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A Review of the Literature on End-of-life Care: Setting a Research Agenda for Maine

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**A Review of the Literature on
End-of-Life Care:
Setting a Research Agenda for Maine**

October 2007



UNIVERSITY OF
SOUTHERN MAINE

**A Review of the Literature on End-of-Life Care:
Setting a Research Agenda for Maine**

October 2007

Prepared for

**The Maine Hospice Council and
Center for End of Life Care**

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Executive Summary

Purpose

In 2002, Last Acts, a national campaign of the Robert Wood Johnson Foundation, issued a report assessing the states on access to end-of-life care and policies supporting its provision. Quite striking for the hospice providers and other stakeholders of Maine, the state ranked second to last in hospice use among persons over age 65 in their last year of life. Although anecdotal and unpublished data suggest that hospice use is on the rise in Maine, concerns about the low use rate remains a concern to those interested in end-of-life care in the State.

In order to better understand the factors influencing the use of hospice in Maine, the Maine Hospice Council asked the Muskie School of Public Service to conduct a literature review synthesizing current knowledge on outcomes, use, cost, and barriers to end-of-life care. This review provides a foundation for setting an overall research agenda for the Council. At the end of the report, we have outlined a set of questions for further research regarding end-of-life care in Maine.

Growth in Use of Services

Use of hospice services has increased significantly in recent years. Perhaps more striking than the increase in hospice use, is the shift in mix of people using hospice services. In 1992, 75% of all diagnoses for hospice care were cancer related. By 2005, cancer related diagnoses had dropped to 46% of all cases. The most prevalent non-cancer diagnoses in 2005 were heart disease (12%), dementia (9.8%) and lung disease (7.5%).¹

Barriers to Use of Hospice

The literature identifies a number of barriers to the use of hospice services. These include:

- Difficulty predicting life expectancy
- Physician practices that do not support discussion of or referral to hospice
- Lack of physician knowledge or exposure to end-of-life issues
- Patient preferences for life-sustaining treatments
- Refusal to acknowledge terminal condition by the patient or caregiver
- Misunderstandings about the benefit

Opportunities for Improving Use of Hospice Services

A number of initiatives have been successful in improving access to and use of hospice care. Opportunities for improving access to hospice include:

- Providing the right information early and often
- Promoting collaborative efforts among nursing homes and hospice providers
- Improving the coordination and transition support provided with case management
- Integrating curative and palliative care in new models of delivery

Cost Effectiveness

Studies of the cost effectiveness of hospice have shown mixed results. Most of the studies have shown savings to the Medicare program from the Medicare hospice benefit although the amount

of savings has varied according to the time frame over which savings are calculated and the diseases that have been studied. One study found that Medicare costs in the last year of life were higher among hospice enrollees than non-enrollees but this varied by diagnosis and age.

Most of the literature focuses on cost savings attributable to the Medicare hospice benefit. One actuarial cost study examined the impact of the Medicaid hospice benefit to the Medicaid program. This study estimated that without hospice, Medicaid would pay an additional \$228 million in order to continue end-of-life care in the hospital; an additional \$41 million to pay for expensive pharmaceutical treatments; and an additional \$13 million for the payment to nursing homes, due to the technical way in which nursing homes are paid when a person who is dually-eligible for Medicaid and Medicare receives Medicare hospice in the nursing facility.²

Very little research has been done on the cost savings to the Medicaid program of the Medicare hospice benefit. For people who are dually eligible for Medicaid and Medicare, the use of the Medicare hospice benefit could produce cost savings if the Medicare hospice benefit supplanted or replaced the services that a person would otherwise be receiving under the Medicaid program (e.g. home and community based services). Further research in this area is needed.

Quality Initiatives

New initiatives are underway to bring quality assessment and improvement activities to the hospice industry. Since 2000, the National Hospice and Palliative Care Organization has sponsored a National Data Set (NDS) to establish benchmarks for hospice practice throughout the country.³ Participation in the NDS allows hospices to compare themselves against other hospice providers performing similar activities. Recommendations around quality have included:

- **The National Quality Forum** endorses a framework for developing a comprehensive quality measurement and reporting system for palliative care and hospice services and endorses a set of preferred practices designed to improve palliative and hospice care.⁴
- **The Medicare Payment Advisory Commission** has recommended that Medicare establish and collect quality measures for public reporting to encourage hospice quality improvement.⁵

Further Research Questions

The results of this literature review suggest a number of further questions for research. These include:

- What is the rate of hospice use by setting (e.g., home, hospital, nursing home, patient home, and residential care) in Maine? How does this compare with national use rates? Who is using those services (e.g. people with dementia, people with cancer, etc)?
- What is the relationship between supply of hospice providers and other providers and use of hospice in Maine? How does this vary by urban/rural areas?
- What percent of people using home care or long term care in Maine have diagnoses and ADL levels that are potentially consistent with hospice use? Are people who might be eligible for hospice being informed of/offered/using hospice?

- What are the factors that promote successful use of hospice in residential care and nursing facilities?
- What is the quality of hospice services provided in Maine?
- What is the impact of Medicare hospice use on Medicaid costs?
- Are there ways to improve the coordination of end-of-life care and financing between Medicaid and Medicare?

Summary

Data is critical to understanding the cost, use and quality of hospice services in Maine. There are a number of data sources available that can help better inform policy and practice in Maine. This includes Medicare and Medicaid data, MDS nursing home data, MDS-RCA residential care data, and Medicare home care data. In addition, the hospice providers have data that is unique and could further inform policy and practice. These include data on supply, use of services by type of providers, and quality of services. Data, as transformed into information, is necessary to fully inform research, policy and practice on an ongoing basis.

I. Background

Purpose

In 2002, Last Acts, a national campaign of the Robert Wood Johnson Foundation, issued a report assessing the states on access to end-of-life care and policies supporting its provision. Quite striking for the hospice providers and other stakeholders of Maine, the state ranked second to last in hospice use among persons over age 65 in their last year of life. Only 9.1% of Mainers over 65 used hospice in the last year of life, compared to the national average of 21.5%.⁶ This literature review seeks to understand the factors influencing low use of hospice in Maine by synthesizing current knowledge and research on outcomes, use, cost, and barriers to end-of-life care throughout the nation and the state. From this synthesis, we will identify opportunities and approaches that can inform policy, professional practice, and public education efforts in Maine. We will also develop a set of research questions that can provide a foundation for setting an overall research and policy agenda for the Maine Hospice Council and others interested in end-of-life care in Maine.

