

Attitude and Self-Reported Practice Regarding Hospice Referral in a National Sample of Internists

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ABSTRACT

Systematic, nationally representative information about physicians' attitudes and behavior with respect to hospice care is not available. We sought to describe these previously unexamined attitudes and practices. We conducted a mail survey of a random national sample of 1311 internists, of whom 697 responded (an unadjusted response rate of 53%). We elicited physician's attitudes and self-reported practice with respect to hospice. Most internists (89%) felt that hospice care was a good form of terminal care. Physicians with longer definitions of what constitutes "terminal" illness and those whose patients were more accepting of their prognoses were more likely to hold this opinion. Over the course of a year, the median internist referred five patients to hospice. Specialists and those with longer definitions of "terminal" were more likely to have done so. When asked "If you knew exactly how long a patient had to live, how long before death would you refer them to hospice?" the average response was 12.1 ± 8.5 weeks, but responses varied from 1 to 52 weeks, and the pattern of responses was bimodal, with one peak at about 13 weeks (73% of internists) and one at about 25 weeks (27%). Moreover, the distribution of hospice enrollment times implied by physician reports about ideal practice is significantly more compact than the distribution of survival that is actually observed; physicians support far fewer very short (<2 weeks) and very long (>6 months) stays in hospice than are observed. We conclude that internists show significant support for, and utilization of, hospice and they endorse a length of stay that is longer than currently observed. These findings suggest that it may be possible to increase both the number of patients using hospice and their duration of use of hospice.

INTRODUCTION

HOSPICE USE IN THE UNITED STATES has grown rapidly in the 16 years since the introduction of the Medicare hospice benefit. By 1996, approximately 260,000 new beneficiaries were receiving hospice care per year at a total annual cost to Medicare in excess of \$1.5 billion; the

number of patients has consistently grown 10% to 20% per year (Health Care Financing Administration, unpublished data). This increasing use is matched by positive attitudes toward hospice in the general public, as documented in at least one national survey of the general public¹ as well as in samples of the terminally ill and their families.²⁻⁵

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The appeal of hospice lies in its advantages over traditional, hospital-based terminal care: it is usually delivered at home, facilitating at-home death⁶⁻⁸; it optimizes pain relief⁹; it increases patient and family satisfaction²⁻⁵; and it is cost effective.¹⁰⁻¹⁵ In light of these benefits, commentators have encouraged physicians to optimize their use of hospice.¹⁶⁻¹⁸ To this end, attention might be directed to both the number of patients referred and the length of time most patients spend in hospice. However, regarding the latter, existing data suggest that timing hospice enrollment is a difficult task for physicians. For example, several commentators^{16,18-20} and studies²¹⁻²⁷ have examined the role of prognostication as a barrier to hospice use. Such difficulty may partially explain the substantial heterogeneity in lengths of stay at hospice that has been noted, with 16% of patients dying within a week of enrollment and 15% living for more than 6 months.²⁸

In light of these complications, it is very difficult to infer physicians' views of "best practice" in regard to hospice referral from observed behavior. How do internists regard the appropriateness of hospice? What do they feel to be an optimal enrollment time? Despite their centrality to any effort to understand (or change) actual hospice use, these questions have not, to our knowledge, previously been addressed. Furthermore, it is not known how these views vary between internists. Therefore, we conducted a survey of a random, national sample of internists to assess physicians' attitudes and self-reported practice with respect to hospice. Because of the central role of the formulation of a prognosis in hospice enrollment, we gave special attention to the relationship between physicians' attitudes and behavior in regards to prognostication on the one hand and their views of hospice use on the other. In a companion paper, we report in greater detail on physicians' attitudes towards prognostication in general.²³

METHODS

Survey instrument

Survey subjects received a 12-page, confidential survey instrument requiring about 20

minutes to complete, a cover letter, a small financial incentive, and a prepaid return envelope. The survey instrument, which has been previously described,^{23,29} also solicited demographic data, attitudes and self-reported practice with respect to prognostication and attendant clinical decisions, and open-ended comments. A verbatim list of key items from the survey that are analyzed in this article is presented in the Appendix. There were three mailing waves.

Subjects

Using the 1994 American Medical Association (AMA) Masterfile,³⁰ the AMA provided a random sample of 1500 internists drawn from the 94,381 internists who had completed their training and were in active practice. This sample size was dictated by a prior power calculation (taking into account typical response rates), which suggests that the sample would have greater than 95% power to detect differences of 10% in the proportions of physicians holding specific views. Of the 1500 names initially provided by the AMA, 82 were excluded because they were only secondarily internists; 71 were excluded because they did not have current addresses (the mail was returned by the post office or the address provided by the AMA was inadequate); and 36 were excluded because they noted themselves to meet exclusion criteria (e.g., they responded but noted that they were retired). The final sample thus consisted of 1311 internists.

