Spousal Illness Burden Is Associated with Delayed Use of Hospice Care in Terminally Ill Patients

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ABSTRACT

Patients' families are important in hospice not only because they themselves might benefit from it, but also because they influence whether and how hospice is used to begin with. We hypothesized that, among the married, people with less capable spouses (in this case, those who are less healthy) should be less able to use home hospice care and should enroll in hospice later in the course of their illness, closer to death. We tested this hypothesis by evaluating the impact of spousal health on the timing of patients' use of hospice in a select group of 517 couples, a total of 1034 patients, for whom we have health data for both partners from Medicare claims records. We evaluated cohort survival using the Kaplan-Meier method and Cox regression, and we measured illness burden using the Charlson comorbidity score. Among the probands, 45.6% had a primary cancer diagnosis, 44.5% were female, 7.5% were nonwhite, their mean age was 80.0 years (±7.6 SD), and their mean Charlson score was 3.1 ± 3.0. The probands' median survival after hospice enrollment was 55 days. Spouses were similarly composed demographically, but were less likely to have a cancer primary diagnosis (35.4% had cancer) and were slightly younger than the probands; their mean Charlson score was 2.9 ± 2.9. Each additional point in the Charlson score of the spouse, controlling for measured characteristics of the proband, is associated with a 5.1% increase in the risk of death after enrollment. That is, after controlling for the characteristics of hospice patients themselves, those with sicker spouses are enrolled later. Compared with patients with the healthiest spouses, those with moderately sick and very sick spouses had considerably later enrollment into hospice, with the median survival decreasing from 111 to 49 to 22 days across the groups. Our data suggest that there may be a separate role of spousal health in affecting the time of hospice enrollment, and that patients' social support may affect not just their health status to begin with, but also their use of health care in general.

INTRODUCTION

THE ABILITY OF HOSPICE to enhance the likelihood that the patient will achieve the sort of death that is most commonly desired—a death free of worrisome symptoms, in one's own home, surrounded by loved ones—is both documented and regarded as a primary benefit of hospice care.[1–5] More generally, however, one of the appeals of hospice care has been the

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emphasis it places on the role and needs of the family, both while the patient is alive and during bereavement. Families are an important element of hospice care and are thought to benefit from it. For example, some previous research has sought to determine if this family focus of hospice might ameliorate the deterioration in health status that is seen in bereaved spouses, a deterioration that has been well studied with respect to mortality.[6–9] Several small studies have examined whether hospice softens the blow from the loss of a spouse and have found that it does.[10–14] On the other hand, two more rigorous studies found relatively few differences between the outcomes for caregivers of those who died in hospital versus those who died in hospice.[15,16]

Patient's families are important in hospice care, however, not only because they themselves might benefit, but also because they influence whether and how hospice care is delivered to begin with. Unfortunately, somewhat less attention has been directed to this initial decision about whether to use hospice at all, and, if so, when to do so. Anecdotal evidence suggests that lack of a care-giver, limitations in the ability of the care-giver to provide care, or poor home support in general might be associated with either the avoidance of hospice altogether or with late hospice referral. Mor and Masterson-Allen, for example, have noted that "it is evident that the nature of the hospice intervention requires a strong informal support system, particularly for home care hospice patients."[17] Lack of such a support system would presumably act as a restraint on the use of hospice. Among the married, people with less capable spouses (*e.g.*, those that are less healthy or less available to provide care) should be less able to use home hospice care (as opposed to alternative terminal care arrangements such as hospital or nursing home care) and should enroll in hospice later, if at all. By extension, people without spouses altogether should be less able to use home hospice at all, or, if they do, should also enroll later, compared with married people.

In this study, we sought to test these hypotheses by evaluating the impact of spousal health on patients' use of hospice. In order to do so, we used a select group of 517 hospice patients and their spouses for whom we had health data for both partners from Medicare claims records. We evaluated whether spousal health influenced the timing of hospice enrollment. Taking into account indicators of the patients' health, we explored whether there exists a separate role of spousal health in affecting the time between hospice enrollment and death. As we have argued elsewhere, survival after enrollment in hospice is much more closely associated with physician and patient behavior in determining the timing of enrollment than with intrinsic disease physiology or with some undemonstrated effect of hospice on mortality.[18,19] That is, patients who live for short periods of time after hospice enrollment will be those who, for whatever reason, were enrolled later in the course of their illness. We will show here that spousal illness burden appears to be just such a reason acting to delay hospice entry.

