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There are only two things in life that are certain, the saying goes: death and taxes. And I certainly am grateful to be here today to talk about the former since I know nothing about the latter.

It is fashionable to be concerned with so-called "vulnerable populations" in medicine as well as in policy-making and law-making, but, to my eye, there could be no more vulnerable a population than the terminally ill. Facing their own imminent death, this group of Americans has limited opportunities to find a political voice and advocate effectively for its interests. I therefore greatly admire and respect the attention the Senate Special Committee on Aging is giving to this issue, and I thank Chairman Grassley and Senator Breaux for their leadership, and Senator Wyden for suggesting me as a speaker. Surely, an important measure of our civilization is the care we give to those among us who are dying.

I was asked to comment on three items in my testimony today: 1) barriers to hospice use in general, 2) the problem of prognosis in particular, and 3) the cost-effectiveness of hospice care. I feel qualified to comment on these matters since I am an internist and sociologist who conducts research on the delivery and outcomes of medical care. I have doctoral-level training in medicine, sociology, and public health and am currently Associate Professor of Medicine, Department of Medicine, and Associate Professor of Sociology, Department of Sociology, at the University of Chicago. I have spent the last ten years studying ways to improve the care of the dying in our society, with a special emphasis on the role of prognosis in medical care and on the use of hospice. My clinical practice, at Horizon Hospice in Chicago, consists of providing home-based hospice care to primarily poor patients dying on the South Side of Chicago. My testimony today is based on my clinical experience, on the published work of other investigators, and on more than a dozen studies conducted by my own research group. Much of my own work that I will discuss today has been funded over the past five years under grants from the National Institute on Aging.

Hospice Use in the United States Today

Hospice is a form of terminal care that emphasizes relief of patients' physical and emotional pain and suffering more than the treatment of the underlying disease. More than 80 percent of the time, hospice care in the U.S. is provided by visiting nurses and other staff in patients' own homes.

It is important to emphasize at the outset that several studies have shown that hospice care does not shorten life. Yet, hospice offers several advantages over traditional, hospital-based terminal care: it facilitates at-home death; it optimizes pain relief; it increases patient and family satisfaction; and it is cost-effective.

In 1982, Congress introduced the Medicare hospice benefit, and, at present, Medicare pays for virtually all people older than 65 who receive hospice care, spending more than \$1.5 billion annually. The number of patients using the benefit has consistently grown 10-20 percent per year. This increasing use is matched by positive attitudes towards hospice, as documented in at least one national survey of the general public as well as in many samples of the terminally ill and their families. Of the 1.6 million people older than 65 who die annually in the U.S., approximately 15 percent receive some hospice care, a percentage that is approximately equivalent to the percentage of Americans who die under nursing home care. And hospice is used by a broad cross-section of Americans; a demographic profile, based on a complete enumeration of 184,843 Medicare hospice users in 1993, is provided in Table 1. Hospice is thus an important source of end-of-life care today. And its special features seem perfectly suited to providing the kind of death most Americans say they want: free of pain, surrounded by loved ones, and not subject to needless technological interventions.

In this sizable population of dying Americans, how is this important form of care currently being employed? When in the course of illness do patients use hospice, how long before death? To what extent do patient, physician, hospice, and market factors act as barriers to the optimal timing of hospice enrollment? Are these barriers interfering with increased use of hospice both in terms of percentage of dying patients using hospice and not just in terms of the duration of use? And how do patterns of hospice use compare to physicians' stated ideals? These are some of the questions I will address today.

Duration of Hospice Use and Timing of Hospice Referral

One survey of a national sample of internists showed that physicians recommend that hospice be used for about three months before death. However, numerous studies have shown that patients typically receive hospice care for less than one-third of this amount of time, that is, for only about two to four weeks.

Studies of patients admitted to single hospices have revealed median survival times of 22 days, 25 days, 29 days, and 62 days, while studies that have reported data from multiple hospices have found median survival times of 26 days, 30 days, 35 days, and 36 days. The most recent and comprehensive study of hospice patients was one we ourselves conducted, and it involved a complete enumeration of all 184,843 Medicare hospice patients newly admitted to hospices in the U.S. in 1993 and followed until late 1996. This study found that median survival was 30 days, that 20 percent of patients die within a week of admission to hospice, and that 80 percent die within three months. At the other extreme, however, there was a minority of patients (less than 15%) which lived for more than six months after hospice enrollment. But, in sum, enrollment in hospice tends to be very late in the course of seriously ill patients' care.

