Access To Hospice Programs: Barriers To Eligibility

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To the Faculty of Washington State University:

The members of the committee appointed to examine the scholarly project of AMANDA LYNN SCOTT and find it satisfactory and recommend that it be accepted.

Chair

[Signatures]
Abstract

Purpose: To explore previously conducted research on hospice program accessibility and to identify the barriers to hospice care that are contributing to the gap between those who deserve and qualify for optimal end-of-life care and those who receive it.

Data Sources: Peer-reviewed medical and nursing journals, The National Hospice and Palliative Care Organization (NHPCO), National Alliance for Hospice Access (NAHA), and Medicare governmental website.

Conclusions: The published articles reviewed identified predominate barriers that have persisted from the inception of hospice programs until current day. Funding policies, eligibility requirements, and societal views on death and dying by both health care workers and the general public, continue to remain among the top barriers.

Implications for practice: The advanced practice nurse has a unique opportunity to initiate hospice care dialogue for patients, families, and other health care workers.
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Access to Hospice Programs: Barriers to Eligibility

Hospice, a program for end-of-life care offered as a benefit service by Medicare, has long been sited as an excellent provider of care services for patients that have entered the end phase of life and have chosen comfort care instead of curative treatment. In spite of this, hospice programs for the terminally ill population in the United States are persistently under utilized. In 2005, the National Alliance for Hospice Access (NAHA) reported that less then 40% of eligible Medicare decedents received any hospice services. That means that about 60% of America’s terminally ill patients still receive their end-of-life care in and out of hospitals and other acute care facilities, or receive no care at all. Despite the availability of the Medicare hospice benefit (MHB) only approximately one-third of Medicare beneficiaries enroll with hospice prior to death (NHPCO, 2007).

Statement of Purpose

The purpose of this literature review is to examine the barriers restricting access to hospice care. How the policies of funding sources, deficits in awareness and education, and cultural influences contribute to the under utilization of hospice programs by health care workers, patients and their families. The intended goal of identifying key barriers to hospice care is to increase societal and health care provider awareness, and present an opportunity for change of existing practices.

Literature Search Strategies

Multiple search engines were used to review available literature. These included: PubMed, MEDLINE, PsycINFO, and Ebscohost. Key words used in the search included; hospice, Medicare benefits, palliative care, hospice access and hospice care coverage, death with dignity, fear of death, hospice utilization. The search was
limited to journal articles referring to hospice access, eligibility, and Medicare benefits, hospice utilization. A total of 37 articles were initially reviewed. A governmental website and 10 other websites from professional hospice organizations were used and 19 articles from scholarly journals were chosen on the basis that they had specific information pertaining to the subject of hospice access.

**Introduction**

Hospice is a program that is diagnosis-dependent. Hospice programs focus on terminally-ill patients, who no longer seek curative treatment and have a life expectancy of six months or less. Hospice care is a choice that may be presented to patients who are in the process of accepting the inevitability of their decline and opt to receive non-invasive therapies and treatment. These treatments focus on relieving symptoms and reducing suffering. Hospice patients can receive the services of a coordinated team of caregivers whose expertise is to effectively manage the broad spectrum of end-of-life issues. While hospice care can be given at a hospice center, hospital, or skilled nursing facility, the program is best known for providing pain management and end-of-life care at the individual’s home (Gazelle, 2007).

A fundamental principle of hospice care is the belief that each of us has the right to die pain-free and with dignity. One of the key components in providing nursing care is facilitating comfort for patients. Comfort care theory, a mid range nursing theory by Kolcaba (1991) provides a framework for comfort care services by creating a baseline of quality care that both nurses and doctors can utilize in providing care to a dying patient. Comfort has been called a distinguishing characteristic of the nursing profession yet, until Kolcaba, had never been conceptualized within a theory for nursing (Kolcaba, 1994).
Kolcaba defines comfort as the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts (physical, psychospiritual, social, and environmental) (Kolcaba & Kolcaba, 1991).

