of life. I will

then explain how these very same elements are imperative to providing good end-of-life care in nursing homes. Finally, I will demonstrate how this must inform and support a new integrated philosophy of care within nursing homes in order to provide better end-of-life care.

<div align="center">Quality of Dying and Quality of Care at End of Life</div>

First and most important is to determine what is paramount to patients nearing the end of life, their families, and their health care providers. It is through this lens that we can begin to assess the quality of end-of-life care in nursing homes. In 2000, Steinhauser et al conducted a national cross-sectional survey of seriously ill patients, bereaved family members, physicians, and other health care providers (nurses, social workers, chaplains and hospice volunteers). The results showed that a majority of all those four groups valued pain and symptom management, spiritual peace, communication with one's physician, a sense of completion, and following treatment preferences being the most important factors at the end of life (Steinhauser et al., 2000). Of note, these items are all addressed in Saunders's concepts of "total care" and "total suffering". As a result of this study and others with similar findings, efforts have been underway to determine optimal measures to assess end-of-life care and outcomes in nursing homes. This in turn will allow for a more reliable assessment of the care provided.

For example, Zimmerman et al. recently completed a study revealing the need to assess not only the quality of dying but also the quality of care in nursing home residents at the end of life. After evaluating 20 scales they found two measures that best evaluate care and two others that best evaluate outcomes. The two measures that evaluated care focused on families' perceptions of physician communication and whether the resident

received all the therapeutic interventions that they could have benefited from during the

dying process. The two measures that evaluated outcomes focused on family and staff

perceptions of symptom frequency and intensity during the dying process. All four of

these measures include the before-mentioned most valued factors at the end of life

highlighted in Steinhauser's article (Zimmerman et al., 2015). What remains unanswered

is whether hospice care in the nursing home setting helps attain these outcomes. We will

explore this question further as we review the scholarly literature surrounding this topic.

<div align="center">Pain and Symptoms of Distress</div>

It has been suggested that 45-80% of nursing home residents have substantial pain

(Ferrell, 1995; Hanson et al., 2008). Additional studies point to the high prevalence of

non-pain symptoms in older adults as well (Claessens et al., 2000; Hanson et al., 2008;

Levenson et al., 2000; Roth et al., 2000). Therefore, those older adults suffering from

life-limiting illness who reside in nursing homes are likely to benefit from improved pain

and symptom management at the end of life. The evidence base for treatment of pain and

symptoms in older adults at the end of life, however, is meager at best. The few studies

that do exist suggest that pain and other symptoms are under-assessed, undertreated, and

are associated with a number of negative outcomes in older adults. Below are two studies

that support to this claim, focusing more specifically on pain.

In 2002 and 2003, Miller et al. published a series of two studies comparing the

analgesic management of daily pain in nursing home residents with life-limiting illness

who were enrolled in hospice and not enrolled in hospice. They found that 15% of dying

hospice residents in daily pain received no analgesics, whereas 23% of dying non-hospice

residents in daily pain received no analgesics. Additionally, a higher proportion of the

hospice residents were prescribed opioids than were the non-hospice residents. Overall, the results of their 2002 study suggested that analgesic management of daily pain was better for nursing home residents enrolled in hospice than for those not enrolled in hospice (Miller et al., 2002). The results of her 2003 study, suggested that hospice enrollment for dying nursing home residents resulted in superior pain assessment and management during the last 48 hours of life. This may not be the case for those referred to hospice late, just prior to death, however, likely due to inadequate time for implementation of the new care plan. The latter study, therefore, suggests that not only hospice involvement but also early hospice enrollment are key factors in providing better pain management (Miller et al., 2003). Both Miller's 2002 and 2003 studies support the value-added benefit of providing timely hospice care to dying nursing home residents.

<div align="center">Spirituality: Sense of Meaning and Purpose</div>

There is a growing recognition of spiritual needs and heightened attention to the spiritual care of seriously ill dying patients and their families (Steinhauser et al., 2000). While there is a dearth of literature on the benefits of spiritual care in nursing home residents near the end of life, I believe we can draw an inference from related scholarly studies that highlight the benefits of addressing the spirituality of patients with serious life-limiting illness through hospice care. Other research studies emphasize the importance of spiritual care from the perspective of patients, their families and health care providers. I will begin by framing the discussion with a definition of spirituality and its implications in American society.

Spirituality is the way many individuals seek and express meaning in their lives. It is the way they experience their connectedness to self, to others, to the moment, and to

the sacred (Puchalski, 2009). Religion has historically been identified as an organized

system of beliefs, practices, and rituals designed to express spirituality. However, an

increasing number of Americans describe themselves as spiritual while simultaneously

reporting no particular religious affiliation (Health Care Chaplaincy, 2012; Newport,

2010).

Numerous studies have documented uncontrolled and increased levels of spiritual

suffering in patients with advanced life-limiting illness (Baer & Hanson, 2000; Desbiens

& Wu, 2000; Fitchett et al., 2004; Mako et al., 2006). Additionally, rates of spiritual

distress have been found to be very high among the elderly, regardless of the patient's

underlying illness (Hui et al., 2011; Murray et al., 2007; Yi et al., 2006). Furthermore,

spirituality not only plays a role in existential distress, but can also have an impact on the

patient's overall health. Spiritual distress has been associated with anxiety, depression,

and increased mortality (Johnson et al., 2011; Pargament et al., 2001). Conversely,

spiritual support has been associated with increased use of hospice, fewer burdensome

treatments, and better overall care at the end of life (Balboni et al., 2010; Daaleman et al.,

2008; Phelps et al., 2009).

Do patients, their families, and their health care providers recognize the

importance of spirituality, especially in the nursing home setting?   A study by Wallace

and O'Shea in 2007 investigated perceptions of spirituality and spiritual care among

nursing home residents at the end of life. They found that most residents rated

spirituality and spiritual care as highly important, supporting it as an essential framework

for life. Residents also reported several interventions that they wished staff would use to

support spirituality, including arranging visits with religious personnel, showing

kindness, spending time listening to residents, and showing respect for their spiritual needs. In conclusion, the study provided information that could be used to increase knowledge and improve spiritual interventions for nursing home residents at the end of life (Wallace & O'Shea, 2007).

A qualitative study conducted by Touhy in 2005 attempted to explore spiritual care for dying nursing home residents from the perspectives of registered nurses, certified nursing assistants, advanced practice nurses, and physicians. In this study, five major themes emerged: (1) honoring the person's dignity; (2) intimate knowing in the nursing home environment; (3) wishing they could do more; (4) personal knowing of self as caregiver; and (5) struggling with end-of-life treatment decisions. In essence, spiritual care was associated with deep personal relationships, holistic care, and support of residents. The study concluded that education and research about how to assist residents and families as they struggle with difficult end-of-life decisions, adequate time and staff to provide the type of care they "wished they could," and development of models that honor the close resident-staff relationship could enhance end-of-life care in the nursing home setting (Touhy, Brown, & Smith, 2005).

These studies illustrate a perceived need for spiritual care and its potential benefits for nursing home residents at the end of life. It also highlights the importance of Saunders's concept of "total care," which involves physical, psychological, social, and spiritual aspects of care. Fortunately, hospice care includes spiritual support and counseling as part of its routine services. Therefore, I believe this suggests the prospective value of attention to spiritual well-being that provision of hospice care in the nursing home setting could provide.

Communication: Prognosis and Treatment Preferences

While there is also a paucity of literature evaluating communication at the end of life in nursing home residents, there are some reasonable inferences that can be drawn from the existing scholarly literature. In this section, therefore, I will first consider evidence supporting the correlation between effective communication and improved end-of-life care. I will then review research that points out lack of communication in the nursing home setting and its association with residents' families' perceptions of poor quality of care at the end of life. Finally, I will explore the impact of hospice care in the nursing home on completion of advance directives and on hospitalization.

Communication and decision making have been found to be critical factors in achieving a "good death" (Tulsky, 2005). Furthermore, physician communication specifically is of central importance to quality end-of-life care. Interviews with patients nearing the end of life and their family caregivers in multiple health care settings reveal substantial need for improvements in physician-patient/caregiver communication (Curtis et al., 2001; Hanson, Danis, & Garrett, 1997; Shield et al., 2005; Steinhauser et al., 2000; Teno et al., 2004; Wenrich et al., 2001). Most prior studies of physician-patient/caregiver communication at the end of life have been conducted in the hospital or hospice setting. These studies have identified common themes in communication that correlate with better end-of-life care: (1) availability; (2) ability to listen and answer questions empathetically; (3) comfort in discussing death and dying; and (4) ability to explain the prognosis (McDonagh et al., 2004; Steinhauser et al., 2000; Wenrich et al., 2001). Effective communication is of such high importance at the end of life that most consider it a formal medical and psychosocial intervention that warrants further research, just like

any other medical intervention (Weiner et al., 2006). Communication interventions have been linked directly to patient outcomes including improved quality of life, mood, survival, and a preference for receiving less aggressive care at the end of life (Kirchhoff et al., 2010; Mohan et al., 2010). Communication interventions also are associated with family and surrogate outcomes such as improved understanding of the patient's goals and better caregiver psychosocial adjustment (Kirchhoff et al., 2010; Temel et al., 2010).

Although qualitative evidence of family dissatisfaction with physician-family caregiver communication in nursing homes is mounting, most data have been obtained from only a small sample of facilities. In those settings, however, it is apparent that physician and staff communication with residents and their families at the end of life is lacking. For instance, inadequate physician presence in nursing homes has been cited as a persistent issue and has been linked to problems with communication and decision-making of residents and family members (Biola, 2007; Hanson, Henderson, & Menon, 2002; Shield et al., 2005).

Furthermore, Resnick et al. demonstrated that nursing home residents not receiving hospice care completed advance directives substantially less often than those receiving hospice care (Resnick, 2009). Zheng et al. and Miller et al. have found that lower nursing home facility-level hospice penetration was associated with an increased risk of hospitalization at the end of life (Miller et al., 2001; Zheng et al., 2015).

These studies clearly illustrate the benefits of better communication in caring for nursing home residents at the end of life. Moreover, they highlight the synergy that can result from the presence of hospice care in the nursing home environment in enabling better communication.

Financial and Policy Implications

One of the main observed benefits of hospice care for nursing home residents has been a lower hospitalization rate. Non-hospice residents who died in nursing homes having a hospice presence have also been found to have lower rates of hospitalization at the end of life (Miller, Gonzalo, & Mor, 2001; Zheng et al., 2015). This decreased rate of hospitalization has two main implications. At the resident level, hospitalization of frail nursing home residents has been shown to include hazards that reduce quality of life, and in many cases these hospitalizations are inappropriate (Creditor, 1993; Saliba et al., 2000). At the policy level, hospitalizations represent the largest component of total health care costs, particularly during the last few months of life. For example, one study using both Medicare and Medicaid claims for nursing home decedents in the state of Florida found hospital expenditures to account on average for 78% of all expenditures in the last month of life among those patients who did not receive hospice and 33% among nursing home residents who had any hospice care in the last 30 days of life (Miller, 2004).

