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Barriers to Medicare Hospice Utilization



A Qualitative Study of
Maine Medicare Hospice
Providers

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Judy Tupper, MS, CHES
Institute for Health Policy
Muskie School of Public Service
University of Southern Maine
jtupper@usm.maine.edu



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Muskie School of
Public Service

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Executive Summary

The Maine Hospice Council, representing a diverse group of stakeholders, successfully petitioned the Carpenter Foundation for funding to examine the low rate of Medicare Hospice benefit utilization in Maine. The funding supported a review of the literature concerning hospice utilization, a review of claims data, a symposium with national experts and focus groups, and a qualitative study of barriers to utilization. This report presents the findings of the qualitative study which includes the perspectives of all 26 Medicare certified hospice providers in Maine.

Significant findings of the qualitative study:

- There is a continuing **need to educate the general public** about hospice and the Medicare benefit. Maine consumers do not know the details of the benefit and they do not actively seek access to the benefit that they are entitled to.
- Maine health care providers have **low referral rates** to the programs and often misunderstand the regulations and guidelines of the benefit.
- Referrals to the hospice programs are based on **fragile systems of communication** that frequently break down due to poor timing, failure to address terminal illness, lack of education, and negative bias of individuals at various points in the referral process. The referral process is fraught with potential miscues, misunderstandings and missed opportunities.
- **Hospice providers in Maine do successfully serve patients in both for-profit and non-profit models.** While misunderstandings and “turf issues” are not uncommon, these providers do feel as though they can learn best practices from each other. Additionally, providers indicate a strong interest in coming to the table to collectively address the underutilization of the Medicare hospice benefit in this state.
- **Active “consumerism” may be an important key to increased dialogue and acceptance of end-of-life care.** Open discussion about the dying process, patient wishes, and palliative care in lieu of curative treatment, must be facilitated and encouraged. Demand for hospice services may not increase until the consumer is engaged in the conversation.
- **The Medicare benefit has certain components that appear open to varying interpretation and application.** This may be a source of confusion for consumers and referring physicians and a potential source of tension between certified agencies.

- **Significant workforce issues** impact the ability of Maine hospice programs to meet even the current demand for services. The nursing shortage, the aging of trained nurses already in the field, competition for personnel with higher-paying positions at hospitals and nursing homes, the challenges of providing care in remote and rural locations, and the emotional toll of caring for persons at the end-of-life, all tax the ability of hospice programs to recruit and maintain staff. Future increased demand by consumers for hospice care may require significant attention to the availability of a larger workforce in Maine.
- **Provision of hospice in long-term care facilities is both an opportunity and a challenge.** Current practice reflects turf issues between hospice and LTC staff and some degree of awkwardness in the coordination of care. Open dialogue concerning reimbursement and definition of duplication of services may help to increase utilization in this setting.

Maine hospice program leaders have many policy and practice suggestions to increase the utilization rate of hospice in this state. They look to the Maine Hospice Council to lead the way in the education of consumers, healthcare professionals, and the business community not only to educate the public about the benefit, but to significantly promote end-of-life care awareness. A media “blitz” was often mentioned as a possible way to desensitize and normalize the public discussion around death, fear of dying and hospice.

It is also felt that state government can take a more active role in the promotion of hospice utilization. Specific suggestions include workforce development, encouraging hospice in psychiatric hospitals, education around MaineCare hospice benefits, analysis of Medicaid data to emphasize potential cost savings to the state, review of state required assessment protocols and finally, a strong endorsement of hospice and palliative care by government officials.

The providers look to the Centers for Medicare and Medicaid Services (CMS) to produce and promote easily understandable consumer and physician information about the hospice benefit. Referrals to hospice programs can be fostered through public policy, a national campaign, and use of consumer support services with the goal of preventing unnecessary hospitalizations and the provision of optimum pain management.

Specific suggestions and issues raised through this survey will be addressed in a small working group of stakeholders. The working group will develop an action plan to meet the identified needs and seek funding to support pilot activities to test solutions.

Background

Recently, Maine ranked 48th in the fifty states in utilization of Medicare hospice services. According to the U.S. Census Bureau, Maine is currently the “oldest” state in the country with potentially high need for hospice services. Yet Maine Medicare certified hospice programs have historically low referral rates and this is particularly true in the southern region of the state. Stakeholders engaged in hospice services, healthcare, social services and advocates for the elderly in Maine have expressed concern about this underutilization. In 2006, the Maine Hospice Council successfully applied to the Carpenter Foundation for grant funding to examine the barriers to hospice access and utilization in Maine. The Maine Hospice Council contracted with the Muskie School of Public Service to conduct several activities as part of this initiative. This included:

- Assistance in convening a stakeholder’s summit
- Summary of issues and action steps identified at the summit (Appendix A)
- Review of literature (separate report)
- Study of barriers to Medicare hospice utilization

This report represents the qualitative study of barriers to utilization from the perspective of the Maine Medicare hospice providers. The goal of the research is to interview each of the 26 Medicare certified and licensed hospice providers in Maine and gather information about barriers. Following the final report, the Maine Hospice Council plans to convene another group of interested stakeholders to develop an action plan to respond to the information collected in the literature review, stakeholder’s summit, provider study and some analysis of claims data. The Council intends to seek additional funding to pilot interventions to address the underutilization.