METHODS

Data sources

From the Health Care Financing Administration, we obtained the "Standard Analytic File" for all Medicare patients admitted to hospice programs during 1993 in the entire country. Additional data files included 1991, 1992, and 1993 Medicare Provider Analysis and Review (MEDPAR) files describing patients' hospital use and comorbidities, as well as vital status files containing dates of death. Patient data were linked on an individual level. There were 184,843 total Medicare patients admitted to hospices throughout the country for the first time in their lives in 1993. This data set is being examined in great detail in its entirety; here we focus on a small subsample.

The cohort of married couples

Our study cohort consisted of the 517 couples (a total of 1034 patients) both members of which were Medicare beneficiaries who happened to be admitted to a Medicare-certified hospice care program during 1993. Our sample is thus extremely limited; of the estimated 100,000 married Medicare beneficiaries who

were admitted to hospice programs in 1993, we examined only those patients who were *both* admitted to hospice. We estimated that there were approximately 800 couples in whom both members were admitted; given the unavoidably imperfect sensitivity of our method for identifying married couples, we were only able to identify 517.[20] However, our cohort is the largest sample of married people using hospice in which health information about both members is available that has yet been examined, has virtually perfect measurement of the variables we are considering, and is drawn from the entire country. The first member of each spousal pair to enter hospice will be referred to as the proband, and the later-entering member as the spouse. In cases of tied entry times, one member of the couple was randomly chosen to be the proband; this occurred 82 times. The analyses presented here do not change substantively when the tied cases are excluded (data not shown).

Statistical analysis

We estimated the cohort survival function using the Kaplan-Meier method.[21] To adjust for the effect of measured attributes of patients and their spouses on patient survival, we performed Cox regression; in Cox regression, the association between a variable and survival is expressed as a hazard rate or risk ratio, similar to an odds ratio.[22,23] In the present context, a risk ratio greater than unity is associated with a higher risk of death and therefore a shorter survival time after hospice enrollment and thus later enrollment.

Using the vital status file, we obtained mortality follow-up for these individuals through August 20, 1996, at which time 51 patients (9.9% of the cohort) were still alive. The dependent variable in the Cox model was survival from enrollment to death, in days. The independent variables included patient age, sex, race, and diagnosis (dichotomized into cancer and noncancer groups) as well as similar spousal attributes. Using MEDPAR information about hospitalizations during the 730 days preceding hospice admission for each individual, we also obtained measures of inpatient hospital use and developed a Charlson comor-

bidity score.[24,25] This score ranges from 0 to a theoretical maximum of 33, is based on the presence of a broad set of diseases with assigned point values, is a measurement of illness burden, and has been validated. Patients with multiple conditions (as detected based on hospitalizations) have higher scores. For example, conditions such as dementia, myocardial infarction, or chronic obstructive pulmonary disease contribute 1 point, conditions such as severe diabetes or renal disease contribute 2 points, conditions such as severe liver disease contribute 3 points, and so forth, to a summed total of points representing a measure of the patient's illness burden. In the present application, patients lacking any hospitalizations in the 730-day period preceding hospice admission were assigned a Charlson Score of 0. As a measure of resource use before hospice admission, we counted the number of days spent in a hospital in the 90-day period preceding hospice admission.

RESULTS

The 517 probands had the following attributes: 45.6% had a primary cancer diagnosis; 44.5% were female; 7.5% were nonwhite; 27.5% had not been hospitalized in the 90 days preceding hospice enrollment; and their mean age was 80.0 years (±7.6 SD), with a range of 50.1 to 98.8 years. The mean Charlson score for the probands was 3.1 ± 3.0, with a range of 0 to 12. Of the 90 days preceding hospice enrollment, probands spent an average of 8.2 (±13.1 SD) days in the hospital. The probands' median survival after hospice enrollment was 55 days, with an interquartile range of 17 to 284 days. In the case of the probands, 59.0% were admitted to freestanding hospices and 27.2% to home health agencies; only 13.8% were admitted to programs sponsored by skilled nursing facilities (1%) or hospitals (12.8%).