Another important benefit of good end-of-life care in the nursing home is in the reduction of burdensome health care transitions. A study by Gozalo et al. examined health care transitions among elderly cognitively and functionally impaired nursing home residents in the last 120 days of life. A burdensome transition was defined on the basis of a previously conducted analysis of narratives with families of residents who had died in the nursing home and with geriatricians and palliative care physicians. Three different types of transitions were identified as being burdensome: (1) any transfer in the last 3 days of life; (2) a lack of continuity in one's nursing home residence before and after

hospitalization in the last 90 days of life (i.e., going from nursing home A to the hospital then to nursing home B); and (3) multiple hospitalizations in the last 90 days of life. They found that, among 474,829 nursing home decedents, 19.0% had at least one burdensome transition. In adjusted analyses, those without an advance directive were at increased risk. Nursing home residents in regions in the highest quintile of burdensome transitions (as compared with those in the lowest quintile) were significantly more likely to have a feeding tube, to have spent time in an ICU in the last month of life, to have a stage IV decubitus ulcer, and to have had a late enrollment in hospice (Gozalo, 2011).

Less important but still notable are the numerous studies that have demonstrated that hospice use is associated with significant cost savings (Miller et al., 2002, 2004; Mor & Kidder, 1985; National Hospice Organization, 1995; Wu et al., 2003). One study estimated that nursing home hospice enrollment reduces government expenditures during the last month of life by 6% (Gozalo et al., 2008). In a more recent study, Gozalo et al. examine whether increased hospice use in the nursing home reduced overall end-of-life expenditures. They also looked at intensive care unit use in the last 90 days of life and, for residents with advanced dementia, feeding tube use and hospital transfers in the last 90 days of life. Of the 786,328 nursing home decedents studied, an increase in hospice use was associated with significant decreases in the rates of hospital transfers, feeding-tube use, and intensive care unit use. In this study, the growth in hospice care for nursing home residents was associated with less aggressive life-prolonging measures near death but at an overall increase in Medicare expenditures. This higher level of expenditures, however, is likely mainly due to increased enrollment and length of stay in hospice when

comparing nursing home residents in 2004 to 2009. It is not likely related to unnecessary or inappropriate utilization of health care resources (Gozalo, 2015).

<div align="center">Conclusion</div>

In this chapter, I have contended that a new philosophy of nursing home care must evolve to incorporate the core philosophical claims of hospice care and to optimize the quality of care near the end of life for nursing home residents. The new nursing home philosophy of care that I propose has the following four guiding principles:

1. Optimizing functional independence and quality of life via preventive, curative, restorative, and palliative components of comprehensive care along the continuum of the resident's life should be paramount.

2. Care of the frail elderly should be provided in a home-like setting in order to foster autonomy and privacy.

3. Maximizing patient integrity and sense of self is essential to finding and creating meaning while aging until death.

4. Care of frail elderly should be both patient and family-centered.

Central to this proposal is the incorporation of palliative models of care within the existing nursing home care philosophy. By 'palliative', I am referring to Saunders's concepts of "total care" and "total suffering," which include the physical, psychological, social, and spiritual aspects of care. Thus, the addition of palliative care to preventive, curative, and restorative components of care incorporates Saunders's model for end-of-life care. The three remaining principles are all equally as important. Providing care in a home-like setting places the patient in the driver's seat. It has always been my understanding throughout my training and practice that nursing homes are indeed home

for many older adults. As such, instead of patients we refer to them as residents. Before

we enter their rooms, we knock. We perform many other customs that uphold a home

environment. This ultimately creates a space for shared decision making when it comes

to residents' care.   In contrast, so many times in the hospital environment care is

mandated by the institution or dictated by the health care team, with little input from the

patients themselves. This often leaves patients feeling vulnerable and abandoned by the

larger medical system. I believe this to be mostly situational and subject to change based

on setting of care, which is why providing care in the home restores the appropriate

balance.

Optimizing integrity and sense of self refers to moral agency. This can occur as

we attend to aspects of the first and second principles. It is easy to imagine how our

high-tech but low-touch medical treatments can violate patient integrity and sense of self,

thereby compromising their moral agency. Maintaining the wholeness and integrity of

self ultimately allows the patient the opportunity to find and create meaning across the

entire dying experience. Finally, providing care that is both patient- and family-centered

recognizes that our identities as individuals have evolved in the context of intimate

relationships with loved ones. Those relationships provide the structural framing in

which we create and discover meaning throughout our lives. Therefore, it only makes

sense that we should include and support patients' loved ones in their care, because those

relationships constitute an ongoing influence in patient identity.

I maintain that these four principles can adequately address the above-mentioned

factors that patients, their families and their health care providers find to be imperative to

providing optimal care at the end of life. Addressing pain and symptoms relates directly

to the first principle, which incorporates palliative models of care. Addressing spirituality can be achieved through adhering to the third principle of maximizing integrity and sense of self. Providing ongoing communication regarding prognosis and treatment preferences is accomplished by upholding all principles but especially the fourth, providing patient and family-centered care. Lastly, financial and policy implications highlight potential harm caused through re-hospitalizations and subsequent burdensome transitions when we ignore the second principle, providing care in a home-like setting. While there is a dearth of research on dying in nursing home settings compared to dying in acute care hospitals or at home, some studies do exist. For areas where research is lacking, I have explained how it is reasonable to draw an inference from related scholarly studies which highlight the benefits of providing "total care" and addressing "total suffering" for patients with serious life-limiting illness. I have explored these and other studies, both empirical and theoretical, as I advocate for this new model of nursing home care which integrates hospice care philosophy.

In 2012 Jean Munn conducted interviews of focus groups containing nursing home residents, family caregivers of decedents, licensed staff caregivers, paraprofessional staff caregivers, and social workers. Two positive common themes emerged--hospice staff as experts in end-of-life care and hospice as beneficial to end-of-life care. However, two negative themes surfaced as well--the existence of substantial barriers to hospice involvement and to collaboration between hospice and nursing home staff. The most significant barriers reported included: (1) resident hesitancy to discuss end of life; (2) doctors' lack of availability and unwillingness to discuss terminal diagnoses; and (3) staff difficulty identifying residents appropriate for hospice care

(Munn, 2012). Resultant difficulties have led to both underuse of hospice in nursing homes and late referrals to hospice. Underuse of hospice contributes to suboptimal end-of-life care and fosters ethical dilemmas resulting in moral distress for all involved. Therefore, it is not surprising that nursing home staff request more education, more time in dealing with ethical decision making, and access to ethics consultation (Gjerberg et al., 2010). In the next chapter I will propose an operational model for how this new integrated philosophy of nursing home care might be implemented and evaluated in order to minimize ethical dilemmas in the care of nursing home residents at the end of life and ultimately lead to better care of these residents.

As for Mr. Boyd, I believe that he and his son would have received better care at the end of life under the new integrated philosophy of nursing home care that I have proposed. He would have avoided repeated hospitalizations and subsequent burdensome transitions between multiple settings of care that resulted in a more precipitous functional decline. He would have had better ongoing communication regarding prognosis and treatment preferences, resulting in improved shared decision making regarding his health care goals. Both he and his son would have had adequate spiritual support through the dying process to maintain greater integrity and sense of self. All together, these changes would have better supported moral agency of Mr. Boyd and his son and would have significantly improved their experience during his final days.

CHAPTER 4

IMPLEMENTING AN INTEGRATED PHILOSOPHY OF CARE

IN THE NURSING HOME SETTING

<u>Introduction</u>

In the first chapter of this thesis, I outlined widely held current philosophies of both hospice care and nursing home care. I argued that while these hospice care and nursing home care philosophies overlap with respect to promoting autonomy and moral agency, they remain very different at their core. Ultimately, hospice care aims to provide optimal end-of-life care while nursing home care aims to provide optimal preventive, curative, and restorative care. In fact, I asserted that continuing to provide certain types of preventive, curative, and restorative care, while ignoring opportunities for palliative care, often directly undermines the integrity and sense of self required to find and create meaning until the final moments of life. I argued that choices among these different types of care raise most ethical issues and cause moral distress when providing hospice care within the nursing home. Therefore, in order to address these ethical issues, I proposed a revised philosophy of nursing home care that incorporates core philosophical concepts of hospice care. The new nursing home philosophy of care that I proposed has the following four guiding principles:

1. Optimizing functional independence and quality of life via preventive, curative, restorative, and palliative components of comprehensive care along the continuum of the resident's life should be paramount.

2. Care of the frail elderly should be provided in a home-like setting in order to foster autonomy and privacy.

3. Maximizing patient integrity and sense of self is essential to finding and creating meaning while aging until death.

4. Care of frail elderly should be both patient and family-centered.

I further explained why this integration is paramount through a review of scholarly literature related to these topics. While there is a paucity of research on dying in nursing home settings, I argued that it is reasonable to draw inferences about end-of-life care in nursing homes from related scholarly studies which highlight the benefits of providing "total care" and addressing "total suffering" for patients with serious life-limiting illness. I appealed to both empirical and theoretical studies to provide evidence for this new integrated philosophy of nursing home care.

The remaining question I will examine is how nursing homes can effectively implement an integrated philosophy of care and address moral issues they will confront in doing so. In this final chapter, I will explore ways in which this should occur. I will begin by outlining some main areas of potential ethical conflict between the two philosophies of care. Then, I will propose an operational model that might mitigate these ethical issues and so achieve the goal of better care for residents in nursing homes at the end of life.

<u>Points of Ethical Conflict</u>

The areas of substantial overlap in the two philosophies of care, highlighted in the new proposed integrated nursing home philosophy of care, can promote synergy and

ultimately lead to better care of nursing home residents at the end of life. Before we can further address how a new operational model might accomplish this, we must first acknowledge issues that can lead to ethical conflict. As such I will describe four specific challenges that create ethical conflict in providing hospice care for nursing home residents:

1. There must be an invitation for hospice to come into the nursing home.

2. Eligible residents must be referred for hospice enrollment.

3. Once enrolled, the dying experience must be managed within the context of the nursing home.

4. Hospice and the nursing home must coordinate care.

I believe the first two challenges are primarily the responsibility of the nursing home. Conversely, hospice organizations bear the primary responsibility for addressing the latter two challenges. I will review each of these below in further detail.

1. Inviting Hospice into the Nursing Home

In order to make hospice care available to its residents, the nursing home must have a formal contract with a hospice organization (Miller et al., 2004). The decision of a nursing home to contract with a hospice provider is predicated on multiple factors. One such factor is a financial disincentive for nursing homes to provide hospice care for their residents. Hospice is funded by the Medicare Hospice Benefit within Medicare Part A (Miller et al., 2004). Medicare Part A also offers a post-acute rehabilitation benefit that reimburses rehabilitative skilled nursing home care after a hospital stay. Often, nursing home residents are left to choose between the two Medicare Part A benefits since one

cannot have both concurrently. Reimbursement is significantly higher through the post-acute rehabilitation benefit than through the hospice benefit, and the rehabilitation benefit is paid directly to the nursing home. Conversely, the hospice benefit is paid directly to the hospice organization, and the hospice then transfers finances to the nursing home, thus delaying nursing home reimbursement (Stevenson & Bramson, 2009). Furthermore, although the hospice benefit covers nursing care, social work, physician services, and physical therapy, it does not include room and board at the nursing home, unlike the post-acute rehabilitation benefit, which covers them all. For residents receiving hospice care, therefore, the nursing home must often continue to bill the resident or Medicaid for room and board, creating yet another complexity for provision of hospice care in nursing homes (Dobbs et al., 2006).