The Study Process

Survey questions were developed by the research staff at Muskie School. These open-ended questions were informed by the literature review, results of the stakeholder focus group sessions at the Medicare Hospice Access and Utilization Symposium on March 30, 2007 and several key informant interviews. (A brief overview of the issues and action steps identified by each of the four discipline specific focus groups from this symposium may be found in Appendix A of the report.) A set of 27 open-ended questions in five categories were designed to provide a comprehensive overview of factors relevant to utilization from the perspective of the hospice provider. Data was collected through a semi-structured interview process. Subjects were asked a series of open-ended questions with opportunity to provide additional insight, experiences, suggestions not covered in the questions. This qualitative data was analyzed for thematic content and organized in the aggregated, de-identified format found in this report. No individual name or agency name will be associated with the responses nor reported to the sponsoring organization or funder.

The survey protocol, consent process and interview questions were reviewed and approved by the University of Southern Maine Institutional Review Board. The Maine Hospice Council provided the research team with a list of current Medicare certified hospice providers in the state of Maine. All of the 26 hospice providers (who are members of the Maine Hospice Council) were sent letters by the Maine Hospice Council informing them of the study. Muskie staff then contacted the administrator at each agency to request participation and set up a phone interview time. Researchers contacted each hospice to ascertain the appropriate individual to participate in the interview and obtained informed consent. In most cases, this individual was the senior administrator for the agency. Semi-structured telephone interviews with 21 hospice executives were completed representing each hospice organization in the state. Interviews were tape-recorded to allow for review of notes. Most interviews lasted an hour or more. Interviewees were given the opportunity to provide opinions or share information outside of the set interview questions. The interviewers used probes or follow-up questioning for expansion of responses or for clarification.

Following the interviews, the researchers met to analyze the results and develop themes from the content. Preliminary findings were then organized and reviewed once again. An overview of the results was presented at the Maine Pain Management Symposium on September 18, 2007. An executive summary and final report will be submitted to the Maine Hospice Council and the funding organization, the Carpenter Foundation.



Under the Surface

Low Utilization

Understanding the low utilization rate in Maine

The Maine hospice providers see an overall lack of information and understanding of the Medicare hospice benefit. They feel that general knowledge about hospice is an issue for all parties involved – those who make referrals and the consumers who are entitled to the benefit. There exists confusion about the costs of hospice and how much the consumer may be responsible for those costs. It is felt that often consumers misunderstand the term hospice and think that hospice is a place rather than a service. Many feel that Maine may lag behind other states because of stronger outreach and consumer/medical provider education elsewhere.

Hospice providers perceive a strong reluctance on the part of Maine physicians to refer their patients to hospice care. It is thought that Maine physicians are often afraid to talk with their patients and families about death. Frequently, referrals to Maine hospices come too late to be particularly helpful to the patient or their families. Mentioned often is the concern that physicians think only of hospice care when the diagnosis is cancer and do not consider referral for other diagnoses such as end stage dementia or the end stage of other chronic illnesses. Some hospice providers feel that older physicians and physicians that practice independently are less likely to refer their patients to hospice.

Another recurring theme involves the “Yankee mindset” of Maine residents. The independent and private character of those who live here may contribute to a reluctance to receive assistance from volunteers, receive care in the home, and receive spiritual and social work support. Several interviewees cited the tendency of American society to ignore death and that this tendency may be just more entrenched in Maine than some other states.

Two other themes emerged from the discussion around Maine’s low utilization rate. One theme is that many providers feel long-term care (LTC) providers are not as receptive to hospice care as in other states. More specific comments regarding LTC referrals can be found further in the report. Second, there may be a lack of a safety net for Maine’s poor to stay at home at the end of life. This is particularly the case for those individuals who are underinsured, too young to qualify for Medicare or who do not meet criteria for Medicaid.

Why is the utilization rate higher in northern rural Maine?

The Maine Hospice Council reports varying rates of utilization within Maine and has noted lower rates of utilization in the southern, more populated regions of the state. The hospice providers were asked to comment on this discrepancy in utilization. Respondents cited the limited access to physicians and fewer specialists (who tend to refer less) as a reason that Maine residents from the northern regions might be more likely to use home-based care. Rural residents are accustomed to receiving their healthcare by nurses as there are fewer physicians available. In reality, there are fewer options available to the consumer, as well as the referring provider. Often times, homecare is a more attractive option to both patients and their families as the distance to a hospital can be quite significant. In the rural areas the family is more likely to be the primary caregiver and may be more willing to receive all the help that is offered. Additionally, many hospice providers feel that a stronger tie and sense of community exists in the northern rural regions of the state. This can lead to strong and positive word-of-mouth, more familiarity with the hospice program, its staff and its volunteers, all positive factors that can increase utilization. Hospice providers cite a long history of poor referral rates in the southern part of Maine and suggest that this has been difficult to change. Finally, some wondered if there is an inverse correlation between hospice utilization and number of hospital beds in a given region.

The Medicare benefit and its influence on the utilization rate

Interviewees were encouraged to discuss both positive and negative aspects of the Medicare benefit that influence utilization. The hospice benefit provides a comprehensive reimbursement package that removes the financial burden of medical care for clients and their families. The actual out-of-pocket costs to the family are low and the hospice agency receives all the billing. Additional services such as medications, durable medical equipment and social work are all covered under the benefit. The services that volunteers provide are an additional help to the family and perceived as highly desirable. In addition, the agencies provide bereavement services to the family of the deceased. Several agencies pointed out the fact the hospice care does not have the homebound requirement like the Medicare coverage for home care services. This is seen as a very positive difference between home care coverage and hospice coverage.