The 517 spouses were similarly composed demographically but were less likely to have a cancer primary diagnosis (35.4% had cancer) and were on average 0.3 (±5.2) years younger than the probands (range, from 17.5 years older to 29.7 years younger). The mean spousal Charlson score was 2.9 ± 2.9 (range 0–12). And

the spouses' median survival was 67 days, with an interquartile range of 15 to 395 days. Most spouses (450 [87.0%]) were admitted to the same hospice program as their partners.

Table 1 presents the results of a Cox regression predicting survival after enrollment in hospice. Patients who were sicker at the point of enrollment in hospice survived for a shorter period of time after hospice. More specifically, each additional Charlson score point raised the risk of death 10% (95% risk ratio [RR], confidence interval [CI] 1.06–1.14), and each additional day in the hospital before hospice enrollment was associated with a 0.9% increase in the risk of death (95% RR, CI 1.00–1.02). Net of these clinical factors, women are enrolled in hospice earlier. After controlling for other variables presented above, age and race were not associated with differential survival after enrollment.

Pertinently, an increased disease burden in probands' spouses also was associated with later enrollment of probands in hospice. Each

TABLE 1. RISK OF DEATH AFTER HOSPICE ENROLLMENT ACCORDING TO ATTRIBUTES OF PATIENTS AND THEIR SPOUSES

	Risk ratio	95% CI
If the proband		
had a primary diagnosis on admission of cancer	1.055	[0.866–1.286]
had a Charlson score that was 1 point higher	1.100	[1.062–1.139][a]
was 1 year older	0.999	[0.986–1.013]
was female	0.694	[0.574–0.840][a]
was nonwhite	0.819	[0.570–1.177]
was hospitalized for 1 more day (before hospice)	1.009	[1.001–1.016][b]
If the proband's spouse		
had a primary diagnosis on admission of cancer	0.946	[0.777–1.152]
had a Charlson score that was 1 point higher	1.051	[1.013–1.090][a]
was hospitalized for 1 more day (before hospice)	1.005	[0.998–1.012]

The table shows a Cox proportional hazards regression model giving the risk ratios and 95% confidence intervals of survival after referral to hospice depending on attributes of patients and their spouses. Analogous to odds ratios, risk ratios greater than unity imply a correspondingly increased risk of death and hence shorter survival time after hospice enrollment and thus later referral. All dichotomous variables were coded as 1 = present and 0 = absent.
[a]$p < 0.01$.
[b]$p < 0.05$.

additional point in the Charlson score of the spouse, controlling for all of the above characteristics of the proband, was associated with a 5.1% (95% RR, CI 1.01–1.09) increase in the risk of death after enrollment. That is, after controlling for the characteristics of hospice patients themselves (e.g., diagnosis and sex), those with sicker spouses were enrolled later. The effects of spousal chronic disease burden on the Kaplan-Meier survivorship function of the probands is summarized graphically in Fig. 1. Compared with patients with the healthiest spouses, those with moderately sick and very sick spouses had considerably and progressively lower survivals, meaning later enrollment into hospice; the median survival of probands decreased from 111 to 49 to 22 days across the groups as the health of the spouse declined. Adjusting for other measured covariates using Cox regression, those probands with the sickest spouses (spousal Charlson scores greater than or equal to seven) had a 54% (95% RR, CI 1.15–2.08) higher risk of death compared with those with the healthiest spouses (spousal Charlson scores of less than or equal to 2). After such adjustment for other measured covariates, patients with the sickest spouses were enrolled 80 days later in the course of their illness compared with patients with the healthiest spouses (the unadjusted difference is simply 111 − 22 = 89 days).