In addition to the financial considerations described above, the nursing home administration's attitude towards hospice care is another important factor affecting its willingness to contract with a hospice organization (Buchanan et al., 2004; Hanson et al., 2005). While nursing home administrators are generally positive toward hospice care, they view it, at best, as supplementing and, at worst, as duplicating care that they already provide. Therefore, nursing home administrators are confronted with the issue that hospice involvement may potentially improve care at the end of life, but at a considerable reduction of revenue for the nursing home. Administrators must then consider whether the potential value added to a resident's care is substantial enough to outweigh the financial losses and complications associated with coordination of care. Over time, the financial losses could adversely affect staffing levels and subsequent care to residents.

Another potential disincentive to inviting hospice into the nursing home is the difficulty of fulfilling the hospice philosophy of treating the whole family as well as the resident. While nursing homes recognize the importance of the family, their primary focus is the resident, and they are responsible for ensuring respect for resident rights, including self-determination. Unfortunately, family's wishes are not always congruent with those of the resident, especially regarding end-of-life care. Furthermore, family members may not know their loved one's wishes for end-of-life care and may disagree among themselves regarding these decisions (Gjerberg et al., 2010). Additionally, there are reports of families interfering with appropriate care of dying residents, specifically when family are absent until the last days of life. The nursing home staff describes these family members as "coming out of nowhere" and suddenly demanding care that is not only inappropriate but also incongruent with the resident's previously stated wishes (Munn et al., 2008). In summary, expanding the focus of care from the resident to the family may not necessarily result in the best interest of the patient and indeed create more distress for nursing home staff (Dreyer et al., 2009).

2. Referring Nursing Home Residents to Hospice

Although 87% of US nursing homes have hospice contracts, only 30% actually have hospice enrollees (Stevenson & Bramson, 2009). Additionally, hospice serves less than 10% of all dying nursing home residents (Hanson et al., 2005). These statistics indicate that while most nursing homes have contracts with hospice, many do not refer eligible residents to hospice. This likely reflects the inherent difficulty in complying with the hospice eligibility criterion that the patient must have a life expectancy of six months or less (Ellershaw & Ward, 2003). Estimating prognosis for survival is often extremely

difficult in nursing home settings, where elderly residents are less likely than younger individuals to die of an illness with a predictable disease trajectory, and more likely to suffer from multiple co-morbidities (Miller et al., 2004). This uncertainty of prognosis makes physicians reluctant to affirm that a nursing home resident's chronic illnesses have crossed the threshold to becoming terminal (Miller, 2014).

The optimal approach to communicating prognosis and making decisions about medical treatment near the end of life is a discussion that involves the nursing home resident, his or her physician, and the resident's loved ones. Unfortunately, physicians are not often present in nursing homes. Therefore, the onus falls on the other team members to discuss prognosis and counsel residents and families about health care options, including hospice care. In an ideal world, a physician-led inter-professional team might be able to reach an evidence-based consensus that a resident's combined illnesses constitute a terminal condition, but nursing home caregivers often do not recognize this until the last hours to days of life (Munn et al., 2006). This inability or failure to recognize a resident's condition as terminal typically delays discussions regarding end-of-life care and prevents hospice referral.

Even if a resident's approaching death is clearly foreseeable, nursing home physicians and staff are often hesitant to discuss death and dying due to a perceived lack of expertise, or they may not see themselves as providing end-of-life care (Miller et al., 2004). If they do mention the option of hospice care, they may do so apologetically and without conviction (Ellershaw & Ward, 2003).   Staff ambivalence and misconceptions regarding hospice care can have a strong influence on residents and families. They may create or reinforce resident and family opinions that involving hospice in their care is

"giving up" and therefore encourage residents either to avoid hospice altogether or to engage hospice only at the very end of life.

3.   Management of the Dying Nursing Home Resident

Another major area in which ethical issues arise in the use of hospice in nursing home settings is in the management of the dying process itself. An important goal of end-of-life care is to care for the individual in his or her place of residence so as to avoid burdensome re-hospitalizations and transitions of care. The fact that nursing homes are often full and hospital beds are readily available may undermine this goal (Decker, 2008). If a nursing home hospice patient has a symptom management emergency, and hospice personnel are not readily available, nursing home staff may decide that they must send the resident to the hospital, and the nursing home may not be able to hold a place for the patient to return. Hospital transfer can also be precipitated by a concern that other residents in the nursing home will be uncomfortable witnessing an end-of-life experience, especially one involving uncontrolled symptom management.

In my experience as a nursing home medical director, for instance, hospice failed to provide an emergency kit containing medications for nursing home staff to administer in the event of an end-of-life symptom emergency, for a resident recently admitted to hospice in the last hours to days of life. The nursing home staff attempted to call the hospice organization and was unable to reach anyone for hours. The resident and family had previously expressed wishes to never return to the hospital, and so the resident did remain at the nursing home, but experienced a very uncomfortable death. The nursing home staff, resident's family, and other nursing home residents were traumatized by this

event. This situation exemplifies a not uncommon ethical issue in nursing home care:
weighing the needs of individual residents against the well-being of the community as a
whole.

4. Coordination of Care Between the Nursing Home and Hospice

In nursing homes, care plans are based on scheduled Minimum Data Set (MDS)
assessments. When hospice becomes involved, hospice staff assume overall
responsibility for developing and managing the plan of care. Because hospice staff are
not continuously present in the nursing home, however, nursing home staff are left to
carry out the plan of care. The need for coordinating care between nursing home and
hospice staff can create challenges (Miller et al., 2004; Unroe et al., 2014).

One such challenge is the coordination of care related to pain management.
Treating pain associated with chronic illness and treating pain at the end of life have
different goals and require different medical management. Hospice staff are more
knowledgeable about and so more likely to manage the pain of nursing home hospice
patients near the end of life. For example, hospice staff might recommend the use of "as
needed" administration of pain medication in addition to or instead of prescheduled
administration. If hospice staff do not communicate this clearly to nursing home staff,
the latter group may be reluctant or even refuse to follow hospice-recommended
protocols, due to misconceptions about the intent and effect of the opioid pain medication
regimen (Dumas & Ramadurai, 2009). To complicate matters further, the administration
of "as needed" pain medication may also be delayed in situations when residents do not
reveal the extent of their pain to avoid upsetting their family or annoying nursing home

staff. Similarly, treatment is delayed when residents with dementia are not able to make their needs verbally known, and appropriate care relies totally on recognizing nonverbal cues. Suboptimal pain management has been linked to inadequate training of nursing home certified nursing assistants (CNAs) who provide the overwhelming majority of personal care to residents and are thus best situated to recognize such cues (Duncan et al., 2008).

Care coordination relates to more than just medication management. There is anecdotal evidence to suggest that nursing home staff may pull away from hospice recipients, seeing their role in the care of the resident as diminished. Existing data indicates that hospice staff are unavailable 25% of the time when requested (Parker-Oliver & Bickel, 2002). Because hospice staff are not always available in the nursing home, there is a potential for large gaps in care at critical times. It has also been suggested, although not established through research, that when hospice organizations have limited resources, they may allocate these to home hospice care rather than to nursing home care, assuming that nursing homes will continue to provide care for their residents in their absence. A recent Office of the Inspector General (OIG) report found that, in 31% of cases examined, hospice services to nursing homes residents were not provided with the frequency stipulated in the plan of care developed by the hospice organization (OIG, 2011). The matter of hospice availability in the nursing home may be the most salient of concerns in coordinating hospice and nursing home care. Before a contract is in place, before residents can be appropriately referred, before care can be coordinated, and before the dying process can be managed, it is imperative first to understand the capacity of a given hospice organization to provide care.

Summary

The four problem areas discussed above raise questions about inadequate care due to lack of resources and breaches in residents' autonomy and integrity. Thus, a critical ethical question seems to be whether care of the resident is improved or rather worsened when hospice care is involved in the nursing home setting. While some data suggest that it is improved, the issues presented in these last two sections suggest that some aspects of care may not be improved and may actually be worsened, when hospice is involved. These ethical issues, if not acknowledged, addressed, and mitigated, can lead to unmet health care needs at the end of life, including suboptimal pain and symptom management, poor spiritual support, inadequate communication, and burdensome re-hospitalizations and transitions from one setting of care to another. Furthermore, these lapses can result in moral distress for both nursing home and hospice staff, marked by feelings of stress, anger, helplessness, and frustration, and can ultimately to staff burnout (Bolmsjo et al., 2006; Turkoski, 2000). Therefore, it is not surprising that nursing home staff request more education, expert support, and time for dealing with ethical decision making surrounding care at the end of life (Gjerberg et al., 2010).

A New Model to Support the New Philosophy

Nursing homes are and will continue to be sites of death for a significant number of older adults in the United States. Therefore, provision of high quality end-of-life care in the nursing home setting is essential, and the characteristics of nursing homes need to be taken into account when developing innovative modes of care. I believe that research is sufficient to suggest that hospice involvement in nursing home end-of-life care can

lead to overall positive outcomes, such as improved pain and symptom management, better spiritual support, improved communication, and decreased burdensome hospital readmissions and transitions of care. As the previous examination of four problem areas in the coordination of hospice and nursing home care illustrates, however, there are significant obstacles to achieving the goal of better care for nursing home residents approaching the end of life. Without addressing these obstacles in the design and implementation of new models of care integration, a new model of care may exacerbate instead of minimize the already existing ethical issues. Therefore, I propose three ways in which synergy between hospice care and nursing home care can be facilitated and ethical conflict mitigated: (1) policy review and development; (2) clinical case consultation; and (3) education. I believe that the institutional mechanism that is best suited to provide these services in health care facilities is the ethics committee. In the remainder of this chapter, therefore, I will describe how a collaborative or shared committee model could improve the provision and outcomes of end-of-life care for residents in nursing homes. To inform this description, I will first briefly review the history of health care ethics committees, with particular focus on nursing homes and hospice organizations.

<u>A Brief History of Health Care Ethics Committees</u>

With the precipitous growth of United States heath care in the decades immediately following World War II, patients, health care professionals, and the American public faced new and challenging moral questions about what treatments should be offered and provided, especially near the end of life. What was once at the hand of fate had become a matter of choice with profound legal and ethical implications

for all involved. Administrators, practitioners, and patients struggled with conflicts at the crossroads of what could be done, technically and medically, and what should be done, morally. In response, a new discipline, now referred to as bioethics, provided a body of knowledge and methods of practical reasoning that led to the emergence of health care ethics committees.

