

Ask the Experts

In this and future issues of *MPM*, we ask a panel of experts to comment on a pressing issue of the day. Let us know if you have suggestions regarding experts you would like to hear from or questions you would like to see addressed.

Why do hospice admissions continue to occur so close to death despite the fact that hospice is commonly stated as a 6-month benefit?



Mark Beers, MD
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Miller School of Medicine*

I am not sure but can guess with some certainty that it has to do with reluctance. Doctors, patients, and families are reluctant to “give up” fighting disease, even disease that can be well defined as terminal in advance of 6 months. It is not until all parties see that death is imminent that they are willing to move to the hospice concept.



David F. Polakoff, MD, MSc, CMD
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I agree with Dr. Beer’s comments regarding “reluctance.” Many physicians not specifically trained in end-of-life care have difficulty communicating with patients and families around these issues. They deal with the issue by avoidance. There continues to be a pervasive misunderstanding of hospice care, which holds that it is the same as “giving up,” or at least, giving up hope. There is also a misunderstanding of the hospice benefit. Many believe that it is strictly limited to 6 months, and fear that if they refer

too early, their patient may “outlive the benefit.” Both of these issues require further education.



Mike Girard, MA, MHA
Co-Founder of Circle of Life Hospice

First the statement above is true. Second, perhaps we should ask ourselves, “Why should we care?”

Dr. Ira Byock in his book *Dying Well* stated that 2 generations of Americans have not been dying well. And what does dying well mean? I would argue that the opposite of what is actually happening is dying well. What is actually happening (dying badly) is portrayed in the following statistical profiles: 40% to 70% of Americans die in pain, 80% die in institutions rather than at home as they prefer, 60% of Americans die in significant suffering, and about 35% of families lose all or most of their life savings in caring for their loved ones.

Now in contrast to the above we can begin to define dying well: to not die in pain, to die at home, and to die healed rather than in suffering. I differentiate pain and suffering in that pain is of the body and suffering is of the soul. In end-of-life care, I like the differentiation that we may not be able to cure the dying, but we can help the dying die healed. In hospice, managing pain and symptoms is the easy part. Assisting patients and families to die healed takes time. By not giving patients time, we truly fail in our obligation to them. By not giving them time we deny them the opportunity to get practical affairs such as wills together. By not giving them time, we do not give them time to forgive and be forgiven, to reach closure and say good bye.

On a deeper level, many patients die consciously, which means that this period of living at the end of life can be a time of incredible growth and development in both the emotional and spiritual dimensions. In my experience over the last 25 years, when patients know and accept that they are dying, they become reflective in an incredibly honest and realistic manner. They often explore the meaning and purpose of their lives through a “life review.” I have also seen a pattern of discernment wherein the dying conclude that the meaning and purpose of their lives lie in their relationship to self, others, and their

higher power, whatever that might be. From these observations I have come to see the wisdom of the truism that “the lessons of dying are truly the lessons for living.” When referrals to hospice come late, we deny the opportunity to die healed.

So now back to the original question—why do we refer so late? In his book *Death Foretold: Prophecy and Prognosis in Medicine*, Dr. Nicholas Christakis, now at Harvard, states that the cause is physician failure to both accurately prognose terminality and communicate that prognosis. Christakis’s research shows that physicians tell patients that they have 4 months to live and they die within a week, leaving life affairs incomplete and loved ones forever regretting that they did not fly in to have their final goodbyes.

With this answer in hand, the larger question looms unanswered: “How do we fix this?” The first part of this answer lies in the future curriculum of our medical schools. Dr. Balfour Mount of Case Western Reserve has proven that making end-of-life care a mandatory element and utilizing “Balint Groups” (journaling on the emotional content) is very effective in improving the science of prognosis and its communication. But this answer is insufficient because it is future oriented, and leaves us with a “what about now” question. The “now” issue has been addressed by the American Medical Association (AMA) through the development of Educating Physicians on End-of-Life Care (EPEC). But this too has been insufficient because it is voluntary and therefore not well attended, leaving the question, should EPEC in one form or another be mandatory?



Tani Bahti, RN, CT, CHPN
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in End-of-Life Issues*

Despite the fact that hospice utilization increased 162% over the past 10 years, the median length of stay has shortened to just 20.6 days. As an end-of-life educator for the past 21 years, I see the 5 key reasons for this sad fact have unfortunately changed little over the years.