Overwhelmingly, the Maine hospice agencies feel that the “six month or less” prognosis eligibility requirement is problematic. They cite the difficulty in both the perception and accuracy of such predictions and that this sets up discomfort for both the referring physician as well as the patient. Mentioned often here and in other related areas of the interviews, this discussion of prognosis with the patient – which is necessary for a referral to hospice – is seen as a barrier to timely referral and frequently results in avoidable delays in referral. This is particularly true for those patients who are experiencing declining health or another non-cancer diagnosis. This is considered a difficult conversation for both physicians and patients and one in which training and guidance could be helpful.

The hospice providers report the challenge of meeting the needs of patients with end-stage renal disease and receiving dialysis, for example. In general, challenges are faced as both patients and physicians often continue to seek curative treatment despite the existence of a terminal prognosis. Increasingly, chemotherapy and radiation are used as part of palliative treatments and this expense impacts the hospice daily reimbursement rate in a significant way.

There is also the perception that hospice care covers 24 hour care. While many hospice patients receive extensive assistance from the hospice team, including volunteers, there is no provision to provide around the clock coverage. Also, the Medicare hospice benefit states that there must be a primary caregiver for the patient. Many patients do not have family available to fit this role and hospices are often creative in their ability to take on such clients and patchwork a system of friends, neighbors and volunteers to allow the admission to hospice care. However, when a hospice referral occurs certain nursing facilities, patients are denied hospice services if the facility does not have 24/7 Registered Nurse (RN) coverage due to CMS regulations. It is not unusual in some of the smaller facilities to find an LPN (Licensed Practical Nurse) providing the overnight or weekend coverage. This is an important factor in a rural state that has a significant shortage of RNs and a wage differential between hospitals and long term care.

Finally, it is not unusual for patients who are admitted to hospice care under the benefit to improve under the extensive care of the hospice program. This scenario sets up a seemingly incongruent situation where the client “graduates” from hospice care temporarily. While this can be seen as a positive situation from the client’s perspective, it only reinforces the difficult nature of the initial 6 month or less prognosis from the referring physician’s perspective.

Clarity of the regulations and guidelines

The respondents split down the middle as they considered the clarity of the Medicare hospice regulations and guidelines. During each interview, the hospice providers weighed the consequences of “black and white” regulations. There is a definite trade-off between flexibility to meet the varying needs of the clients and the uncertainty that may lead to confusion, inappropriate or late admissions, and financial risk to the agencies. Some felt that the guidelines need to be updated to reflect current medical advances, particularly in regard to newer palliative care treatments.

There were some specific guidelines/regulations that the providers raised as sources of potential uncertainty. Some of the less clear areas:

- What exactly is “routine care”? Does this vary significantly based on the diagnosis?

- Why are there significant variations between agencies in admission standards? This is confusing to both consumers and providers.
- What is meant by “short-term use of inpatient benefits”?
- Particular to long-term care hospice admission, what is considered duplication of services?

Potential for denial of claims and impact on utilization

Most of those interviewed felt that that the potential for denial does not impact utilization. Many said that fraud and abuse occurs in other states, not here in Maine and they see a very low rate of denial of claims. They point to their reliance on the interdisciplinary team (IDT) to make good decisions and that the development of internal policies and procedures help them avoid denial of claims.

However, some hospice providers feel the pressure of conflicting messages from both the state and federal government – increase utilization of hospice benefits but watch out for claim denial, probe audits, and fraud investigation. Sometimes the documentation process can be difficult and it can be a challenge to provide the burden of proof. As previously mentioned, there is some awkwardness in the process when a patient’s clinical situation improves while under hospice care. Some reported incidences where family members have worried unnecessarily about denial of claims and whether the family will ultimately owe money to Medicare if claims are found to be inappropriate.

Differences between Medicare hospice benefit and private insurance hospice benefit

In general, the Medicare hospice benefit is considered the “gold standard” and in fact better than a number of private insurance benefits. The Veterans Administration (VA) benefit is also rated highly. Often, private insurance tries to mirror the Medicare package, but there are caps in the coverage not seen in Medicare. It was pointed out however, that private insurance covers a different population. Private insurance covers younger patients with different needs with higher cost drugs. Sometimes, Maine hospice providers have found more flexibility in the care of these private insurance patients as they tend to sign on to the program earlier and have a case manager provided through the insurer. The reimbursement structure can vary significantly from plan to plan and the hospice providers must thoroughly examine these benefits in order to fully meet the needs of their clients. It is not unusual to find private insurance clients unaware of their hospice coverage.



Finding the Harbor

Barriers to Referrals

The barriers to referral to hospice care generated much discussion. There are many factors that come into play and impact the rate of utilization. These factors can be summarized as the “Bermuda Triangle” of hospice referral.



Fear is a powerful emotion and hospice providers talked a lot of fear of death and the importance of acknowledging and addressing this fear. They feel that this is a societal and cultural issue and may be more pronounced in the northeastern United States. Since many individuals consider hospice synonymous with death, it is not hard to see where open discussion about hospice is also considered taboo. It is also not unusual to see a lack of open communication within a family particularly about issues related to caregiving, health care, death and dying.

The interviewees also commented frequently about physicians and the fears that they experience. They suggest that physicians have a fear of failure and that introducing the topic of hospice to a patient may represent a failure on the part of the physician to cure or successfully treat the patient. Physicians also tell the hospice providers that they do not wish to “remove hope” for their patients by referring them to hospice. Some physicians have also expressed a fear that patients will blame them for a terminal diagnosis.