There is evidence that, over the course of the 1990's, patients have been enrolled progressively later in the course of their illness. For example, a representative cohort of patients admitted to hospices in the U.S. in 1990 had a median survival of 36 days; in 1993, a different cohort had a median survival of 30 days; and in 1996, still another cohort had a median survival of 24 days. Anecdotal reports from numerous hospices, and my own clinical experience, confirm this trend, and also its ongoing evolution, to the point where at my hospice today 50% of patients are currently enrolled within about two weeks of their death.

Consequences of Sub-Optimal Timing of Hospice Referral

To reap the maximum benefit from hospice care, the decision to refer a patient should be properly timed. Unnecessarily long or short stays -- which might arise from unduly early or late referral, respectively -- should be avoided. Such short or long stays may have adverse clinical implications for patients and adverse economic implications for payers.

"Early" death due to unduly late referral provides several reasons for concern. For patients, early death may reflect an inadequate use of what many patients and caregivers consider to be a desirable mode of terminal care. For such patients, a longer stay in hospice would make their experience of terminal illness more humane and more clinically appropriate. Late referral often means that hospice professionals have inadequate time to become familiar with the patient, to evaluate properly the patient and the home situation, and to develop and implement a comprehensive care plan. In addition, late transfer of a patient to hospice results in a discontinuity at a critical point in the patient's illness, and may be undesirable because death might have been managed just as well by the referring hospital or doctor, avoiding the need to establish new caregiver-patient relationships. For hospices, the extensive work typically necessary at the beginning of the care of a new patient is organizationally disruptive and possibly

financially burdensome. Finally, early death may mean that the patient received costly and possibly unnecessarily aggressive care for too long prior to referral.

Of course, some early deaths at hospice may be both unavoidable and quite appropriate. For example, a patient might become terminally ill suddenly, be immediately referred to hospice, and then die rapidly (or "early"). In such a situation, the physician would not have had an opportunity to refer earlier. However, such cases account for a small minority of late referrals, given the pattern of illness seen in studies of patients referred to hospices.

"Late" death due to unduly early referral also can provide some reasons for concern. In some situations where death occurs very late after referral, the patient may actually have been more suited to, and have derived greater benefit from, long-term nursing care or rehabilitative care rather than hospice care. Premature referral to hospice may thus have adverse clinical implications. In addition, such an extended stay in a constant state of anticipation of death may be demoralizing to the patient and may oblige hospice nurses to deliver a type of routine nursing care which is inconsistent with their specialized training. To the extent that a lengthy stay results in the needless use of hospice resources, it may result in cost inefficiencies.

BARRIERS TO HOSPICE USE

Barriers to hospice care can occur at many levels: (1) the patient/family level, (2) the physician level, (3) the hospice level, and (4) the market level. At several of these levels, provisions of Medicare regulations may contribute or interact with these barriers.

These barriers can operate on two distinct but interconnected levels: (1) particular factors may affect *whether* patients use hospice at all, and (2) the same or different factors may affect *when* in the course of their illness they use hospice (if they indeed use it). This distinction is illustrated by the following example: it may be the case that poor people are less likely to use hospice care at all (they may be under-represented in hospice rolls), but, when they do use it, they may use it *earlier* in the course of their illness. So, paradoxically, poverty may act as a *barrier* to hospice use in one sense, but act as a *facilitator* to hospice use in another. Surprisingly, much less is known about *whether* hospice is used than about *when* it is used. While these problems are distinct, they are nevertheless related, and so I will mostly focus on the latter here.

The Problem of Physician Prognostication

The need for a prognosis, and the presence of inaccuracy in any prognosis that might be made, is one of the most important barriers to hospice use, both practically for physicians and psychologically for patients. According to Medicare regulations, a beneficiary is eligible for the hospice benefit only if the patient's doctor and the hospice medical director both certify that the patient is "terminally ill," which is defined as having "a medical prognosis that the individual's life expectancy is six months or less." Physicians have difficulty interpreting or applying this standard, however. Indeed, commentators have noted that physicians typically make poor judgments about intermediate term survival in terminally ill outpatients and that unduly "optimistic" prognoses (with consequent late referral to hospice) and unduly "pessimistic" prognoses (with early referral) have adverse implications. Some editorialists, concerned especially with the problem of late referral, remarked as far back as 1984 that "in the absence of objective criteria, the only patients referred to the hospice may be those who are so obviously close to death that the hospice's palliative care will be offered too late." This prescient concern has proven to be largely true given the way Americans use hospice today.

