

LDI *Issue Brief*

Volume 11, Number 3
December 2005/January 2006

Leonard Davis Institute of Health Economics

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Understanding and Improving Hospice Enrollment

Editor's note: Hospice is considered the "gold standard" for end-of-life care, providing dying patients and their families access to a broad array of services across settings. Despite its comprehensive approach, hospice care remains underutilized; many patients who might benefit from hospice do not enroll, or enroll only in the last days of life. This Issue Brief summarizes a series of studies that shed light on the decision making process about hospice, and describes a simple, effective way to improve referrals to hospice among nursing home residents.

Many patients enroll in hospice only in the last weeks, or days, of life

Hospice delivers comprehensive palliative care to patients with a prognosis of six months or less. It provides access to a basket of benefits and services, including payment for medications, durable medical equipment, home health aides, and a team of providers experienced in end-of-life care (physician, nurse, social worker, chaplain, volunteer coordinator, and bereavement services). Previous studies have shown that hospice results in improved pain assessment and management, with excellent patient and family ratings of satisfaction with care.

- Hospice programs currently provide care for about one-third of all patients who die in this country, and for about two-thirds of patients who die of chronic progressive illness. However, most patients benefit from hospice for only a short time: the median length of stay in a hospice program is less than 3 weeks. One-third of hospice patients enroll in the last week of life, and 10% in the last day of life.
- For patients and families, the decision to enroll in hospice is difficult, often reflecting a reluctance to accept a terminal diagnosis. In addition, most insurers (e.g., Medicare) require that hospice patients give up access to aggressive, life-sustaining treatment.
- Little is known about the factors that influence enrollment in hospice. Who makes decisions about enrolling? How and when do discussions about hospice happen? What features of hospice are most attractive to patients and families, and which services do they value most? The studies described below begin to answer these questions, and suggest ways to improve the referral and enrollment process.

Families report receiving little information about hospice services from their physician

To understand the hospice decision-making process from the family's perspective, Casarett and colleagues interviewed 100 family members of 100 patients who died in hospice. Families were drawn from one of three Medicare-certified hospice organizations, and interviews were conducted two months after the patient's death.

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- About half of family members reported that the patient's physician initiated the discussion of hospice, while one-third said that they or the patient initiated the discussion spontaneously. However, only 22% of families said that a physician had provided information about hospice services. Most information about hospice came from a hospice representative.
 - Most family members recalled at least one event that precipitated the hospice discussion, such as escalating needs for home care, a decision to withhold or withdraw life-sustaining treatment, or difficulty in managing pain or symptoms. The vast majority of decisions to enroll were made after just one discussion.
 - Almost half of family members reported that the patient was not involved in the decision to enroll in hospice, mostly because of the patient's cognitive impairment.
 - Almost all family members identified aspects of hospice care that they wished they learned of sooner. They were surprised by the 24-hour availability of the hospice team and the visiting nurse, and had not expected that the hospice would coordinate care and services. They frequently mentioned the value of spiritual and emotional support that they had not realized they needed.
 - Note that these interviews were performed only with families of patients who enrolled in hospice and did not include families of patients who did not—many of whom may never have known about the availability of hospice or its services.

Patients and families rate practical issues as most important in deciding about hospice

To understand the hospice enrollment decision as it happens, Casarett and colleagues interviewed 237 patients and families at the beginning of an informational visit to an urban, not-for-profit hospice. Interviewees described their pre-existing knowledge of hospice, and were asked to identify three of eight categories of information that were most important to them in deciding whether to enroll in hospice. The eight categories were based on families' responses in the retrospective study described above.

- The majority of patients and families (60%) had no knowledge of hospice at the time of the initial hospice visit. Only 31% could describe the hospice's goals for care or any hospice services.
- Most patients (90%) enrolled in hospice at the interview visit. In 57% of cases, family members made these decisions entirely.
- The types of information most frequently cited as important were frequency of visits (60%), payment for hospice (59%) and the sort of practical help that hospice provides at home (52%). Only a small minority of patients and families wanted information about emotional support (18%) or spiritual support (12%).

Families feel that they receive greater benefits from longer lengths of stays in hospice

Building on these studies, Casarett and colleagues interviewed 275 patients and families at enrollment in a not-for-profit hospice, and re-contacted family members one month after the patient's death. Interviews assessed the anticipated and actual helpfulness of different hospice services, and determined whether length of stay in hospice affected families' perceptions of the benefits of hospice.

- At the time of enrollment, patients and families anticipated that some services (e.g., pain and symptom management) would be more helpful than other services (e.g., emotional and spiritual support). Patients and family members, when both could participate in the interview, had high levels of agreement about services considered most helpful.
 - After the patient's death, families of patients with longer lengths of stays reported that they received more services, and that the services they received were more helpful.
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- The proportion of families who said they benefited from the services they thought would be helpful peaked at hospice stays of three months. This figure is consistent with physicians' views about an optimal length of stay in hospice. However, most families reported benefiting from hospice services even with very short lengths of stay.
 - Most patients and families believed that they were enrolling at the right time. After the patient's death, most families (80%) maintained that belief. Families who believed that enrollment was too late had shorter lengths of stay than those who thought enrollment was at the right time. Of the families who said that enrollment was too late, 74% had a length of stay of less than three weeks, suggesting that this amount of time might be a reasonable minimum length of stay for most patients.