Timing of referrals is also a significant source of difficulty. When the referral comes late in the dying process, hospice care can be less helpful for the patient and more expensive to the hospice agency. The movement of homecare patients already receiving services to the “hospice side of the house” can be a challenging timing issue. It can be hard to determine the end stage of chronic illness for some patients and successfully admit them to the hospice program at the optimum time.

Expert **knowledge** of both the hospice benefit and the capacities of the agency are often necessary when issues of life expectancy prognosis, lack of caregiver, expensive drugs or other palliative treatments come into play. Frequently hospices receive low numbers of referrals from LTC facilities and lack of knowledge and communication are cited as factors.

In general, **communication** with all referral sources is a never ending struggle. In many cases, hospice providers sense a lack of trust from physicians, hospitals and LTC facilities. The paperwork for hospice referral and continuing care is often viewed as cumbersome by the staff in physicians’ offices and discharge planners at the hospitals.

The relationship with hospital discharge planners

Maine hospice providers state that their relationship with hospital discharge planners plays a huge role in the utilization of the Medicare benefit. They feel that this is a vital relationship that requires constant and focused attention and a strong customer service orientation. It requires that agencies be extremely responsive to the timing of hospital discharges. It may in fact be easier for a discharge planner to move a patient to a skilled care facility than to work through all the patient, family, physician, and agency issues and coordination that comes with a referral to hospice care. Since discharge planners are under pressure to move patients out of the hospital in a timely way, waiting for all the parties to come together to begin hospice care at the patient’s home can derail a potential referral.

The providers describe the need to continually educate the discharge planners about the benefit and the services of their agencies. And this education and relationship should be nurtured and re-evaluated on a regular basis to ensure that the referrals continue to take place. Agencies can be helpful to discharge planners by providing timely inpatient hospital informational visits to the clients and their families.

The relationship with the discharge planner is an important bridge between the physician and the agency as the physician may not be thinking in terms of hospice care for the patient and the physician must sign the referral for the care to begin. This can be particularly true when the patient is being treated at a distant hospital and the discharge planner will be bridging the gap between the primary care physician and the hospice agency. The discharge planner also acts as an important bridge between the agency and the long-term care facility as many patients are admitted to the hospital from LTC and may be eligible for hospice benefits.

A delicate and controversial issue surfaced at several points during the interviews in which the hospice providers broached the existence of referral issues with the discharge planners. This can be problematic when relationships vary from hospital to hospital and some discharge planners are seen as making “exclusive” referrals to certain agencies. This is seen as an issue in regions where hospices are in a competitive environment and there are both agencies with non-profit and for-profit status within the same service area.

Physician Referrals

The hospice providers in our survey were quite emphatic about the influence of physicians in the utilization of the hospice benefit. Similar to the relationship building and maintenance required with discharge planners, hospice providers cite the need to constantly work on their relationships with physicians. There is a need to continuously address education deficits and facilitate communication in order to keep referrals coming in. One bad experience can stop the flow of referrals. The Medical Director of the hospice agency plays a key role in this communication and education process. Some concerns in their relationships with physicians include:

- Physician difficulty with determining prognoses
- Discomfort with pain management medication and protocols
- Preference for death in the hospital setting due to perceived burden on family and physician
- Worry about drug diversion when narcotics are used in the home
- Referrals that come too late to be helpful or cost-effective
- Authoritarian style with patients that diminishes patient-centered hospice care
Families often don't bring up hospice as an option if the physician has not presented it first
- Perception of “double-dipping” with Medicare hospice in LTC
- A high turnover rate of physicians in rural areas of the state
- Physicians unaware of how to stay involved in the care of their patient after admission to hospice care
- Physicians and office staff unaware of how to bill for continued care of the hospice patient.

Of particular note is the difficulty found with physician specialists. The agencies report that hospice care is often not “on the radar screen” for specialists, especially oncologists, pulmonologists, endocrinologists and cardiologists. They find that specialists are focused strongly on curative treatment and often erroneously expect that the referral to hospice care will come from the referring primary care physician if needed. This absent peer to peer communication is often results in missed referrals. A physician champion at each hospital, perhaps the hospitalist, could be helpful to increase referrals.

There is no doubt that education for physicians is important. Physicians need to know more about hospice philosophy, the benefit itself, hospice programs, and individual agencies.

Non-cancer hospice referrals

As stated previously, there remains the perception that hospice equals cancer. Over the years, the percent of patients who have terminal diagnoses other than cancer have increased dramatically. However, the agencies feel that there still remain significant challenges in these non-cancer referrals. The expenses for medications and durable medical equipment that are absorbed by the hospice agency are higher for non-cancer patients. The criteria for admission are often complex. This seems to be particularly true for “decline” and “discharge” criteria. Other guidelines that seem difficult include those for Alzheimer’s disease, failure to thrive, and ALS. Patients too may have difficulty accepting the end of curative treatment in non-cancer diagnoses, especially with conditions such renal and heart disease where the treatment period may have been particularly long. Again, hospice providers feel that specialists don’t seem to know that hospice exists. One interviewee said, *“Cardiologists’ patients never die of heart disease!”*

For physicians to stay involved with their hospice patients,
physicians need to know:

- **What they can do**
- **How they can do it**
- **How to get paid for it**

Gatekeeper role

In each interview, there was some discussion around the admission decision and who might function in the gatekeeper role. Each agency makes good use of the Interdisciplinary Team to review these admissions, but ultimately the agency medical director and administrator make the final decision based on the resources of the agency at the time. Admissions that hit the “gray” area of the guidelines, or involve creative use of the caregiver role, or involve some degree of “free” care are in the hands of the individual in the gatekeeper role. While this may, in fact, impact certain admissions through the referral process, it is evident that at any point along the referral, a single individual can make or break the process.