On more than one occasion, I have seen the avoidance of prognostication altogether, or needlessly incorrect prognoses, harm patients by interfering with their timely use of palliative or hospice care. For example, one bereaved wife poignantly noted:

The Thursday before my husband died, I thought he was dying and he thought he was dying. But the doctor was talking about aggressive chemotherapy. I asked if this was palliative, and he said that he still hoped for a cure. [But my husband died three days later.] I was with him at the time of his death, but the room was filled with eight other people hanging bags of blood and monitoring vital signs. It was about as horrifying as anything that could have happened. I don't think the [doctors] were trying to mislead us. They thought he might be the one case that would have a positive outcome. [But if I had been told the truth,] we could have spent days with the children, together, not filled with painful regimens in the hospital.

The failure to predict this patient's death -- in the sense of not thinking about the prognosis clearly, in the sense of not articulating it, and in the sense of having an unduly optimistic expectation -- was harmful. Such a failure can contribute to a therapeutic imperative that prevents families from taking steps to prepare for death as they might wish and from availing themselves of hospice care. The physicians in this case did not want to conclude that the therapy would not result in the desired outcome. They did not want to predict that the patient was about to die. And they did not want to take action, such as limiting therapy or referring to hospice, based on those predictions. But if doctors were to think more cogently about the outcomes of their actions, if they were to develop prognoses more consciously (even in all their uncertainty), and if they were to share their prognostic estimates sensitively with patients, it would help them to avoid such outcomes. My feeling is that the problem in this case, and countless other cases like it, arises more from errors in prognosis than from errors in therapy. In our rush not to abandon patients therapeutically at the end of life, we abandon them prognostically.

I see this kind of problem every week in my practice. For example, last month, I was to take care of an elderly patient with AIDS. He had been sick with this disease for more than a decade, and had deteriorated substantially over the previous two months, to the point where he was clearly dying. He was initially evaluated by our hospice program on August 2, when his physician finally suspected that the patient was about to die. However, the patient appeared unaware of the seriousness of his condition and refused hospice enrollment. On August 14, we were re-contacted regarding admitting the patient for hospice care, and, after some planning, we formally admitted the patient on August 15. Our nurses started to pay him daily visits to help get his pain, shortness of breath, and diarrhea under control, as well as sort out his complicated psychosocial issues. I called the patient on August 18 to schedule a home visit for the next day, but the patient died at 6:00 pm that night, having had only three days of hospice care, and having missed the opportunity to have me visit him. We simply did not have enough time to do what we do best, to do what the patient, I am sure, would have wanted us to do. And I am wondering why, after ten years of a very serious illness, and two months of substantial deterioration, we did not receive this admission until three days before the patient died. Was it not possible for his doctors to formulate a reliable prognosis any earlier in his course? Is it not possible to design a system of health care that affords better and prompt terminal care for dying patients?

Part of the problem when it comes to hospice referral is in fact that physicians do not like to prognosticate. This aversion to prognostication has numerous sources. Neither medical training nor research treat prognostication as important. Lacking training, physicians find prognostication difficult and stressful. The "difficulty" and "stress" in rendering prognoses are both technical (in the sense of how complicated it is to formulate them) and operational (in the sense of how emotionally and professionally unsettling it is to communicate them). Moreover, physicians feel that patients expect too much certainty and that both patients and (to a lesser extent) colleagues will judge them adversely for prognostic errors. For these and many other reasons -- including a belief in self-fulfilling prophecy -- physicians feel that

they should accentuate the positive in making predictions and avoid making them altogether.

Quite beyond their aversion to prognostication, contemporary physicians are not very accurate when it comes to prognosticating. One of our recent studies was a prospective cohort study of terminally ill patients directed at evaluating the extent and determinants of prognostic error. This study involved a cohort of 504 patients referred to five outpatient hospice programs in Chicago by 365 physicians during 130 consecutive days in 1996. We contacted the physicians at the time the patients was referred to the hospice and asked them to make a prognosis about how long the patient had to live. Then we followed the patients forward to see how long they lived, and we compared the predicted to the observed survival. This allowed us to quantify the extent of prognostic error and to evaluate its possible dependence on attributes of patients, physicians, or the physician/patient relationship.

Figure 1 illustrates the extent of the error. The median observed patient survival was 24 days. The mean ratio of predicted to observed survival was 5.3. Defining an "accurate" prediction as between 0.67 and 1.33 times the actual survival, only 20% of predictions were accurate; 63% were optimistic errors and 17% pessimistic errors. Defining an "accurate" prediction as between 0.50 and 2.0 times the actual survival, 34% of predictions were accurate; 55% were optimistic errors and 11% pessimistic. Death occurred within one month of the predicted date for 42% of patients, occurred at least one month before the predicted date in 46%, and occurred at least one month after the predicted date in 12% of patients. These are substantial rates of error by any measure and speak to the unreliability of physicians' predictions (at least, as they currently practice).

