

A Retrospective Study Of Patient Care Needs On Admission To An Inpatient Hospice Facility

Eric Wall, MD, MPH, Glenn Rodriguez, MD, and John Saultz, MD

Background: The care and support of dying patients and their families are among the most important skills of a family physician. In this century, an increasing proportion of deaths have occurred in hospitals with resulting medicalization of the dying process. Hospice care has emerged to focus on the relief of suffering rather than the cure of illness. This descriptive study reports information about the diagnoses, care needs, and attending physicians of a cohort of patients admitted to a free-standing, inpatient hospice program.

Methods: We undertook a retrospective chart review of 335 patients admitted to a hospice program during a 26-month period, collecting data recorded on standardized nursing assessment forms. These forms provided information on 19 biologic, functional, and psychosocial symptom groups at the time of admission.

Results: Family physicians were the admitting physicians in a minority of hospice admissions. Pain and mobility problems were the most frequent symptoms encountered. Other common issues included bowel, respiratory, and nutritional problems. Emotional difficulties were noted less frequently than these common biomedical problems.

Conclusions: Family physicians should be trained to address core problems encountered in the care of dying patients. Multidisciplinary team approaches are essential in the management of many problems encountered in hospice care. (J Am Board Fam Pract 1993; 6:233-238.)

Caring for terminally ill and dying patients is among the most basic skills of a family physician. Traditionally, most of this care was provided in the home by family members with support from family physicians. In the past half century, fewer patients have died at home and a higher proportion have died in hospitals. In 1967, St. Christopher's Hospice was founded in England to provide relief for patients with terminal illness, using a multidisciplinary approach involving family members, volunteers, and health care professionals. The first US hospice was founded in Connecticut in 1974. In 1983, Medicare began offering hospice care coverage for patients with terminal illnesses as an option to Medicare Part A insurance. The Medicare hospice benefit is available only to certified hospice programs; it requires the majority of care to be in the home and capitates payment of a defined benefit. The past

8 years have witnessed rapid growth in the hospice industry from 516 hospices in 1983 to more than 1700 hospices, including 600 Medicare-certified hospices in the United States in 1989.¹

In November 1988 Hospice House, Inc., a nonprofit, free-standing inpatient hospice serving a maximum of 12 patients, was founded in Portland, Oregon. It grew from a dedicated group of citizens and professionals committed to providing an alternative to home hospice care programs (which are only available to patients with a capable care giver in the home) or hospital-based hospice facilities. Hospice House offered 24-hour nursing coverage, as well as on-site dietary services, pastoral services, a full-time social worker, a well-organized volunteer program, and bereavement counseling. Hospice House was built on a remodeled estate and received initial development funds from private and corporate donors.

Operating costs were to be covered by patient care revenue. Most of its patient care revenue came from private insurance plans. It was not a Medicare-certified hospice because Hospice House had no home hospice program. Hospice House closed in December 1990 because of inad-

Submitted, revised, 30 December 1992.

From the Department of Family Medicine, Oregon Health Sciences University, Portland. Address requests for reprints to Eric Wall, MD, MPH, Department of Family Medicine, Oregon Health Sciences University, 3181 S.W. Sam Jackson Park Road, Portland, OR 97201.

equate revenue to cover operating costs (\$330 per patient day at the time of closure).

Hospice House care was holistic and multidisciplinary. Skilled hospice nurses provided 24-hour care and did comprehensive assessments at the time of admission. A standardized initial evaluation form was used to define areas of active problems for incorporation into the patient care plan. This care plan was formulated at weekly, multidisciplinary patient care conferences to which patients, their families, the attending physician, and the entire Hospice House care team was invited. Before January 1990 attending physician involvement had been through completion of the comprehensive standing orders at the time of admission and telephone messages in the majority of cases. Attending physicians rarely visited their patients at Hospice House or attended care conferences. In January 1990 the authors were collectively hired to serve as part-time medical directors to increase physician input at care conferences, to provide medical coverage to patients without physicians, to reorganize the medical staff to facilitate certification as an inpatient facility, and to expedite reimbursement. This paper describes all patients admitted to this facility during its 3-year existence and classifies their care needs on admission.