The referral to hospice care is a “house of cards.”

One card

(one individual through miscommunication, lack of education, or personal bias – whether that be the discharge planner, the primary care physician, the specialist, a family member, an individual at the hospice agency)

can take the whole referral down.

One way to avoid this potential collapse of the referral process

is to foster the ultimate referral

– the consumer driven referral.

The role of the caregiver in utilization

On the positive side, CMS allows the hospice agencies to make their own agency policies concerning caregiver involvement. Many agencies do take on clients without a clear caregiver. Agencies continue to support a patient’s right to make a poor decision concerning the availability of family and friend assistance and prepare with a contingency plan. The agencies in the survey feel that caregiver involvement plays a big part of hospice care in Maine and that the agencies are very skilled at creating matrixes of help.

On the negative side, planning for contingencies can be quite challenging, particularly when it comes to the availability of 24 hour coverage. Many family members are not close by and as Maine is the oldest state in the country, there are many elderly people and fewer caregivers. This kind of contingency planning needs to be captured in writing and can be difficult to accomplish at the start of the hospice relationship. Often issues with power of attorney surface. Sometimes family dynamics, burnout, and emotions come into play and the family requests that the hospice patient be moved from the home to a nursing facility. The caregiver role can often be complex and unclear when the hospice patient resides in a nursing facility. Staffing (both paid and volunteer) can be tested by the level of caregiver involvement in the hospice case. This is particularly true when 24 hour monitoring for pain control is not available through the caregiver and costly pain management by medication pumps must be used.



Life in the Harbor

Providing Hospice Services in Maine

“Dedicated Team” and hospice utilization

It appears as though the interpretation of the term “dedicated team” varies significantly. However we used this topic to explore the human resource issues that appear for the agencies. Small agencies in rural areas are pressed to find staff to provide care for their hospice patients. In fact, a number of the agencies cannot afford the “luxury” of a hospice dedicated team. Many of those interviewed discussed the difficulties with recruiting and maintaining skilled individuals who are “good” at hospice. Staff exclusively focused on hospice care were described in the following positive light:

- Facilitates the development of experts in pain management and grief counseling
- Provides the best outcomes for the patient and family
- Supports high utilization of the hospice benefit
- Allows for specialization, strong communication and coordination when hospice care is provided at LTC facilities

The agency administrators also discussed several other more negative concerns about dedicated teams. There seems to be an inherent conflict when an agency is in the position of moving clients from homecare services to the hospice team. Often the staff that have cared for a patient for a long time and have established a relationship are reluctant to “turn over” their patient to a different team. This can lead to a delayed or even missed referral. This reluctance to have a new team involved can also be met with reluctance from the patient and/or family. Another concern is for the emotional health of the team that works exclusively with hospice. Some feel that the potential to experience a large number of deaths in a short time can be traumatic and lead to burn-out.

Human Resources Ideas

- **Create a support group for staff who provide hospice care.**
- **Educate homecare staff about the positive benefits that hospice can bring to their patients.**

Hospice Provider Type – Non-profit vs. For-profit

Some of the providers said that differences in utilization between provider type should not exist as both types of providers should and do provide the same care. Others had a lot to say about differences in profit status and generally feel that the two types can learn “best practices” from each other. Interestingly, the ability to “take on free care” was brought up as a unique difference for both profit and non-profit agencies.

Quality of Care Idea

One hospice initiated an “Active Dying Vigil Program” that improved quality of care for the patients and their families and increased physician satisfaction with the hospice program.

For profit agencies are considered to be business savvy with beneficial corporate and financial resources. They have access to good systems, policies and procedures. However, they have the pressure to market their services as they are not often considered the “local resource”. It is felt that these agencies must provide high quality care or face elimination in the marketplace. A focus on LTC hospice allows these agencies to maintain a higher volume of patients and concentrate resources.

Not for profit agencies are described as mission driven with a passion and mission to serve their community. An advantage is that many of these non-profit agencies provide a continuum of care and

can move their clients through these levels as their needs change. It was discussed that while these agencies will accept anyone who is considered hospice appropriate, they may in fact be short-sighted in terms of management of financial and human resources. Provision of charity care may be restricted by the level of donations received.

Competition within geographic regions

Competition is definitely viewed as a factor that impacts utilization in Maine. Hospice providers in Maine agree strongly that more hospice programs increase the awareness of hospice in both the community and among clinicians. It was pointed out that the infiltration rate in this state is still relatively low and that there is capacity for a significant increase in referrals. They feel that competition raises the bar and sharpens the hospice response team to referrals. While choice for patients and improved access can be a significant outcome of competing hospice programs, it can also confuse the public, especially since consumer knowledge about hospice programs and the Medicare benefit is so low. There is concern that political or territorial issues may block access for some patients. Most hospice providers talked about the reality of varying admissions criteria in that a patient may be denied admission at one hospice and then accepted at a competing agency. Some worry

about what is considered “cherry-picking” of patients where programs admit those patients whose course of care is expected to be at the lower end of the cost spectrum.