Careful examination of physician and patient attributes revealed that most physician and patient attributes were *not* associated with prognostic error. That is, all types of physicians are prone to error, in all types of patients. However, the tendency of physicians to make prognostic errors was lower among experienced physicians. Moreover, the better the doctor knew the patient -- as measured, for example, by the length and recency of their contact -- the *more* likely the doctor was to err.

I need to stress that the prognoses examined above were physicians' best guesses about their patients' survival prospects (objectively communicated to the investigators) and *not* the prognoses the physicians might or might not have communicated to the patients themselves.

These findings have several implications. First, undue optimism about survival prospects may contribute to late referral for hospice care, with negative implications for patients. Indeed, as mentioned above, while physicians state that patients should ideally receive hospice care for three months before death, patients typically receive only one month of such care. The fact that physicians have unduly optimistic ideas about how long patients have to live may partly explain this discrepancy. Doctors who do not realize how little time is left may miss the chance to devote more of it to improving the quality of patients' remaining life. Second, to the extent that physicians' implicit or explicit communication of prognostic information affects patients' own conceptions of their future, physicians may contribute to patients making choices that are counter-productive. Indeed, one study found that terminally ill cancer patients who hold unduly optimistic assessments of their survival prospects often request futile, aggressive care rather than perhaps more beneficial palliative care. Third, this work hints at corrective techniques that might be employed to counteract prognostic error. Disinterested physicians, with less contact with the patient, may render more accurate prognoses, perhaps because they have less personal investment in the outcome. Clinicians may therefore wish to seek "second opinions" regarding prognoses, and our work suggests that experienced physicians may be a particularly good source of opinion. Finally, our work suggests that prognostic error in terminally ill patients is rather uniformly distributed. This finding has implications for physicians' training and self-assessment since it suggests that there is not one type of doctor who is prone to error, nor is there one type of patient in whom doctors are wont to err.

I believe that the medical profession can do better, and that the science of prognostication can be vastly improved. A key response to contemporary defects in prognostication is to try to enhance the science or prognosis (e.g., through more research).

In the meantime, however, given physicians' poor training in prognosis, their aversion to it, and their present levels of inaccuracy, a useful policy response to the problem would be to decrease the reliance on prognosis as a criterion for hospice use. Alternatives in the setting of hospice referral include:

switch to performance-status-based criteria for hospice entry rather than prognosis-based criteria (e.g., a patient with one of a list of serious illnesses and who is bedridden more than 50% of the time would be deemed suitable for enrollment, by definition);

switch to probabilistic based measures of prognosis (e.g., elicit the prognoses from physicians in terms of units of probability rather than units of time, thus modifying the criterion for hospice use from "the patient is expected to die within six months" to, say, "the patient has more than a 50% chance of dying within four months");

switch to a reliance on objective prognostic standards and algorithms, along the lines of those recently promulgated by the National Hospice Organization (NHO), in which patients meeting certain clinical standards are felt to have poor prognoses (though the particular system currently promulgated by the NHO has recently had its reliability called seriously into question and would need improvement .

Other Physician-Level Barriers to Hospice Care

Most physicians (89%) report feeling that hospice is "an appropriate mode of care for most terminally ill patients." And a majority of physicians (84%) refer at least one patient to hospice in any given year; the median number of patients referred is five. This experience varies substantially with specialty, however. For example, in this study, the median general internist reported having referred five patients to hospice; the median pulmonologist/critical care physician referred ten patients; and the median hematologist/oncologist referred 38 patients to hospice.

Despite these favorable attitudes towards hospice and despite this frequent use, there are a number of physician-level barriers to optimizing the use of hospice in our society, in addition to the problem of whether and how well physicians prognosticate, as discussed above. These include:

- * aversion to prognosis
- * difficulty making accurate prognoses
- * fear of facing death
- * poor skills in communicating with patients regarding death, prognosis, and hospice referral
- * stigmatized views of hospice (e.g., hospice seen as failure by physicians)
- * misunderstanding about hospice care (e.g., misperception that hospice is only for cancer patients)
- * concern about loss of control of the patient
- * concern about loss of income

* specialty-specific practice patterns (e.g., more favorable attitudes of generalist physicians than of specialist towards hospice)

* attitudes towards patient traits (e.g., preferential referral by physicians of patients with certain socioeconomic traits or diagnoses)

Difficulties with communication are likely an important barrier to increasing hospice use, and physicians, who understandably have difficulty breaking bad news, often avoid discussing the fact that the illness has entered its terminal phase.

There may be a lack of knowledge about hospice availability on the part of both physicians and patients, particularly in non-cancer diagnoses, or physicians may simply have unfavorable attitudes towards hospice.