Historical Context

Credited with establishing the modern hospice movement, Dame Cicely Saunders sought to address dying patients' isolation within hospitals, their need to reflect on their lives, and the safe use of opiates for pain control. In 1967, Dr. Saunders opened the first modern hospice, St. Christopher's Hospice of London, assembling professionals and volunteers to promote comfort and quality of remaining life among dying patients. In 1969, *On Death and Dying* by Elizabeth Kubler-Ross argued for the provision of home care for the terminally ill and the involvement of patients in decisions affecting their care. Inspired by these events, students of Yale University launched the first United States hospice in Connecticut in 1974.^{7,8,9} Hospices that opened in these early years were based primarily within inpatient facilities and funded initially through grants and contributions. The Medicare hospice benefit was enacted in 1982 emphasizing hospice care within the home.¹⁰ States were given the option of including hospice in their Medicaid programs in 1986.

Hospice Services

Today, hospice provides for the physical, emotional, and spiritual needs of patients nearing the end-of-life and their caregivers. Emphasizing palliation rather than cure, patients' physical needs are met through pain management and symptom control, while emotional and spiritual needs are addressed through counseling, pastoral care, and bereavement support of family and caregivers.^{11,12,13} The hospice interdisciplinary team includes providers such as physicians, nurses, social workers, chaplains, and volunteers.¹⁴ Though most hospice care is delivered within the patient's or caregiver's home, hospice care can also be delivered in nursing homes, hospitals, and within free-standing hospice agencies. Hospice is primarily paid for by the Medicare program, but Medicaid, military, and commercial coverage also offer these benefits.

Medicare Hospice Benefit Package

To be eligible for the Medicare hospice benefit, beneficiaries must be certified as having six months or less to live by their physician. They must also be willing to forego other services related to curative treatment of their terminal illness. Beneficiaries remain eligible if they live

longer than six months as long as a hospice physician re-certifies that the patient has a terminal illness.¹¹

Patients' out-of-pocket costs are minimal. Medicare covers 95% of patients' hospice costs and most hospices do not collect a 5% co-payment.¹⁵ Room and board costs for hospice care provided at home or in a nursing home or hospice residential facility are not covered by Medicare. Patients also pay up to \$5 for prescription drugs and other products for pain relief and symptom control and pay 5% of the Medicare payment amount for inpatient respite care.¹¹

Demonstrated Benefits

Patients receiving hospice and their caregivers have reported better medical and social outcomes compared to other terminally ill patients not receiving hospice, particularly around pain and symptom management. Dying patients and their families have been shown to benefit from hospice by experiencing control of pain, fewer hospitalizations and invasive treatments and greater overall satisfaction.¹⁶ Results from the National Hospice Study (1985) indicated that patients served by home-based hospices received substantially more care at home and were hospitalized for fewer days in their last months than those in hospital based programs or those receiving conventional care. Patients in any type of hospice were less likely than those getting conventional care to receive diagnostic testing or intensive therapies.¹⁷

In Utah, hospice was associated with improved pain relief and spiritual and emotional support.¹⁸ Examining hospice care delivered by nursing homes in five states, hospice patients were more likely to have their pain detected and treated than those patients not in hospice.¹⁹ Interviews in four states with hospice staff and family members found hospice care associated with enhanced personal care and symptom management compared to patients not receiving hospice care. However, very few patients in either group reported receiving spiritual services and a small minority reported needing more spiritual services.²⁰ A national mortality follow-back survey of family members also found unmet needs for emotional support among one in four terminally-ill patients in home-based hospice.²¹

II. Use and Supply of Hospice

Growth in Use of Services

Use of hospice services has increased significantly in recent years. The number of hospice patients increased from 158,000 in 1985 to 1.2 million in 2005,¹ while adult patients nearly tripled in number between 1991 and 2000.²² Hospice use among Medicare decedents increased from 22% in 2000 to 31% in 2004.²³ Hospice use varies greatly across the country. In 2002, hospice use rate for people over 65 was 28.6% but varied from a low of 8% in Alaska to a high of 45% in Colorado. Maine had the second lowest use rate of 14%. Rates in other states were: New Hampshire (24%); Vermont (19%); Massachusetts (23%); Florida (42%).²⁴

Considering patient characteristics, hospice use increased significantly throughout the 1990s for patients over age 85 and those with non-cancer diagnoses, Alzheimer's disease, or dementia.²² In 1992, 75% of all diagnoses were cancer related and by 2005, this had dropped to 46% of the diagnoses of people using hospice. The most prevalent non-cancer diagnoses in 2005 were heart disease (12%), dementia (9.8%) and lung disease (7.5%).¹

As of 2004, white Medicare decedents were the highest users of hospice, though hospice use has grown among beneficiaries of all racial groups.²³ Among Medicare beneficiaries, hospice use is typically higher among managed care over fee-for-service enrollees.²⁵

Lower Use of Hospice in Rural Areas

Patient use of hospice care is generally lower in rural areas compared to urban. Rural areas not adjacent to an urban area had lowest hospice use at 15.2% of Medicare deaths. The highest rate of use was found in urban areas at 22.2% of Medicare deaths, while rural areas adjacent to urban areas were at 17%.²⁶ A 2003 study found the rate of hospice enrollment among rural patients was approximately 35% lower than urban patients for two types of cancer. However, rural residents enrolled in hospice had a longer median enrollment than urban residents.²⁷ Delivering hospice care in rural areas is complicated by travel distance to patients' homes, low reimbursement amounts for rural providers, and the challenges of recruiting sufficient staff.^{28,29}

While nearly all (99%) metropolitan zip codes are served by a Medicare-certified hospice, fewer rural areas are served by a hospice. Only 76% of zip codes in rural nonadjacent areas and 90% of zip codes in rural adjacent areas are served by a hospice. In 2002, Maine had a relatively high proportion (95.6%) of its Medicare population living in areas served by hospice.³⁰ As of 2000, about 60% of Maine's population lived in non-metropolitan areas.³¹ Since hospice use is lower in rural areas, Maine's rural nature may factor into low hospice use.