As the number and complexity of ethical questions in health care increased, provisional ideas were offered regarding potential sources of guidance in order to address these questions. In 1975, pediatrician Karen Teel suggested that hospital ethics committees could be established for this purpose. Her suggestion received prevalent attention when it was cited by the New Jersey Supreme Court in its 1976 Quinlan decision (Teel, 1975). The case of Karen Ann Quinlan raised national awareness of the issues and the need for criteria and procedures for establishing decision making authority (In re Quinlan, 1976). The New Jersey Supreme Court's decision and recommendation in the Quinlan case motivated some hospitals to establish ethics committees as a way of avoiding judicial review of each and every fraught case involving end-of-life decisions. In 1983, the President's Commission for the Study of Ethical Problems in Medicine suggested that institutions give "serious consideration" to establishing ethics committees to review treatment decisions made on the behalf of patients who lack decision-making capacity (President's Commission, 1983b).

Another major impetus for the creation of institutional ethics committees emerged out of the fiercely debated issue in the 1980s of life-sustaining treatment for severely ill newborns that resulted in the Baby Doe rules issued in 1985 (DHHS, 1985; Weir, 1983). These regulations provided a strong incentive for hospitals with neonatal intensive care

units to establish infant care review committees. As a result, a doubling of hospital ethics committees between 1983 and 1985 was reported by the American Hospital Association's Society for Patient Representatives (Anonymous, 1985).

By the mid-1980s, hospital ethics committees were quite prevalent, but their purpose and role was not yet well defined or understood. In 1986, the American Hospital Association published a handbook delineating case consultation, policy development, and education as the three core functions of ethics committees, and offering guidance for establishing such committees (Ross et al., 1986). In 1998, a task force was convened by the Society of Health and Human Values to develop guidelines for the practice of health care ethics consultation. Initially published as "Core Competencies for Health Care Ethics Consultation," it has recently been updated and remains an authoritative guide for health care ethics committees (ASBH, 2010). As a result of these monumental endeavors, by the end of the 20th century health care ethics committees were well established in almost all hospitals and standards of operation and practice had begun to be prescribed by professional organizations (Fox et al., 2007; McGee et al., 2001).

The extent of ethics committees in hospice organizations can only be estimated as their prevalence and activities are not well documented. As of this writing, no formal studies exist that explore the operationalization of dedicated ethics committees in hospice organizations. The meager relevant literature suggests that 73% of hospice organizations have access to an ethics committee and only 23% have a committee of their own. Apparently, many hospices access hospital ethics committees and otherwise rely on informal review by administrators and senior clinical staff, or include discussions regarding ethical issues in inter-professional team meetings (Csikai, 2002).

Unfortunately, none of these approaches is optimal for conducting in-depth ethical deliberation that is explicitly grounded in hospice philosophy. There is some evidence that ethical issues are capturing an increased degree of attention and conversation in the field. In 2005, the Hospice Foundation of America dedicated its annual teleconference, usually focused on grief and bereavement, to ethical issues at the end of life, and it returned to this topic again in 2012. The case of Terri Schiavo, a subject of bitter public debate between 1998 and 2005, fueled interest in ethical issues pertaining to hospice care. As a result, in 2006 the National Quality Forum's National Framework for Preferred Practices in Palliative and Hospice Care Quality recommended that hospices establish or have access to ethics committees or consultation across care settings to address ethical conflicts at the end of life. Additionally, in 1988 the National Hospice Organization (now the National Hospice and Palliative Care Organization) issued guidelines for the development of hospice ethics committees, which were updated in 2007. As a result, the booklet, "Starting an Ethics Committee: Guidelines for Hospice and Palliative Care Organizations," and its companion, "Ethical Principles: Guidelines for Hospice and Palliative Care Clinical and Organizational Conduct," are the most current resources for hospice-specific ethics committees (NHPCO, 2006 & 2007).

Similar to hospice, literature documenting the prevalence and activities of ethics committees within nursing homes is limited. The studies that do exist are either dated or do not distinguish nursing homes from other long-term care settings. A 1988 study estimated that only 2% of nursing homes had an established ethics committee (Glasser et al., 1988). This study found that larger facilities, i.e. those with more beds and a larger medical staff, and those with religious affiliation, were more likely to have an ethics

committee. Although 60% saw no need for an ethics committee, 17% of nursing homes without an ethics committee reported that they were considering forming one. Though awareness and need are growing, nursing homes often do not have usable mechanisms in place to deal effectively with complex ethical issues on site due to budgetary constraints, understaffing, and the necessary reliance on providers with limited training and education (Glasser et al., 1988). In 1991, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) mandated all licensed hospitals and nursing homes to establish a mechanism to consider ethical issues in patient care and to educate health care professionals, and patients in these issues (JCAHO, 1992). Most nursing homes, however, do not have JCAHO accreditation.

Although nursing homes may have ethics committees, at least on paper, committee members are often not ethics trained nor do they have trained ethicists available for onsite consultation. Unfortunately, deliberation about the ethical concerns of nursing home residents often occurs in times of crisis and after a patient has been transferred to the hospital. As a result, many of the critical issues related to futility, respecting residents' treatment preferences, and optimizing palliative measures in place may not be dealt with prior to transfer, when such considerations could most effectively be managed by those closest to the resident – the nursing home physician, nursing home staff, and family.

Before more nursing homes will be interested in establishing a committee, however, the functions of the committee must be clarified. Moreover, buy-in from nursing home administrators also appears to be a critical factor. Apparently, nursing home administrators are often wary of ethics committees, perhaps fearing that they will

make unilateral judgments regarding resident care that may adversely affect the entire

organization. This fear appears to underlie the concerns of those administrators who feel

that committees are poor means for resolving ethical issues because of their potential to

create undesirable bureaucracy and diffusion of responsibility (Glasser et al., 1988). I

believe that a new model of ethical support in nursing homes with better clarification of

its functions will be more likely to garner support from administration and therefore

solidify its presence.

A New Model of Ethical Support in Nursing Homes

As mentioned previously, I believe that health care ethics committees, rather than

ad hoc groups or individual consultants, is the most appropriate provider for ethics

consultation in nursing homes, as it is the best champion for the new interdisciplinary

team-based ethos I have proposed, which incorporates hospice and palliative care.

Therefore, I propose the creation or revitalization of nursing home ethics committees to

serve as a gathering place for focused conversation on ethical matters, foremost, but also

a moral compass for the facility, its residents and families, and even its referral sources

and partners. I propose this model as a grassroots movement at that could occur at the

level of individual nursing homes or regional alliances. I will explain this in further

detail in what follows.

Nursing Home Ethics Committee Structure, Composition, and Training

The ethics committees I envision should be interdisciplinary, consisting of

members whose backgrounds bring different perspectives to the committee. Specifically,

they should include representation from each clinical discipline – physicians, nurse

practitioners, nurses, certified nursing assistants (CNAs), social workers, physical

therapists, occupational therapists, speech therapists and chaplains as well as

administration and legal representatives. In addition to being interdisciplinary, the

committees should be inter-institutional, in which hospice and palliative care are

represented. Individuals should be selected not just because of their role-based

perspective, but also for their abilities in reflection and reasoning. To the extent feasible,

committees should include a mix of ethnicities, religions, races, genders and other

demographic characteristics that appropriately reflects the facilities' staff and residents it

serves. Having socially diverse committees will ensure a variety of viewpoints and assist

in culturally fraught cases. Additionally, community members – civic leaders,

representatives of patient advocacy groups or disease organizations, business leaders,

etc., can be an excellent source of diverse members. They can play an important role

representing community values uncomplicated by medical knowledge.

Members of the committee should collectively possess the skills, knowledge, and

attitudes required to carry out the mission and functions of the committee. As a result,

committee members should be educated in ethical principles and deliberation. Just how

much education ethics committee members should have has long been a matter of

vigorous debate within the health care ethics community (Dubler & Blustein, 2007;

Fletcher & Hoffman, 1994; Smith et al., 2010; Williamson, 2007). Advocates of

expertise argue that the practice of ethics is no less complex and demanding than the

practice of medicine. As long ago as 1994, the lack of standards and mandatory expertise

among ethics committee members and consultants prompted some theorists to worry than

an ethics disaster was waiting to happen (Fletcher & Hoffman, 1994). Conversely, the

pragmatic jury model of ethics consults holds that reasonable people with a modicum of specialized training, instruction in the process of ethics consults, and comprehension of the facts of the case can make sound moral judgments. In fact, these individuals may even do a better job of representing community and societal values than would highly trained specialists. Even the American Society of Bioethics and Humanities (ASBH) acknowledges that it is unrealistic to expect that highly trained clinical staff volunteering their time could also be expected to undertake advanced study in ethics. ASBH does recommend that committees seek to attract varying expertise so that they collectively have a full range of core competences for ethics consultation (ASBH, 1998). Since this debate is unlikely to be resolved anytime soon, ultimately it is a matter to be decided by each individual nursing home facility.

Terms of membership and staggered rotation of retiring and new members are necessary to keep committees from becoming too complacent or dominant by one group or individual. Conversely, it takes time for committees to become cohesive as a group, as it takes time to learn and apply relevant skills. As a result, a three-year term would likely be optimal, understanding that professional changes might require early resignation and replacement. The committees chair position, however, can rotate more frequently than every three years, but never less often to avoid over-identification of the committee with a single individual. Again, since it takes time for committees to gel, I would recommend monthly meetings. Additionally, facility leadership should support but not actively manage the activities of committees. Furthermore, at a minimum the facility should pay for staff time to attend committee meetings.

<u>Scope and Mission of Nursing Home Ethics Committee Activities</u>

The principal purpose of an ethics committee in any health care setting is to improve the provision of health care and its outcomes through the identification, analysis, and resolution of ethical issues as they emerge in the clinical setting (ASBH, 1998). In general, the core activities of ethics committees are policy review, consultation and education. These are just as appropriate in the nursing home as they are in the hospital setting. This discussion will consider each of these activities in the nursing home setting, identifying its special configurations as it pertains to integrating hospice and palliative care.

Policy review and development is an example of the contribution that ethics committees can make to the larger organization. Clinical case consultations may prompt development of policies in order to avoid repeating ethical conflicts, generalize conclusions from specific cases, or clarify philosophical positions. Additionally, policy review need not be limited to issues of patient care but could also refer to organizational practices and operations as well. This might be of particular importance in addressing some of the ethical issues mentioned earlier in this chapter regarding the coordination of care between the nursing home and hospice.

As a core function of nursing home ethics committees, case review and consultation should be a consistent and frequent activity. When no cases are active, then the committee can perform retrospective or practice consultations. Committee deliberations and consultation should have the following four characteristics: (1) deliberation should be consistent, systematic, and rigorous; (2) it should be focused on ethical principles and issues; (3) it should be evaluated; and (4) it should be faithful to the new proposed integrated nursing home care philosophy and its related goals of care.