First, we remain a death-denying society, unable to talk about the inevitable until it is literally ‘in our face.’ This avoidance and denial are shared by the healthcare professional, patient, and family alike. Admittedly, advances in technology have made it more

difficult to declare when we have come to the natural end of life, identifying the point at which we are no longer prolonging living, but prolonging dying.

Second, lack of training, personal comfort, and time contribute to healthcare professionals not having the necessary discussions to transition into comfort care earlier.

Third, fear, misinformation, and lack of information contribute to a patient and family not getting a clear picture of disease progression, the benefit and burden of treatment, and the impact of treatment on quality of life. This too often leads to more futile treatments and, therefore, delayed hospice admissions.

Fourth, myths about hospice remain: beliefs that hospice is only a place to go to die and only for the final days of life, that hospice euthanizes people, and that hospice is only for cancer patients.

Fifth, people still don’t know that hospice is an available comprehensive Medicare benefit. Improved education and communication for both the healthcare and lay communities are key to preparing people for the end of life and improving hospice utilization.



Eric G. Tangalos, MD
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The true moment of death approaches rather quickly for most of us. It does not leave a text message saying, “ill b cn u in 6 mths :(.” More often than not, antibiotics or fluids or diuretics and an occasional prayer vanquish death’s early visits. Physicians and families have seen the evanescent nature of death’s presence so many times that to order up hospice is to demand an outcome that may not be forthcoming.

That hospice is underused is a true sadness. Patients and families can be helped by the rich services provided through this Medicare benefit. Once initiated, families can usually rest easy knowing that our goal in patient care is not to prolong life but to value and support the remaining days. The purpose of hospice is to help patients and families make the final transition more measured and more thoughtful.

In general, we feel guilty when someone dies, but why? When I suggest the patient is ready for hospice, families generally tend to breathe a sigh of relief. They almost immediately switch gears and are thankful that

someone has given them permission to let go. Families are so caught up in the moment that they are generally surprised when hospice is first mentioned.

Physicians need to practice to get good at what they do. Opening the hospice discussion is not an easy task for the uninitiated. However, family feedback and appreciation from the patient are usually obvious well before the first nurse or aide knocks on the door.



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First of all, hospice care is not so much a “6-month benefit” as it is implementing an interdisciplinary “Care Package” for patients who, from the nature of their illness, would not be expected to live longer than 6 months. It is exciting to note the literature reporting better quality and longer life for many entered into this more effective, more economical, and more nurturing mode of treatment. My hospice team celebrates when patients improve so well from team interventions that they can be discharged from the hospice-care program. Offering and accepting this proven benefit too late for patients and their loved ones to profit from it is due, I observe, to many commonly misguided points of view:

1. A prevailing attitude that the Medicare-provided hospice-care program is a death benefit, rather than a program of palliative care capable of nurturing body, soul, and spirit for those dealing with a life-limiting illness
2. The equating of “hospice care” with just “comfort care”
3. The impression that hospice care is a “nothing more I can do for you” recommendation
4. The difficulty in recognizing when “aggressive” interventions have lost their power to prolong life and/or improve well-being
5. The tendency of patients and decision-responsible caregivers to equate hospice with “giving up”
6. Difficulties we physicians have in assessing hospice-ready prognosis and being able to predict when patients will die

It is rewarding to see *MPM* addressing the need to overcome these barriers. I’d like to see an *MPM* panel of hospice team members—nurse, aide, social worker, pastor, administrator, pharmacist, team volunteer, fu-

neral director, physician, and patient each tell us “what they do.” I recommend to our *MPM* readers internet access to the End of Life/Palliative Education Resource Center (EPERC) site <http://www.eperc.mcw.edu/> as a fine resource for primary care and allied healthcare providers. Consider inviting a hospice team representative to your office to learn about what hospice is and does, an educative service they will also provide to those patients and families whom they think are appropriate for timely entry into this “gift of care.”



Joel Policzer, MD, FACP, FAAHPM
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There are multiple factors that affect this phenomenon and vary according to the stakeholder involved. Physicians view deterioration and death as the enemy; ask most physicians why they wanted to be a doctor, and the answer usually has some element of wanting to help, to heal, to cure. Assisting people while they die is not the usual reason. The training and socialization of physicians all focus on making the patient and the disease better; everyone expects a positive outcome.

Physicians internalize a feeling of failure when a patient dies, even if the death was an expected outcome of the situation. This all leads to physicians poorly prognosticating their patients’ survival and delaying referral for hospice services.