Racial Differences in Hospice Use Rates not Apparent

An analysis of hospice data across all payers found that significant racial differences in the use of hospice apparent in the early 1990s had nearly disappeared by 2000.²² Among the Medicare population, white decedents remain the highest users of hospice, but hospice growth has occurred among beneficiaries of all racial groups.²³ Black patients do differ from white patients in that they were more likely to be younger, have Medicaid as their payment source, and were more likely to have HIV/AIDS than white hospice patients.²²

Increase in For-profit and Larger Hospices

Like use, the availability of hospice care has also increased substantially, particularly during the 1990s. The number of Medicare-certified hospice providers grew by 82% between 1992 and 1998, from 1,208 providers to 2,196.³² Growth in the hospice industry was particularly strong among for-profits and large hospice programs as well as among providers in rural areas. Between 1992 and 1999, rural providers increased by 116% while the number of urban providers increased by 64%. However, even among these growing sectors, the majority of hospices were small (with fewer than 100 patients each year), non-profit, and located in urban areas.³²

Growth in hospice availability has continued in more recent years, albeit more slowly than during the 1990s. The number of hospice agencies participating in Medicare rose 26% between 2001 and 2005, attributable to a 57% increase in freestanding hospice providers.²³ As of 2006, 46% of hospice providers were for-profit compared to 31% in 2001.²⁵ In a survey conducted in Maine, 96.5% of Maine physicians reported that hospice services were available in their community in 2005.³³

Home is Primary Setting of Hospice Use

Most hospice care is provided in the home by voluntary nonprofit agencies and by hospice agencies affiliated with some other type of provider. In 2000, most hospice discharges had received hospice care at home (61.2%), while slightly more than one-third (34.9%) had received care at a health facility. Only a small proportion (3.5%) received care from an assisted living or residential care facility. Most hospice discharges were served by voluntary nonprofits (80%), while 15.8% were proprietary and 4.5% were owned by government or another source. About two-thirds of discharges were from hospice providers affiliated or owned by a chain, hospital, nursing home, or HMO.³⁴

Length of Stay

Hospice length of stay (LOS) and timing of hospice care prior to death have been sources of concern to the industry and patient advocates since Medicare implemented its benefit in 1982.¹³ Various data sources show a trend toward many short stays and few long stays prior to the year 2000. From 1992 to 1998, average LOS declined by 20% (from 74 to 59 days), while median LOS declined 27% (from 26 to 19 days).³² Among Medicare beneficiaries, one-fifth (20%) entered hospice one week before their death while 6% entered more than 6 months before death.²⁷ Between 1991 and 2000, the percent of patients with hospice stays of 7 days or fewer increased significantly by 14%. The percent of hospice patients enrolled for six months or more also significantly declined during that time.³⁵ Overall, 58.9% of discharges had a LOS less than 30 days.³⁴ More recent data indicates a modest reversal in short LOS. In 2005, average LOS was 59 days, while median LOS was 26 days.¹ As of 2001, Maine mirrored that median with a LOS of 27.4 days.⁶

LOS varies by demographic characteristics, diagnosis, and geography. Among Medicare beneficiaries, shorter hospice stays were predicted by demographic characteristics such as being male, white, married, and having fee-for-service insurance.²⁷ Patients with Alzheimer's disease had a mean stay of 44.9 days while persons with cerebrovascular disease had a much shorter

length of stay of 6.1 days, with much longer stays for patients with heart disease (61.2 days). Patients with cancer had an average length of stay of 43.3 days.³⁴

Average LOS varied by state from a low of 41 days in South Dakota to a high of 122 days in Mississippi in 2004.²⁵ The average LOS for Maine was 59-68 days during 2004.²³

III. Barriers to Hospice Enrollment

Difficulty Predicting Life Expectancy

Repeated consistently throughout the literature, hospice referral is hampered by the difficulty in accurately predicting a patients' death to within six months, the standard eligibility criteria for most third party payers.³⁶ Prognosis is especially difficult with non-cancer diagnosis because the course of disease is often uneven. Patients with cancer typically experience a long period of good function, with a few weeks or months of rapid decline leading to death. Other conditions such as organ system failure are characterized by a slow decline in physical capacity marked by serious exacerbations and sudden death. Dementia and frailty are marked by decreasing function over the long-term, requiring years of personal care.^{32,37,38}

In a national sample of internists, physicians disagreed about the length of time prior to death that indicates a terminal condition. Physicians who defined terminal as meaning a longer length of time until death (24 weeks) were more likely to refer to hospice than physicians that defined terminal as a shorter length of time (four weeks). Physicians who felt that terminality could not be defined by time were 52% less likely to favor hospice use.³⁹

Physician Practice Patterns and Knowledge

Though the vast majority of physicians report positive opinions of hospice,^{36,39,40,41} significant variations in the actual practice of hospice referral are apparent. Among internal medicine physicians within a non-profit HMO, 37% identified the difficulty in predicting a patients' death to within six months, the most commonly identified barrier to hospice referral.³⁶ It appears that some physicians may not be aware that Medicare hospice eligibility can be recertified indefinitely once the initial six months has past. Other barriers included: lack of time to discuss dying and hospice care; rapid demise of patient; family did not need additional support; and physician did not think to make referral.³⁶ Some physicians may delay hospice referral out of concern that they may lose control of the patient's care, unaware that they may continue to care for a patient referred to hospice.^{32,40} Also, physicians may not be fully aware of the minimal cost of hospice care to patient and family under Medicare.⁴⁰

Hospice leaders perceived medical specialists, surgeons, younger physicians, and physicians located in and around research centers as most likely to continue curative treatment beyond benefit to the patient. Hospice leaders perceive physicians as too busy to manage dying patients well and unlikely to refer because it is not in their financial best interest.⁴²

Though use of hospice in Maine is low compared to the nation, Maine does have a relatively high proportion of primary care physicians and primary care subspecialty physicians certified in palliative medicine: 0.78% of Maine primary care physicians have this certification compared to the national average of 0.33%.⁶