Physicians may also worry that they will lose control of, or contact with, their patients if they refer them to hospice. In fact, however, this concern is mostly unfounded, in that patients can still see their own doctors (the doctors can even bill for the visits) and virtually all hospices update their referring physicians as often as they desire. (There is, however, an issue having to do with hospitalizations which can interfere with the doctor/patient relationship and which is discussed below.) Physicians may also resist hospice referral in order to preserve the ability to bill for curative services (such as chemotherapy) that are not covered by the hospice benefit. Many observers believe that this is a widespread phenomenon, but I am not familiar with any published research documenting it.

In prior work, we have investigated the specific variation in physicians' preferences regarding the timing of hospice enrollment. In one study, we asked a random sample of American internists the following 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 care was appropriate?" The range of responses to this question is shown in Figure 2. The average so-called "*lead time preference*" was 12.1 ± 8.5 weeks (that is, physicians, on average, prefer for patients to be referred to hospice about three months before death). At the extremes, only 2.0 percent would prefer for their patients to spend a week or less in hospice, and only 3.6 percent would prefer for their patient to spend more than twenty-six weeks. Responses varied from one to 52 weeks and the pattern of responses was bimodal. That is, as shown in Figure 2, 73 percent had a lead time preference of less than 16 weeks to live, with a peak at about 13 weeks; and 27 percent thought it meant having 16 or more weeks to live, with a peak at about 25 weeks. Lead time preference was not associated with years in practice, amount of time in patient care, gender, or board certification. But adjusting for these factors, physicians who thought hospice was an appropriate mode of terminal care were 3.7 times as likely to have a lead time of 16 weeks or more, and generalists were 1.7 times as likely as specialists to have such a preference.

All of the foregoing barriers to hospice referral have at least two consequences. First, an unnecessarily small fraction of terminally ill patients might be referred to hospice. And second, referral, when it occurs, might be delayed.

Hospice-Level Barriers to Hospice Care

Hospice provider factors can affect whether and when hospice is used. Such factors include:

* referral constraints

* poor relations with referral base (physicians, hospitals, social workers, etc.)

* inefficiency of intake mechanisms

* organizational features

"Referral constraints" encompasses a number of barriers. One obvious (but, I think, infrequent) problem, is when institutional or managed care arrangements interfere with the physician being able to use a particular hospice. A more problematic barrier, however -- and one which might be ameliorated by legislation -- is as follows: hospices are obliged to be able to provide inpatient hospitalizations for patients if needed (e.g., to stabilize the patient's pain, to provide respite for the family). They typically contract with particular hospitals for these services to fix the cost at the Medicare-specified amount. So, for example, my hospice, which serves patients all over Chicago, has relationships with several north Chicago hospitals. Physicians tend to refer patients to hospices according to where the patient resides (since hospices also tend to have geographic catchment areas). Thus, a patient residing on the north side of Chicago who sees a doctor at the University of Chicago (on the south side of the city) could be referred to my hospice for care. But, should that patient require hospitalization, my hospice would not admit them to the hospital at which the referring physician has admitting privileges (the University of Chicago), but rather to the hospital with which we have an arrangement. As a consequence, the referring physician might justifiably fear that his relationship with the patient might be compromised since his patient, in case of hospital admission, would not necessarily go back to him.

Barriers to the timely use of hospice can also arise when hospices themselves provide poor quality service or otherwise alienate their physician referral base; as a consequence, patients residing in the catchment area of that hospice might be deprived of the opportunity to get hospice care if physicians justly conclude that they do not want to use the hospice. Hospices might also have inefficient intake mechanisms which delay hospice enrollment after the referral has been made; for example, it may take them several days to send a nurse to evaluate the patient for admission. This is primarily a problem of resource constraints or of geography (e.g., a hospice nurse in rural northern Wisconsin once told me that she sometimes can only see two patients a day in the middle of winter since physically getting to them requires driving across icy lakes in a tractor with tire chains).

Finally, our research has shown that a number of organizational features of hospices are associated with the timing of referral of patients: freestanding hospices get patients earlier than hospital-based hospices; smaller hospices get patients earlier; newer hospices get patients earlier; and for-profit hospices get patients earlier. How are for-profit hospices able to achieve earlier enrollment of patients? Because the survival of patients after enrollment is short, because evaluating newly admitted patients is expensive, and because payment is on a per diem basis, this observation suggests that such hospices may foster the early enrollment of patients in order to recoup the high up-front costs associated with patient admission. Do for-profit hospices have efficient outreach programs or fewer barriers to enrollment? Do they offer care in such a way that patients, families, and physicians are willing to consider earlier enrollment? Or do they inappropriately admit patients they expect with certainty to die years after enrollment? Conversely, do they refuse referrals that are "late"? If so, how do they identify such patients? These questions are the subject of ongoing research.