Methods

Data collection involved a retrospective review of the medical records of all 335 patients who were admitted. Abstracted information included the patient's age, sex, primary diagnosis, three secondary diagnoses, the name of the admitting physician, length of stay, and payment status. Information was tabulated from the standardized intake nursing assessment form used to record active problems in 19 biologic, functional, and psychosocial symptom groups. The specialty of each patient's admitting physician was determined by his or her listing in the local Yellow Pages and in the county medical society directory.

Results

A total of 335 patients were cared for at Hospice House. One hundred fifty-one (45 percent) were women and 184 (55 percent) were men. The age range of patients was from 25 to 95 years with a mean of 63.1 years and a median of 64.7 years. Two hundred ninety-four of the patients died at

Hospice House (88 percent). The remaining patients were either discharged (8 percent) to home or another facility. Disposition could not be determined from the record in 5 percent of patients. The average length of stay in the facility was 21.1 days with a median of 10 days and range from 1 to 387 days. Seventy-five percent of the patients had some private insurance, 4 percent had Medicare sponsorship, 4 percent were Medicaid patients, and 17 percent had no recorded method of payment.

Table 1 lists the primary specialty of the physicians of record for these patients. Oncologists were the admitting and attending physicians of record for almost 41 percent of patients, followed by internists and family physicians or general practitioners. Table 2 lists the most common diagnoses among these patients. Metastatic neoplasms were most common. Human immunodeficiency virus disease became an increasingly common admitting diagnosis during the 2½-year history of the facility. Table 3 displays problems listed on the structured intake nursing assessment in order of decreasing frequency. Biomedical problem assessments were recorded for 93 percent of patients, whereas functional and psychosocial assessments were present for only 80 percent (Table 4). At the time of admission each patient's level of consciousness was assessed. Two hundred twenty-eight patients (68.1 percent) were completely alert and oriented when admitted to the facility. Although 238 (71 percent) of patients had a problem with mobility, 116 patients (34.6 percent) were able to walk with assistance, 48 patients (14 percent) needed a wheelchair, and 22 patients (6.5 percent) required a walker for ambulation. Two hundred twenty-five (67 per-

Table 1. Specialty of Admitting Physicians for All Hospice House Admissions (n = 335) (November 1988 – December 1990).

Specialty of Admitting Physician	No. of Patients (%)
Hematology-oncology	137 (40.9)
Internal medicine	91 (27.9)
Others (neurosurgery, urology, gastroenterology, infectious disease, etc.)	59 (17.6)
Family practice-general practice	35 (10.4)
Surgery	10 (3.0)
Unknown	3 (0.9)

Table 2. Most Common Diagnoses for Patients Admitted to Hospice House.

Diagnosis	No. of Patients*
Secondary malignant neoplasm of other specified sites (metastases)	97
Malignant neoplasm of the trachea, bronchus, and lung	83
Secondary malignant neoplasm of the respiratory and digestive system (metastases)	78
Human immunodeficiency virus disease and complications	51
Breast cancer	28
Malignant neoplasm of the brain	25
Prostate cancer	16
Colon cancer	14
Total	392

*Includes both primary and secondary diagnoses.

cent) of the 335 patients had bowel problems, 107 (31 percent) had constipation, 48 (14 percent) were incontinent of stool, and 22 (6.5 percent) patients had diarrhea.

Table 3. Intake Nursing Assessment of Hospice Facility Patients (n = 335).

Problem Area	Assessed as a Problem	Assessed as No Problem	Not Able to Be Assessed or Assessment Not Recorded
	No. (%)	No. (%)	No. (%)
Pain	259 (77)	68 (20)	8 (3)
Mobility	238 (71)	38 (11)	59 (18)
Bowel problems	225 (67)	74 (22)	36 (11)
Respiratory	217 (65)	112 (33)	6 (2)
Nutrition	215 (64)	78 (23)	42 (13)
Safety	183 (55)	101 (30)	51 (15)
Mental status	179 (53)	134 (40)	22 (7)
Patient's emotional status	179 (53)	92 (27)	64 (20)
Family emotional status	156 (46)	99 (30)	80 (24)
Skin integrity	151 (45)	142 (42)	42 (13)
Urinary problems	135 (40)	164 (49)	36 (11)
Nausea or vomiting	134 (40)	190 (57)	11 (3)
Circulatory problems	125 (37)	141 (42)	69 (21)
Sleep disorders	119 (36)	154 (46)	62 (18)
Sensory perception	110 (33)	173 (52)	52 (16)
Intimacy needs	69 (21)	188 (56)	78 (23)
Infection	67 (20)	217 (65)	51 (15)
Seizure activity	54 (16)	252 (75)	29 (9)
Spiritual or religious needs	50 (15)	197 (59)	88 (26)