Hospice services include, but are not limited to, nursing care, physician visits and oversight, and the medications and devices necessary for palliative care. In addition, hospice provides volunteers and professionals for personal assistance in the activities of daily living, respite care, and many various types of therapy. Services such as dietary counseling, spiritual and psychological counseling, as well as grief therapy and guidance on bereavement services, are also provided. These services are in place to relieve stress and provide support to both the patient and family. They are custom-designed to enhance the quality-of-life for the terminally-ill person and support them and their family during their final stages of life (Gazelle, 2007).

The Center to Advance Palliative Care (CAPC) describes palliative care as specialized care focused on pain, symptoms, and stress of serious illness. Hospice programs always include delivery of palliative care, but the terms hospice care and palliative care are not interchangeable. Hospice is a program that includes palliative care to terminally-ill patients, in addition to emotional support for the patient and family, typically refraining from taking extraordinary measures to prolong life. Palliative care programs and hospice care programs also differ greatly in the care location, timing, payment, and eligibility for services (Villet-Lagomarcino, 2000).

Currently, the major funding source for hospice services is the Medicare Hospice benefit (MHB), a federally funded health care benefit granted to Americans 65 and older. In 2009, 83% of patients served were under the Medicare Hospice benefit (table 1), the
remaining 17% were paid for by private insurance, Medicaid, private pay, or charity (NHPCO, 2010).

To be eligible for Medicare hospice benefits, patients must be eligible for Medicare Part A (Hospital Insurance). To qualify for Medicare part A, patients must meet certain criteria (i.e., aged 65 or older, paid or have paid spouse Medicare taxes while working, or aged less than 65, but who are on disability). Medicare part A services cover blood products, home health services (if specific criteria for homebound status is met), hospital inpatient stays, skilled nursing services (after a three day hospital stay), and hospice services. If patients elect their hospice benefit, they choose to forego any curative treatment of their terminal illness. They can however, continue to use their regular Medicare benefit for management of other illnesses that are not related to their terminal illness.

If hospice services are elected, Medicare will reimburse only to a Medicare certified hospice agency. MHB reimbursement for services is roughly $147.00 per day for routine home hospice care with a cap of roughly $24,000 (CMS, 2010). This reimbursement rate is meant to cover all expenses for any palliative services surrounding a patient’s terminal illness. These services include, but are not limited to: palliative medications, equipment, skilled nursing visits, physician, or NP oversite, social workers, bath aides, trained volunteers, and bereavement services for up to one year following death. It is important to note, hospice programs can provide any services, which would be considered palliative and not curative including: blood products, chemotherapy, and surgical procedures. These options are at the discretion of the agency of the hospice
program as larger hospices can afford to absorb the higher cost of those treatments where as smaller hospices could not.

In addition to accessing the MHB, it is required that two physicians certify a patient has a terminal illness that will end in death within six months or less. Medicare provides broad guidelines to assist physicians in prognosticating decline for many medical conditions (Gazelle, 2007). In 2009, 59% of patients admitted to hospice programs were admitted with illnesses other than cancer. The top four diagnoses for non-cancer related illnesses were debilitating, unspecified dementia, heart disease, and pulmonary disease (NHPCO). Some of the prognostic indicators (Table 2).

**The Emergence of Hospice**

By the end of the 1960s, end-of-life medical treatment in the United States had evolved to include a new model of care. The model, inspired in part by the publication in 1969 of Dr. Elizabeth Kubler-Ross’s book, *On Death and Dying*, was based on more than 500 interviews with terminally-ill patients. The book identified the five stages through which many terminally-ill patients progress; denial and isolation, anger, bargaining, depression, and acceptance. Dealing frankly and explicitly with a topic that had long been considered taboo, Dr. Kubler-Ross’s book became an international best seller. *On Death and Dying* is widely credited with being the genesis for changing the way many Americans think about and deal with end-of-life issues (NHPCO, 2010).