When questioned about a practice called “open access” found in some larger hospice programs in other states, most Maine providers feel that their agencies are too small and lack the volume to cover the higher financial costs of a truly open access policy. Some see the potential for expanded access, but ultimately must consider the financial bottom line and the viability of the agency. Issues concerning newer models of palliative care and relief of distressing symptoms need to be addressed within the context of current reimbursement rates until changes are considered at the CMS level.

Quality of Care issues

Achieving the appropriate balance of staffing has a strong impact on quality of care. High caseloads can result in less than optimum hospice care. The Maine hospice providers named team approaches, good volunteer training, and excellent customer service as key factors in maintaining strong physician and community support for hospice care. Certainly, poor quality of care will result in decreased physician referrals and many hospices depend on strong word of mouth endorsement from families who have experienced hospice. The timing of referrals is also related to quality of care. Many clinicians are concerned with referring a patient too early to the hospice program, when in fact, most patients are referred too late and do not receive the entire spectrum of services that are part of the hospice benefit.

Regulatory Suggestion

Allow advance practice nurses to sign off care plans for hospice patients who receive care in their homes. This practice is allowed in nursing homes, but not currently with homecare patients.

Workforce issues

All hospice providers interviewed agreed that the shortage of registered nurses, certified nursing assistants, and social workers in Maine impact the utilization of hospice. Staff shortages impact the ability of individual hospice programs to maintain census levels. In addition, the aging of the nursing workforce in Maine factors in the employment of nurses in the high stress, significant travel and independent working conditions that typify hospice care in the home. Agencies are looking for experienced, community service minded staff and are not often able to compete with hospital or nursing homes in terms of pay and/or

benefits. Many of the hospices in Maine cover large geographic regions. Geographic challenges are noted in travel time to client homes, the expense of mileage reimbursement and the need for reliable vehicles. Traveling significant distances during the off hours that are often required in hospice care can be particularly tough. Travel in rural regions is also a factor in the requirement that hospices make an initial visit within 24 hours of the admission. Small agencies are impacted when even one staff nurse is unavailable because of illness or vacation. As previously mentioned, hospice staff are susceptible to burn out and management needs to plan proactively to deal with the daily stress of the hospice work. Regulatory changes could potentially ease some of the paperwork burden for hospice nurses.

Hospice care in the Long-term Care Facility

While significant economies of scale can be achieved while providing hospice care in LTC facilities, there remain many challenges for hospice programs in the referral, delivery and coordination of care in this setting. Many LTC facilities experience a high turnover rate of staff and this presents as a constant training and retraining regarding the referral process, benefit structure, pain management and symptom management by the hospice programs in order to ensure that policies, procedures and quality of care are met. This can become somewhat complicated when multiple agencies serve patients within a single facility. Some hospice providers spoke about situations where LTC facilities have exclusive referral contracts with certain agencies. Turf issues have surfaced in which there is uncertainty of roles with LTC and hospice staff; both sides need to be clear and work to resolve conflicts before they impact the care of the patient. Relationship building is key to success as the hospice staff is not there to replace the LTC staff.

Other issues faced when providing hospice care in nursing facilities:

- Quality improvement activities are cumbersome, but necessary
- Communication and coordination with the care plan
 - Sending patients to the hospital
 - The use and monitoring of PRN(as needed) medications
 - Communication with the patient's physician
- Concern about duplicative services and possible “double-dipping” through claims
- LTC staff reticent to refer patient to hospice care (“they think hospice is not needed”)
- Not enough staff in the LTC to meet the patient needs
- A single individual can derail the referral or care process in the LTC
- Some hospice staff prefer to provide care in the home environment versus a facility
- Care of the actively dying can be difficult in the LTC setting

Ideas for Improved Hospice Utilization in LTC

- **Cultivate a hospice advocate in each facility**
- **Life expectancy in SNF is 2-3 years; every resident should be screened for hospice**
- **Establish clear expectations with LTC staff through regular meetings, check training needs and troubleshoot issues**
- **Choose a consistent spot for hospice chart in facility, create a bedside journal**



Help to reach the harbor

Strategies

Effective Marketing in Maine

Maine hospice providers were asked to share their ideas about marketing strategies that may improve utilization here in this state. Most described the need to pull out all the stops with a media blitz that encompasses all available modes of communication. Suggestions included public service announcements on television and radio, advertisements in newspapers and magazines, even computer pop-ups. They encouraged the use of the human interest story and think that testimonials from families of hospice patients would be effective.

Another suggested area of marketing involves various types and modes of community outreach. Informational seminars could be delivered to community groups such as service organizations like the Rotary. Retirement communities, assisted living facilities, and other “aging in place” housing could be logical places to bring information to consumers. Volunteer recruiting as well as educational outreach can occur in churches. Some hospice administrators feel that it is important to address the religious issues that may surface as they have heard confusion from patients regarding the church’s role in hospice programs and varying perceptions about organized religion’s philosophy or doctrine related to hospice. Also, some clarification about the role of the hospice chaplain and connection to organized religion (and the religious affiliation of the patient) would be helpful. Marketing to hospital-based physicians and long-term care administrators is considered a very important activity and key to building strong and successful working relationships.

Two distinct messages were identified as crucial in this marketing process. The first is about the benefit itself. The benefit is not understood by the average consumer even though it is a benefit that anyone who receives Medicare is entitled to. Consumerism has definitely been lacking when it comes to hospice care.

“If you knew the facts about the hospice benefit, why wouldn’t you choose to receive this care?”