Consistent, systematic, and rigorous methods have discrete steps, each leading to the next and culminating in an ethically defensible conclusion. The degree of rigor keeps the committee focused and provides substance and authority to the process should anyone question the conclusions. Another benefit from having structured consultations is that it distinguishes them from interdisciplinary team (IDT) meetings and care conferences. While some hospices and nursing homes have used IDT meetings to discuss and resolve ethical issues, the intent and goals of these discussions are significantly different. Ethical deliberation begins with gathering the relevant facts of a case in order to have as much information and context as possible to identify the ethical principles in conflict. This is only the first step in the process and is intended to assist with the second step, identifying the ethical principles in conflict. With the ethical principles identified, the committee can frame the core ethical question. Structured discussions of ethical questions entail in-depth consideration of the ethical principles at issue and the moral implications of choices and outcomes. Then, conclusions for case consultation involve one or more recommendations arrived at by consensus.

Consultations should also have some manner of follow-up to determine the value of the process and efficacy of the recommendations. There is considerable discussion in the ethics literature regarding the importance and difficulty of consultation evaluation (ASHB, 2010; Fletcher & Siegler, 1996; Fox & Arnold, 1996). However, evaluation is essential to improve processes and prove the worth of the resources devoted to the committee. Additionally, before you can evaluate outcomes you must delineate measureable goals that can then determine success or failure. As such, resolution of ethical issues entails finding the best path toward the ultimate goal of care. Goals of care

in the hospital are profoundly different from those in the nursing home and hospice settings. As a result, not only are the ethical issues that arise different but also the means of consideration and resolution of these issues. Therefore, applying consultation methods, goals, and evaluations used in traditional hospital settings to that of nursing home and hospice settings are likely to be unsuccessful. Finally, case consultation need not be limited to clinical topics but should also serve as a forum for examining regulatory and organizational issues as well. In this way, the nursing home ethics committee can inform and ensure ethical behavior and orientations throughout the facility and hospice organization.

For instance, questions concerning decision-making capacity and treatment decisions at the end of life are some of the most common ethical issues confronting residents, families, and providers in the nursing home setting. As mentioned earlier in this thesis, most residents in nursing homes suffer from some degree of dementia, and many residents lack decision-making capacity. These individuals are particularly vulnerable, and their ability to exert control over their situation and make rational choices regarding treatment and other aspects of their life is markedly limited. Nursing home ethics consultations could provide protection of these vulnerable residents from unwanted provision or limitation of life-sustaining treatments. Residents, family members, nursing home staff, and hospice staff could request consultations whenever there is disagreement about the goals of care or the best treatment for residents as they approach the end of life.

In general, education tends to be the predominant activity of ethics committees in between consults and I would expect the same to be true for those in nursing homes. It is critical to its proper functioning that its members be steeped in the new integrated nursing

home philosophy of care, ethical concepts, methods, and theories as well as the clinical, regulatory, and organizational realities in which they work. Its broader educational mission would be to expand the knowledge and awareness of ethical issues and processes through the facility and organization. This can take multiple forms, ranging from delivering in-service seminars to participating in new-employee orientation. Yet another focus would be to offer educational programs to other professionals and lay community at large. As the wider societal movement to improve care, ensure comfort and honor residents' wishes as they age and at the end of life gains momentum, as it surely will with the aging population, the ethical dimension of nursing home and hospice care provision will be increasingly debated in public forums. I believe nursing homes and hospices have an obligation to engage these conversations and offer well-reasoned and morally justified analyses of these ethical issues. It is through this new integrated philosophy of nursing home care that we can best examine these ethical issues and offer better care to our aging population residing in nursing homes.

<div align="center">An Alternative or Supplement</div>

I realize there are limitations to the implementation of such a committee in nursing homes. As a result, I believe this warrants a brief discussion of a potential alternative, or better yet, supplementary activity. That alternative or supplement might be the use of palliative care consultation in the nursing home in order to improve care of dying nursing home residents. Contrary to common belief, palliative care is not identical to hospice care. While they share a very similar, if not the same, philosophy of care, the time at which each is provided, along the disease trajectory, is different. Unlike hospice care, palliative care is not restricted to patients who are dying and is available to patients

who still benefit from life-prolonging treatments. Palliative care is thus often provided

further up-stream from the point of end-stage disease processes. Furthermore, palliative

care reimbursement structure does not directly interfere with that of nursing homes,

which may be viewed as less of a disincentive than hospice care. Similar to hospice care,

palliative care is able to address all the before-mentioned valued elements of pain and

symptom management, spiritual peace, communication with one's physician, a sense of

completion, and following treatment preferences (Steinhauser et al., 2000). Moreover,

recent studies suggest that quality of care, even survival, is better in nursing home

residents who receive palliative care (Mitchell et al., 2009; Kurella et al., 2009).

Therefore, I believe that integration of palliative care consultation into the nursing

home as a supplement to ethics committees might be a viable way to further support a

new integrated philosophy of care within nursing homes. I believe there is some natural

synergy between palliative care and ethics committees in this arena. For instance,

palliative care consultants could enhance the committee's educational and consultative

endeavors within the nursing homes with their clinical expertise. I personally fear,

however, that palliative care consultants in and of themselves would not be able to further

a substantial philosophical change without the assistance of a new ethical support system

in nursing homes. It is for this reason that I view palliative care consultants as more of a

supplement than an alternative to ethics committees in the nursing homes.

Conclusion

The practices of nursing home care are steeped in ethical intent. In an attempt to

better uphold and promote its core values, I have proposed a new integrated philosophy

of nursing home care. Additionally, I have suggested a generalized model of nursing home ethics committee to guide these practices and mitigate ethical issues, such as the four challenges mentioned earlier in the chapter. The issue of inviting hospice into the nursing home might be addressed via policy and regulatory review. This may ultimately lead to advocacy at the national level regarding Medicare regulatory and financial barriers. Educational efforts regarding hospice eligibility criteria and disease prognostication might aid in more timely referral of eligible residents for hospice enrollment. Once a resident is enrolled, management of the dying experience within the nursing home and coordination of care might be optimized via clinical case and operations review. For instance, reviewing clinical cases pertaining to inadequate symptom management may prompt ideas that could improve management and coordination of care. In addressing these issues, I believe that ethics committees in the nursing home setting can serve as a platform for ethical deliberation and education.

I also speculate, although quite ambitiously, that such committees might serve as consultants to administration potentially influencing policy, regulations, and operations of the organization. This would, of course, depend on the openness of administrators to seek this kind of advice. Evidence suggests, however, that nursing home administrators are potentially becoming more aware of ethical issues in their facilities and recognizing their importance (Hogstel, 2004). Furthermore, when administrators were surveyed regarding barriers to forming an ethics committee, they reported only small logistical barriers, none of which insurmountable. For example: (1) absence of guidelines for committees; (2) time commitment from individuals; and (3) privacy of health care information compliance (Hogstel, 2004). I believe that recognition of the ethical issues

described above along with systematic proposals for addressing them will ultimately facilitate greater acceptance of ethics committees from administrators.

Could the ethics committee, therefore, serve as a gathering place for select individuals, from executives to those providing direct personal resident care? A place where staff come together for structured reflection and conversation regarding the values, goals, and mission of the nursing home? A place of moral light where ethical issues can be mitigated if not resolved in order to find the best path towards honoring the goals of care for nursing home residents? I believe these are lofty but potentially attainable goals, if they are grounded in a new integrated philosophy of nursing home care that recognizes the importance of providing better care at the end of life for nursing home residents and their families.

REFERENCES

- American Society for Bioethics and Humanities (ASBH). (1998). Core competencies for health care ethics consultation. Glenview, IL: American Society for Bioethics and Humanities.

- American Society for Bioethics and Humanities (ASBH). (2010). Core competencies for health care ethics consultation (2nd ed.). Glenview, IL: American Society for Bioethics and Humanities.

- Anonymous. (1985). Ethics committees double since '83: survey. Hospitals, 59(21), 60, 64.

- Backer, B., Hannon, N., & Russell, N. (1982). Death and dying: Individuals and institutions. New York, NY: Wiley.

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

- Balboni, T., Paulk, M., Balboni, M., et al. (2010). Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. Journal of Clinical Oncology 28(3), 445–452.

- Biola, H., Sloane, P., Williams, C., Daaleman, T., Williams, S., and Zimmerman, S. (2007). Physician communication with family caregivers of long-term care residents at the end of life. Journal of the American Geriatrics Society 55, 846–856.

- Bolmsjo, I., Sandman, L., & Anderson, E. (2006). Everyday ethics in the care of elderly people. Nursing Ethics, 13(3), 249-263.

- Buck, J., (2007a). Netting the hospice butterfly: Politics, policy, and translation of an ideal. Home Healthcare Nurse, 25(9), 566-571.

- Buck, J., (2007b). Reweaving a tapestry of care: Religion, nursing, and the meaning of hospice, 1954-1978. Nursing History Review, 15, 113-145.

- Buck, J., (2010). Nursing the borderlands of life: Hospice and the politics of heathcare reform. In S. Lewenson & P. D'Antonio (Eds.), Nursing interventions through time: History as evidence (pp. 203-220). New York, NY: Springer.

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

- Centers for Medicare and Medicaid Services (CMS). (2010). Nursing home data compendium 2010 edition. Retrieved July 2015, from http://www.cms.gov/CertificationandComplainc/Downloads/nursinghomedatacompendium_508.pdf.

- Centers for Medicare and Medicaid Services (CMS). (2011). Minimum Data Set (MDS) 3.0. Retrieved July 2015, from https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/NursingHomeQualityInits/NHQIMDS30.html.

- Clark, D., (2000). Total pain: The work of Cicely Saunders and the hospice movement. American Pain Society Pain Bulletin, 10(4), 13-15.

- Claessens, M., Lynn, J., Zhong, Z., et al. (2000). Dying with lung cancer or chronic obstructive pulmonary disease: Insights from SUPPORT. Study to

Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Journal of the American Geriatrics Society 48(S5), S146–S153.

- Chung, A., Gaynor, M., & Richards-Shubik, S., (2012). Subsidies and structure: the lasting impact of the Hill-Burton program on the hospital industry: Preliminary and incomplete draft. http://igpa.uillinois.edu/system/files/HBCrowdOutpaper_AEAs.pdf. Accessed July, 2014.

- Connor, S., (1998). Hospice: Practice, Pitfalls, and Promise. Taylor & Francis. p. 4. ISBN 1-56032-513-5.

- Creditor, M. (1993). Hazards of hospitalization of the elderly. Annals of Internal Medicine 118(3), 219–23.

- Csikai, E. (2002). The state of hospice ethics committees and the social work role. Omega, 45(3), 261-275.

- Curtis, J., Wenrich, M., Carline, J., et al. (2001). Understanding physicians' skills at providing end-of-life care perspectives of patients, families, and health care workers. Journal of General Internal Medicine 16, 41–49.

- Decker, F. (2008). Dying in a nursing home: The role of local bed supply in nursing home discharges. Journal of Aging and Health, 20(1), 66-88.

- Department of Health and Human Services, Health Care Financing Administration. (1989, February 2). Federal Register/Rules and Regulations, 54(21) Washington DC: US Government Printing Office.

- Desbiens, N., and Wu, A. (2000). Pain and suffering in seriously ill hospitalized patients. Journal of the American Geriatrics Society 48(5), S183-S186.

