

Common Myths about Caring for Patients with Terminal Illness: Opportunities to Improve Care in the Hospital Setting

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BACKGROUND: Shortcomings in the quality of care of hospitalized patients at the end of life are well documented. Although hospitalists and residents are often involved in the care of hospitalized patients with terminal illness, little is known about their knowledge and beliefs concerning terminal illness, despite the importance of such physicians to the quality of care at the end of life.

DESIGN: In 2006 we conducted an exploratory study at a large academic medical center to examine the knowledge, attitudes, and practices of hospitalists and residents (n = 52, response rate = 85.2%) about the care of terminally ill patients. Data were collected using a 22-item survey instrument adapted from previously published instruments.

RESULTS: Several common myths about treating terminally ill patients were identified. These myths pertained to essential aspects of end-of-life care including pain and symptom control, indications for various medications, and eligibility for hospice. Physicians reported positive attitudes about hospice care as well as the belief that many patients who would benefit from hospice do not receive hospice at all or only late in the course of their illness.

CONCLUSIONS: Our findings identified misunderstandings that hospitalists and residents commonly have, including about facts essential to know in order to provide appropriate pain and symptom management. Future interventions to improve knowledge need to focus on specific clinical knowledge about opioid therapy, as well as information about eligibility rules for hospice. *Journal of Hospital Medicine* 2007;2:357–365. © 2007 Society of Hospital Medicine.

KEYWORDS: hospice, hospitalist, end-of-life.

Shortcomings in the quality of care of hospitalized patients at the end of life, especially in the final days, are well documented.^{1,2} Recent studies have highlighted inadequate pain and symptom control for hospitalized terminally ill patients,^{2–4} poor communication about treatment preferences,^{5–7} and limited or delayed referral for hospice care.^{8–10} Efforts to improve the quality of end-of-life care have been diverse, including increased educational programs,^{11–13} development of palliative care units in hospitals,^{14,15} and greater exposure to palliative care for physicians during residency training.¹⁶ Despite these efforts, studies assessing the attitudes and knowledge of physicians about hospice and palliative care continue to show deficits in knowledge about managing pain^{17,18} as well as hospice policies and services.⁹

Among the interventions aimed at improving hospital care, the hospitalist movement has emerged as a model of care for

improving the quality and cost efficiency of hospital care.^{19–22} Because hospitalists spend substantial time on inpatient services,²³ they are often involved in the care of patients with terminal illness, with potential to improve the quality of care that these patients receive while hospitalized. However, little is known about what specific knowledge and perspectives hospitalists and residents have about the care of patients with terminal illness. Although many studies have been conducted among physicians in private practice,^{9,10,24–26} they have not focused on the knowledge, reported practices, and attitudes of hospitalists and residents concerning key aspects of end-of-life care and hospice. Such information can help to identify potential areas for improving knowledge and addressing common barriers highlighted in linking hospital and posthospital hospice care.

METHODS

Study Design and Sample

During 2006 we surveyed hospitalists and medical residents who were on their oncology rotation at a large academic medical center that did not have a hospital-based palliative care unit in order to examine their knowledge, attitudes, and practices regarding terminally ill patients and hospice referrals. Hospitalists (n = 23) and medical residents (n = 29) made up a convenience sample of 52 physicians. The medical residents were completing their oncology rotation during the spring of 2006. The Institutional Review Board at Yale University School of Medicine approved the research protocol and verbal consent procedures.

Survey

The brief survey instrument (see Appendix) assessed physicians' knowledge and attitudes about and practices in caring for patients with terminal illness. The survey was adapted from previously published instruments^{8,24} that have been shown²⁴ to have good test-retest reliability and construct validity. The survey contained 5 items pertaining to clinical knowledge about palliative care practices, including common symptoms and drug indications, doses, and side effects.²⁷ An additional 2 items pertained to respondents' knowledge about nonclinical issues concerning eligibility rules for hospice,⁸ such as how a patient becomes eligible for hospice and whether Medicare benefits can be revoked or reinstated after hospice is elected. The

TABLE 1
Demographic Characteristics of Respondents (n = 52)

Characteristic	n	%
Sex		
Female	28	53.9%
Male	24	46.1%
Years since graduation from medical school		
1-2 Years	26	56.5%
3-5 Years	12	26.1%
>5 Years	8	17.4%
Missing	6	
Physician type		
Hospitalist	23	44.2%
First-year resident	9	17.3%
Second- or third-year resident	16	30.8%
Fellow	4	7.7%

survey also included 10 statements²⁴ assessing physician attitudes about caring for patients with terminal illness. Responses, provided using a 5-point Likert scale, were collapsed for reporting into a 3-point scale of agree, neutral, and disagree. The instrument also included an open-ended question asking physicians to specify what from their perspective was needed to ensure timely referral for hospice and palliative care.