A total of 697 physicians responded to the survey, yielding an unadjusted response rate of 53% (697 of 1311). This response rate compares favorably with response rates achieved in such lengthy surveys of physicians.³¹ Assuming that subjects who did not respond were eligible to participate in the same proportion as those whose eligibility status could be ascertained, the estimated denominator for the survey may be adjusted downward to 1179; consequently, the adjusted response rate is 59% (697 of 1179).³² Due to occasional missing data, and because a few subjects returned unusable surveys, not all totals in the analyses equal 697.

Two techniques were used to evaluate non-response: (1) respondents and nonrespondents

were compared along several demographic variables that were available for all 1500 subjects, and (2) the pattern of responses across time was assessed. In keeping with previous research examining response rates based on Masterfile samples,³³ our respondents did not differ from nonrespondents in terms of age, specialty, or geographic location. Moreover, time to response was not associated with any of the variables reported here in a statistically significant fashion, including, for example, age, sex, specialty, proportion of time spent in patient care, experience with hospice referral, or attitudes toward prognostication. Thus, the incremental addition of respondents to the survey sample had no observed effect on sample representativeness.^{33,34}

Statistical analysis

Multivariable techniques were necessary and appropriate for three questions presented here in order to separate the core associations from possibly spurious associations. Logistic regression was used to examine which subgroups of internists were most likely to regard hospice favorably, since this was a dichotomized response variable. The second set of analyses below interrogate which characteristics of internists are associated with greater referral to hospice. For count data of this type, negative binomial regression was used.³⁵ This technique is an extension of Poisson regression that estimates an additional error term with a log gamma distribution, and it was required because the regressions showed that there was substantial extra-Poisson variation in the data. The third set of multivariable analyses again use logistic regression to show the degree to which characteristics are associated with preferences for relatively earlier referral. All the regression results are reported as the odds-ratios (OR) associated with each variable.³⁶

RESULTS

Respondents

As previously reported,²³ respondents had a mean (\pm SD) age of 45.8 ± 10.7 and had spent a mean of 18.9 ± 11.0 years in practice; 77.6%

spent 90% or more of their time in clinical practice; 80.7% were male; and 79.8% were board certified. Their specialties were as follows: 47.8% were general internists, 12.5% were cardiologists, 9.5% were gastroenterologists, 6.9% were pulmonologists, 6.6% were hematologist/oncologists, and the remaining 16.7% were some other internal medicine subspecialty.

Attitude toward and practice of hospice referral

With respect to attitude, most physicians (89.2%) reported feeling that hospice is "an appropriate mode of care for most terminally ill patients." As shown in Table 1, this attitude was not associated with physician characteristics such as specialty, years in practice, proportion of time in patient care, board certification, or gender; however, it was associated with having a definition of "terminal" that involved longer survival. We asked physicians, "When physicians say that a patient is 'terminal,' how many weeks, on average, should the patient have left to live?" Adjusting for other factors, each 1-week increase in the definition of "terminal" was associated with a 6% increase in the

TABLE 1. FACTORS ASSOCIATED WITH INTERNISTS' ATTITUDE TOWARD HOSPICE USE

Variable	Odds ratio	95% CI
Generalist (vs. specialist)	1.03	0.59-1.82
Percentage of time in patient care (10% increment)	0.98	0.85-1.12
Board certified	0.88	0.42-1.82
Years in practice	1.01	0.98-1.03
Male gender	1.05	0.50-2.17
Definition of terminality in weeks	1.06	1.02-1.10 ^a
Definition of terminality not quantifiable in weeks	0.48	0.23-0.99 ^b
Prognostication is stressful	0.92	0.51-1.64
Patients do not expect too much certainty	2.35	0.96-5.74
Patients accept prognoses that are offered	2.32	1.09-4.93 ^b
Physicians should wait to be asked before offering prognoses	1.09	0.62-1.92

The table shows a logistic regression model of response to the question "hospice is an appropriate mode of care for most terminally ill patients." There were complete data for 571 cases.

^a $p < 0.01$.