- Dobbs, D., Hanson, L., Zimmerman, S., Williams, C., & Munn, J. (2006). Hospice attitudes among assisted living and nursing home administrators and the Long-Term Care Hospice Attitudes Scale. Journal of Palliative Medicine, 9(6), 1388-1400.

- Dreyer, A., Forde, R., & Nortvedt, P. (2009). Autonomy at the end of life: Life prolonging treatment in nursing homes – relatives' role in the decision-making process. Journal of Medical Ethics, 35, 672-677.

- Dubler, N., & Blustein, J. (2007). Credentialing ethics consultants: An invitation to collaboration. American Journal of Bioethics, 7(2), 35-39.

- Duff, R., & Hollingshead, A. (1968). Sickness and society. New York, NY: Harper & Row.

- Dumas, L., & Ramadurai, M. (2009). Pain management in the nursing home. Nursing Clinics of North America, 44, 197-208.

- Duncan, J., Forbes-Thompson, S., & Bott, M. (2008). Unmet symptom management needs of nursing home residents with cancer. Cancer Nursing, 31(4), 265-273.

- Ellershaw, J., & Ward, C. (2003). Care of the dying patient: The last hours or days of life. British Medical Journal, 326, 30-34.

- Ferrell, B. (1995). Pain evaluation and management in the nursing home. Annals of Internal Medicine 123, 681-687.

- Fitchett, G., Murphy, P., Kim, J., Gibbons, J., Cameron J., and Davis, A. (2004). Religious struggle: prevalence, correlates and mental health risks in diabetic, congestive heart failure, and oncology patients. International Journal of Psychiatry Medicine 34(2), 179-196.

- Fletcher, J., & Hoffman, D. (1994). Ethics committees: Time to experiment with standards. Annals of Internal Medicine, 120(4), 335-338.

- Fletcher, J., & Siegler, M. (1996). What are the goals of ethics committees? A consensus statement. Journal of Clinical Ethics, 7(2), 122-126.

- Fox, E., & Arnold, R. (1996). Evaluating outcomes in ethics consultation research. Journal of Clinical Ethics, 7(2), 127-138.

- Fox, E., Myers, S., & Pearlman, R. (2007). Ethics consultation in United States hospitals: A national survey. American Journal of Bioethics, 7(2), 13-25.

- Glaser, B., & Strauss, A. (1965). Awareness of dying. Chicago, IL: Aldine.

- Glasser, G., Zweibel, N., & Cassel, C. (1988). The ethics committee in the nursing home: Results from a national survey. Journal of the American Geriatrics Society, 36(2), 150-156.

- Gjerberg, E., Forde, R., Pedersen, R., & Bollig, G. (2010). Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. Social Science and Medicine, 71, 677-684.

- Gozalo, P., Plotzke, M., Mor, V., Miller, S., and Teno, J. (2015). Changes in Medicare costs with the growth of hospice care in nursing homes. New England Journal of Medicine, 372, 1823-1831.

- Gozalo, P., Miller, S., Intrator, O., Barber, J., and Mor, V. (2008). Hospice effect on government expenditures among nursing home residents. Health Services Research 43, 134-153.

- Gozalo, P., Teno, J., Mitchell S., et al.(2011). End-of-life transitions among nursing home residents with cognitive issues. New England Journal of Medicine 365, 1212-1221.

- Habor, C., & Gratton, B., (1994). Old age and the search for security: An American social history. Bloomington, IN: Indiana University Press.

- Hallenbeck, J., Hickey, E., Czarnowski, E., Lehner, L., & Periyakoil, V. S. (2007). Quality of care in a veterans affairs' nursing home-based hospice unit. Journal of Palliative Medicine, 10(1), 127-135.

- Hanson, L., Danis, M., Garrett, J. (1997). What is wrong with end-of-life care? Opinions of bereaved family caregivers. Journal of the American Geriatrics Society 45, 1339–1344.

- Hanson, L. C., Henderson, M., Rogman, E. (1999). Where will they die? A national study of nursing home death. Journal of the American Geriatrics Society, 47, 9.

- Hanson, L., Henderson, M., and Menon, M. (2002). As individual as death itself: a focus group study of terminal care in nursing homes. Journal of Palliative Medicine 5(1), 117-125.

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

- Hanson, L., Eckert, J., Dobbs, D., Williams, C., Caprio, A., Sloane, P., and Zimmerman, S. (2008). Symptom experience of dying long-term care residents. Journal of the American Geriatrics Society 56, 91-98.

- Health Care Chaplaincy. Literature Review – Testing the Efficacy of Chaplaincy Care. http://www.healthcarechaplaincy.org/templeton-research-project/literature-review.html. Accessed September 4, 2015.

- Hogstel, M., Curry, L., Walker, C., & Burns, P. (2004). Ethics committees in long-term care facilities. Geriatric Nursing, 25(6), 364-369.

- Holstein, J., & Cole, t., (1996). The evolution of long-term care in America. In R. Binstock, L. Cluff, and O. Mering (Eds.), The future of long-term care. Baltimore, MD: Johns Hopkins University Press.

- Hospice, Inc. (1971). Steering Committee Minutes. [Florence and Henry Wald Papers, Series I, Box 1, Folder 9]. Sterling Memorial Library, Yale University, New Haven, CT.

- Hui, D., de la Cruz, M., Thorney, S., Parsons, H., Delgado-Guay, M., Bruera, E. (2011). The frequency and correlates of spiritual distress among patients with advanced cancer admitted to an acute palliative care unit. American Journal Hospice and Palliative Care 28(4), 264–270.

- Illinois State Charities Commission, Second Annual Report of the State Charities Commission, 1912, pp. 457-508.

- In re Quinlan, 70 NJ 10, 355 A.2d 647 (1976).

- Johnson, K., Tulsky, J., Hays, J., et al. (2011). Which domains of spirituality are associated with anxiety and depression in patients with advanced illness? Journal of General Internal Medicine 26(7), 751–758.

- Joint Commission for Accreditation of Heathcare Organizations (JCAHO). (1992). Accreditation Manual for Hospitals. 1993 edition. Oakbrook Terrace, IL: Joint Commission for Accreditation of Heathcare Organizations.

- Katz, M., (1986). In the shadow of the poorhouse: A social history of welfare in america. New York, NY: BasicBooks.

- Keay T., Fredman L., Taler G., Datta S., & Levenson S. (1994). Indicators of quality medical care for the terminally ill in nursing homes. Journal of the American Geriatrics Society, 42, 853–860.

- Kerr, D., (1993). Mother Mary Aikenhead, the Irish Sisters of Charity, and Our Lady's Hospice for the Dying. American Journal of Hospice and Palliative Care. 9(3), 13-14, 36-38.

- Kirchhoff, K., Hammes, B., Kehl, K., Briggs, L., Brown, R. (2010). Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. Journal of the American Geriatrics Society 58(7), 1233-1240.

- Kiely, D. K., & Flacker, J. M. (2003). The protective effect of social engagement on 1-year mortality in a long-stay nursing home population. Journal of Clinical Epidemiology, 56, 472-478.

- Kirk, T., & Jennings, B. (2014). Hospice ethics: policy and practice in palliative care. New York, NY: Oxford University Press.

- Kurrella, T., Corvinsky, K., Chertow, G., Yaffe, K., Landefeld, C., & McCulloch,C. (2009). Functional status of elderly adults before and after initiation of dialysis. New England Journal of Medicine, 361, 1539-1547.

- Lamberton, R,. (1980). Care of the dying, New York: Penguin.

- Lerner, M. (1970). Where, why, and when people die. In O. G. Brim, H. E. Freeman, S. Levine, & N. A. Scotch (Eds.), The dying patient. New York, NY: Russell Sage Foundation. pp. 5-29.

- Levenson, J., McCarthy, E., Lynn, J., Davis, R., & Phillips, R. (2000). The last six months of life for patients with congestive heart failure. Journal of the American Geriatrics Society 48(S5), S101–S109.

- Lewis, M. (2007). Medicine and Care of the Dying: A Modern History. Oxford University Press US. p. 21. ISBN 0-19-517548-4.

- MacIntyre, A., (1981). The nature of the virtues. Hastings Center Report, 11(2), 27-34.

- Mako, C., Galek, K., & Poppito, S. (2006). Spiritual pain among patients with advanced cancer in palliative care. Journal of Palliative Medicine 9(5), 1106-1113.

- McDonagh, J., Elliott, T., Engelberg, R., et al. (2004). Family satisfaction with family conferences about end-of-life care in the intensive care unit: Increased proportion of family speech is associated with increased satisfaction. Critical Care Medicine 32, 1484–1488.

- McGee, G., Caplan, A., Spanogle, J., & Asch, D. (2001). A national study of ethics committees. American Journal of Bioethics, 1(4), 60-64.

- Miller, S., Gozalo, P., & Mor, V. (2001). Hospice enrollment and hospitalization of dying nursing home patients. American Journal of Medicine 111, 38–44.

- Miller, S., Vincent, M., Wu, N., Gozalo, P., & Lapane, K. (2002). Does receipt of hospice care in the nursing homes improve the management of pain at the end of life? Journal of the American Geriatrics Society 50(507), 507–515.

- Miller, S., Vincent, M., & Teno, J. (2003). Hospice enrollment and pain assessment and management in nursing homes. Journal of Pain and Symptom Management 26(3), 791-799.

- Miller, S., Intrator, O., Gozalo, P., Roy, J., Barber, J., & Mor, V. (2004). Government expenditures at the end of life for short- and long-stay nursing home residents: differences by hospice enrollment status. Journal of the American Geriatrics Society, 52, 1284–1292.

- Miller, S. C., Teno, J. M., & Mor, V. (2004). Hospice and palliative care in nursing homes. Clinics in Geriatric Medicine, 20(4), 717-734.

- Miller, S. C., Lima, J., Gozalo, P. L., & Mor, V. (2010). The growth of hospice care in U. S. Nursing Homes. Journal of the American Geriatrics Society, 58, 1481-1488.

- Miller, S. (2014). Hospice and palliative care in nursing homes: Challenges and opportunities for enhanced access. Rhode Island Medical Journal, 98(4), 26-29.

- Mitchell, S., Morris, J., Park, P., & Fries, B. (2004). Terminal care for persons with advanced dementia in the nursing home and home care settings. Journal of Palliative Medicine, 7(6), 808-816.

- Mitchell, S., Teno, J., Miller, S., & Mor, V. (2005). A national location of death for older persons with dementia. Journal of the American Geriatrics Society, 53, 299-305.

- Mitchell, S., Teno, J., Kiely, D., Shaffer, M., Jones, R., Prigerson, H., et al. (2009). The clinical course of advanced dementia. The New England Journal of Medicine, 361(16), 1529-1538.

- Mohan, D., Alexander, S., Garrigues, S., Arnold, R., Barnato, A. (2010). Communication practices in physician decision-making for an unstable critically ill patient with end-stage cancer. Journal of Palliative Medicine 13(8), 949-956.

- Mor, V., & Kidder, D. (1985). Cost savings in hospice: final results of the national hospice study.' Health Services Research 20, 407–422.