Data Analysis

We used standard frequency analysis to describe the distribution of responses to the survey items. Based on an analysis of common erroneous answers to clinical knowledge questions, we identified several common myths prevalent among hospitalists and medicine residents. We also examined whether knowledge, reported practices, and attitudes differed significantly between the hospitalist and the resident samples using ANOVA or chi-square statistics as appropriate. We used content analysis to summarize the open-ended responses about potential ways to overcome what respondents perceived was underutilization of hospice.

RESULTS

Overview

The response rate for the survey was 85.2%. Almost half of the respondents (44.2%) were hospitalists (Table 1). The remaining respondents included first-year (n = 9) and second- or third-year (n = 16) residents or fellows (n = 4). Approximately 54% of the 52 respondents were

TABLE 2
Knowledge about Hospice and Palliative Care Practices and Eligibility for Hospice Care (n = 52)*

Questions about hospice and palliative care practices	Response (%)
The incidence of psychological dependence (addiction) to opioids and analgesics when treating pain from cancer or other medical conditions is:	
Common (1 in 10 patients)	17.3
Uncommon (1 in 100 patients)	48.1
Very rare (fewer than 1 in 1000 patients)	34.6
When a patient with cancer who is receiving opioids for pain complains of increasing pain, it most likely indicates:	
Opioid tolerance	69.2
Increasing pathology of the cancer	26.9
Patient noncompliance	0.0
New onset of a different opioid-resisting pain	3.9
In the pain patient receiving opioids, 30 mg of oral morphine is equipotent to of IV morphine	
1 mg	4.0
5 mg	40.0
10 mg	56.0
20 mg	0.0
The 2 classes of drugs most commonly recommended for treating terminal dyspnea are:	
Beta-blockers and Lasix	7.7
Opioids and benzodiazepines	82.7
Beta-blockers and corticosteroids	9.6
Beta-blockers and Singulair (montelukast)	0.0
A hospice patient whose agitation is primarily from anxiety should be treated with:	
Chlorpromazine (thorazine)	0.0
Haloperidol	21.6
Lorazepam (Ativan)	76.4
Morphine	2.0
Questions about eligibility for hospice care	Response (%)
Under the Medicare program, a physician must certify that the patient is expected to die within a specified time for the patients to be eligible for hospice services. To the best of your knowledge, patients become eligible for <i>inpatient hospice care</i> when they are expected to die in:	
2 Weeks	5.8
6 Weeks	9.6
2 Months	9.6
6 Months	69.2
Other	1.9
Don't know	3.8
To the best of your knowledge, patients become eligible for <i>home hospice care</i> when they are expected to die in:	
2 Weeks	0.0
6 Weeks	5.8
2 Months	7.7
6 Months	73.1
Other	0.0
Don't know	13.4

*Correct answers, that is, facts, are in bold.

female, and the majority (83%) had graduated from medical school between 2000 and 2005. Several common myths were apparent and pertained to essential areas of treating patients with terminal illness: pain control, symptom control, and eligibility for hospice (Table 2). Respondents generally had strong beliefs about caring for patients with terminal illness, and most agreed that many patients who would benefit from hospice either

do not receive hospice or receive it only late in the course of their illness (Table 3).

Common Myths in Treating Patients with Terminal Illness

Myth 1. *Treating cancer pain with opioids or analgesics causes addiction in 1 in 100 patients.* Most physicians thought that addiction in patients treated for cancer pain with opioids or analgesics

TABLE 3
Physicians' Beliefs about Caring for Patients with Terminal Illness (n = 52)