^b $p < 0.05$.

odds of favoring hospice (95% CI, 2–10%). Thus, a physician whose definition of terminality was in the 75th percentile (24 weeks) was 3.3 times more likely to view hospice favorably than a physician whose definition was in the 25th percentile (4 weeks). In addition, physicians who felt that terminality could not be defined in terms of weeks (or a time frame in general) were 52% less likely to favor hospice use. Furthermore, those physicians who feel that their patients display more trust in their (the physicians') judgment (measured in two ways) are more approving of hospice (OR, 2.32; 95% CI, 1.09–4.93; and OR, 2.35; 95% CI, 0.96–5.74, respectively, for questions regarding patients' acceptance of physicians' prognoses and the certainty they expect).

A majority of physicians had at least some experience with hospice referral; 84.1% had referred at least one patient to hospice in the year prior to the survey; the median number of patients was five, and the interquartile range extended from two to ten. This experience varied substantially with specialty, however. For example, in the year prior to responding to the survey, the median general internist reported having referred 5 patients to hospice; the median pulmonologist/critical care physician referred 10 patients; and the median hematologist/oncologist referred 38 patients to hospice. (The differences between these groups are all significant at the <0.001 level.) As shown in Table 2, adjusting for other factors, generalists referred fewer patients to hospice; male physicians and those spending more time in patient care referred patients more often. Importantly, physicians who felt favorably about hospice were much more likely to report having referred patients. Moreover, longer definitions of what it means for a patient to be "terminal" were also consistently associated with increased use of hospice. There was a negative association between viewing one's patients as accepting of one's prognoses and one's frequency of hospice referral. Physicians' attitudes toward prognostication overall were not consistently associated with hospice referral.

Preferred length of hospice use

Given the extensive use of at least some hospice, we investigated variation in physicians'

TABLE 2. FACTORS ASSOCIATED WITH INTERNISTS' SELF-REPORT OF NUMBER OF PATIENTS REFERRED TO HOSPICE IN THE PRECEDING YEAR

<i>Variable</i>	<i>Coefficient (ratio)</i>	<i>95% CI</i>
Generalist (vs. specialist)	0.65	0.51–0.81 ^a
Percentage of time in patient care (10% increment)	1.13	1.06–1.19 ^a
Board certified	1.12	0.84–1.51
Years in practice	0.99	0.98–1.00
Male gender	1.36	1.02–1.81 ^b
Definition of terminality in weeks	1.03	1.01–1.04 ^a
Definition of terminality not quantifiable in weeks	1.13	0.80–1.60
Prognostication is stressful	0.97	0.77–1.22
Patients do not expect too much certainty	1.15	0.86–1.52
Patients accept prognoses that are offered	0.61	0.42–0.88 ^c
Physicians should avoid being specific in offering prognoses	0.86	0.60–1.24
Physicians should wait to be asked before offering prognoses	0.97	0.77–1.21
Hospice is appropriate for most terminally ill patients	2.04	1.41–2.96 ^a

The table shows a negative binomial regression model of self-report of number of patient referred to hospice in the preceding year. The constant and alpha parameter have been omitted; the alpha parameter indicated substantial overdispersion in the data relative to the Poisson. There were complete data for 555 cases.

^a $p \leq 0.001$.

^b $p < 0.05$.

^c $p < 0.01$.

preference regarding timing of hospice enrollment. We asked "If you knew exactly when a patient was going to die, how many weeks before death would you refer the patient for home-based hospice care, if you felt that hospice care was appropriate?" The range of responses to this question is shown in Figure 1. The average "lead time preference" was 12.1 ± 8.5 weeks; only 2.0% would ideally prefer for their patients to spend only a week or less in hospice, and only 3.6% would ideally prefer for their patient to spend more than 26 weeks. Responses varied from 1 to 52 weeks, and the pattern of responses was bimodal. That is, as shown in Figure 1, 73% had a lead time preference of less than 16 weeks to live, with a peak at about 13 weeks, and 27% had one of 16 or more weeks to live, with a peak at about 25 weeks.

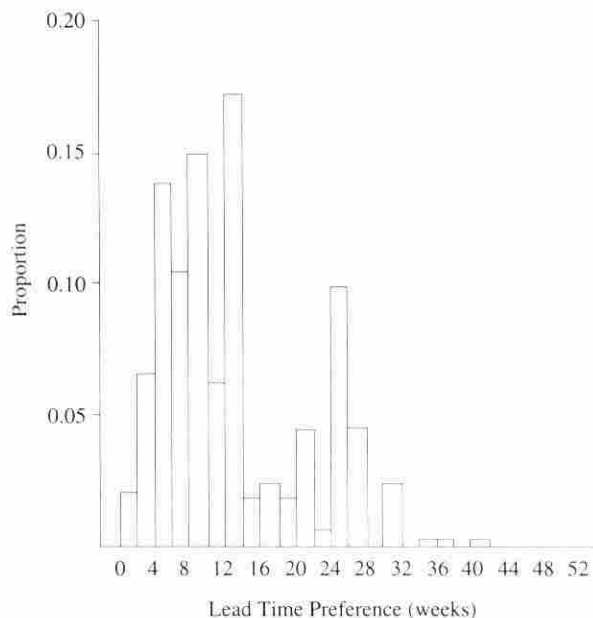


FIG. 1. Distribution of "lead time preference" with respect to hospice referral in a national sample of internists.

