

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.

In light of the fact that a great deal of medical expenses are concentrated in the last 3 months of life, what do you think can be done to more efficiently and effectively manage end-of-life care?



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Dialogue regarding end-of-life care should begin when a patient is newly diagnosed with a terminal or potentially terminal diagnosis. End-of-life care should be discussed as a natural progression of treatment when life-saving measures are no longer realistic. The primary care physician (PCP) should initiate this care as soon as life-saving treatments have proven ineffective in improving the patient's condition.

Every PCP's office should have a standing set of orders for the special needs of these patients. PCP offices unable to provide this treatment should discuss this with the patient when the initial dialogue regarding end-of-life care takes place. Many hospices and palliative care programs have physicians who are able to help the patient during this difficult time.

The goal of end-of-life care is to allow the patient to live out the rest of life in comfort by preventing debilitating pain and other symptoms of disease from being the primary focus. When end-

of-life care is not started until close to death, controlling symptoms becomes the goal and often inpatient treatment is necessary. But inpatient treatment doesn't allow the patient to live the rest of life and increases costs over a shorter period. By referring early and providing standing orders, the patient and family adjust more quickly to this time in their lives and have a smoother transition when all of their needs are met before pain and other symptoms arise. Prevention of debilitating pain and symptoms is the key to meeting patients' needs in end-of-life care and allowing them to live the rest of their days peacefully.



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The two essential keys to providing high-quality end-of-life care to seniors are compassion and communication. The common causes of anticipated death in the elderly population—refractory heart failure, end-stage Alzheimer's disease, malignancies, and others—require physicians and other care providers to shift their focus from aggressive diagnosis and treatment to anticipatory management of death with an emphasis on comfort. The timing of this shift is critical and must be carried out through an ongoing communication plan. Siblings, friends, children, and grandchildren need and desire to know what is happening and what is likely to happen in the patient's future. Clearly and consistently communicating with these parties requires patience and persistence, but the interpersonal reward can be great.

When I practiced geriatrics, we used hospice care as much as possible because hospice caregivers are exceptionally adept at guiding patients and families through life's final phase with a strong communication plan. We did not have regular access to case managers for coverage and insurance issues, nor access to disease management programs for additional educational resources. I highly recommend these types of programs to participants in Medicare Advantage and their families. They can generally be ac-

cessed by calling the health plan's Member Service phone number (always found on the ID card). They'll provide access to nurses and other health plan staff who can provide important information not always readily available to the patient's direct care staff. This combination of resources—direct care staff who care deeply and communicate well and health plan staff who provide clarity about coverage and supplementary information—can provide families with meaningful assistance and reassurance.



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No one can argue that people with advanced, potentially fatal illnesses and those close to them need to be assured of reliable, skillful, and supportive care. Over the years several studies have demonstrated that care at the end of life is less than reliable, skillful, or supportive for those who are dying and those who are left behind. In 1983 Medicare initiated a hospice benefit based on provision of services intended to address the physical, psychosocial, and spiritual needs of patients and families during the dying process. Qualifying hospice programs must provide certain core services including nursing, medical, counseling (bereavement, dietary, spiritual), and social services. Hospices are patient centered and interdisciplinary in providing relief and support for terminally ill patients and their families. The goal of the team of nurses, physicians, clergy, social workers, certified nurse assistants, volunteers, and therapists is to provide pain and symptom control, not to cure the medical problem. A parallel goal is to make the end of life tolerable and, more important, meaningful to those directly affected by a terminal illness. Control of pain and its associated burdens (palliative care) has been shown to reduce the pursuit of assisted suicide and other methods of unnaturally hastening one's death. As America's population grows older, succumbing to more chronic diseases, and medicine increases its capabilities for providing medical care, the role of hospice becomes a significant partner in the continuum of care. For those who have acknowledged that they have a terminal illness, generally 6 months or less to live, the benefit of

hospice care must be considered.

About 80% of hospice is provided within the home setting, allowing patients and families to avoid acute-care settings. The goal of hospice care is to maximize the quality of a patient's life when the quantity of that life is limited either by an incurable disease or by age. This goal requires an interdisciplinary team approach by physicians, nurses, nurse's aides, social workers, clergy, and volunteers. Research has shown that the interdisciplinary team approach in health care improves the overall quality of care. Quality of life is a subjective measure of well-being in which personal integrity is restored. Terminally ill patients who have maintained their cognitive abilities are confronted by many quality-of-life issues, including unbearable pain and suffering, loneliness, loss of meaning, and loss of dignity. Hospice relieves pain and suffering, alleviates loneliness, helps patients find meaning in their lives, and maintains their dignity in death. Hospice represents an option that allows an individual to have a choice and autonomy in making end-of-life decisions.