Beliefs	Disagree (%)	Neutral (%)	Agree (%)
Most patients want me to tell them their life-expectancy.	0.0	17.4	82.6
Generally, family caregivers want me to tell them the patient's life expectancy.	4.4	8.7	86.9
Telling the patient and family members that the patient's illness is incurable is difficult for me.	23.0	13.5	63.5
I think it is essential to discuss the prognosis with a patient, even if it is very poor.	0.0	4.4	95.6
Most patients' physical symptoms (eg, pain, shortness of breath, and nausea) are controlled better with hospice than with the care that they would receive in the hospital.	0.0	21.7	78.3
Most patients' emotional symptoms (eg, depression, anxiety) are controlled better with hospice than with the care they would receive in the hospital.	0.0	8.7	91.3
Hospice meets the needs of the family better than conventional care does.	0.0	8.7	91.3
Many patients who should receive hospice care <i>do not</i> receive hospice care.	21.8	13.0	65.2
Many patients would benefit if hospice care were initiated <i>earlier</i> in the course of their illness.	0.0	9.1	90.9
I feel knowledgeable enough to discuss palliative and hospice care with patients and families.	19.2	38.5	42.3

was much more common than it is. Almost half the respondents (48.1%) thought addiction occurred in 1 in 100 patients, and an additional 17.3% of respondents thought addiction occurred in 1 in 10 patients treated for cancer pain with opioids or analgesics. In contrast, the incidence of addiction in patients treated with opioids or analgesics for cancer pain is fewer than 1 in 1000 patients.²⁸

Myth 2. *When patients with cancer already receiving opioids for pain control complain of increasing pain, it most likely indicates opioid tolerance.* Nearly 70% of respondents reported that the most likely reason for complaints of increased pain was tolerance to the opioid. However, the most likely reason for increased pain is increasing pathology of the cancer.²⁷

Myth 3. *The equipotent to 30 mg of oral morphine is 5 mg intravenous.* More than half of respondents were inaccurate in their conversion of oral to intravenous (IV) morphine dosing, a common task of physicians caring for terminally ill patients. Almost half the physicians (44%) erroneously reported that 30 mg of oral morphine was equipotent to 5 mg or less morphine IV. However, in fact, 30 mg of oral morphine is equipotent to 10 mg of morphine IV.²⁷

Myth 4. *The most highly recommended drug for treating terminal dyspnea is a beta-blocker, and the most appropriate drug for agitation due to anxiety is Haldol or morphine.* Most respondents were able to identify the correct drugs; however, a sizable proportion of respondents (17.3%) erroneously responded that beta-blockers and Lasix or beta-blockers and corticosteroids were the best drugs for treating terminal dyspnea. About

one-fifth of respondents (21.6%) responded that Haldol or morphine was the recommended medication for treating agitation. In fact, opioids and benzodiazepines are the recommended drugs for treating terminal dyspnea,²⁷ and the proper drug for treating agitation is lorazepam (Ativan).²⁷

Myth 5. *Patient life expectancy must be 2 months or less to be eligible for hospice.* One-quarter of respondents believed this to be true for inpatient hospice, and nearly 13.5% of respondents believe this to be true for home hospice. In fact, patients are eligible for hospice benefits earlier in the course of their illness. Under Medicare and most insurance policies, patients are eligible for hospice benefits as soon as their life expectancy is 6 months or less, not 2 months or less.²⁷

Physician Beliefs about Caring for Patients with Terminal Illness

The physicians' beliefs about hospice were generally positive; the vast majority of respondents agreed or strongly agreed with the statement that physical and emotional symptoms of patients and family needs are better addressed with hospice than with the hospital care (Table 3). Most respondents also agreed that many patients do *not* receive hospice as they should and that hospice should be initiated earlier in the course of the illness. In addition, more than 80% of respondents believed patients and their families want their doctors to tell them the patient's life expectancy, and 95.6% of respondents thought it was essential to discuss prognosis, even a poor one, with the patient. Nevertheless, many respondents

TABLE 4
Physicians' Suggestions for Improving the Process of Hospice Referral (n = 42)

Response	n	%*
Involving family members as well as patients in discussions of hospice	16	38.1
Having earlier discussion with patients	11	26.2
Being clear with patients and families about patient prognosis	8	19.0
Providing education about hospice to patients and families	6	14.3
Discussions of goals of care with patients and families	6	14.3
Involving social worker in discussions	4	9.5
Providing literature to patients and families about hospice	3	7.1
Having hospice representative available to provide education to patient and families	2	4.8

*Percentages add up to more than 100% because some respondents made more than 1 suggestion.

(65.3%) reported it was difficult to tell patients and their families that an illness was incurable. Furthermore, fewer than half the respondents (42.3%) believed they were knowledgeable enough to discuss hospice and palliative care with patients and their families.

In subgroup analyses comparing responses to knowledge and attitude items reported in Tables 2 and 3, we found no significant differences between hospitalists and any subgroup of residents by year of training or fellows, or between hospitalists and the full sample of residents and fellows. Because of the sample size, the statistical power for evaluating significance was limited in these exploratory subgroup analyses.