Market-Level Barriers to Hospice Care

Attributes of the health care market in which patients reside and hospices operate are also important. Such attributes include:

* medical infrastructure (e.g., number of hospital beds in the area, HMO market penetration)

- * for-profit hospice market penetration
- * specialty mix of physicians in the area
- * local customs (e.g., there is substantial geographic variation in hospice use)

For example, in our study of 184,843 Medicare hospice patients enrolled in 1993, we found that certain market factors were meaningfully associated with the timing of enrollment. An increase in the number of hospital beds (but not of nursing home beds) per 1,000 people over 65 was associated with relatively earlier enrollment. An increase in the number of hospice patients per 1,000 people over 65 newly admitted to hospice in the local county was also associated with earlier enrollment. An increase in population density or in for-profit hospice market penetration (but not in HMO market penetration) was associated with later enrollment. The number of physicians per capita was not associated with timing of hospice enrollment, but an increase in the percentage of generalist physicians was associated with earlier enrollment. If a market with a structure conducive to *late* enrollment (e.g., hospital beds *per capita* of 17.2 per 1,000 people over 65, nursing home beds of 30.1, and hospice patients of 5.1 -- all values at about the 25th percentile for each variable) was compared to a market with values of these variables conducive to *early* enrollment (e.g., hospital beds of 34.6, nursing home beds of 56.8, and hospice patients of 9.4 -- all values at about the 75th percentile for each variable), then the difference in median survival between patients enrolled in favorable and unfavorable markets, even holding constant individual and hospice provider attributes and other market traits, would be only 29 compared to 32 days.

Thus, certain features of local health care markets are associated with duration of survival after hospice enrollment. In the case of hospital beds specifically, this may have been because, at the individual patient level, discharge from a hospital to a hospice may be a way to decrease costs for a hospital caring for a seriously ill patient. This specific finding is perplexing, however, and it appears to run counter to work on the impact of hospital bed capacity on home death. It is possible that hospital bed capacity is associated with a low likelihood of using hospice, but also with an earlier enrollment of patients when they are actually enrolled; more research will be required to sort out such complex effects. While the number of doctors *per capita* was *not* associated with timing of referral, a higher proportion of generalists was associated with earlier referral, a finding in keeping with other work that suggests that, compared with specialists, generalists favor earlier hospice referral, perhaps because they are more willing to cease aggressively curative efforts. The effect of for-profit hospice market penetration, while appreciable and associated with later enrollment, is somewhat harder to account for. One possible explanation is that markets with higher for-profit hospice penetration are more competitive, driving all hospices to accept "marginal" patients with what might prove to be short survivals.

In keeping with some past work on market variation in health care use, we found in this study that the measured role of market factors was *smaller* than the role of patient-level factors. While market-to-market variation in survival after enrollment remains meaningful even after adjustment for multiple patient and hospice provider attributes, it seems quantitatively less important than each of the several individual-level patient traits we considered. This may reflect, in part, the nationwide uniformity of the Medicare hospice benefit.

In other work we have done, which we have not yet published, we have examined the geographic variation in hospice use by closely examining variation in whether and when hospice is used at the level of the approximately 3,000 counties in the U.S.. In terms of whether hospice is used, we found that counties can vary enormously in the percentage of decedents who use hospice -- from 0% to 39%. That is, some counties in Florida, for example, have very high levels of hospice use and some counties in Indiana have very low levels of use. In terms of when hospice is used, we found somewhat less

geographic variation, with fewer obvious patterns; however, at the county level, median survival could range from 20 to 60 days. Thus, in most counties in Kentucky, for examples, large percentages of patients use hospice, and they tend to do so earlier in the course of their illness.

Patient- and Family-Level Barriers to Hospice Care

Finally, it is important to note that some of the problems encountered in optimizing hospice use originate in patients and their families. These include:

- * fear of death
- * misconceptions about the purpose of hospice
- * aversion to home death
- * age, race, gender, marital status, income, education, etc.
- * attributes of the illness (e.g., its duration or type)
- * home structure (e.g., whether the patient is living alone or not, how sick the patient's spouse is)

Patients and their families may resist referral, typically out of a fear of managing death at home, a fear of stopping curative therapy, or a misplaced fear of being abandoned by the medical establishment. Clearly, patients and families need help in understanding the purposes of hospice care and its benefits. Certainly, it is difficult to face one's own death or the death of a loved one, regardless of whether one in fact realizes that hospice care might offer advantages in terms of achieving a "good death." Some patients have misconceptions about hospice care, thinking it somehow means that "nothing is being done for the patient" or that the patient is obliged to die at home (whereas, in fact, hospices can, to the extent it is possible to predict this, admit patients to a hospital for the actual act of death, if this is what the family wants).