- Morley, J., (2013). The nursing home movement. In Nursing Home Care: A core curriculum for the international association for gerontology and geriatrics (pp. 91-127). New York, NY: McGraw-Hill Education.

- Munn. J., Hanson, L. C., Zimmerman, S., Sloane, P. D., & Mitchell, C. M. (2006). Is hospice associated with improved end-of-life care in nursing homes and assisted living facilities? Journal of the American Geriatrics Society, 54(3), 490-495.

- Munn, J., Dobbs, D., Meier, A., Williams, C., Biola, H., & Zimmerman, S. (2008). The end of life experience in long-term care: Five themes identified from focus groups with residents, family members, and staff. Gerontologist, 48(4), 485-494.

- Munn, J. (2012). Telling the story: Perceptions of hospice in long-term care. American Journal of Hospice and Palliative Medicine 29(3), 201-209.

- Murphy, K., Hanrahan, P., & Luchins, D. (1997). A survey of grief and bereavement in nursing homes: The importance of Hospice grief and bereavement for end-stage Alzheimer's disease patient and family. Journal of the American Geriatrics Society, 45, 1104-1107.

- Murray, S., Kendall, M., Grant, E., Boyd, K., Barclay, S., Sheikh, A. (2007). Patterns of social, psychological, and spiritual decline toward the end of life in lung cancer and heart failure. Journal of Pain and Symptom Management 34(4), 393–402.

- National Hospice Organization. (1995). An analysis of the cost savings of the Medicare hospice benefit. Miami, FL: Lewin-VHI Inc., Item Code 712901.

- National Hospice and Palliative Care Organization (NHPCO). (2006). Ethical principles: Guidelines for hospice and palliative care clinical and organizational conduct. Alexandria, VA: National Hospice and Palliative Care Organization.

- National Hospice and Palliative Care Organization (NHPCO). (2007). Starting an ethics committee: Guidelines for hospice and palliative care organizations. Alexandria, VA: National Hospice and Palliative Care Organization.

- NHPCO Facts and Figures: Hospice Care in America. Alexandria VA: National Hospice and Palliative Care Organization, September 2015. http://www.nhpco.org/about/press-room.

- Newport, F. In U.S. increasing number have no religious identity: 2010. http://www.gallup.com/poll/18276/Increasing-Number-No-Religious-Identity.aspx.

- Office of the Inspector General (OIG). (2011). Medicare hospice care for beneficiaries in nursing facilities: Compliance with Medicare coverage requirements. Retrieved March 2016, from http://www.oig.hhs.gov/oei/reports/oei-02-06-00221.pdf.

- Pargament, K., Koenig, H., Tarakeshwar, N., Hahn, J. (2001). Religious struggle as a predictor of mortality among medically ill elderly patients: a 2-year longitudinal study. Archives of Internal Medicine 161(15), 1881–1885.

- Parker-Oliver, D., & Bickel, D. (2002). Nursing home experience with hospice. Journal of the American Medical Directors Association, 3(2), 46-50.

- Phelps, A., Maciejewski, P., Nilsson, M., et al. (2009). Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. Journal of the American Medical Association 301(11), 1140–1147.

- Presidents Commission for the Study of Ethical Problems in Medicine. (1983). Deciding to forego life-sustaining treatment: Ethical, medical, and legal issues in treatment decisions. Retrieved March 2016, from http://bioethics.georgetown.edu/pcbe/reports/past_commissions/deciding_to_forego_tx.pdf.

- Puchalski, C., Ferrell, B., Virani, R., et al. (2009). Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. Journal of Palliative Medicine 12(10), 885-904.

- Resnick, H., Schuur, J., Heineman, J., et al. (2009). Advance directives in nursing home residents aged ≥65 years: United States 2004. American Journal of Hospice and Palliative Medicine 25(6), 476-482.

- Robbins, J. (1983). Caring for the Dying Patient and the Family. Taylor & Francis. p. 138. ISBN 0-06-318249-1.

- Ross, J., Bayley, C., Michel, V., & Pugh, D. (1986). Handbook for Hospital Ethics Committees. Chicago, IL: American Hospital Publishing.

- Roth, K., Lynn, J., Zhong, Z., Borum, M., & Dawson N. (2000). Dying with end stage liver disease with cirrhosis: Insights from SUPPORT. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. Journal of the American Geriatrics Society 48(S5), S122–S130.

- Rutman D. (1992). Palliative care needs of residents, families, and staff in long-term care facilities. Journal of Palliative Care, 8, 23– 29.

- Saliba, D., Kingston, R., Buchanan, J., et al. (2000). Appropriateness of the decision to transfer nursing facility residents to the hospital. Journal of the American Geriatrics Society 48,154-163.

- Saunders, C. (1966). The moment of the truth-some aspects of care of the dying patient. [Cicely Saunders Papers Box 57]. Hospice History Project, Trent Palliative Care Centre, Sheffield, UK.

- Saunders, C. (1971). The patient's response to treatment: A photographic presentation. In Catastrophic illness in the seventies: Critical issues and complex decisions (pp. 33-46). New York, NY: Cancer Care.

- Saunders, C. (1978). The philosophy of terminal care. In C. Saunders (Ed.), The management of terminal disease (pp. 193-202). London, UK: Edward Arnold.

- Saunders, C. (1979). The nature and management of terminal pain and the hospice concept. In J. J. Bonica & V. Ventafridda (eds.), Advances in pain research and therapy (Vol. 2, pp. 635-651). New York, NY: Raven Press.

- Sellman, D., (2011). Professional values and nursing. Medicine, Health Care, and Philosophy, 14(2), 203-208.

- Shield, R., Wetle, T., Teno, J., Miller, S., & Welch, L. (2005). Physicians "missing in action": family perspectives on physician and staffing problems in end of life care in the nursing home. Journal of the American Geriatrics Society 53, 1651–1657.

- Smith, M., Sharp, R., Weise, K., & Kodish, E. (2010). Toward a competency-based certification of clinical ethics consultants: A four-step process. Journal of Clinical Ethics, 21(1), 14-22.

- Steinhauser, K., Christakis, N., Clipp, E., McNeilly, M., McIntyre, L., & Tulsky, J. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA 284(19), 2476-2482.

- Stevenson, E., & Bramson, J. (2009). Hospice care in the nursing home setting: A review of the literature. Journal of Pain and Symptom Management, 38(3), 440-451.

- Teel, K., (1975). The physician's delimma. a doctor's view: what the law should be. Baylor Law Review, 27, 6-9.

- Temel, J., Greer, J., Muzikansky, A., et al. (2010). Early palliative care for patients with metastatic non-small cell lung cancer. New England Journal of Medicine 363(8), 733-742.

- Teno, J., Clarridge, B., Casey, V., et al. (2004). Family perspectives on end of life care at the last place of care. Journal of the American Medical Association 291, 88–93.

- Tulsky, J. (2005). Beyond advance directives: importance of communication skills at the end of life. JAMA 294(3), 359-365.

- Turkoski, B. (2000). Home care and hospice ethics: Code for nurses. Home Healthcare Nurse, 18(5), 308-316.

- Unroe, K., Cagle, J., Dennis, M., Lane, K., Callahan, C., & Miller, S. (2014). Hospice in the nursing home: Perspectives of front line nursing home staff. Journal of the American Medical Directors Association, 15(12), 881-884.

- US Census Bureau. (2010). The 2010 statistical abstract: The national data book. Retrieved May 2015, from http://www.census.gov/compendia/statab/cats/births_deaths_marriages_divorces.html.

- US Department of Health and Human Services. (1985). Services and treatment for disabled infants: Model guidelines for health care providers to establish infant care review committees. Federal Register, 50(72), 14893-14901.

- Virginia State Board of Charities and Corrections, First Annual Report of the State Board of Charities and Corrections, 1909.

- Vladeck, B. (1980). Unloving care: The nursing home tragedy. New York, NY: BasicBooks.

- Wald, F. (1986). In search of the spiritual component of hospice care. In F. Wald (ed.), In quest of the spiritual component of care for the terminally ill: Proceedings of a colloquium (pp. 24-37). New Haven, CT: Yale University Press.

- Wallace, M. & O'Shea, E. (2007). Perceptions of spirituality and spiritual care among older nursing home residents at the end of life. Holistic Nursing Practice 21(6), 285-289.

- Weiner, J., Arnold, R., Curtis, J., Back, A., Roundsville, B., Tulsky, J. (2006). Manualized communication interventions to enhance palliative care research and training: rigorous, testable approaches. Journal of Palliative Medicine. 9(2), 371-381.

- Weir, R., (1983). The government and selective nontreatment of handicapped infants. New England Journal of Medicine, 309, 661-663.

- Wenrich, M., Curtis, J., Shannon, S., et al. (2001). Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death. Archives of Internal Medicine 161, 868–874.

- Williamson, L. (2007). The quality of bioethics debate: Implications for clinical ethics committees. Journal of Medical Ethics, 24, 357-360.

- Wu, N., Miller, S., Lapane, K., & Gozalo, P. (2003). 'The problem of assessment bias when measuring the hospice effect on nursing home residents' pain. Journal of Pain and Symptom Management 26(5): 998–1009.

- Yi, M., Mrus, J., Wade, T., et al. (2006). Religion, spirituality, and depressive symptoms in patients with HIV/AIDS. Journal General Internal Medicine 21 (suppl 5), S21–27.

- Zheng, N., Mukamel, D., Friedman, B., Caprio, T., & Temkin-Greener, H. (2015). The effect of hospice on hospitalizations of nursing home residents. Journal of the American Medical Directors Association 16, 155-159.

- Zimmerman, S., Cohen, L., Van Der Steen, J., Reed, D., Van Soest-Poorvliet, M., Hanson, L., & Sloan, P. (2015). Measuring end-of-life care and outcomes in residential care/assisted living and nursing homes. Journal of Pain and Symptom Management 49(4), 666-679.