To further assess the proposition that spousal sickness was directly affecting hospice enrollment behavior and 1) not simply measuring some proxy (in the spouse) for unobserved disease burden (in the proband) or 2) not simply capturing some overall help-seeking orientation of both members of the couple, we conducted two further analyses. We defined "early" hospital days as those in the 2 years before hospice enrollment that did not occur in the 90 days immediately preceding hospice enrollment. Inclusion of the number of early hospital days in the Cox regression did not alter the effects of spousal Charlson score (data not shown). Furthermore, there were only weak correlations between the illness levels in the two members of each couple, even in this sample where both used hospice in the same year. The Pearson correlation coefficients were 0.17 between spouses for Charlson scores, 0.12 for
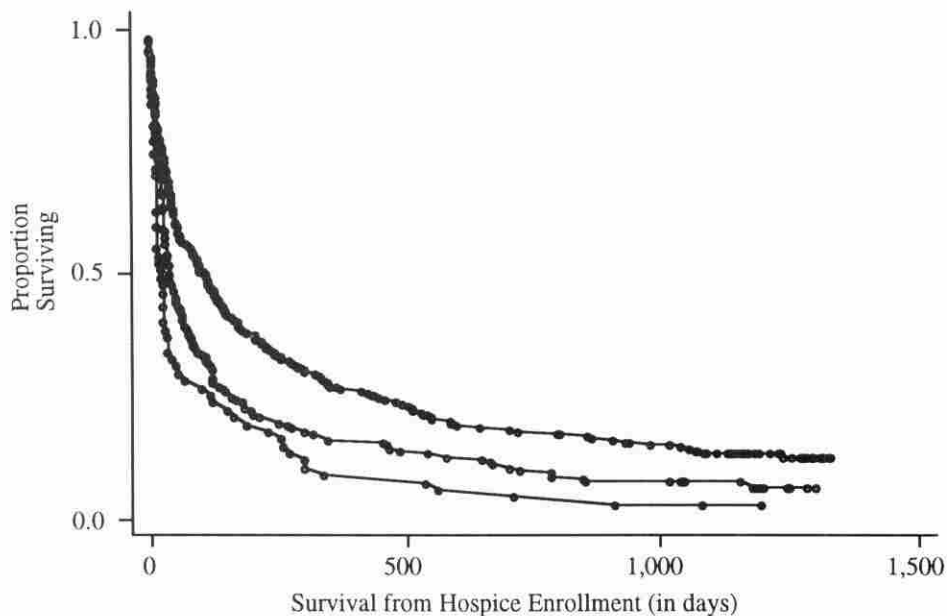
FIG. 1. Patients' survival after hospice enrollment as a function of their spouses' health status. The unadjusted Kaplan-Meier survivor functions are graphed for patients (probands) as a function of their spouses' health. Probands with sicker spouses die more quickly after hospice enrollment. The highest line shows the experience of those with the healthiest spouses (Charlson score of 0–2; n = 278). The intermediate line shows the experience of those with intermediately sick spouses (Charlson scores of 3–6; n = 172). The bottom line shows those with the sickest spouses (Charlson scores of 7–12; n = 67). These groups are significantly different by the log-rank test ($\chi^2 = 27.5, p < 0.0001$).

hospital use in the 90 days preceding hospice enrollment, and 0.24 for total number of hospitalizations in the preceding 2 years.

DISCUSSION

In a highly selected sample of hospice users—where both members of the couple used hospice in 1993—we demonstrated a significant difference in the timing of enrollment as a function not only of attributes of the proband, but also of the proband's spouse. Those with sicker spouses enrolled in hospice later, closer to death. We were able to discern this effect even among a population in which all spouses were significantly ill; all the spouses were, after all, enrolled in hospice (and they died in a median of 67 days after their enrollment).

It is important to stress that we are taking the influence of spousal illness burden on patient length of survival after hospice enrollment as *ipso facto* evidence of different timing of enrollment. However, there are other possible explanations that data such as ours—involving solely patients enrolled in hospice and ob-

served only from the time of enrollment—cannot exclude. For example, it is conceivable that hospices have differential effects on mortality after enrollment, effects that vary with the social support of the probands; that is, hospice care might happen to shorten the life of patients with low social support, but not of those with high social support. Or patients with healthy spouses may have longer survival compared with other patients because their life is somehow being prolonged (even after hospice enrollment) by a factor of 80 days by the existence of such a spouse; in other words, lower social support may lead directly to more rapid death after hospice enrollment (rather than leading to later enrollment). Although such effects would explain the results and cannot be ruled out with the data at hand, they do not seem credible. Differences in time of enrollment seem a more parsimonious explanation for the very substantial differences in median survival rather than believing in a substantial difference in the tendency of hospice to accelerate death or in the ability of relatively well spouses to substantially prolong life in their seriously ill partners.