Certain attributes of patients can also affect whether or when they use hospice care. For example, Table 1 gives the adjusted median survival in days, according to certain patient attributes in a sample of 184, 843 hospice patients. At the median, non-white patients were enrolled in hospice four days (13%) earlier prior to death compared to whites; women were enrolled in hospice five days (17%) earlier prior to death compared to men; older people were enrolled one day (3%) earlier prior to death than younger people (comparing 84-year-olds to 73-year-olds); and those with substance abuse, psychiatric disease, or dementia were, on average and after adjustment for all other factors, enrolled three days (10%) earlier prior to death. After adjustment for the other covariates, income and education were *not* associated with the duration between hospice enrollment and death. The even greater impact of some of these variables in combination is also apparent; for example, after adjustment for all other measured factors, the median time prior to death that patients were referred to hospice was 26 days for white men versus 37 days for black women.

Our major finding in this research was thus that several variables ordinarily associated with *shorter* survival or *worse* health outcomes, including, for example, non-white race, lower education, lower income, psychiatric history, substance abuse history, dementia history, and advanced age, were associated with *longer* survival after hospice enrollment. For most of these variables, this held true after adjustment for each other and for other clinical, provider, and market factors. As shown in Table 2, these factors, even taken individually, are of a potentially clinically significant magnitude (an up to 30%

impact on the median survival, depending on the variable, and still more if variables are taken in combination). The existence of a pattern in the results, wherein the impact of being within any socioeconomically disadvantaged group had a similar effect, supports the supposition that such factors are associated with an earlier hospice enrollment rather than with some beneficial effect of these factors on survival after enrollment.

If certain groups are being enrolled in hospice earlier than others, why might this be occurring? This study did not permit definitive conclusions, but there are at least three possible explanations.

First, predictions of death or evaluation of symptoms may be more difficult in some patients (*e.g.*, in those with dementia or psychiatric disturbance) thereby complicating decisions about when to switch from traditional medical care to hospice care and thereby leading to earlier referral. Faced with prognostic or clinical indeterminacy near the end of life, for example, physicians may choose to refer such patients relatively early. However, most research suggests that, if anything, prognostic uncertainty results in postponement of hospice referral.

Second, outside help may be brought in more quickly by family members, physicians, or other concerned parties for those patients likely to be difficult to care for at the end of life (*e.g.*, those with dementia, psychiatric disorders, or substance abuse problems) or those who usually fill the care-giving role and therefore possibly lack a caregiver themselves (*e.g.*, women). That is, the *preferences* of the members of the groups defined by our variables may be such as to *favor* earlier use of hospice care. However, some prior work examining the relevance of patients' social support for the timing of hospice enrollment has tended to show that, if anything, lack of social support delays enrollment in home-based hospice care. Lack of social support (*e.g.*, being a widow) may indeed preclude hospice care altogether - a contention suggested by the fact that women in our sample are less numerous (51.4%) than in the underlying Medicare population as a whole (59%).

A third possibility is that socially stigmatized groups may possibly be seen as less appropriate for the costly, aggressive, "curative" care that is ordinarily offered in the period preceding the use of hospice, and so might be referred to hospice relatively early, in a form of "turking." Disquieting support for some role for the fourth explanation comes from previous examinations of the role of race, sex, age, education, and psychiatric illness, in access to and use of medical technology in general.

To sort out which of these explanations, if any, explain the patterns we observe will require further research. It is hard to determine whether patients or doctors or both are driving these observations about how certain attributes of patients are associated with their timing of hospice use. If poor patients are enrolling in hospice earlier, it may be because they are electing to use hospice in this fashion (*e.g.*, because they must rely on formal supports since they lack their own financial resources) or it may be because physicians are referring poor patients to hospice sooner. It is worth noting, however, that even if referral to hospice is occurring earlier in some patients than in others for reasons that are possibly inappropriate, this might not actually be harming such patients if hospice referral is occurring too late for patients in general. Indeed, hospice care appears to be used later in the course of illness than most physicians prefer.

Attributes of the patients' illness may also affect whether and when hospice is used, as summarized in Table 3, which is based on unpublished data from a large-scale study we are presently conducting of 1.3 million seriously ill patients. As can be seen, depending on the type of cancer involved, from 16% to 35% of dying patients may use hospice (with patients with leukemia being much less likely to use hospice and patients with pancreatic cancer being much more likely to do so). In general, non-cancer diagnoses are much less likely to use hospice, with approximately 7-10% of decedents with heart attacks, strokes, hip fractures, and the like using hospice care.