Discussion

This study is the first to describe the patients and types of problems that occur in an inpatient hospice setting. The paucity of basic descriptive data from such settings suggests that they are utilized less commonly than are home hospice services, but they are perhaps most often sought for caregiver respite. Generalizability of our findings must be viewed with caution. The spectrum of hospice care varies considerably by setting and by kinds of patients admitted to such settings, and it is particularly difficult for research in this area to control for such variables.

The results of our study are, however, compatible with previous published findings regarding the most common diagnoses of patients at the time of admission to hospice care.²⁻⁴ Pain was the most commonly cited problem for this population. There have been numerous studies suggesting that physicians consistently undertreat pain.⁵⁻⁸ Nevertheless, it was surprising that many of these terminally ill patients, most of whom were transferred from hospitals where they were

receiving active medical management, did not have their pain needs adequately controlled at the time of hospice admission. The physical and emotional uncertainties of transfer could have temporarily exacerbated patients' pain. Nevertheless, it was the authors' impression that most patients experienced substantial improvement in the control of their pain at Hospice House. Knowledge about pain management is essential for all physicians, particularly those working with terminally ill patients in a hospice setting.

Bowel (especially constipation), nutritional, respiratory, and skin problems were also frequent biomedical problems; they are excellent examples of problems that can be effectively managed by a multidisciplinary team. Thus training and skills in interdisciplinary collaboration could be the most important skill for physicians in a hospice

Table 4. Symptom Groups Not Able to Be Assessed or No Response Noted.

Problem Areas	Not Able to Be Assessed	No Response Noted
	No. (%)	No. (%)
Biomedical symptoms (n = 10)		
Respiratory problems	2 (< 1)	4 (1)
Pain	4 (1)	4 (1)
Nausea or vomiting	4 (1)	7 (2)
Mental status	2 (1)	20 (6)
Seizure activity	10 (3)	19 (6)
Urinary problems	3 (1)	33 (10)
Bowel problems	11 (3)	25 (8)
Skin	4 (1)	38 (12)
Infection	19 (6)	32 (10)
Circulatory	4 (1)	65 (20)
Mean	6 (2)	2 (7)
Functional symptoms (n = 5)		
Mobility	0 (0)	59 (18)
Safety	1 (< 1)	50 (15)
Nutrition	1 (< 1)	41 (12)
Sleep	10 (3)	52 (16)
Sensory	4 (1)	48 (14)
Mean	3 (1)	50 (15)
Psychosocial symptoms (n = 4)		
Patient's emotional status	33 (10)	31 (9)
Intimacy needs	21 (6)	57 (17)
Family emotional status	20 (6)	60 (18)
Spiritual or religious needs	21 (6)	57 (17)
Mean	24 (7)	54 (16)

setting. Mobility and safety issues were surprisingly common. The high rates of these problems reflect the special needs of hospice patients unable to be cared for in the home and referred to an inpatient hospice program. Mental status changes and emotional difficulties for the patient and family were present for more than one-half the patients at the time of admission. This finding highlights the importance of early discussion of advance medical directives, such as living wills and durable powers of attorney for health care, before the final phase of terminal care.