CURRICULUM VITAE

NAME: Timothy Mark Corbett, MD, HMDC

TITLE: Associate Medical Director

WORK ADDRESS: Hospice & Palliative Care Center
                               101 Hospice Lane
                               Winston-Salem, North Carolina 27103
                               Telephone: (336) 768-3972

HOME ADDRESS: 625 Jersey Avenue
                               Winston-Salem, North Carolina 27101
                               Telephone: (336) 655-1896

EDUCATION:
          1995-2000   Bachelor of Science, Industrial Design, cum laude
                               Appalachian State and North Carolina State
                               University
                               Boone and Raleigh, North Carolina

          2000-2002   Non-Degree Pre-Professional Medicine Program
                               East Carolina University
                               Greenville, North Carolina

          2003-2007   Doctorate of Medicine
                               Brody School of Medicine at East Carolina
                               University
                               Greenville, North Carolina

          2013-2016   Master of Arts in Bioethics
                               Wake Forest University
                               Winston-Salem, North Carolina

POSTDOCTORAL TRAINING:
          2007-2010   Resident, Family Medicine
                               Wake Forest School of Medicine
                               Winston-Salem, North Carolina

          2010-2012   Fellow, Geriatrics and Palliative Medicine
                               Wake Forest School of Medicine
                               Winston-Salem, North Carolina
                               And
                               W. G. (Bill) Hefner Veterans Affairs Medical
                               Center

Salisbury, North Carolina

2011-2012   Fellow, Geriatric Faculty Development Fellowship
Department of Geriatrics and Palliative Medicine
Mount Sinai School of Medicine
New York, New York

ACADEMIC APPOINTMENTS:

2015-Present   Adjunct/Volunteer Professor
Department of Internal Medicine
Section on Gerontology and Geriatric Medicine
Palliative Care Program
Wake Forest School of Medicine
Winston-Salem, North Carolina

2012-2015   Assistant Professor
Department of Internal Medicine
Section on Gerontology and Geriatric Medicine
Palliative Care Program
Wake Forest School of Medicine
Winston-Salem, North Carolina

OTHER PROFESSIONAL APPOINTMENTS AND INSTITUTIONAL SEVICE:

2015-2016   Medicine and Patients in Society Course
Core Education Faculty
Wake Forest School of Medicine
Winston-Salem, North Carolina

2014-2016   Clinical Skills Seminar
Core Education Faculty
Wake Forest School of Medicine
Winston-Salem, North Carolina

2014-2016   Learning Communities Red House Mentor
Wake Forest School of Medicine
Winston-Salem, North Carolina

2014-2015   Medical Director
Brookridge Retirement Community
Winston-Salem, North Carolina

2013-2014   Medical Director
Bermuda Village Retirement Community
Bermuda Run, North Carolina

PROFESSIONAL LICENSURE:

2010	North Carolina State Medical License (active)

SPECIALTY CERTIFICATION:

2011	Board Certified, Family Medicine
2012	Board Certified, Geriatric Medicine
2012	Board Certified, Hospice and Palliative Medicine
2015	Board Certified, Hospice Medical Director

PROFESSIONAL MEMBERSHIPS:

2003-Present	American Medical Association
2003-Present	American Academy of Family Physicians
2005-Present	U.S. Albert Schweitzer Fellows
2007-Present	North Carolina Academy of Family Physicians
2010-Present	American Geriatrics Society
2012-Present	American Academy of Hospice and Palliative Medicine

EMPLOYMENT:

2012-2015	Physician, Full-Time, Wake Forest University Health Sciences, Wake Forest School of Medicine, Department of Internal Medicine, Division of Gerontology and Geriatric Medicine, Palliative Care Program.
2002-2003	Teacher, Full-Time Engineering and Architectural Design J. H. Rose High School Greenville, North Carolina

HONORS AND AWARDS:

2010	Geriatric Certificate of Achievement, Department of Family Medicine, Wake Forest School of Medicine. Given annually for embodiment of the principles of excellence in geriatric medicine and professional commitment to this endeavor.
2005	North Carolina Albert Schweitzer Fellow, Department of Rural Medicine, East Carolina University Brody School of Medicine. Dedicated to the development of "leaders in service": individuals who are dedicated and skilled in addressing the health needs of underserved communities, and whose example influences and inspires others.

GRANT SUPPORT: PAST, CURRENT AND PENDING:

2012-2014	John A. Hartford Foundation Corbett (PI) $30,000 Hartford Foundation Scholar The Hartford Foundation Center of Excellence at Wake Forest School of Medicine is a comprehensive plan to strengthen the

geriatrics education and training at all levels of learning. The focus of my scholarly proposal is to develop a Telegeriatrics Interdisciplinary Team Training Curriculum within Long-Term Care.
Role: PI

RESEARCH EXPERIENCE:

2004-2005
North Carolina Albert Schweitzer Fellow. The Albert Schweitzer Fellowship. There are four major aims: Provide direct services that address health-related needs of underserved communities; Influence the professional development of students in health-related fields in ways that strengthen their commitment to, and skills in, public service; Alter the culture of professional schools so they more effectively address needs of surrounding disadvantaged communities; Support program alumni who continue in lifelong community service and who, as Schweitzer Fellows for Life, are influential role models for other professionals. Project (INHOME) consisted of the implementation of a first and second year medical student run home visit program targeted at home bound individuals. The focus of our home visits was to provide preventative health care assistance to the elderly within the setting of their home.

2012-2014
PI, Pilot of a teleGeriatrics Interprofessional Curriculum in Long-Term Care. Wake Forest School of Medicine and W.G. (Bill) Hefner VA Medical Center. Mentors, Kathryn E. Callahan and Hal H. Atkinson. Development, implementation and evaluation regarding the effectiveness of a video teleconference geriatric interdisciplinary team training curriculum. This project aims to: 1) Evaluate interdisciplinary team training impact on attitudes toward teams and self-perceived teamwork skills, 2) Assess interdisciplinary team training impact on knowledge of geriatric multidisciplinary competencies: Dementia and Delirium and 3) Compare the impact and acceptability of video teleconference geriatric interdisciplinary team training versus in-person geriatric interdisciplinary team training.

2013-2015
Co-Investigator, Geriatric Principles for Specialists (GPS). The aims of the proposed Geriatrics Principles for Specialists (GPS) curriculum are to: 1) Evolve and expand an efficient, adaptable, and sustainable specialty-focused curriculum for diffusing core aspects of geriatrics knowledge, skills, and related teaching expertise throughout all remaining medical specialties and key surgical specialties at Wake Forest and, 2) Develop specialist experts in team leadership and care for older adults.

SELECTED INVITED PRESENTATIONS AND CONFERENCES:

Local

April 2016   "Clinical Pearls in Geriatric Pain Management." 11th Annual Erik Lie-Nielsen Geriatrics Symposium. Northwest Area Health Education Center and Wake Forest School of Medicine.

September 2015   "Clinical Implications of Advance Directives: What Physicians Want Every Attorney to Know." Wake Forest School of Law.

November 2014   "Can this patient consent? Issues of cognition and capacity" Wake Forest Geriatrics Principles for Specialists (Wake-GPS) Retreat. Department of Internal Medicine, Section on Gerontology and Geriatric Medicine, Wake Forest School of Medicine.

September 2014   "Clinical Implications of Advance Directives: What Physicians Want Every Attorney to Know." Wake Forest School of Law.

August 2014   "Palliative Care and Critical Care Medicine." Critical Care Medicine Fellow's Summer Conference Series. Department of Internal Medicine, Section on Pulmonary and Critical Care, Wake Forest School of Medicine.

June 2014   "The ABC's of Responding to Behavioral Symptoms in Dementia." Bermuda Village Retirement Community Nursing Staff. Bermuda Run, NC.

June 2014   "Pain Assessment and Management at End-of-Life" Wake Forest Baptist Medical Center's End-of-Life Nursing Education Consortium (ELNEC) Curriculum.

April 2014   "Palliative Care throughout your Survivorship," Panel Discussion at the Seventh Annual North Carolina Comprehensive Cancer Program Survivorship Summit, Greensboro, NC.

April 2014   "The Goal Setting Conversation." Wake Forest Geriatrics Principles for Specialists (Wake-GPS) Retreat. Department of Internal Medicine, Section on Gerontology and Geriatric Medicine, Wake Forest School of Medicine.

March 2014   "Prognostication Science & Art, (or just another dirty word)?" Grand Rounds. Department of Family Medicine, Wake Forest School of Medicine.

February 2014   "Prognostication." 10th Annual Erik Lie-Nielsen Geriatrics Symposium. Northwest Area Health Education Center and Wake Forest School of Medicine.

November 2013   "Assessing and Managing Pain in the Elderly." Wake Forest Geriatrics Principles for Specialists (Wake-GPS) Retreat.

Department of Internal Medicine, Section on Gerontology and
Geriatric Medicine, Wake Forest School of Medicine.

April 2013   "Transitions of Care." Chief Resident and Fellow Immersion
Training Retreat. Department of Internal Medicine, Section on
Gerontology and Geriatric Medicine, Wake Forest School of
Medicine.

April 2013   "Polypharmacy in the Elderly." Chief Resident Immersion
Training Retreat. Department of Internal Medicine, Section on
Gerontology and Geriatric Medicine, Wake Forest School of
Medicine.

March 2013   "Prognostication Science & Art, (*or just another dirty word*)?"
Grand Rounds. Department of Family Medicine, Wake Forest
School of Medicine.

December 2012   "Geriatric Medicine. "Gerontology Course Lecture, Division of
Humanities and Social Sciences, Forsyth Community College.

December 2012   "Hazards of Hospitalization in the Elderly." Grand Rounds.
Department of Family Medicine, Wake Forest School of Medicine.

September 2012   "Management of Insomnia in Older Adults." Grand Rounds,
Department of Internal Medicine, Section on Gerontology and
Geriatric Medicine, Wake Forest School of Medicine.

June 2012   "A Review of Consequences and Predictors of Driving Among
Cognitively Impaired Older Adults." Grand Rounds, Department
of Internal Medicine, Section on Gerontology and Geriatric
Medicine, Wake Forest School of Medicine.

Regional
October 2014   "Ethical Issues in End-of-Life Care for the Primary Care
Physician." 34th Annual Mountain Medical Meeting, Wake Forest
School of Medicine Office of Continuing Medical Education,
Asheville, NC.

October 2014   "Palliative Care: The Basics - What a Primary Care Physician
Needs to Know." 34th Annual Mountain Medical Meeting, Wake
Forest School of Medicine Office of Continuing Medical
Education, Asheville, NC.

September 2012   "Fellow & Junior Faculty Development Session." Co-Presenter,
Gerolina: Annual educational consortium composed of Academic
Geriatric Medicine Programs throughout North and South
Carolina.

National
February 2015   "Palliative Sedation: Clinical and Ethical Controversies." Case
                     Presentation. Annual meeting of American Academy of Hospice
                     and Palliative Medicine, Philadelphia PA.

ASTRACTS AND SCIENTIFIC EXHIBITS:
National
February 2015   Corbett TM, Callahan KE, Phillips KC, Russell GB, Williamson
                     JD,
                     Atkinson HH. Pilot of a teleGeriatrics Interprofessional
                     Curriculum in Long-Term Care. Poster presentation, Annual
                     meeting of American Academy of Hospice and Palliative
                     Medicine, Philadelphia PA.

October 2014   Corbett TM, Iltis AS. Palliative Sedation: Clinical and Ethical
                     Controversies. Poster presentation, Annual meeting of the
                     American Society for Bioethics and Humanities, San Diego CA.

May 2014   Corbett TM, Callahan KE, Phillips KC, Russell GB, Williamson
                     JD, Atkinson HH. Pilot of a teleGeriatrics Interprofessional
                     Curriculum in Long-Term Care. Poster presentation, Annual
                     meeting of the American Geriatrics Society, Orlando FA.

March 2013   Corbett TM, Callahan KE, Phillips KC, Williamson JD, Atkinson
                     H. Pilot of a teleGeriatrics Interprofessional Curriculum in Long-
                     Term Care. Poster presentation, Annual meeting of the American
                     Medical Directors Association-Long Term Care Medicine,
                     Washington DC.