

“Slow Medicine”...? Why Not Palliative Care?

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A recent *New York Times* piece¹ framed an approach to advance care planning and medical decision making for older adults that its originators term *slow medicine*. *Slow medicine* is, at its essence, a partnership between physician and patient to plan ahead—establishing goals for care, embracing the patient’s values and preferences for treatment, and resisting the imperative to treat when comfort and support are both appropriate and desired. The outcome for the patient is a comfortable, dignified life—and death—in the final chapter that lies ahead for each of us. The outcomes for providers and payers are positive as well—humanism trumps heroics, and the system can redirect resources to other healthcare goods and services. For practitioners of palliative care (the discipline that provides a framework for hospice practice), *slow medicine* should sound familiar. *Slow medicine* is, in fact, palliative care.

Palliative care is both a philosophy and a system for care delivery, in which the goals are to prevent and relieve suffering, optimize functioning, and support decision making and quality of life. Palliative care can be delivered concurrently with other forms of care (cure focused or disease remitting) or can comprise the main focus of care.² The Latin root for palliation is *palliare*, which means to “cloak” or “shield.”³ Thus, palliative care could be viewed as protection (a shield) for patients,³ not unlike the “slow medicine” concept, and also as “cloaking” or cov-



ering up problems.⁴ What these two interpretations share is an understanding of the inevitability of disease progression and death balanced by a rational, patient- and family-centered approach to relieving symptoms and supporting quality of life. Palliative care recognizes that while we cannot change the fact that our patients will die, we can modify the manner in which patients with serious, progressive illnesses *live* each day. Although there are emerging standards for palliative care (National Consensus Project, for example), there is currently no direct reimbursement for palliative care services. As a result, the service bundle varies depending on the provider structure and resources.

Hospital-based Palliative Care

Experts agree that providing high-quality palliative care to patients who need it and their families, re-

gardless of prognosis, is an important and necessary advancement in health care. Hospital-based palliative care has emerged as a trend, spearheaded by physicians who identified a need for better coordination of care and attention to symptoms and advance care planning while patients are hospitalized. The Center to Advance Palliative Care (CAPC) argues that hospital-based palliative care is both critical and necessary for 3 primary reasons⁵:

1. Hospitals are the location of most severely ill patients and the location of death for 53% of all decedents, thereby underscoring the need for comfort-focused care that complements acute care.
2. Hospitals are the location where the most significant amount of health dollars are spent.
3. Hospitals are the best place to plan for transition to another setting. Hospital-based palliative care

programs have grown dramatically in recent years, largely through development of nonoperating revenue sources (foundation and individual donors, for example), through redirection of existing resources in the setting (such as nursing, social work, pastoral care, and case management), and by billing for services where feasible under existing codes.

Generally, hospital-based palliative care programs are of 4 types. The most common model is the (1) palliative care consult service,⁶ but hospitals also have (2) dedicated inpatient units where patients needing palliative care can be clustered; (3) some hospitals use a “scatter” bed approach, where palliative care services are brought to the patient’s unit; and (4) some hospitals operate outpatient and ambulatory palliative-care services. Many hospitals operate more than 1 model, such as a consult service in addition to a dedicated unit. According to CAPC, hospital-based palliative care programs have been successfully administered by varied hospital services or departments, such as oncology, geriatrics, critical care, nursing, and case management as well as through partnership with a community hospice.⁵ In a study published in the *Journal of Palliative Medicine*, researchers at Mount Sinai School of Medicine reported that the number of palliative care programs increased from 632 (15% of hospitals) in 2000 to 1027 (25% of hospitals) in 2003—a 63% increase in only 3 years.⁷ Growth has continued. An American Hospital Association survey published in 2007 reported that 30% of the 4103 hospitals appropriate for palliative care have a program.⁵

Hospice Care: An Application of Palliative Care

The discipline of palliative care is most familiar to healthcare professionals and patients as hospice care. In the United States, hospice care evolved as a grass roots, spiritually based alternative to technologically

driven, disease-focused intervention for patients whose disease could not be cured. Codified under Medicare Conditions of Participation in 1983, hospice has evolved as both an approach to care for patients nearing end of life and an insurance benefit under Medicare and most Medicaid and commercial plans. The latter understanding of hospice care has generated confusion among providers and patients (about the “rules,” ie, when a patient is eligible, what services are “covered”) and tension between hospice providers and palliative care professionals practicing outside of hospice settings. Palliative care is