Patients also expect a positive outcome to their medical treatment and, therefore, will continue to search for potential treatments. The speech used to refer to situations when no further effective treatment is available—“there is nothing left to do,” the situation is “hopeless”—is highly negative. The American ethos is not supportive of “giving up,” if one only “tries harder” one will succeed at every task. So it is not surprising that the average patient will delay referral for end-of-life services.

Hospice referral is often a self-fulfilling prophecy that does not break the stereotype of hospice service. Hospice is perceived as “where you go to die.” Patients and physicians delay referral, as the patient and the situation deteriorate, until it cannot be delayed further. The patient accesses care and soon dies, leav-

ing everyone to say: “See? Hospice is where you go to die.”

Only when end-of-life is seen as a true continuum of the care cycle will hospice referrals occur earlier.



Sue C. Warren, MD, FACP
Medical Director, Hospice Care

It takes more time and is more emotionally draining for healthcare workers to bring up and discuss hospice than it is to punt—and write another prescription. Hospice—or at least end-of-life fears and issues—may well be on the minds of patients and/or families, but it is a feared topic—the elephant in the room. Denial is often the path of least resistance, and if the doc doesn’t bring it up, then that feeds the hope that things will get better for a while longer.

Many patients and families support hospice as a “wonderful” service, but when it comes to starting it for themselves, the reply is often “not just yet.” Until there is an acknowledged need for the kind of services hospice provides, resistance is not surprising. It is part of being human.



Janet M. Lieto, DO, CMD
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There are multiple reasons why patients continue to access hospice too late. The root of most reasons is lack of education of patients, families, physicians, and other healthcare providers regarding hospice benefits. As physicians we cannot depend on stressed patients and family members to understand the benefits of hospice without understanding them ourselves. Physicians and healthcare providers must be comfortable and informed enough to initiate the discussion with our patients. We need to become educated about admission criteria for hospice as well as the benefits that a patient is entitled to while on hospice.

As a hospice physician who treats patients in an Inpatient Hospice Unit, I have the opportunity and privilege to open these discussions with patients and families who are having difficulty processing their disease, symptoms, and prognosis. It takes our staff’s under-

standing of each patient’s disease; expectations; and religious, emotional, and psychosocial issues to help patients gain the most from the hospice experience. This process relies on a whole team of hospice professionals (physicians, nurses, social workers, chaplains, and possibly others) to help the patients accept and benefit from hospice. This is the first time many of our patients are accessing hospice.

How can we expect physicians to provide this kind of service in the community?? We can’t! But we can educate ourselves to know when to make a referral to hospice. Hospice workers can make informational visits to patients and their families to explain services and dispel erroneous myths about hospice.



G. Jay Westbrook, RN, MS, CHPN
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The global reason for late hospice admissions is lack of understanding and education on the part of physicians, patients, and families. More specifically, there are 10 reasons why patients aren’t referred to hospice earlier:

1. The physician and/or patient may have had a previously negative experience with hospice or formed a negative impression of hospice from media coverage of high-publicity end-of-life cases.
2. The physician may misunderstand when and how to introduce hospice. It should be introduced at the time of diagnosis although identified as an option that may not ever or not now be appropriate.
3. Most patients and physicians think hospice is forever. But Medicare designed the benefit so the patient can go on and off hospice as often as the medical situation and/or family dynamics dictates. I have seen patients thrive on hospice, and then say that because they feel better, they want to revoke hospice and try another cycle of chemotherapy.
4. Physicians may not know they can continue to see their patients as well as bill Medicare for those visits. It is not necessary, nor ideal, for a physician to lose control of a patient just because the patient enrolls in hospice.

5. Physicians/patients may think of hospice as giving up and/or failing. We all know there are times when cure is not possible, but hospice provides healing and palliation of physical, emotional, and spiritual suffering. It is not giving up; it is pursuing aggressive palliative care.
6. Physicians may fear that the patient will view the suggestion of hospice as the physician's abandonment, particularly if there has been a lengthy relationship. However, physicians can continue to see their patients.
7. Some physicians think hospice is limited to 6 months. The prognosis criterion has the caveat that says, if the disease follows its natural progression, the patient probably has 6 or fewer months to live. It does not insist that the patient die within 6 months.
8. Patients misunderstand hospice funding. Hospice is provided at no cost to the patient.
9. Television's medical shows may unduly influence patients to believe there is always a medical miracle to save them, and thus they are reluctant to embrace hospice.
10. Patients, families, and physicians may think hospice is about dying, or that hospice will accelerate the dying process; this is not true. Hospice does nothing to prolong life nor to hasten death, but does ensure comfort and living with as much quality as possible until the last breath.