The second major message concerns normalizing communication about death and dying. This speaks to the taboo in our society that reflects fear and avoidance. Tapping into the desensitization process that occurs through media exposure may indeed create a more open discussion of options for individuals at the end of life.

“If you can advertise on TV about the medications for restless leg syndrome, why isn’t hospice and dying important to consumers?”

Ways for the Maine Hospice Council to help increase utilization

Those interviewed were offered the opportunity to suggest ways that the Maine Hospice Council can act to increase the Medicare hospice utilization rate. These suggestions may be organized in the following areas.

Educate

- General education and promotion of hospice, including showcasing the new facility in the state
- Sponsor physician education
- Educate local Emergency Medical Services (EMS) units regarding hospice philosophy, standard protocols and procedures
- Educate volunteer hospices about the Medicare and Medicaid hospice benefits
- Reduce confusion regarding the role of the hospice chaplain through education of religious leadership
- Benchmark with states with similar socioeconomic and geographical features

Coordinate

- Reach out to all hospice providers and sponsor networking and education sessions for hospice providers, LTC staff and hospitals
- Partner with large business to promote consumerism regarding hospice

Advocate

- Work with CMS and state government to improve regulations (example: 24 hour RN coverage in the SNF)
- Encourage consumer demand by desensitizing hospice, death and fear of dying
- Advocate for hospice utilization through relationships with the religious community
- Support the development of more in-patient hospice care in nursing facilities, hospitals and stand alone facilities
- Urge consumers to question and clarify the purpose of curative treatments with terminal illnesses
- Spark the consumer mentality of the “baby boomer” generation.

Ways for Maine state government to encourage utilization of hospice

There is agreement among the hospice administrators that significant attention should be paid to increasing the understanding of the MaineCare benefit by consumers, providers, physicians and LTC. Many spoke of the confusion that arises from the state provided Good assessment and hospice referral and eligibility. Some suggest that claims data – although imperfect – may be able to demonstrate the cost savings of hospice versus usual care in the hospital or nursing home. Another area that needs attention concerns the workforce issues that impact hospice programs in Maine. As discussed earlier, hospice programs in rural and northern regions of the state struggle to recruit and keep qualified staff. It was suggested that the State support the workforce through incentives for non-traditional students to receive training and employment in underserved regions – much like the Federal government support of public health services through tuition breaks and loan forgiveness.

Other ways to encourage hospice through state interventions:

- Provide public explanation of hospice benefits
- Encourage the use of hospice in psychiatric hospitals
- Address the exclusion of non-categorical clients for the hospice benefit
- Expand the benefit to include more residents who receive assistance from the state
- Fund palliative care programs
- Support hospice through a “top-down” philosophy – encouragement from the Governor’s office on down

Engaging the help of CMS to increase utilization

Many suggest that CMS can do more to encourage utilization of hospice and that this activity could begin with a national campaign. Literature and information belongs in the hands of the beneficiaries before they need it. The message can go out to Medicare beneficiaries to treat their hospice benefit as an entitlement and that making use of the benefit is a consumer issue more than a clinical one. Consumers can be told to ask their physicians about hospice and encouraged to contact their local hospices to find out what is available in their local area. It was suggested that CMS make use of the RSVP volunteer network to get the message out to beneficiaries about the features of their Medicare hospice benefit. CMS should make it a matter of public policy to promote hospice as a way to prevent unnecessary hospitalizations, save healthcare resources, and optimize comfort and pain management at the end of life. Promoting hospice utilization through the joint efforts of the Quality Improvement Organization and Area Agencies on Aging was also suggested. While CMS does make resource material available to the clinical community now, most feel that this could certainly be increased, judging by the lack of knowledge that the administrators see on a daily basis and that there is a place for direct contact education with physicians in addition to published materials. Maine does present some geographical and travel challenges in the delivery of hospice services not unlike other rural states with sparse resources and a scattered population base. As discussed above, some suggest that there is a federal role to assist with the workforce issues that are experienced in rural states through development funds.

Hospice administrators also feel that the federal government could support hospice utilization through funding careful research that seeks to understand the true costs and benefits of hospice care. This type of study is necessary in order to demonstrate cost savings and provide fair and equitable reimbursement rates to the hospice agencies. While Maine has limited managed Medicare at this point, it is a concern for some administrators that future increase in managed care may negatively impact hospice utilization. The role of the care manager in these programs could serve either as a help or a barrier.

Significant public policy change, practice and public acceptance occurred in recent years around the use of *advance directives*.

Who and what drove that movement and what can we learn from it?

Some other specific suggestions to CMS that may help with regulatory and reimbursement issues that impact utilization are listed below.

- Clarify definition of duplication of services when hospice is provided in nursing facilities
- Extend the life expectancy prognosis to one year
- Consider higher travel costs in the rural areas the same way that urban areas consider higher costs of wages
- Tighten up gray areas that allow for discrepancies in admission between competing agencies
- Review the reimbursement rate to reflect the increased costs for newer palliative treatments
- Regularly update reimbursement formulas to assure solvency of agencies



The tide may be changing...

Final Reflections

Normalization of the Medicare Hospice Benefit

Consumerism is a powerful movement that can precipitate tremendous change in acceptance and utilization of the benefit. Many Americans currently do not consider hospice services as a benefit which they are entitled to via a lifetime of payroll taxes. Will there be an increasing demand for hospice services as the new consumer style patient/physician relationship grows? Will the new consumer-style patient question curative treatments at the end of life or expect their physicians and other health care providers to have answers about the latest in palliative care and pain management? Does the Medicare hospice benefit reflect and reimburse for current and future demand for palliative care? Will Medicare cover the costs of hospice services in settings that reflect this new consumerism?