Table 3 presents a logistic regression model of the characteristics of physicians associated with having preferences for relatively earlier enrollment (defined as enrollment greater than or equal to 16 weeks *before* death). Lead time preference was not associated with years in practice, amount of time in patient care, gender, or board certification. But adjusting for these covariates, physicians who thought hospice was an appropriate mode of terminal care were 3.72 times as likely to prefer a lead time of 16 weeks or more (95% CI, 1.29–10.80), and generalists were 1.66 times as likely (95% CI, 1.07–2.58).

What do these expressed preferences imply about the survival distribution of these physicians' patients taken as a whole? We weighted each physician's lead time preference by the number of patients they reported having referred to hospice in the previous year and developed an implied survival distribution for patients who might have been referred in this way, as shown in Figure 2. This distribution demonstrates the survival times following enrollment in hospice that would be observed if physicians could make perfect predictions and they were willing and able to act on their stated lead time preference. The median survival in such a distribution is 11.8 weeks, with an interquartile range of 7.6 to 23.6 weeks. Fewer

than 1% of patients would live less than a week, and fewer than 0.5% would live longer than 6 months.

DISCUSSION

We surveyed a national random sample of internists to assess certain of their attitudes and practices regarding hospice care. We found that there is substantial support for, and referral to, hospice. In addition, attitude and self-reported behavior were highly linked. It is not possible, given this cross-sectional data, to determine the causal ordering between these favorable attitudes toward hospice and the frequent practice of referral; it is likely that the two are codetermined.

Although a large majority of physicians support hospice as a form of terminal care, there remains significant heterogeneity in attitudes and practice with respect to hospice referral. As might be expected given their different patient populations, specialists refer more patients to hospice in a year than do generalists. As reported previously,²³ there is also substantial

TABLE 3. FACTORS ASSOCIATED WITH INTERNISTS' SELF-REPORTED PREFERENCE FOR EARLIER ENROLLMENT IN HOSPICE

Variable	Odds ratio	95% CI
Generalist (vs. specialist)	1.66	1.07–2.58 ^a
Percentage of time in patient care (10% increment)	0.96	0.86–1.06
Board certified	1.51	0.86–2.65
Years in practice	1.00	0.98–1.02
Male gender	1.21	0.70–2.11
Prognostication is stressful	0.76	0.48–1.19
Patients do not expect too much certainty	1.39	0.83–2.34
Patients accept prognoses that are offered	0.82	0.41–1.64
Physicians should wait to be asked before offering prognoses	1.20	0.77–1.85
Hospice is appropriate for most terminally ill patients	3.72	1.29–10.80 ^a

The table shows a logistic regression model of response to the question "If you knew exactly when a patient was going to die, how many weeks before death would you refer the patient for home-based hospice care, if you felt that hospice was appropriate?" Responses were dichotomized at ≥ 16 weeks versus < 16 weeks. There were complete data for 468 cases.

^a $p < 0.05$.

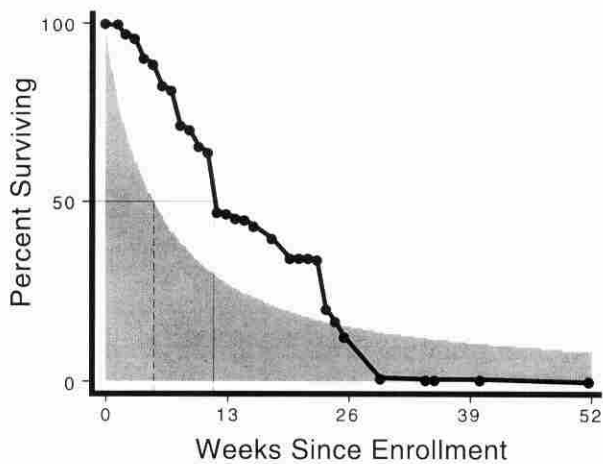


FIG. 2. Implied survival distribution from hospice lead time preferences of a national sample of internists weighted by self-reported referral experience (*heavy line*). The shaded curve is the observed survival distribution in the United States.²⁸ Median survival times are indicated for comparison.

disagreement among internists in what constitutes a "terminal" patient. Physicians who define "terminal" patients as those with relatively longer to live are more likely to approve of and use hospice.