Physician Knowledge and Comfort in Addressing End-of-Life Issues

Physicians and residents may have little knowledge of or exposure to end-of-life issues and little comfort addressing these concerns with patients and caregivers. Though all internal medicine physicians within a staff-model HMO regarded hospice as providing high-quality end-of-life care, very few (16%) correctly identified the National Hospice Organization's eight diagnoses

considered appropriate for hospice referral and fewer (12%) were aware of that organization's guidelines for determining prognosis in non-cancer diseases.³⁶ In examining the ability of medical residents to discuss end-of-life care with patients, very few residents met expert recommendations for the content of advance directive discussions with patients or had received useful feedback from residents or attendings about their ability to discuss end-of-life issues.⁴³ Physicians expressed hesitancy in confronting patients with the terminal nature of their disease, fearing they may signal a loss of hope to these patients by initiating the discussion.^{13,44,45} Physicians may also struggle to accept palliative care when they are trained to find a cure.⁴⁶ Physicians also expressed concern that patients would interpret hospice referral as a cost-containing measure.³⁶

Patient Preferences

Overall patient preferences for life-sustaining treatment are a barrier to hospice enrollment. In a prospective cohort study, few patients had treatment preferences that would make them eligible for hospice; even among those patients who had preferences consistent with hospice, few enrolled.⁴⁷ Other sources indicate that availability of new treatment options may be an important factor in patients' decisions to continue with curative care²⁹ or to focus on curative care until very shortly before death, contributing to shorter hospice stays.³² Even when patients with end-stage cancer were fully informed of hospice alternatives, the majority elected to continue interventional treatment.⁴⁸ On the positive side, however, patient and family preferences for quality end-of-life care are consistent with hospice philosophy including goals of pain and symptom management, achieving a sense of completion, maintaining strong relationships with health care professionals, and attention to spirituality.⁴⁹

Refusal to Acknowledge Terminal Condition

Refusal or failure to acknowledge the patients' terminal condition by the patient or caregiver may also impede hospice enrollment. Patients anticipating their own death appear more inclined to use hospice than those who hope for a cure or improvement. Among two groups of terminally ill patients, 36% of non-hospice patients believed there was a chance of cure or improvement compared to 16% of hospice patients.⁵⁰ In a region of South Carolina, physicians felt that reluctance on the part of the patient and family to admit that death was imminent resulted in late referrals to hospice.⁵¹ Among physicians in a small Midwestern city who referred to hospice care in the community, nearly 70% reported patients and families were unwilling to accept a hospice referral. Over half of physicians reported that families did not want strangers in their home.⁴⁰

Misunderstandings about Benefit

Misconceptions about hospice care and lack of knowledge of end-of-life care also act as barriers. In interviews with caregivers at one hospice agency, caregivers had difficulty describing hospice during study interviews and were particularly unaware that providing comfort is a main focus of hospice care. Over half of caregivers perceived hospice as a last resort service and one-quarter saw hospice as a service for cancer patients only.¹³ Outpatients in Oregon lacked knowledge of general end-of-life issues, even among those who have previously authored an advance directive.⁵²

Cultural or Social Issues Effecting Hospice Use

Cultural or social issues limiting hospice use include the lack of awareness of hospice services and lack of culturally and linguistically appropriate services. In focus groups with African-Americans and Hispanics, the primary barrier to hospice use was an overwhelming lack of awareness of hospice among participants. Additionally, African-Americans reported mistrust of the quality of care they might receive.⁵³ Focus group discussions in California revealed that hospices may discriminate against patients because of staff fears and prejudices (e.g., visiting poor neighborhoods) and that they often lack resources to provide culturally-appropriate care. Some communities and families view planning for death in advance as inappropriate or undesirable.³⁷

Despite these barriers, African-Americans and Hispanics focus group participants described strong preferences for end-of-life care that involved family members and provided for the well-being of the patient and family, preferences that are consistent with hospice care.⁵³

Eligibility Requirements

Hospice is typically available for patients with a terminal illness whose physician believes they have six or fewer months to live. Implementation or interpretation of eligibility may vary in practice, with some hospice agencies restricting enrollment based on patient characteristics or patient use of medical or palliative interventions. Among California hospice programs in 1999-2000, a significant proportion mandated that patients meet several requirements prior to enrollment. These requirements included: patient must have a willing caregiver in the home (26%); patient must be willing to forgo future hospital admissions (29%); patient cannot be receiving total parenteral nutrition (38%); and patient cannot be receiving radiotherapy (36%), chemotherapy (48%), and transfusions (25%). Larger hospices and hospice programs part of a chain were consistently less likely to limit admission.⁵⁴ From a national perspective, interviews with hospice experts revealed concern that Medicare beneficiaries without a caregiver or who have a frail caregiver may be denied hospice access. These experts also reported that hospices may restrict access to beneficiaries using curative interventions (such as chemotherapy, radiation therapy, or surgery) that may also provide palliation because these interventions are not covered under the Medicare hospice benefit and represent an additional cost to the hospice.²⁹

As part of a Medicare fraud and abuse investigation, the OIG examined compliance with the six-month eligibility rule for Medicare beneficiaries receiving hospice services in 1995 and 1996. Advocates and the hospice industry expressed concern that this scrutiny would slow hospice entry for patients with non-cancer diagnoses, because of the difficulty in determining life expectancy for these patients.³² In response, Congress modified the six month rule in 1997 to permit physicians to recertify patients who did not die within six months. Since then, beneficiaries have been eligible for an unlimited number of 60 day extensions as long as their physician continues to certify the patient as terminal. However, this has not resulted in any effect on hospice length of stay.²⁷

Payment Structure in Nursing Homes

A potential barrier to receiving hospice care in a nursing home includes the payment structure of room and board costs for patients dually-eligible for Medicare and Medicaid. Room and board costs for hospice care are not covered by Medicare; however, state Medicaid programs cover

these costs for dual-eligibles in a nursing home.¹¹ Hospices are paid by state Medicaid programs and must, in turn, pay nursing facilities for room and board for these patients. The state nursing facility payment is reduced by 5% when a beneficiary enrolls in hospice. The hospice then negotiates a room and board rate with the nursing facility. This has been perceived as controversial because of the potential for kickbacks.⁵⁵ Other barriers include the need for training of nursing home staff in caring for the terminally ill and better specification of the distinction between responsibilities of nursing home and hospice staff.⁵⁵