Simple intervention identifies nursing home residents who might benefit from hospice and facilitates referrals

The investigators used the information from these studies to design a simple intervention to improve communication about hospice in nursing homes. They tested this intervention in a randomized study conducted in three nursing homes from December 2003 to December 2004.

- The study included 205 residents and family members, of whom 107 were randomly assigned to receive the intervention, and 98 received usual care. All residents were interviewed to assess the potential appropriateness of hospice care. A short, structured interview elicited the resident's goals for care, treatment preferences, and palliative care needs.
- In the intervention group, results of interviews for hospice-appropriate residents were faxed to the resident's physician, who was asked to reply by fax, indicating whether the resident had a prognosis of six months or less, and if so, whether nursing home staff should arrange a hospice visit. The usual care group received a brief description of hospice and hospice services, and hospice-appropriate residents were told that they could learn more about hospice from their physician.
- Residents were followed for six months, or until death. When residents died, the family was interviewed two months after the death to measure their perceptions of the quality of end-of-life care.

Intervention leads to earlier hospice referrals, fewer hospital admissions, and higher satisfaction with end-of-life care

The interviews identified 84 residents (35 in the intervention group and 49 in the usual care group) who were hospice-appropriate. Faxes were sent to 26 physicians responsible for the 35 intervention residents.

- Intervention group residents were more likely than usual care residents to enroll in hospice in 30 days [21/107 (20%) vs. 1/98 (1%)], and in the next six months [27/207 (25%) vs. 6/98 (6%)].
- Intervention residents had fewer hospital admissions and spent fewer days in the hospital (on average, 1.2 days vs. 3.0 days). Almost all the hospital admissions in the intervention group occurred when the resident was not enrolled in hospice.
- Twenty-three residents died within six months. Mortality rates were similar between the intervention and control groups, and between hospice-appropriate residents and those who were not.
- Intervention residents received more days of hospice care than usual care residents (on average, 64 days vs. 14 days), but were not more likely to be enrolled in hospice when they died.
- Families of intervention residents rated the resident's care in the last week of life more highly than did families of usual care residents. Families of residents with longer hospice stay rated the resident's end-of-life care more highly.

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POLICY IMPLICATIONS

Taken together, these studies provide insight into how to improve the decision making process about hospice, and how to improve end-of-life care in a long-term care setting.

- Although families perceive the value of hospice care even in the last few days of a patient's life, earlier referrals and longer hospice stays are associated with greater perceived benefits. Defining the optimal length of stay in hospice is difficult, but these studies suggest that most benefits are provided when patients stay three weeks to three months.
- Patients and families who are deciding whether to enroll in hospice have predictable patterns of information needs: specifically, they want to know about the frequency of visits, practical support, and payment options. To be effective, efforts to encourage earlier enrollment in hospice should focus on communicating these aspects of hospice services to patients and caregivers.
- These results show that a simple communication intervention can improve the quality of end-of-life care and decrease resource utilization by promoting earlier access to hospice care in nursing homes. The intervention is simple, inexpensive, and easily exportable to most long-term care settings. The brief, scripted interview and simple criteria to determine hospice appropriateness can be administered in 5-10 minutes by any member of the health care team.

This Issue Brief is based on the following articles: D. Casarett, J. Karlawish, K. Morales, R. Crowley, T. Mirsch, D.A. Asch. Improving the use of hospice services in nursing homes. JAMA, July 13, 2005, vol. 294, pp. 211-217; J. Kapo, J. Harrold, J.T. Carroll, E. Rickerson, D. Casarett. Are we referring patients to hospice too late? Patients' and families' opinions. Journal of Palliative Medicine, June 2005, vol. 8, pp. 521-7; E. Rickerson, J. Harrold, J. Kapo, J.T. Carroll, D. Casarett. Timing of hospice referral and families' perceptions of services: are earlier hospice referrals better? Journal of the American Geriatrics Society, May 2005, vol. 53, pp. 819-823; D. Casarett, R. Crowley, C. Stevenson, S. Xie, J. Teno. Making difficult decisions about hospice enrollment: what do patients and families want to know? Journal of the American Geriatrics Society, February 2005, vol. 53, pp. 249-54; D.J. Casarett, R.L. Crowley, B. Hirschman. How should clinicians describe hospice to patients and families? Journal of the American Geriatrics Society, November 2004, vol. 52, pp. 1923-8.

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Leonard Davis Institute
of Health Economics
University of Pennsylvania

Issue Brief



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