A British physician, Dame Cicely Saunders, founded the first modern hospice. In 1967, she founded St Christopher’s Hospice in southwest London. It is now one of many such facilities of its kind, but St. Christopher’s is still the leader in the field having
pioneered the way for future centers. It was Saunders personal achievement and has been imitated all over the world. Though there were a number of homes in existence for the dying, most were run by religious orders and eventually led to the development of hospice care in the United States (Richmond, 2005).

After the publication and dissemination of her book, Dr. Kubler-Ross became a leading advocate for the movement, dedicated to honoring the dignity of people in the process of dying. Kubler-Ross testified in 1972 (NHPCO, 2010) before the U.S. Senate Special Committee on Aging on the subject of death with dignity; Featuring testimony on findings from the seminars she conducted for her book. She advocated that, “We should not institutionalize the dying and the old. We could give families help with home care and visiting nurses, spiritual support, and financial assistance to facilitate end-of-life care at home” (NHPCO, 2010).

The first hospice in the United States was established in New Haven, Connecticut in 1974. Shortly after an in-patient hospice at Yale Medical Center and a hospice program in Marin County, California were instituted (NHPCO, 2010). Four years later, the U.S. Department of Health, Education, and Welfare published a report citing hospice as a viable concept of care for terminally-ill people and their families that provides humane care at a reduced cost. By the late 1970s, the Health Care Financing Administration started hospice demonstration projects across the country (Hospice of Michigan [HOM], 2010).

In 1982, Congress enacted a provision to create a Medicare hospice benefit. In 1986, MHB was made permanent by Congress. The Medicare hospice benefit
contributed to a three-fold increase in the number of patients served; from 200,000 patients in 1987 to 1.4 million in 2007 (NHPCO, 2010).

In spite of the large numbers of patients using and being reimbursed for hospice care with non-cancer diagnosis', it is important to consider this in context. In its early years, hospice care was principally offered to patients with solid tumor cancers. This is because solid tumor cancers lend themselves well to the prognostication of six months life expectancy. However, as time passed and hospice programs gained in recognition and use, patients with other illnesses began to become aware of and opt for hospice services (Jennings, Rydes, D’Onorio, & Baily, 2003). This resulted in a significant increase in the number of patients being served by hospice programs, and a corresponding growth in Medicare’s budget being allocated for reimbursement of hospice care.

As more diagnoses fell into the realm of eligibility and benefits for hospice care, the pool of potential beneficiaries grew rapidly. Medicare spending increased 88% between 1991-2001 (Robinson, 2009). In 1994, Medicare asked for the first focused medical review of hospices. The review focused on benefit eligibility requirements and documentation in determination of terminal illness and six-month life expectancy (NHPCO, 2010). In the two years following the review, Medicare required more eligibility requirement documentation for patients seeking the hospice benefit (Lanf, Cabin, Cotton & Domizio 2010) and a 4.25% budget cut for reimbursement (HAA, 2010).

By 1998, the percentage of hospice non-cancer admissions had decreased dramatically, and hospices nationwide reported rapidly declining average and median
lengths of stay in hospice programs. According to the Hospice Association of America (HAA), the fall-off in hospice use reflected the problems associated with determining a six-month prognosis for patients with illnesses other than solid tumor cancers (2010).

The fall-off in hospice utilization was significant enough to come to the attention of the U.S. Senate in 2000. The Senate held hearings to question why Medicare-covered hospice stays were getting shorter, and to consider options for strengthening the program for current and future generations (U.S. Senate, 2010). As a result of the hearings, Congress passed the *Benefits for Improvement Act of 2000*. This measure increased hospice reimbursement by five percent, and was an attempt to strengthen hospice programs (HAA, 2010). By 2003, congress passed the Medicare prescription drug and modernization act which authorized payments for a hospice palliative care consult, allowed Nurse Practitioners to follow their patients onto the hospice benefit, and allowed hospices to contract with other hospices for highly specialized services.