Without hospice, most patients face substantial pain and isolation and much preventable adversity as they die. A noted medical ethicist, Joanne Lynn, MD, believes that a care delivery system could be designed around the important priorities of relief of pain and other symptoms, maintenance of function and control, support of family and personal relationships, avoidance of impoverishment, trustworthiness and continuity, attentiveness to meaningful activities, and spiritual issues. For the dying patient, priorities need to shift from medical treatment toward caring.

Each year more than 220,000 Medicare beneficiaries receive hospice care. Enrollment requires certification by a physician that the patient has a life expectancy of less than 6 months. A study of 1990 Medicare claims data showed that the mean age of patients receiving hospice care was 76.4 years; 92.4% were white, 50% were women, and 80.2% had some type of cancer. The median survival after enrollment was only 36 days, and 15.6% of the patients died within 7 days.¹ This points out the need to better educate patients, their families, and healthcare providers about the role of hospice in end-of-life care.

The Institute of Medicine has developed recommendations for improving the care of the dying patient²:

1. Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for the dying patients and use existing knowledge effectively to prevent and relieve pain and other symptoms.

2. Because many problems in care stem from system problems, policymakers, consumer groups, and purchasers of health care should work with healthcare practitioners, organizations, and researchers to:

(a) Strengthen methods for measuring quality of life and other outcomes of care for dying patients and those close to them;

(b) Develop better tools and strategies for improving the quality of care and holding healthcare organizations accountable for care at the end of life;

(c) Revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate a coordinated system of excellent care; and

(d) Reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering.

3. Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to appropriately care for dying patients.

4. Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and research.

5. The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care.

6. A continuing public discussion is essential for developing a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death.

Physicians and other healthcare providers need to be more sensitive to their patients and respectful of family wishes when it comes to the dying process. The use of an advance directive for health care and open discussion among all involved parties goes a long way toward improving end-of-life care.



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End-of-life management is clearly a complex issue that is rendered virtually impossible in the United States to-

day because of our highly litigious and cost-constrained healthcare market. Appropriate management requires a collaborative understanding of personal, social, and clinical outcomes desired by physicians, patients, and payers of healthcare costs. Large payers such as Medicare need to find the appropriate forum to coordinate patients' desires with the appropriate evidenced-based clinical protocols. Until this paternal role is developed, we will continue to see inappropriate and inefficient care being instituted during end-of-life situations.



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Since the inception of the Medicare hospice benefit in 1983, comprehensive, patient- and family-centered, interdisciplinary services for patients approaching the end of life have been entitlements for Medicare beneficiaries. Over the past 24 years, hospice has been recognized as the gold standard for palliative, or comfort-focused, care and a cost-effective means for supporting symptom management and quality of life at the end of life. While hospice enrollment has increased in the past 25 years (in fact, most Medicare decedents with cancer were enrolled in hospice at end of life³), hospice services are still underutilized by many patients—those who have noncancer diagnoses, who are non-white or are children, and who desire to remain at home but lack sufficient family caregiver support. Under current regulatory guidelines, a patient whose prognosis is limited and who opts for palliative rather than cure-focused care is eligible for hospice. With each passing year, life-prolonging treatment and treatment delivery options increase, making referral to hospice a question of when to *stop* treatment—a prospect that most patients find difficult to accept. However, surviving family members consistently report that they wish they had known about hospice sooner. Furthermore, physicians, nurses, and other clinicians struggle with how to disclose bad news, support patient and family hope as disease progresses, and recognize when a patient is ready for hospice.

In my view, the challenge of improving care at end of life is to counter the prevailing healthcare culture's bias on treatment by introducing a broader frame-

work in which goals of care are repeatedly clarified and clinicians accept that although we cannot change the inevitability of death, we can reduce suffering at end of life; provide opportunity for closure through open, supportive, usually painful discussions initiated by us and other healthcare professionals; and reduce the overuse of costly, often unwanted technological intervention at life's close.