Payment Rates: Financial Vulnerability of Rural Hospices

Many rural hospices serve a low volume of patients, leaving them vulnerable to financial instability when faced with high cost patients. Defining low volume as average daily census of three patients or less, 28% of rural nonadjacent hospices were low volume, compared to 15% of rural adjacent hospices, and 5% of urban hospices.²⁶ Summed across patients, the overall median daily payment by Medicare to hospices in 1999 was \$1,421 per day; however, low-volume hospices had Medicare reimbursement of only \$163 per day.²⁶ In case studies of rural hospices, Medicare and insurance reimbursements were insufficient to cover costs, with rural hospices requiring fundraising and donations to cover operating expenses. Smaller hospices may not provide high-cost treatments such as palliative radiation or chemotherapy because they have an insufficient volume of patients over which to spread these costs.²⁸ Several studies have questioned whether Medicare's reimbursement structure adequately addresses the needs of small, rural hospices.^{28,26,56}

IV. Interface between Hospice Providers and Nursing Homes

Benefits and Use

The provision of hospice care in nursing homes is a growing phenomenon that offers both challenges and opportunities. When enrolled in hospice, a nursing home resident and their families receive physical, psychosocial, and spiritual support and care from a hospice team, including drug coverage for medications related to their terminal illness. Residents who receive Medicare Part A skilled nursing facility care cannot access Medicare hospice.

It is estimated that approximately one quarter of all deaths occur in nursing facilities with mortality rates as high as 34% during the year after a nursing home admission. Similarly, residential care and assisted living facilities increasingly provide end-of-life care, with one study documenting mortality rates between 16% and 22%.²⁰

Between 1991 and 2000, the number in inpatient facilities providing hospice care increased by more than nine times and the majority of these patients resided in nursing homes rather than hospitals or other facilities. Many hospice patients received nursing home care before they began receiving hospice care in the same facility.³⁵

End-of-Life Care in Nursing Homes

Studies of end-of-life care in nursing homes suggest that nursing home residents do not receive optimal palliative care. In one study, almost one quarter of residents with daily cancer pain received no pain medication and residents were often transferred to hospitals for aggressive care in the last weeks of life.⁵⁷ Families have also expressed dissatisfaction with end of life care in nursing facilities.²¹

Quality of Hospice Care in Nursing Homes

Hospice use in nursing facilities has been associated with indicators of quality care, including enhanced personal care and pain and symptom management,²⁰ reduced hospitalizations,¹⁹ and was well-valued by family members.⁵⁸

Satisfaction of family members of nursing home residents who use hospice and those who did not have found mixed results. One study conducted in a sample of residential care and nursing facilities in four states found high levels of family satisfaction of both groups. The study found no differences in care and outcomes between decedents who did and did not receive hospice, with the exception of treatment of pain.²⁰ Another study found that those nursing facility residents who enrolled in hospice had fewer acute care admissions, spent fewer days in acute care, and families rated the resident's care more highly than did families of residents who did not receive hospice.⁵⁹

Variation in Use of Hospice in Nursing Homes

The rate of hospice use in nursing homes varies considerably across the country. The percent of nursing homes with at least one person receiving Medicare hospice in 2001 ranged from 37% in

Wyoming to 96% in Florida. Maine ranked 49th with 41% of nursing homes collaborating with a hospice.⁶⁰

A number of factors contribute to the differences in use of hospices in nursing facilities. States with higher levels of collaboration tended to have larger hospices. In addition, states with a higher percent of older adults in rural areas and states with higher nursing home occupancy rates had lower rates of hospice collaboration. The presence of Medicaid case mix payment was also associated with lower levels of nursing home/hospice collaboration but since state case mix payment systems differ significantly, the association is not entirely clear. Some states with Medicaid case mix reimbursement began removing residents enrolled in hospice from a nursing home's calculated case mix rate creating a chilling effect on hospice/nursing home collaboration.⁶⁰

Organizational and Policy Factors

Other organizational and policy factors contribute to the rate of nursing home and hospice collaboration. Some nursing home administrators are hesitant to collaborate because they fear surveyor citation when care approaches are different than what regulations encourage (e.g., honoring a person's wish not to eat or drink). Initiation of hospice can be administratively burdensome. Policies and procedures must be established to achieve well coordinated billing, to integrate care and care planning across programs and staff, and ensure consistent communication at all levels. Hospices providing large amounts of care in nursing homes have special teams for nursing home residents and manuals and forms specific to coordinating care.⁶⁰

The complexities of payment particularly for residents who are dually eligible for Medicaid and Medicare can be a barrier. In some states, the nursing home Medicaid per diem is paid directly to the hospice who in turn pays the nursing home. In other states, Medicaid pays a per diem rate directly to the nursing home. This often results in delays in payments. It is often not clear what constitutes a duplication of services when hospice is provided in a nursing home.

Professional Factors

Another major challenge is the difficulty of two organizations and two specialties working together to provide end-of-life care. Barriers related to interprofessional and interorganizational collaboration impede such collaboration. Nurses, aides, social workers, clergy and physicians employed in nursing homes and hospice have training and experience in environments with different care philosophies, approaches and goals of care.⁶¹ Barriers related to nonprofessional collaboration include distrust of other occupational groups and lack of respect and trust of other approaches to care. Other challenges include role competition, role confusion, and turf issues.⁶¹

Successful Collaboration

A study of 19 nursing home/hospice collaborations examined the barriers as well as the practices that resulted in successful collaboration. Interviews were held with 19 nursing homes and hospice providers. Of those studied, all hospices initiated the collaboration although their reasons for initiating the collaboration varied. Some felt that their mission required them to offer hospice in any nursing home while others more selectively worked with nursing homes with quality reputations. Nursing homes on the other hand often limited the number of hospice contacts to reduce the number of contacts with which the staff had to contend.