Similarly, there exists a substantial diversity of opinion as to what constitutes the ideal time prior to death at which a patient should be referred to hospice. Generalists and those supportive of hospice care reported preferences for longer use of hospice. These results were aggregated to demonstrate that if physicians' preferences were acted on and were the sole determinant of hospice timing, the median length of stay in hospice would be just under 12 weeks; moreover, there would be virtually no very short (<1 week) or very long (>6 months) enrollments.

This work provides another view on the recent attention to the variation in the timing of hospice use. For example, a recent study demonstrated that the majority of patients enrolled in hospice programs under the Medicare benefit, especially those with cancer, are enrolled relatively late in the course of their illness; many patients (25%) die within 2 weeks of referral, and most (85%) die within the 6-month Medicare standard.²⁸ Our results indicate that physicians do not affirmatively desire such survival times; the variation that exists in

physician ideals is insufficient to explain the variation observed in actual survival following enrollment. In particular, physicians' ideals of behavior would place far fewer individuals in the tails of the distribution.

While documenting this incongruity between physicians' ideal referral practice and the observed survival of patients following hospice enrollment, the data presented here only support speculation on its origins. It is possible that patients have different understandings of what it means to be terminal and different ideals about the use of hospice than do physicians; if so, the observed distribution may represent an imperfect compromise between patients and their physicians. Complicating the possibilities of such a compromise, the SUPPORT study has shown that patients in some serious diseases substantially overestimate their own probability of long-term survival, and that these predictions affect their treatment preferences, reducing the appeal of palliative care.³⁷ However, the degree to which physicians incorporate patient preferences into their treatment regimens at the end of life has been questioned.³⁸ Work in progress suggests that this discrepancy between observed and ideal survival distributions might be explained by the systematic errors physicians make in prognosis.³⁹ Alternatively, hospices are not always and uniformly available.⁴⁰ That is, even if physicians and patients agreed about the ideal timing of hospice enrollment and were accurate in their predictions, the facilities to meet this desire promptly might not exist. Further research into the relative contributions of physicians' behavior, patients' preferences, and the organizational context of hospice use is therefore necessary.

Our study has several limitations. First, we studied physicians' behaviors and attitudes by directly asking physicians; such self-reports have not been validated by comparison with physicians' revealed preferences during actual patient care. Second, given the response rate of less than 100%, the possibility of recruitment bias suggests caution in generalizing our results. However, our response rate is very similar to that of other reported surveys requiring physician completion,³¹ there was no change in sample representativeness associated with tim-

ing of response, and there was only a minimal difference between respondents and nonrespondents on attributes of both groups that we were able to measure. And third, we only studied internists; studies of different populations of physicians might yield different results.

Despite these limitations, the results presented here suggest that physicians are aware of hospice. Moreover, internists in general agree with hospice providers about the need for stays longer than a few weeks. Our results suggest, therefore, that efforts to improve the care of the dying, and, in particular, to optimize the use of hospice, must move beyond the basic educational task of increasing familiarity with hospice. Instead, it is necessary to seek a more nuanced understanding of the role of physician and patient preferences as well as institutionally constrained opportunities in order to explain whether and when hospice is used as a form of terminal care.

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APPENDIX

Select survey items.

For each of the following questions, please circle an answer

1. I find it stressful to make predictions about the course of a patient's illness.

Agree	Disagree
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2. I usually wait to be asked by a patient before offering a prediction about the course of a patient's illness

Agree	Disagree
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3. My patients often expect too much certainty when I make predictions about their illness.

Agree	Disagree
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4. My patients accept the prognoses I offer, when I render prognoses.

Agree	Disagree
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5. Physicians should avoid being too specific when making predictions to patients.

Agree	Disagree
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6. Hospice is an appropriate mode of care for most terminally ill patients.

Agree	Disagree
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For each of the following questions, please enter a number.

1. Approximate number of patients who have asked you "How long do I have to live?" in the last year: _____ patients
2. Approximate number of patients you have referred for inpatient or outpatient hospice care in the last year: _____ patients
3. If you knew exactly when a patient was going to die, how many weeks before death would you refer the patient for home-based hospice care, if you felt that hospice care was appropriate? _____ weeks
4. When physicians say that a patient is "terminal," about how many weeks, on average, should the patient have left to live? _____ weeks