The question is, how do we ease the transition from cure-focused goals to palliative goals at end of life? First, physicians, nurses, social workers, chaplains, psychologists, and others who counsel patients with chronic or advancing terminal illness need to have both *skills* and *will* to speak with patients and families openly, yet supportively, about options for care and the benefits and burdens associated with each. Second, this team of healthcare professionals must be *held accountable* and *rewarded* for open, supportive, goal-focused advance care planning conversations. Managing such emotionally charged conversations requires *skill, practice, and time*. The former requires curricular change; the second could be supported through quality standards applied across settings (such as the voluntary standards introduced by the National Quality Forum⁴) and reimbursement reform that compensates practitioners for the time required to counsel patients at end of life. Finally, the current hospice reimbursement structure must be modernized so that at least some services and support are available to patients and families across a broader continuum, earlier in the disease process, and without requiring them to choose between pursuing cure and remaining ineligible for hospice support or abandoning such treatment goals. These are not small issues to tackle, and the solutions require political and social will.



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Do we spend too many healthcare dollars in our last 3 or 6 months or even year of life? The answer may rest in what accounts for an unexpected death and your time line. If you use the hospice rule of thumb, survival of less than 6 month is the norm. If it is a human

life span, don't be too disappointed if you are not here to celebrate the arrival of the next century.

You have probably heard your patients' lament, "If I knew I was going to live this long, I would have taken better care of myself." Better planning might help smooth out those final transitions and eliminate much of the cost and suffering that draws us into the end-of-life debate. If we knew when we were going to die, we would probably live differently. Advance care planning should start way before the last 3 or 6 months of life. One study suggests that there is a 10-fold increase in healthcare costs in the last 5 years of life.⁵

The elimination of unnecessary care is not just about eliminating *do not resuscitate (DNR)* or *do not intubate* orders. By the time our frail elderly patients finally try to die, these order exercises don't make any difference. A study by the Community Coalition for Long Term Care in Rochester, New York analyzed the relationship between participant-specific and program-specific characteristics and the place of death for participants in the Program of All-Inclusive Care for the Elderly (PACE). Data showed that the probability of death at home is twice as great (45%) for PACE participants as for the general population of older Americans. Twenty-one percent of PACE participants die in hospitals, compared with 53% of Medicare beneficiaries.⁶ Death, like taxes, has some predictability and among a group of frail older persons living in the community, planning to die in a particular place was common, timely, and implemented successfully most of the time, according to a retrospective chart review of a geographically defined area in southeast Baltimore, Maryland.⁷

More appropriate discussions must focus on what will be the last hospitalization, last ride to the emergency room, or last course of antibiotics, and better decisions must be made. My advance care planning for patients with Alzheimer's disease usually starts on the day we make a diagnosis⁸ of a disease that generally leads to death 8 to 10 years later. We tend to pick away at our frail elderly, piece by piece, holding out hope that with the next intervention we will reverse course and achieve wellness. As was eloquently written by David Eddy in *A Conversation with My Mother*,⁹ the end of life just doesn't happen this way. Our job is to help patients and families understand the point at which there is convincing evidence to know that a person has started to unravel and there is no turning back.



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There are at least three problems that complicate management of the last 3 months of end-of-life care and the concomitant medical expenses. One, we do not know at the outset of the final 3 months that the patient will die within 3 months: so when does the 3-month calendar start? Two, patients or their families may not wish to have any limitation placed on the efforts to prolong life. Three, Medicare offers medical treatment options and hospice care as an “either/or option,” when many people might choose something in between. If Medicare were to pay for options that allowed people who are diagnosed with serious, likely fatal conditions to go in and out of hospice without restriction, many of the psychological, financial, and institutional barriers that prevent patients and their families from accepting the likely outcome of death would be mitigated. If patients and families did not perceive that they were making an immediate and forced choice between treatment and no treatment (hospice), they could be counseled relatively effectively in live sessions or over media such as the Web. Payment needs to be linked to the true psychological status of patients, their families, and treating physicians, in my view, and not the other way around, as is currently the case.



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Since the creation of the world, dying is biological and inevitable; only in America is it an option. Of the many impediments to the provision of economical, acceptable care near life’s end, four barriers to acceptance of the fact of mortality are:

1. Almost universal fear of death and dying. (“We’d rather bear the ills we have than go to places we know not of.” – Hamlet)

2. Physician reluctance to accept death as inevitable.
 3. The technology that allows prolonged biological existence past the irretrievable loss of soul and self. (“Where does he get those wonderful toys?” – Joker in the first Batman movie)

4. Physician inability to assess futility of interventions and to recognize, define, and indicate that patients have a life-limiting illness.

Medicare Patient Management addressed this issue well in its July/August, 2006, issue dedicated to the role of hospice-level care as an issue-effective, cost-effective, and humanistic-effective template for providing economically productive palliative care with positive outcomes for patients, their loved ones, and, notably, caregivers. (Nurses, aides, and physicians comment glowingly and lovingly on the rewards gleaned from their involvement in the delivery of palliative care.)