Most of the nursing home staff reported receiving hospice training on Medicare admission criteria. The most common reasons for referring to hospice were presence of poorly managed pain and family problems with impending death. Physicians rarely initiated hospice referral; referral most often occurred after hospice was suggested by the social worker. Nursing home nurses and social workers appeared to be the gatekeepers of hospice referral. Families often requested hospice after seeing the additional services provided to another patient in the facility who received hospice care. Care planning between the nursing home and hospice was not typically integrated into one plan; nursing homes reported that they included the hospice in their care plan but the hospices usually had separate care plans.⁶¹

Differences in the philosophies regarding approach to care tended to diminish the longer a hospice was partnering with a nursing facility. When interviewed, the nursing home staff identified a number of benefits from the provision of hospice in the facility including extra one-on-one care and psychosocial support to residents and families. It was also important to the nursing home staff that their knowledge and skills be recognized. The presence of hospice influenced the care within the home particularly related to pain and symptom management, staff attitudes toward death and dying, and focus on comfort care.⁶¹

In instances of successful hospice/nursing home collaboration, nursing home staff and administrators reported that hospice helps to provide more one-on-one care to dying residents and there was a “spill-over” effect when there was greater hospice presence in the nursing home. Such homes are likely to have fewer hospitalizations at end-of-life and more frequent assessments of pain.⁶⁰

V. Care of People with Dementia at End-of-Life

Alzheimer's disease is the fifth leading cause of death among older Americans, and the mortality rate due to Alzheimer's is increasing faster than any other fatal condition. Approximately 70% of older adults with dementia die in nursing homes, compared with 21% dying with cancer and 28% with other chronic diseases. Furthermore, the percent of hospice recipients with dementia exceeds that in the community. The difficulty of prognosing death for people with dementia has hindered access and appropriate timing of referrals for dementia patients. Studies of the end-of-life experience of people with dementia have been limited.

For this reason, a more recent study examined families' end-of-life experience for those with dementia compared with decedents with other common terminal illnesses. Using a national sample of the Family Evaluation of Hospice Care Survey, the study examined family members' experience with hospice care. In general, all respondents rated hospice care as excellent, regardless of diagnosis. Seventy-six percent of respondents rated their satisfaction as excellent compared with 73% of families whose loved one had dementia. In all groups, approximately 17% of respondents reported at least one problem with coordination of care; 20% reported at least one problem with the patient's overall condition; and 30% with the provision of emotional support to the family. The responses from family members of decedents with dementia versus cancer or other chronic disease were similar across groups.¹⁶

The difficulty of accurately estimating life expectancy of people with dementia has been cited as a barrier to timely and appropriate access to hospice care. The Medicare hospice benefit requires that beneficiaries have an estimated life expectancy of less than six months. National surveys of hospice providers have cited the difficulty of predicting survival as a major problem in the delivery of care to people with dementia. A recent study used MDS data from nursing homes to develop a risk score for predicting six month survival. The results of the study indicate that 12 variables from the MDS estimate six month mortality for nursing home residents with advanced dementia with greater accuracy than existing prognostic guidelines.⁶²

A recent report from the Alzheimer's Association identifies the important aspects of end-of-life care for people with dementia in residential care settings. The most important issues included communication and decision making about end-of-life care. Experts agreed that health care professionals (doctors, nurses, social workers) must be prepared to discuss resident's care goals and progressive and inevitable decline toward death that is expected with dementia. This includes "planting the seed" for discussion about goals for the resident as early as possible.

Symptom management, particularly because of residents' aphasia, was noted as a particular challenge. Psycho-social and spiritual support for residents and family members is also important. A key component of this support is the interaction with the facility staff and the resident. Providers also play a key role in supporting family caregivers throughout the long grieving process and in providing bereavement support after the death of a resident. The major public policy barriers to delivering quality palliative care in nursing homes included: the incompatibility of the Medicare skilled nursing facility benefit and the hospice benefit; Medicare hospice eligibility criteria; differences in quality assurance systems, and inadequate provider reimbursement.⁶³

VI. Payment Issues

The Medicare hospice benefit covers an array of services including skilled nursing services, drugs, physical, occupational and speech therapy, counseling, home health aids and homemaker services, short-term inpatient care, short-term respite care and other services necessary for palliation and management. Payments for hospice are made according to a fee schedule that has four basic components: routine care, continuous home care, inpatient respite care, and general inpatient care. The payments vary by location and intensity of services provided and are adjusted for differences in area wage rates.⁶⁴ In addition to these rates, there are two fixed annual caps; one is a dollar amount and the other limits the number of days of inpatient care. The caps are based on an agency level rather than on a patient specific level.⁵

MedPAC has recommended an evaluation of the hospice payment structure to ensure rates are consistent with costs of providing adequate care. Specific recommendations were made to examine adjustments for patient case mix, outliers, length of hospice enrollment, setting (home or nursing home), geographic region (urban or rural) and eligibility requirements.⁵

Changes in the mix of patients served by the Medicare hospice program, the settings in which people are receiving services, and changes in palliative treatments raised questions about whether the Medicare hospice payment system accounts for the current costs of caring for hospice users. Limitations on data for cost and use of hospice by Medicare beneficiaries in nursing homes have impeded full analysis of these questions. Historically, Medicare hospice data did not readily allow identification of nursing home residents and did not include beneficiary level data on the number and types of visits, use of drugs, equipment and supplies, etc. MedPAC and others continue to examine the adequacy of the payment rates and the need to re-examine their structure given the changes in the use patterns of hospice beneficiaries since the time the original program and payment system was designed.

VII. Cost Effectiveness

Studies on the high cost of health care in the last year of life have focused attention on the cost effectiveness of hospice programs. Previous studies have shown that spending in the last year of life is almost six times higher, on average, than the annual spending of Medicare beneficiaries who do not die.⁵ One study of expenditures in Massachusetts and California found that Medicare expenditures in the last year of life decrease with age, especially for those 85 years of age and older. This is in large part because the aggressiveness of medical care in the last year of life decreases with increasing age.⁶⁵

Many studies have examined whether the use of hospice services saves money for the Medicare program. In fact, the hospice benefit was originally designed (with restrictive eligibility criteria, waiver of curative care and the cost caps) to reassure policymakers that it would not substantially increase Medicare costs.⁵ Early results from the National Hospice Study found that home-based hospice and hospital-based hospice patients cost less than those without hospice, particularly in the last months of life and overall in the last year of life.⁶⁶

The change in enrollment patterns and the mix of patients served in hospice (e.g. an increase in non-cancer patients such as patients with COPD, congestive heart failure and Alzheimer's disease) have provided impetus for continued study of this question.