Among physicians who provided responses to the open-ended question (n = 42) about how to enhance hospice referral rates and improve their timeliness, the most commonly reported suggestions were: (1) involve family members, not only patients, in discussions of hospice (38.1%), (2) have discussions about hospice earlier in the course of care with patients (26.2%), and (3) be clear with patients and families about the patient's prognosis (19.0%). Table 4 has a list of all responses provided to this question.

DISCUSSION

This study demonstrated that, among hospitalists and residents, there are several misconceptions about fundamental aspects of caring for terminally ill patients. Given the potential importance of the role hospitalists play in improving the quality of inpatient care,¹⁹⁻²² it is critical to iden-

tify and address these misconceptions. Additionally, physicians in this study indicated that more and earlier communication with patients and families about prognosis and about the option of hospice would be beneficial, but they themselves did not feel knowledgeable enough to discuss hospice and palliative care with patients and their families.

The nature of the misconceptions identified in this study shed light on the well-documented phenomena of inadequate pain control^{2-4,29} and poor symptom management^{2,4} at the end of life. Having many of the erroneous beliefs apparent in this study may be consistent with providing less pain medication than needed and appropriate. For instance, many physicians believed that developing addiction to opioids used for cancer pain is more likely to occur than it really is, according to research evidence. It is extremely rare for these patients to become addicted to opioids or other analgesics (fewer than 1 in 1000 patients).²⁸ In addition, most physicians believed that complaints of increased pain among patients receiving opioid therapy for pain control meant tolerance to the medication, a belief consistent with physician reluctance to prescribe more medication because it would lead to tolerance.²⁸ In reality, the increased pain experienced in these situations is typically not a result of tolerance to the pain medication but to the cancer getting worse.²⁷ Additionally, many physicians mistakenly decreased the dose of morphine in converting the route of administration from PO to IV, as is often done in hospitals. Such an error may be a contributing factor to the unintended undertreatment of pain in hospitals. Given the variability of cancer pain⁴ and the difference in time to peak effect depending on the route of administration,⁵ it is critical for physicians to understand proper dosing in order to effectively treat cancer pain. Furthermore, many physicians were incorrect about the recommended medications for dyspnea and for agitation, 2 symptoms that are prevalent among patients at the end of life.

The hospitalists and residents reported having very positive views about hospice, as is consistent with the literature.^{10,30} However, many respondents indicated that patients who would have benefited from hospice did not receive it at all or only late in their illness. Physicians indicated that better communication with patients and families about hospice, prognosis, and goals of care would enhance

appropriate use of hospice. While hospitalists and residents are in a position to initiate such discussions, they reported that these discussions were difficult for them. The challenge is how to promote what is necessary and valuable conversation with patients and families despite their difficulty, so that a realistic plan of care can be designed for all involved. Providing hospitalists and residents with evidence about what approaches are most effective in such discussions would be helpful to better prepare them for their roles in caring for hospitalized patients with terminal illness.

The results of this study have substantiated the need to enhance the education of hospitalists and resident physicians, who can play a vital role in improving the transition from hospital to hospice. Such education could take place as part of the residency experience or be embedded in various continuing medical education requirements that most states now have. The results of a recent national survey of hospitalists³¹ indicates they consider their palliative care training inadequate and feel ill prepared to care for patients with terminal illness. Our findings are consistent with those of that survey, highlighting information that is poorly understood by both residents and hospitalists. As hospitalists continue to play key roles in linking hospital to posthospital care,²¹ including hospice, there is greater opportunity to improve end-of-life care by expanding hospitalists' understanding of these issues.

Our findings should be interpreted in light of the study's limitations. First, this was an exploratory study, and the sample was modest in size. Nevertheless, the response rate was high: 85.2%. Second, we conducted the study in a single location; results may differ in other geographical areas. Last, we were unable to link reported knowledge and attitudes to patient experiences including quality of care or adequacy of pain control. Inadequate knowledge likely limits the quality of clinical practices, but the magnitude of this effect remains unknown and worthy of future study.