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The reasons for late and no referral of hospice-eligible individuals mirrors the healthcare system in complexity. On the one hand, polls indicate that Americans' preferred place of death is the home. Yet fewer than 25% die at home,¹ and for those enrolled in a hospice program, the median length of stay on the program continues to hover around 3 *weeks*. First, and perhaps least obvious yet most difficult to change, is the death-denying nature of American society. While news reports and popular films ensure that we are exposed to images of death in every compartment of our lives, the notion of a particular death—our own, for example—is something that we prefer to view as optional. In some ways, this should

come as no surprise. We are programmed for survival as is every other life form. In fact, Finucane noted the single greatest barrier to improving end-of-life care is the “widespread and deeply held desire not to be dead.”² In a healthcare context, death has come to be viewed as a sign of failure of technology and medical expertise, not as a natural conclusion to life. Failure to conceptualize death as an inevitable conclusion to life has its costs—lack of interpersonal preparation, pursuit of technological “fixes” that may or may not extend life while increasing suffering, and enormous financial costs.

Hospice originated in this country in the early 1970s in reaction to the depersonalization of dying. The hospice philosophy of care centers on several premises: (1) although we healthcare providers cannot change the fact that our patients will die, we can change the way in which their deaths are experienced; (2) just as individuals have the right to make choices about where and how they live, so too do they have the right to make choices about end of life; (3) death is a natural process that like birth, can be facilitated by skilled practitioners; and (4) death takes just an instant—every preceding moment is a moment of living—to be cherished and lived as comfortably and meaningfully as possible.³ Given that death is inevitable, that Americans say that they favor death at home, and that hospice exists as a compassionate, supportive provider of palliative care for persons at end of life—then why the disconnect? In addition to the death-denying nature of American society and the healthcare system's focus on cure, referral to hospice relies on a reasonable expectation of *prognosis*. For patients with a more predictable end-of-life trajectory, such as those with advanced cancer, the prognostication challenge is less daunting. For patients with chronic, progressive illnesses, detecting “end stage”—and 6-month prognosis—is much more difficult. Numerous approaches to this dilemma have been attempted or suggested: development of models to identify those with poorest prognosis; development of hospital-based palliative care services to assist with clarifying goals of care, advance care planning, and psychosocial support; and proposed elimination of the 6-month prognosis criterion for hospice eligibility.

While better identification of hospice-eligible patients and provision of palliative care services in hospitals have been shown to be beneficial in increasing hospice referral, no clear, or single solution is evident. In addition to challenges around prognosis, healthcare providers are typi-

cally not trained to disclose “bad news” and support patients and families across a continuum of decision making about serious illness. Many clinicians fear honest disclosure about prognosis out of a misguided belief that patients who understand the seriousness of their illness will lose all hope. While it is true that loss of *hope for a cure* is devastatingly painful, what is also evident is that patients and their families have incredible tenacity—with time and support, most can reframe hope so that its focus is more immediate, particularized, and relevant. What is also evident is that patients and their families can experience end of life as a time of growth and fulfillment—healing relationships, creating legacies, and finding a balance between the inevitability of what lies ahead and the fulfillment of what is available in the present.⁴

Training of healthcare providers is needed to ensure that they consider treatment options in the context of patient/family goals for care and survival likelihood, and to communicate effectively with patients and families around these choices. Perhaps most important, patients and families need reassurance that they will not be abandoned because they choose hospice. Healthcare providers must learn to present palliative

care as an option that complements disease-remitting or cure-focused medical care, and should permanently discard the oft-applied lead-in to a discussion of hospice: “There is nothing more that can be done.” This statement, while not meant to harm, creates a barrier to hospice care nonetheless as it firmly stitches hospice care to...“nothing” ...that can be done. Instead, clinicians should describe hospice as is active, aggressive, patient- and family-centered support and services that enable persons approaching end of life to live as fully as possible in whatever time remains.

Finally, we need healthcare policy that closes the chronic illness gap, improving both coordination and continuity of care, and that encourages appropriate referral to palliative care teams and to hospice. MPM

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