By 2008, the Center for Medicare & Medicaid Services (CMS), made corrections to hospice caps and sent out letters to hospices that were over the cap. Revisions were made to the Conditions of Participation (CoP), which are the requirements for obtaining Medicare certification for a hospice program. The requirements for being a Medicare certified hospice program were finalized and enacted. This was the first revision of the CoP's since the original document was written. Several conditions were revised and redefined. The major new revisions for Medicare certified hospice programs that want to be reimbursed by Medicare are (CMS, 2010):

- Strengthened provisions for comprehensive patient/family assessments completed in a timely manner
• Quality assessment and performance improvement
• Redefinitions of the organizational environment including but not limited to: dietary services, all licensed professionals, physician and physician designee, clinical notes and bereavement counseling.

On July 22nd, 2010, CMS issued a notice that hospice programs would receive a 1.8% Medicare payment rate increase for fiscal year 2011. CMS also requires a face-to-face assessment by a physician or Nurse Practitioner for patients following a 90-day stay with a hospice program. Currently, Nurse Practitioners cannot initially certify a patient will die in six months or less but they can follow a patient’s care while the patient receives the MHB.

**Emerging Themes of Barriers to Hospice Access**

**Policies of Funding Sources**

Despite the availability of the MHB only approximately one-third of Medicare beneficiaries enroll with hospice prior to death (NHPCO, 2007). A number of studies suggest that prognostic difficulty in adhering to six-month criterion plays a substantial role in limiting use of hospice (Carlson, Morrison, & Bradley, 2008). A hospice stay of over six months can lead to denial of further benefits by Medicare, as well as penalties to hospices and physicians (Ferrera-Reid, 2004). These penalties may contribute to exclusion of patients who would benefit from these services and yet they are deemed ineligible.

A consistent emerging barrier from the literature to accessing a hospice program and receiving the corresponding Medicare benefit is the difficulty in predicting the rate of disease progression for terminal diagnoses other than solid-tumor cancer. Several articles
spanning from the late 90’s to current day address that difficulty prognosticating life span will be six months or less (Freidman, et al, 2002; Gazelle, 2007; Hill, 2005; Hogan, et al, 2001; Robinson, et al, 2007; Shega & Tozer, 2009). Illnesses like heart disease, pulmonary disease, dementia, and general debility cannot always be predicted with the specificity the Medicare health benefit regulations require (Jennings, et al, 2003). These patients, anecdotally known as, “the dwindlers,” are patients whose illness can linger without rate of decline predictability.

For example, an article by Berry in 2010 cites heart disease as the number one illness that prohibits access to hospice services. About 18% of patients in 2005 who were dying of heart failure and were hospice-eligible actually received hospice services. Lack of reliable prognostic indicators and the lack of a consensus on when to stop life prolonging therapies were among the contributing factors cited.

Pulmonary disease is the fourth leading cause of death in the U.S., and also happens to be an illness with a very unpredictable rate of decomposition (Gronkiewicz & Borkgren-Okenk, 2004). Patients with pulmonary disease may have several acute exacerbations, however, it is difficult to predict if these patients will live longer then six months.

A 1996 study by Connors et al, of over 1000 patients admitted to 1 of 5 tertiary hospitals, revealed there was a 11-24% mortality rate in patients needing ICU admission for severe COPD. Although 89% of patients with COPD survived the hospital admission in the study, there was a 33% risk of death over the next 6 months and a 42% chance at 1 year. Fifty percent of patients in the study were readmitted in the six months after discharge and reported a fair to poor quality of life.
Dementia patients are also cited as some of the most challenging patients to become eligible for the hospice benefit. In an article by Shega & Tozer in 2009, the authors point out that many persons dying with dementia receive poor end-of-life care. Given its sometimes slow progression, physicians are hesitant to certify that a patient with dementia will die in six months.

**Physician Influence on Hospice Referral**

Physicians have primary control regarding if and when hospice services should be recommended for patients. Given that two physicians must certify that a patient is eligible for services, usually the patient’s attending physician and a hospice medical director must agree on a six months or less prognosis (Connor, 2009).