Accessibility of the Medicare Hospice Benefit

It is clear from the interviews with the hospice administrators that as it stands now, the referral process is fraught with potential miscues, misunderstandings and missed opportunities. This referral process is indeed a “house of cards” where the actions or non-actions of a single individual in the process may result in a non-referral. It has been suggested that the ultimate goal of the education process may result in the highest degree of access - the consumer self-referral with subsequent authorization by the clinician, hospice provider and payer.

Standardization of Ongoing Education

Education will always be a constant need. Looking to opportunities to standardize the educational process through ongoing sessions and distribution of materials could ease the frustration of all parties involved. It has been suggested that hospice providers look to the success of the marketing and policy changes that have occurred in recent years around the use of advance directives. Could a similar approach work where all providers of Medicare and Medicaid services are required to provide information and discussion of hospice to patients?

Clarifications of Role for the Referring Physician

There is room to clarify where the physician fits in once the referral to hospice is made. Many physicians have expressed their frustration with the documentation and claims process that now exists to receive reimbursement for continuation of care when a patient is admitted to a hospice program. Not only is the financial structure unclear, but the professional and interpersonal role could also use some clarification so that the physician does not feel as though they are ending their relationship with their patients through hospice admission.

Unification of Purpose

The hospice programs in this study reflect both nonprofit and for profit business models. Most of those interviewed expressed healthy respect for each delivery model and seem to want to work cooperatively to meet the common goal of increased utilization of hospice in this state. Opportunities to explore mutual challenges can occur in collegial forums. Certainly, many of the action steps put forward in these interviews can only be achieved through a unification of forces, sharing of best practices and collaboration on initiative or pilot activities.

Next Steps

Information gathered through the review of literature, the symposium with national experts, discipline specific focus groups, claims analysis and this study of hospice providers in Maine, will assist the Maine Hospice Council as they try to respond to the low rate of hospice utilization in the state.

This report is designed to provide the “insider’s perspective” as well as identify and highlight potential areas for action. The Maine Hospice Council aims to assemble a new planning group of stakeholders to create an action plan and develop pilot activities to address the issues raised by the hospice providers. Funding for such pilot activities will be sought through grants and other charitable support.

Appendix A

Social Worker Focus Group

Top Three Issues

1. Lack of education and understanding
2. Lack of a quarterback – coordinate all people involved and keep everyone informed
3. Should be more than one discussion, a series of ongoing discussions with all involved

Action Steps

- Develop a multi-disciplinary team of social workers and discharge planners from various settings to provide outreach/education to the public and civic organizations
- Include independent volunteer hospice agencies to support collaborative team

What will have the greatest impact?

- Interdisciplinary team to provide outreach/education to the public

Physician Focus Group

Top Three Issues

1. Lack of education for health care providers and general public
2. Lack of “can-do” policy; entry barriers at multiple levels
3. Advance directives need revamping to align with goals of care

Action Steps

- Increase education for current physicians (e.g. knowledge, attitudes)
- Create resources for physicians such as navigators and the team approach
- Training program for navigators

What will have the greatest impact?

- Education of physicians and the general public

Nurses Focus Group

Top Three Issues

1. The way hospice is communicated
2. Easy access, understandable (insurance is confusing)
3. Cultural view of death, need for education; hospice is about life and not death

Action Steps

- Start conversations within families, immediate community, then larger community
- Do public health notices or public service announcements to educate public on value of hospice, benefit to families (bereavement counseling, support) as well as patient/client. Do short “blips” so people get used to the topic
- Have nurses speak about hospice at special events
- Use lawyers as communicators – when discussing wills, advance directives

What will have the greatest impact?

- Educate “ourselves” (nurses) first
- Nurses have the ear of the patient and family more than others and can educate about hospice

Administrators Focus Group

Top Three Issues

1. Need for people to assist patients, families and providers in navigating complex system
2. Targeted education that takes into account the specific demographics of Maine including higher rates of illiteracy and poverty
3. Need for more advocacy and legislative attention

Action Steps

- Build collaborative relationship with people along the whole continuum: patients, family and hospice organizations, nursing facilities, referral sources, religious/ethnic communities

What will have the greatest impact?

- Building collaborative relationships and identifying champions

Research Focus Group

Research Questions

- Would the use of a hospice “navigator” improve the use of hospice? How have cancer navigators increased access?
- What percentage of people in SNF, residential care or home care score on the Flacker scale (assessment tool to identify residents at high risk of dying within one year) and of those what percent die in the year. How might that information be used in palliative care?
- What are the cost/savings implications for Medicaid of using hospice care in Maine?
- What are the utilization rates of Medicaid and other payers of hospice benefit?
- What are utilization rates of hospice in rural/urban areas; and relationship to availability of hospice services, hospital services, other?
- What is cost of medical care in Maine compared with other states?
- What are use rates of hospice services in assisted living facilities?
- What percent of people die during a skilled Medicare stay?
- What are the incentives/disincentives for use of hospice in NFs and how does it affect hospice use?
- What are patterns of transition for people and where people die? Look at cohort of people who died and where (in hospice, in SNF, in residential care, at home)
- What are the Medicare utilization rates by diagnosis, length of stay, use rates by area?
- What factors influence utilization: payment rate, literacy/education, managed care, rural/urban, program size?