Home-based hospice care at the end of life is more consistent with Americans' preferences about death than is terminal care in an institutional setting.[26] In this light, early enrollment in hospice is beneficial for patients. Our results demonstrate that those with the healthiest spouses receive more of this beneficial care. The role of marital status or social support in health care *seeking*, and not just in health *status*,[27–30] is deserving of attention beyond the specific situation of hospice, however. Do people who are married use health care more often because they have an advocate in their spouse? Or do they use it less often because they can rely on their spouse rather than on formal institutions? Or are there meaningful differences in the patterns of health-care seeking, and not just in amount, across marital groups?

Our findings are consistent with some of the literature on the effects of marriage and social support on health-care utilization. The married are less likely to be placed in nursing homes.[31] Those with more social support engage in significantly more regular cancer screening.[32, 33] Among the married, provision of social support to a care-giver has even been shown to reduce the care-receiver's health-care utilization; that is, patients were less likely to get sick if their spouses received more social support, thereby presumably making the spouses more able to care for the patient.[34] Finally, studies of *inpatient* hospice have shown that patients with good support (*e.g.*, those that are married) tend to use inpatient hospice later, consistent with both the ability and desire to avoid institutionalized care (even if it is hospice care).[35,36] Elements of the patient's home environment, such as whether the patient lived alone, whether the primary care-giver was male, and whether the primary care-giver was employed, were shown to be associated with the choice of hospital-based rather than home-based hospice terminal care.[37] In short, if there was not adequate support at home, there was reluctance to use home-based terminal care. On the other hand, and unlike the results presented here, one study failed to find a relationship between home support and timing of outpatient hospice use.[38]

The reasons for differences in health-care use according to whether one has a spouse and whether that spouse is able to provide support are less clear and are deserving of further research. It is one thing for patients' own attributes, such as age, diagnosis, and comorbidities, to be associated with their use of health-care resources. It is quite another for attributes of their family to have an independent effect. In the case of hospice care, it could be that the married have a stronger preference for dying in their own home (in the presence of their healthier spouses), and that the observed results are completely consistent with differences in patient desires. Alternatively, there could be differences between those with healthy spouses and the unmarried (or those with sick spouses) in the availability of resources for informal care. More pessimistically, given the SUPPORT study's findings regarding physicians' reluctance to incorporate patient preferences at the end of life,[39] the earlier hospice use by those with healthier spouses may be evidence of the importance of vigorous spousal advocacy in obtaining optimal end-of-life care.

Of course, these underlying causes cannot be differentiated in the present study. Moreover, our study has other limitations. The greatest limitation is the restriction imposed by a sample of patients and spouses all of whom used hospice. It is possible that the effects might be different in a sample with a wider range of spousal health and health-care use represented. Furthermore, although our sample is drawn from the entire nation, there might be regional or socioeconomic effects that we lacked the power to detect. The individuals in our cohort may have been unrepresentative of the typical hospice patient in other ways as well. Relative to a nationally representative cohort of Medicare patients (which had, however, some balance between both married and unmarried people),[40] patients in the cohort examined here had an average Charlson score that was about 2 points lower, were less likely to have a cancer diagnosis, were older, and lived substantially longer after enrollment. Finally, we only studied Medicare beneficiaries in this study, and our results might be different if we had been able also to examine hospice patients (and their partners) with other types of insurance coverage.

Until our findings are confirmed in a popu-

lation-based cohort including both patients who were referred to hospice and those who were not, the results here can only be considered suggestive of our general concern. In order to fully address the issue of the impact of marital status and spousal incapacity on the selection of hospice care, a population-based sample of all potential hospice users and their spouses would be necessary. Such a data set does not yet exist. Nevertheless, we believe that the extent to which the home situation of patients, including their amount and type of social support, influences the health care they seek is an important area of focus, particularly at the end of life.

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