THE COST-EFFECTIVENESS OF HOSPICE

There have been several studies published in the peer-reviewed literature concerning the cost-effectiveness of hospice care, and several well conducted unpublished studies as well. My summary of this literature is as follows: Most studies agree that hospice care saves money compared to alternative ways of caring for the terminally ill. Indeed, estimates of cost saving run as high as \$1.20 saved for every \$1.00 spent. What is still unclear, however, is over what time horizon hospice saves money. That is, it is clear that hospice is cost-effective for the last 30 days (i.e., it is cheaper to provide care using hospice for the last 30 days than to use the standard type of hospital-based care otherwise prevalent in our society). It is also quite likely that hospice care is cost-saving for the last 90 days of life. What is less clear is whether hospice saves money over the last six or twelve months of life. Put another way, if we were to enroll all patients in hospice care six months prior to their deaths (assuming we were able to reliably prognosticate this), hospice care (as it is currently reimbursed) might be *more* expensive than the standard care currently being used in our society -- which typically includes a hospitalization or two in the last six months, a few doctor visits, and then a 1-2 week hospital stay before dying. If we added up all these costs, they might, in fact, be lower than the cost of a continuous six-month hospice enrollment.

Nevertheless, one thorough review of cost savings at the end of life concluded that existing data suggest that hospice and advance directives can save between 25% and 40% of health care costs during the last month of life, with savings decreasing to 10-17% over the last six months of life and decreasing further to 0-10% over the last 12 months of life.

It would therefore seem prudent to try to implement changes in the Medicare hospice benefit that would enhance the use of hospice care, both because it is a valuable and desirable form of end-of-life care, and because it is cost-effective. Current patterns of use of hospice (with very short stays) coupled with current reimbursement mechanisms are making it difficult for hospices to provide care in a financially viable fashion and may be wasting Medicare funds. Interventions which result in earlier referral or which compensate hospices for the fact that they do not, under the current system, recover their costs for patients who live less than about two weeks after referral would be beneficial.

It is important to emphasize, however, that regardless of whether hospice costs more or less than standard terminal care, hospice is probably *better* care for the dying, care that Americans might well feel entitled to receive from our superb health care system. In other words, six months of hospice care might possibly be more expensive, but it might be worth it.

CONCLUSION

Responding to some of the barriers to increasing hospice use in our society -- both in terms of increasing the proportion of decedents who use hospice and in terms of increasing the duration of stay under hospice care for those patients that are referred -- will require a number of educational, policy, and legislative responses. Certain selected opportunities on the legislative front include:

shifting away from the current prognostically based entry criterion for hospice (e.g., shifting to a criterion that patients who have certain specific diseases and who are bedridden a certain fraction of the day are perforce considered eligible for hospice care)

providing funds to educate physicians and patients about the suitability of hospice and the need to use it earlier in the course of a patient's disease (e.g., three months before death); such educational initiatives might be conducted on a grass-roots level, by local hospices working with their local physician referral

base; indeed such efforts could be mandated and compensated through Medicare

changing the way that hospices are obliged to contract with hospitals for admission (e.g., by requiring hospitals receiving Medicare funds to admit hospice patients from any hospice program, and not just from specific ones, for a Medicare specified reimbursement; alternatively, it could be possible to change regulations to make it possible to provide respite care at home, with a higher reimbursement level than the usual *per diem*)

provide additional reimbursement for hospices when they care for patients dying in their own homes all by themselves (i.e., without a spouse or other family caregiver), thus making it easier for independently living elderly people to die in their own homes, should they chose; similarly, extra payments may be appropriate for other challenging situations presented by particular types of patients, e.g., those residing in hard-to-reach rural areas or inner cities where it can be very hard to provide hospice care in a financially efficient manner under the current system

moving to a system whereby hospices receive some kind of fixed initial payment for evaluating and admitting patients, thereby covering their high initial admission costs and making it easier for them to overcome any administrative barriers that delay hospice enrollment after the patients have been referred for evaluation

Health care decisions at the end of life are made at a time when patients are at their most vulnerable. In general, patients get only one chance to elect hospice care, and if the care is inadequate for any reason, it is unlikely they will have an opportunity to switch or improve on their choice. For these reasons, parties who contribute to the hospice enrollment process should act with the greatest probity. Since patients in general are enrolling in hospice late in the course of their illness, thought might be given to addressing some of the barriers to more timely referral. The apparent role of certain social and provider and market factors in the timing of hospice enrollment suggests that it is not merely the patient's clinical status, but other factors as well, that influence this important end-of-life transition in care. This in turn suggests that it may be possible to change the way hospice is used for the better of both dying patients and our society as a whole.