Some attitudes and practices of physicians, who are the gatekeepers of the system, are barriers to accessing hospice programs (Adams et. al, 2009; Gazelle, 2007; Ferrera-Reid, 2004; Friedman, et al, 2002; Jennings et.al, 2003). Although oftentimes unintentional, physicians were identified as the most common reason for the too-late hospice referral (Adams et. al, 2009). The median length of hospice service according to the NHPCO in 2008 was about twenty-one days. A quantitative-qualitative study by Adams, Bader, & Horn in 2009 concluded that one-third of their study patients or families agreed it would have been easier if they started hospice services earlier. For many physicians recommending hospice care means having to acknowledge that a disease has not and will not be cured and may be perceived as a failure by physicians working toward healing a patient (Ferrera-Reid, 2004; Friedman, et.al. 2002; Gazelle, 2007).

While physicians have stated that patients should ideally receive conventional
hospice care for three months before death, when asked why they have delayed informing patients of the hospice option, they often say they do not wish to withdraw hope from their patients (Friedman, et. al, 2002; Jennings, et. al 2003; Lamont & Christakis, 2002). A study was conducted by Lamont & Christakis in 2001, to evaluate how often physicians favor communicating frank survival estimates to patients with terminal cancer who request them. Successfully completed survey’s with 258 physicians from multiple specialties who cared for 326 patients with terminal cancer, revealed that physicians favored providing frank survival estimates for only 37% of these cases. Physicians favored providing knowingly inaccurate survival estimates to 40% of these cases and favored providing no survival estimates for 22% of these cases.

Misconceptions Surrounding Hospice Services

A small phenomenological study conducted by Melvin (2010) included interviews with 13 people who were patients themselves or family members of patients on a palliative care unit. Lack of knowledge about palliative care, was reported by all study subjects. Misconceptions surrounding hospice services or absence of knowledge of hospice services can exclude patients who could benefit from services.

A survey by the National Hospice Foundation found that 75% of the general public in America did not know that hospice care can be provided in the home, and 90% do not realize that hospice care can be fully covered through Medicare (Jennings et. al, 2003).

Lack of knowledge surrounding hospice care and what type of interventions can be used for palliation limit understanding of hospice services. Notions that a person can not chose to be hospitalized, must forgo therapies, such as antibiotics for any acute infections and that they must avoid artificial nutrition and hydration (Shega & Tozer...
2009) were some of the common misconceptions identified. Patients and their families lack consensus on when to stop life-prolonging therapies (Berry, 2010).

Patients and families may also fear that admission to hospice will result in abandonment by their doctor and the medical establishment. A qualitative study conducted by indepth interviewing of 30 experts in hospice services (Friedman, 2002) revealed that like physicians, patients and families are uncomfortable confronting end-of-life issues and may view the term hospice negatively. People are often concerned with spiritual or existential issues and struggle to come to terms with the meaning of life in general and their own lives in particular (Jennings, 2003).

Many families do not have the confidence to take care of a loved one at home. Furthermore, many families do not have a schedule or physical space that allows for the care of a terminally ill person, even with the support of hospice services. It is well documented and fairly well-known that caregiver strain occurs when the stress of providing care outweighs the tools used to cope with the situation (Family Care Research Program 2010). Families that are already under stress are often reluctant to take on additional responsibilities.

**Significance for Practice**

In addition to providing patients with an option that is not curative in focus, hospice has economic advantages and was originally intended to decrease costs for end-of-life care. In 2004, a major study out of Duke University published in *the Journal of Pain and Symptom Management* shows that hospice services save money for Medicare and bring quality care to patients and families. For the majority of patients with sixteen of the most common terminal diagnoses, those choosing hospice, under most conditions, saved
money on their end-of-life care (Duke, 2004 & Robinson et. al, 2007). Further research for cost effectiveness would assist health care workers, when directing their efforts toward convincing Congress that hospice care saves money.

Medicare payment policies have a substantial influence on the financial viability of hospice care (Vrnig, Moscovice, Durham, & Casey, 2004). Future growth in hospice and palliative care in the United States may hinge on changes to the Medicare hospice benefit that align payment with severity of illness or need for services and allow more flexibility in the provision of hospice palliative care to patients during the transition from curative to palliative care (Connor, 2009).