More recent studies have shown mixed results. A study using a 5% sample of all Medicare beneficiaries in 1999 and 2000 examined the costs of 16 narrowly defined types of diagnoses including a number of cancers, COPD, Alzheimer's disease and stroke. The study examined the cost until death for patients choosing or not choosing hospice, starting with the date of a predefined "indicative marker." The indicative marker was used to indicate the point at which a patient would shortly thereafter be advised to consider obtaining hospice. For all diseases except prostate cancer and stroke, mean cost was lower for patients who chose hospice, but this was significant only for CHF, liver cancer and pancreatic cancer. The study also showed that certain patients who chose hospice lived longer than those who did not.⁶⁷

Another study published the same year, however, found that Medicare costs in the last year of life were higher overall among hospice enrollees than non-enrollees, although this varied according to diagnosis. The study found that hospice use appeared to reduce Medicare expenditures for those with cancer who are younger than 85 years of age but to increase costs for patients without cancer and all patients over 85 years of age. Overall, hospice users were found to incur costs that were 4% greater than similar patients who did not use hospice, with the relative costs of hospice highest among patients with dementia and relatively nonspecific diagnoses. The authors suggest that these patterns reflect differences in service needs and in trajectories to decline and death. Cancer, for example, is associated with a short period of decline at end-of-life; diseases associated with organ system failure, such as heart and lung disease, tend to be associated with long-term limitations with intermittent serious episodes; and deficits in self-care associated with frailty or dementia have prolonged and dwindling declines.⁶⁸ One key factor explaining this result was that hospice decedents without cancer tend to use more intense hospital inpatient services before they enter hospice and have more expensive hospice stays.

A more recent study used an approach intended to account for weaknesses in earlier studies, namely the period of time over which costs of hospice users and nonusers are compared. Previous studies have used the last year of life as the focal point for such comparisons. Because of the extreme variation in the length of hospice use, determining the appropriate time over which to estimate cost savings is difficult. This study used an approach that identified the length of hospice use associated with the maximum expenditure reductions possible. This was done using a retrospective case control method that identified hospice users and then created a control group of similar people who did not use hospice. Hospice use reduced Medicare expenditures by around of \$2,300 per hospice user; expenditures after initiation of hospice were \$7,318 for hospice users compared with \$9,627 for controls. Total costs for the entire last year of life did not differ between hospice users (\$32,727) and controls (\$33,837). However total Medicare costs during the last year of life prior to hospice entry were higher for hospice users compared to controls. Most of this cost difference occurred in the week prior to initiation of hospice.⁶⁹

All of the above studies and indeed most of the literature focus on cost savings attributable to the Medicare hospice benefit. An actuarial analysis conducted by Milliman for the National Hospice and Palliative Care Organization in 2003 examined the question of the value of the hospice to the Medicaid program. This study focused primarily on the Medicaid only hospice program although it also looked at the impact of Medicare hospice on Medicaid patients in nursing homes. This study estimated that without hospice, Medicaid would pay an additional \$228 million in order to continue end-of-life care in the hospital; an additional \$41 million to pay for expensive pharmaceutical treatments; and an additional \$13 million for the payment to nursing homes, due to the technical way in which nursing homes are paid when a person who is dually-eligible for Medicaid and Medicare receives Medicare hospice in the nursing facility.²

We found no studies of the substitution effect and potential cost savings associated with the use of the Medicare hospice benefit by Medicaid participants. For Medicaid patients who are receiving care at home or in a long term care facility, the use of the Medicare hospice benefit could potentially result in reductions in Medicaid costs associated with home care services, and residential care and nursing facility services. This is an area worthy of further study and could have significant cost and policy implications.

VIII. Opportunities for Improving Access

The barriers to the timely use of hospice discussed above still leave open the question of how to improve access and early use of the services available. Those who have studied this question suggest that it is time to look at the use of hospice through the view of the user and consider the factors that improve the usability of the program. Casarett proposes the use of the usability paradigm to better understand ways to improve the system. According to this approach, it is helpful to review the definition of “usability.”⁵⁷

Usability is “that quality of a system that make it easy to learn, easy to use and encourages the user to regard the system as a positive help in getting the job done.” Under this theory, one can either make the product more usable (e.g., the design of the benefit, structure of payments) or improve the user interface. Casarett argues that it is important to view the program from the perspective of the user. The key elements to consider as part of the user interface are 1) who initiates the hospice decision 2) the timing of the decision 3) who makes the decision and 4) the information that patients and family members need to know and when they need or want to know it.⁵⁷

Decision Making Process for Entering Hospice

Physicians and families are important contributors to the decision to enter hospice care though their actual rank of importance in decision making is unclear. One study found that families made the decision to enter hospice for 42% of patients, while 28% of patients made their own decision, and 27% of physicians made the decision.⁵⁰ Another found that physicians initiated 76% of hospice referrals, with patients and family jointly initiating 10%.⁷⁰ However, there may be greater reliance on physicians for end-of-life issues in Maine. Speaking hypothetically about their own needs for end-of-life care, nearly all (98%) of Maine adults would discuss these issues with a physician. Only 35% said they would discuss their needs with a family member.⁴¹

Preparing for Hospice Care

The literature reveals specific information needs for terminally-ill patients and ways to identify patients potentially eligible for hospice. Patients and families deciding whether to enroll in hospice have specific information needs including the frequency of hospice visits, the type of practical support hospice provides at home, and payment options. Efforts to enroll patients earlier in hospice should focus on providing these pieces of information to patients and family.¹⁴ An intervention in nursing homes composed of a brief scripted interview and simple criteria to determine hospice appropriateness resulted in hospice referral for approximately 20% of nursing home residents within 30 days. The interview identified residents whose goals for care, treatment preferences, and palliative care needs made them appropriate for hospice care. The authors suggest this intervention could be implemented in any long-term care setting and used with minimal staff training.⁵⁹