Only 10 percent of the patients in this study had a family or general practitioner as their admitting physician, whereas 40 percent had a hematologist or oncologist. The most common time of referral was at hospital discharge. Hospice House was a powerful therapeutic milieu. The authors found providing care at Hospice House extremely rewarding. As noted earlier, however, most attending physicians did not visit their patients at Hospice House. The lack of direct physician involvement in their patients' care was a complaint expressed by many patients and family members. Barriers to physician participation

could include inadequate physician training or interest, separation of primary care physicians from terminal care after referral to a subspecialist, or poor reimbursement. Irrespective of the cause, care at Hospice House would have benefited from greater physician participation.

Benefits for hospice care from third party payers are usually based on the following four criteria established by Medicare⁹: (1) the patient must be terminally ill with a life expectancy of 6 months or less, (2) the patient should be unable to benefit from further aggressive (curative) therapy, (3) the patient should be able to receive most of his or her care at home, and (4) the patient must have a care giver. Although all of the patients admitted to Hospice House presumably met the first two criteria, a lack of home care options

was often the real reason for admission to Hospice House. Hospice House was dedicated to caring for all patients admitted until their death. Because hospice benefits from payers are often time limited, length of stay had major financial implications. The average length of stay at Hospice House (21.1 days) is comparable with other reports suggesting a median life span of 3.5 weeks for patients in hospice settings.¹⁰⁻¹² Previous authors have indicated that health care professionals are inaccurate in predicting survival times for terminally ill patients.^{7,10} Patients were not admitted to Hospice House until their physicians certified a prognosis of 6 months or less. Only 3 (1 percent) of the 294 patients who died at Hospice House lived longer than 6 months, indicating more accuracy in prognosis than might have been expected. Nevertheless, more research needs to be done to prognosticate survival of terminally ill patients more effectively. If inpatient hospice care is to be a viable option, the most appropriate patients must be selected, and intensive, multidisciplinary care must be adequately reimbursed.

Data regarding the most common symptoms in these patients are useful indicators of neces-

sary clinical skills for health care professionals in caring for hospice patients.¹¹⁻¹⁴ Bulkin and Lukashok¹⁵ have proposed a five-part curriculum to train physicians to care for the dying. This curriculum includes the following components: (1) clinical skills including pain and symptom management, prognostication, and care in various settings; (2) communication skills; (3) psychosocial skills; (4) administrative management and team building skills; and (5) bioethical expertise. In the area of clinical skills, it seems clear from our data that physicians caring for hospice patients should be experts in multidisciplinary management of severe pain. The rate of major problems of mobility, respiratory and nutritional problems, constipation, and altered mental status emphasizes additional important areas of competence for physicians practicing in a hospice setting.

Table 4 separates patient problems into biomedical, functional, and psychosocial groupings. Functional (mobility, safety, sensory perception, nutrition, and sleep) and psychosocial (patient's emotional status, family's emotional status, and spiritual and intimacy needs) problems were twice as likely to have no assessment noted as were biomedical problems. Thus even a trained cohort of hospice nurses more consistently focused on biomedical than functional and psychosocial issues. The implications for physician training, for which we would predict even less attention to functional and psychosocial issues,¹⁶ are clear. Hospice physicians will benefit from close familiarity with assessment tools for functional and psychosocial problems. Physicians must also encourage routine evaluation of these issues by other team members. The authors were often impressed with the skills of the Hospice House pastor to point out issues critical to effective care plans that were not recognized by any other team members.

That this study is retrospective and much of the data are based on the admission assessment by the Hospice House nursing staff limit the study. Many of these nurses were employed at Hospice House throughout the history of the institution. In most respects they were much more skilled than the average physician in making such patient admission assessments. They were also extremely compliant in completing the admission assessment form, which was in a checklist format, thus

enhancing the uniformity of the data. Each patient was discussed within 3 days of admission by a multidisciplinary team, at which time the nursing assessment form was reviewed by the entire team and utilized to formulate a treatment plan. As a result, the working definition of "problem" was its relevance to the hospice care plan.

Conclusion

Future research regarding the care of hospice patients should re-examine the most frequently occurring problems and concerns of patients and their families, not only on admission but throughout the course of hospice care. Had the facility not closed, it was our intention to organize such a study. The care of patients and families at the end of life is a central and important component of family medicine. Better understanding of the health care needs of patients and families in such circumstances will only serve to improve the quality of care and enrich the lives of patients and care givers alike.

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