The number one recommendation by Jennings et al, in 2003 was for healthcare leaders, policymakers, and key stakeholder groups come to consensus on the definition of palliative care and develop a framework for greater accountability in palliative care delivery in concert with financing mechanisms.

Further research into how health care providers perceive and communicate end-of-life care options to patients with terminal illness would be beneficial. A study by Hansen et al. (2009), found the need for education of physicians, nurses, and patient families continues. Leaders in the hospice community and in mainstream medicine must promote hospice-hospital partnerships in order to meet the current and projected needs of the rapidly expanding volume of chronically and terminally-ill patients (Jennings et.al., 2003).

Awareness and dialogue on issues related to death and dying should continue to evolve, with health care providers taking more of a leadership role with their patients. Hospice-focused public education on the philosophy and availability of end-of-life
healthcare services should be developed. Health care leaders need to begin focusing educational efforts on the key concepts of hospice which include dying with dignity, dying at home without necessary pain, and reducing the burden placed on family caregivers (Gazelle, 2007).

**Conclusion**

The overarching primary barriers to patients receiving hospice include prognosticating a patient will live 6 months or less to access the MHB, dependence on physicians as the primary referral source, lack of awareness and misconceptions about hospice amongst health care providers and patients, and persistent cultural issues concerning death and dying. Further research into American’s current beliefs about choosing palliative treatment over curative treatment in terminal illness would provide depth to our current understanding of where our end-of-life care fits into our society, and help to close the gap in numbers between those who would benefit from hospice care, and those who have the good fortune to receive it.

The Nurse Practitioner (NP) can play a key role in bringing about change to the way hospice is perceived, and positively impact rates of utilization. The advanced practice nurse has a unique opportunity to initiate hospice care dialogue for patients, families, and other health care workers. Nurse practitioners must continue to support professional nursing organizations that advocate at the federal level to influence public policy and restructure hospice care.
References


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<td>Other Payment Source</td>
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### Table 2 Medicare Hospice Eligibility Guidelines for Selected Diagnoses

#### Alzheimer’s disease
Eligibility is based on Reisberg Functional Assessment Staging (FAST), stage 7 or greater. Stage 7 is defined by the following criteria:
- need for assistance with at least three activities of daily living
- increased frequency of incontinence of bowel and bladder
- ability to speak only six or fewer intelligible words in the course of an average day

In addition to the FAST criteria, the patient must have one of the following:
- a history of upper urinary tract infection, sepsis, or pneumonia within the past 12 months
- multiple stage III or IV decubitus ulcers within the past 12 months

If the patient meets neither of the two preceding criteria, the patient must show nutritional decline, as evidenced by one of the following:
- unintentional progressive weight loss of 10% of body weight over the past 6 months
- a serum albumin level of <2.5 g/dl

#### Pulmonary disease
Eligibility is based on severe chronic lung disease, as defined by the following criteria:
- disabling dyspnea at rest and poor response to bronchodilators, resulting in decreased functional capacity
- disease progression reflected in increased emergency department or physician visits or by increased hospitalizations
- hypoxemia at rest — oxygen saturation ≤88% with patient breathing ambient air

#### Heart disease
Eligibility is based on New York Heart Association classification of class IV, as defined by the following criterion:
- inability to carry out any physical activity without discomfort (documentation of an ejection fraction of <20% is helpful but not required)

In addition, the patient must be optimally treated with diuretics and vasodilators as tolerated in relation to blood pressure and renal function

If the criteria for class IV do not apply, eligibility can be based on one of the following:
- the patient has angina, which must be present at rest or resistant to standard nitrate therapy
- the patient is not a candidate for or declines invasive procedures

#### Debility (no one specific terminal diagnosis identified)
Eligibility is based on the progression of disease, as documented by one of the following:
- recurrent or intractable infections, such as pneumonia, upper urinary tract infections, or sepsis
- progressive weight loss of >10% of body weight over the past 6 months
- dysphagia leading to recurrent aspiration or inadequate nutritional intake
- progressive deep decubitus ulcers