Since physician and caregiver education is a key-stone for overcoming two of the four barriers I cited, *MPM* could provide a meaningful service to its readers by dedicating articles, on an ongoing basis, to improving a physician’s ability to:

1. Tell bad news (telling the truth when prognosis is poor).

2. Learn when palliative modes of management are appropriate (assessing prognosis).

3. Become proficient in applying precepts of palliative medicine (shifting the patient care paradigm from curing and managing diseases to providing comfort care and symptom management).

4. Learn how a primary care physician can function successfully as an educator to patients and loved ones about the positive and rewarding outcomes, when appropriate, of palliative care. The economic savings would certainly follow.



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As many patients with advanced complex illness approach the end of life, they and their families see no alternative to aggressive, expensive, technology-intensive care with rapidly diminishing returns. It is as if we’ve stuffed the whole family into a high-performance sports car, placed them on a superhighway, nailed

the gas pedal to the floor, and waved goodbye. Unfortunately, the bridge is out ahead and there are no exit ramps. Wrong car; wrong road.

How do we offer better cars, the right roads? Patients and families need information, alternatives, and support. *Information* about the natural history of the illnesses they face, the decisions that will have to be made, and the resources available to them will prepare families for the difficult road ahead. *Alternative* pathways may be offered through hospice, home nurses or aides, palliative care consults, and inpatient palliative care units. *Support* is provided through the effective focus on the needs of patients and families by interdisciplinary teams that include physicians, nurses, social workers, chaplains, and others.

When and where do we provide the information, alternatives, and support? We must be prepared to provide all three when the patient and family are ready *wherever* they happen to be physically (home, extended-care facility, or hospital) and physiologically in the trajectory of their illness. I am personally fortunate to work with an integrated delivery system here at Summa within a geriatrics and palliative medicine program, with the resources mentioned above and strong ties to the long-term care (LTC) community. While many roads remain to be built, we know we are building the infrastructure for 21st century care.

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Medications are an integral part of the care provided throughout all facets of life. But caring for individuals at the end of life incorporates many difficult decisions, including deciding when to continue, discontinue, or initiate a medication. Family members, caregivers, and patients should be consulted during this decision-making process.

A recently published model for determining medication appropriateness for patients late in life discusses four considerations that are part of evaluating the continuation or initiation of a medication.¹⁰ These four considerations include goals of care, treatment targets, time until benefit, and remaining life expectancy. Prescribers have the most influence during consideration of goals of care. It is critical that the prescriber is realistic about the benefits as well as risks of the various medications. For example, a class of medication that war-

rants consideration of its necessity during end-of-life care is lipid-lowering agents (eg, simvastatin, atorvastatin). These agents have limited use in end-of-life care, and the risks and benefits of use should be communicated to patients, family, and caregivers.¹¹

When determining medication appropriateness, especially at end of life, the consultant pharmacist is an important resource. A recent article demonstrated that more than 75% of the pharmacists' recommendations regarding medications during end-of-life care achieved their intended therapeutic effect, which resulted in better management of the patients' physical symptoms.¹² Consultant pharmacists can help ensure the appropriate use of medications that will improve the quality of end-of-life care.



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Chronic illness is the cause of death for 70% to 80% of the Medicare population, and one third of all Medicare expenditures occur in the last year of life. This places a premium on effective healthcare management for people with long-term or advanced illnesses.

Most health care under Medicare is point of service and based on episodic illness. However, the most effective means of achieving better health outcomes and reining in healthcare costs for people with chronic conditions is through integrated-care delivery models. Programs using this approach coordinate care across settings and from diagnosis through cure or disease progression, including end-of-life care, based on an individual's underlying condition.

This integrated approach can be found in special needs plans, other Medicare Advantage plans, and state Medicaid programs. These programs coordinate health care and behavioral and social support services for beneficiaries, both from the care and payment standpoints. There is a heavy focus on preventive care, early intervention, and integration of treatments; moreover, provider payment and clinical care priorities are aligned to achieve this focus more effectively.

The integrated approach provides a continuum of health support that helps ensure more effective healthcare delivery than the emergent care model prevalent for

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more than 100 years. Research supports the value of the integrated care delivery model. A 2006 study¹³ found that making lower utilization of acute care hospitals and physician visits could actually lead to better results for patients and prolong the solvency of the Medicare program. In fact, the study found that utilization of these services in the last 2 years of life in the most efficient regions of the country, often characterized by integrated-care delivery models, was 30% less than that of high-cost regions.

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