Despite these limitations, this study has contributed to the literature by identifying a set of misunderstandings or myths that may be common among hospitalists and residents who frequently care for hospitalized patients with terminal illness. Many of these misunderstandings were related to pain and symptom management, although some misunderstandings related to logistical issues such as hospice eligibility rules. Previous studies have described interventions to improve physicians' knowledge about palliative and end-of-life care practices at the undergraduate, graduate, and post-graduate levels.¹⁻³ Our findings identified specific gaps in physicians' knowledge. Interventions aimed at closing these gaps might emphasize both specific clinical information about pain management and medication recommendations, and more general information about eligibility for hospice and best practices for communicating early with patients and family is needed to promote more effective care for patients with terminal illness being cared for in acute care settings.

As the use of hospitalists has become a widely accepted model of hospital care,³² ensuring their increased training and education in the care of patients with terminal illness is an important step in improving end-of-life care. Larger comparison studies are needed to identify differences in the practices and perspectives of hospitalists and residents and to target educational interventions to meet their particular needs. Further, conducting these studies at additional sites including those with established palliative care programs would be useful for identifying needs among a more diverse set of physicians involved in delivering end-of-life care.

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APPENDIX

Survey on Hospice and End-of-Life Care

Survey ID _____

Date _____

I. DEMOGRAPHICS

- 1) What is your gender?
 - 1 Male
 - 2 Female

- 2) What year did you graduate from medical school? _____

- 3) What is your primary specialty or area of practice?
 - 1 Hospitalist
 - 2 Oncology fellow
 - 3 Oncology resident
 - 4 Physician assistant
 - 5 Other: _____

II. KNOWLEDGE OF HOSPICE AND PALLIATIVE CARE PRACTICES

- 4) The incidence of psychological dependence (addiction) to opioids and analgesics when treating pain from cancer or other medical conditions is:
 - a. Common (1 in 10 patients)
 - b. Uncommon (1 in 100 patients)
 - c. Very rare (fewer than 1 in 1000 patients)

- 5) When a patient with cancer who is receiving opioids for pain complains of increasing pain, it most likely indicates:
 - a. Opioid tolerance
 - b. Increasing pathology of the cancer
 - c. Patient noncompliance
 - d. New onset of a different opioid-resisting pain

- 6) In the pain patient receiving opioids, 30 mg of oral morphine is equipotent to _____ of IV.
 - a. 1mg
 - b. 5 mg
 - c. 10 mg
 - d. 20 mg

- 7) The 2 classes of drugs most commonly recommended for treating terminal dyspnea are:
 - a. Beta-blockers and Lasix
 - b. Opioids and benzodiazepines
 - c. Beta-blockers and corticosteroids
 - d. Beta-blockers and Singulair (montelukast)

- 8) A hospice patient whose agitation is due primarily to anxiety should be treated with:
 - a. Chlorpromazine
 - b. Haloperidol
 - c. Lorazepam
 - d. Morphine

III. ELIGIBILITY FOR HOSPICE CARE

9) Under the Medicare program, a physician must certify that the patient is expected to die within a specified time for the patients to be eligible for hospice services. To the best of your knowledge, patients become eligible for *inpatient hospice care* when they are expected to die in:

- 1 2 Weeks
- 2 6 Weeks
- 3 2 Months
- 4 6 Months
- 7 Other: _____
- 9 Don't know

10) To the best of your knowledge, patients are eligible for *home hospice care* when they are expected to die in:

- 1 2 Weeks
- 2 6 Weeks
- 3 2 Months
- 4 6 Months
- 7 Other: _____
- 9 Don't know

IV. ATTITUDES ABOUT HOSPICE CARE

Following is a series of statements. Please state whether you strongly agree, agree, neither agree nor disagree, disagree, or strongly disagree with each statement.

	Strongly agree				Strongly disagree
11) Most patients want me to tell them their life expectancy.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
12) Generally, family caregivers want me to tell them the patient's life expectancy.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
13) Telling the patient and family members that the patient's illness is incurable is difficult for me.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
14) I think it is essential to discuss the prognosis with a patient, even if it is very poor.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
15) Most patients' physical symptoms (eg, pain, shortness of breath, and nausea) are controlled better with hospice than with the care they would receive in the hospital.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
16) Most patients' emotional symptoms (eg, depression, anxiety) are controlled better with hospice than with the care they would receive in the hospital.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
17) Hospice care generally meets the needs of the family better than conventional care does.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
18) Many terminally ill patients who should receive hospice care <i>do not</i> receive hospice care.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
19) Many patients would benefit if hospice care were initiated <i>earlier</i> in the course of their illness.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
20) I feel knowledgeable enough to discuss palliative and hospice care with patients and families.	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
21) What do you see as the primary ways to facilitate earlier initiation of hospice care for patients who are eligible? _____					

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