



Article Review

How Should Clinicians Describe Hospice to Patients and Families?

David Casarett, MD, MA, Roxane L. Crowley, BA, Karen B. Hirschman, Ph.D.

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Key Points

- ✓ Hospice patients are typically referred late in the illness and gain only limited access to the services hospice offers.
- ✓ In the study, half of the participants recalled that the patient's physician initiated the hospice discussion, but only 22% recalled the physician providing information about hospice services.
- ✓ Most participants identified at least one precipitating medical event that prompted discussions about hospice:
 - Escalating home care needs
 - A decision to withhold or withdraw life-sustaining treatment
 - Difficult pain and symptom management issues
 - The need for additional care before discharge from a facility
- ✓ Three categories of hospice features motivated the decision to enroll:
 - Availability of home care
 - Care team with expertise in pain and symptom management
 - Services for caregivers
- ✓ The most common concerns about enrolling in hospice were:
 - Reluctance to accept a terminal diagnosis
 - Whether hospice could provide the degree of support the family member felt the patient needed
 - Money and payment for hospice services
- ✓ Family members said they wished they had learned earlier about the extent of hospice services available, the type of staff available, and the hospice philosophy and expertise. See table on following page.

**For More Information Contact Your Community
Hospice Compassus Team**

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Table 3. Information About Hospice That Motivated Enrollment or Would Have Motivated Enrollment If the Patient or Family Had Known

Hospice Information (n *)	Information That Motivated Enrollment	Information That Would Have Motivated Enrollment
	n	
Services available		
Terminal care at home (49)	30	19
Pain and symptom management (50)	26	24
Caregiver services, including transportation and respite care (35)	20	15
Help 24 hours a day by phone (43)	12	31
Durable medical equipment and medications (31)	10	21
A hospice inpatient center (23)	7	16
Nursing home services (9)	6	3
Coordination of care and case management (31)	6	25
Patient and family education about physical care and the dying process (31)	4	27
Financial aid and assistance (14)	4	10
Bereavement counseling and assistance with postdeath arrangements (29)	2	27
Hospice staff available		
Nurse (40)	13	27
Home health aide (30)	8	22
Physician (12)	3	9
Social worker (12)	1	11
Chaplain (12)	0	12
Volunteer (4)	0	4
Philosophy and expertise		
Provides care that can ensure a peaceful death (22)	15	7
Emphasis on care rather than cure (40)	7	33
Focus on, and expertise in, end-of-life care (47)	15	32

* Total number of family members who volunteered a category of information.

OBJECTIVES: To describe hospice enrollment from the perspective of bereaved family members and to identify information about hospice that would encourage patients and families to enroll sooner.

DESIGN / SETTING / PARTICIPANTS: Cross-sectional interviews. / Three Medicare-certified hospice organizations. / One hundred family members of 100 patients who died in hospice.

MEASUREMENTS: Semistructured interviews assessed prior knowledge of hospice, patients' and physicians' involvement in the enrollment process, features of hospice that motivated enrollment, and features that patients and families wished they had learned about sooner.

RESULTS: Almost all family members (n=92) and patients (n=71) knew about hospice before the patient's illness. Almost half the patients (n=44) were not involved at all in the hospice enrollment decision. The patient's physician (n=51) or the patient or family (n=34) initiated most hospice discussions, but patients and families usually obtained information about hospice from a hospice representative (n=75) rather than from the patient's physician (n=22). Family members identified several kinds of information about hospice that were particularly helpful in deciding whether to enroll and described several aspects of hospice that they wished they had known about sooner. Many patients and families learn about hospice from someone other than the patient's physician, and most learn about valuable hospice features and services only after enrollment. By providing more information about hospice earlier in the illness course, clinicians may be able to facilitate more-informed and more-timely decisions about hospice enrollment.