Hospice use appears to be predicted among persons well-prepared for end-of-life issues in general. In Utah, hospice use was associated with having a living will, knowledge that illness would lead to death, and information about what to expect at the time of death and after death.¹⁸

Earlier referrals and longer hospice length of stay are associated with greater perceived benefits among caregivers. Longer hospice enrollment before death was associated with higher family ratings of residents' quality of care^{59,71} as well as greater relief of caregiver burden¹³ and caregiver mental health.⁷² Optimal length of stay is difficult to identify but studies suggest that most benefits are provided when patients stay between three weeks and three months¹⁴ or as soon as active treatment is discontinued.¹³

Coordination and Transition Support

The literature reveals provider models using elements of curative and palliative care that have successfully demonstrated continuous care and increased hospice referral. These include home-based programs that ease the transition between curative and hospice care^{73, 74} and concurrent care by cancer and hospice providers.⁷⁵ Many commercial plans do not require the suspension of curative treatment while a patient undergoes hospice. Two large insurers – Aetna and Kaiser Permanente have started programs that allow patients with terminal illnesses to receive a combination of palliative and curative care⁵, approaches that combine life-prolonging treatment, palliation of symptoms, and support for caregivers may potentially be a more effective form of end-of-life care and remove barriers to hospice access.³⁵ Some suggest that one way to move palliative care “upstream” is to introduce a care manager to the process early on. The care manager would walk the patient and family through the disease process from diagnosis to bereavement.⁷⁶ A number of the programs that have been developed to offer more comprehensive and coordinated programs for end-of-life care have done so through the use of capitated payments that provide greater flexibility to providers in developing and managing care and services.

Medicaring

Many researchers have called for Medicare to encourage the provision of palliative care that is not so tightly tied to prognosis.⁵ One model of care that is being discussed for end of life care is called Medicaring. The core idea is to have eligibility criteria more appropriately align with the three major trajectories of decline. The criteria would be “replicable and administratively feasible” rather than accurate. Supporters suggest that this approach provides an opportunity to blend the interdisciplinary team, continuity and symptom relief that are part of hospice with the self education, timely reminders for prevention and advance care planning associated with successful chronic illness management. The ideal funding for such an idea is a capitated rate that blends Medicaid and Medicare payment.⁵⁴

Advanced Illness Management Program

Another example of a program that seeks to support the continuity of care for people with advanced but not necessarily terminally ill patients is the Advanced Illness Management Program. A program of a VNA and hospice provider, the program provides a full range of services for people at home with a serious illness that are nearing the end-of-life. This program offers a combination of home care, which can be episodic, and palliative care for people who have not yet chosen hospice. The program provides concurrent disease modifying and comfort care. An evaluation of the program found a 28% difference in the number of hospice referrals between patients who received the AIM intervention and those who did not. The program was considered successful at increasing hospice utilization through a targeted intervention focused on palliative and end-of-life care, increased patient education, and a dynamic treatment approach.⁷³

IX. Opportunities for Improving Quality

New initiatives are underway to bring quality assessment and improvement activities to the hospice industry. The National Hospice and Palliative Care Organization (NHPCO) developed standards of care for hospice programs in 1979; however, there has been no enforcement of those standards or way to determine compliance. Since 2000, the NHPCO has sponsored a National Data Set to establish benchmarks for hospice practice throughout the country.³ Participation in the NDS allows hospices to compare themselves against other hospice providers performing similar activities. A 2006 report by the National Quality Forum endorses a framework for developing a comprehensive quality measurement and reporting system for palliative care and hospice services and endorses a set of preferred practices designed to improve palliative and hospice care.⁴ The Medicare Payment Advisory Commission has recommended that Medicare should establish and collect quality measures for public reporting to encourage hospice quality improvement.⁵

A Robert Wood Johnson Foundation Initiative funded a Toolkit of Instruments to Measure End-of-Life Care (TIME). A goal of this program is to incorporate perspectives of patients and family members that are clinically meaningful and are reliable and valid.¹⁷

The minimum data set for nursing facilities (MDS) has core information that provides a starting point for developing some quality measures for end-of-life care. These include indicators such as: use of advance directives in terminally ill patients; do-not-resuscitate orders among nursing facility residents with severe cognitive impairment; use of feeding tubes among people with severe dementia; and use of hospice by nursing facility residents. Similar measures could be developed from the MDS-RCA (for people in residential care facilities) and people using home care.

Two organizations provide accreditation services to hospice agencies. Since 1984, the Joint Commission (formerly the Joint Commission for Accrediting Health Organizations) has offered accreditation of home-based hospice programs. It does not appear that the Joint Commission offers accreditation for hospice provided in other settings. Since 1999, the Community Health Accreditation Program, Inc. has been the regulatory authority to survey agencies providing hospice services, to determine whether they may provide services to Medicare beneficiaries.

X. Research Questions for Maine

The results of this literature review suggest a number of further questions for research. These include:

- What is the rate of hospice use by setting (e.g., home, hospital, nursing home, patient home, and residential care) in Maine? How does this compare with national use rates? Who is using those services (e.g. people with dementia, people with cancer, etc)
- What is the relationship between supply of hospice providers and other providers and use of hospice in Maine? How does this vary by urban/rural areas?
- What percent of people in long term care in Maine have diagnoses and ADL levels that are potentially consistent with hospice use? Are people who might be eligible for hospice being informed of/offered/using hospice?
- What are the factors that promote successful use of hospice in residential care and nursing facilities?
- What is the quality of hospice services provided in Maine?
- What is the impact of Medicare hospice use on Medicaid costs?
- Are there ways to improve the coordination of end-of-life care and financing between Medicaid and Medicare?

XI. Conclusion

Data is critical to understanding the cost, use and quality of hospice services in Maine. There are a number of data sources available that can help better inform policy and practice in Maine. This includes Medicare and Medicaid data, MDS nursing home data, MDS-RCA residential care data, and Mecare home care data. In addition, the hospice providers have data that is unique and could further inform policy and practice, These includes data on supply, use of services by type of providers, and quality of services. Data, as transformed into information, is necessary to fully inform research, policy and practice on an ongoing basis.

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