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generally viewed as the broader umbrella or discipline, in which hospice is an application aimed at a specific population (terminally ill patients whose life expectancy is less than 6 months if the disease follows its expected course). In other words, all hospice care is palliative care, but not all palliative care is delivered in hospice settings. Hospice is a combined application of palliative care principles and evidence-based practice standards at life’s end. Since the first hospice opened its doors in 1974, the hospice industry has developed with a central purpose of providing compassionate, comprehensive, person-centered care to terminally ill patients and their families at home, or in a home-like setting. The success of the hospice philosophy and delivery model is borne out by its

growth, acceptance, and reputation in the past 3 decades.

Medicare Hospice Benefit

The Medicare Hospice benefit, authorized in 1983, ushered in a period of industry growth including for-profit entrants into the market, a trend that has accelerated in the past decade. The National Hospice and Palliative Care Organization (NHPCO) reported that 46% of hospice programs have a for-profit tax status. The number of hospices has grown from a single program in 1974 to 4500 distinct programs in 2006.⁸ There are hospice programs in every state and in Puerto Rico (NHPCO HelpLine, personal communication, May 22, 2008) and in most urban and rural settings.⁹ In 2006, the nation’s hospices served more than 1 million terminally ill persons and countless family members. The greatest growth has been in small, freestanding programs with an average daily census of fewer than 100 patients.⁸

Greater Acceptance of Hospice

While hospice programs have predominantly served cancer patients in the past, the ratio of cancer to noncancer hospice admission diagnoses has shifted in recent years—cancer diagnoses now account for roughly 44% of hospice admissions, with heart disease, dementia, lung disease, and other unspecified debilities comprising the majority of noncancer admitting diagnoses.

Racial and ethnic diversity among hospice patients has increased. Although the majority (81%) of hospice patients served in 2007 were white, 9% were identified as multiracial, and 8% were African-American.⁸ Admission of patients with noncancer diagnoses to hospice reflects the industry’s significant emphasis on outreach and improving access for all persons who can benefit from hospice care in the final decades, years, and months of life. The trend toward admission of patients with noncancer diagnoses

raises new challenges for hospices—accurate prediction of prognosis for such patients is difficult, and hospice referral may not be accepted by patients and families who have lived through years of illness exacerbations followed by hospital admission and medical stabilization.

More than 10 years ago, Inspector General June Gibbs Brown reported an investigation of 12 hospice programs in which she raised concerns about possible overpayments to hospices for patients who were not eligible under Medicare guidelines.¹⁰ Since that time, CMS has increased its scrutiny of claims for long-stay patients and patients with noncancer diagnoses. Medicare expenditure for hospice has also increased dramatically—from \$2.9 billion in FY 2000 to \$8.2 billion in FY 2005.¹¹ Spending for FY 2008 is expected to exceed \$10 billion.⁸ While the absolute spending is still small compared to other Medicare programs, the rapid growth in spending has placed hospice on the CMS radar screen.

Limitations of the Hospice Model

Since 1983, the limitations of the hospice model have also become evident. Patients and their families, as well as the referring physicians who provide medical management for their patients enrolled in hospice, are generally very satisfied with hospice care and services. Yet patients are typically referred to hospice late in their illnesses—the national median length of stay on hospice is just under 21 days.⁸ The challenge for hospice is to appeal to *prospective* patients and their physicians at an earlier stage—a time when they are more likely to avoid direct discussion about end of life, often delaying referral until the reality of advanced illness can no longer be ignored. Although hospices have made significant inroads with patients, families, and physicians with respect to viewing end of life as an opportunity for comfort,

personal healing, and growth, death denial is deeply ingrained in Western society. While progress will continue, it is likely that denial, coupled with advances in technology and availability of new treatments, will continue to act as barriers to hospice enrollment.

Emerging Trends in Palliative Care and Hospice

Generally, hospice is a philosophy and business model that has achieved increasing acceptance in the healthcare industry. While there are those who argue that hospice has evolved almost as a parallel system, often referred to as the “best-

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kept secret” in health care, others maintain that hospice providers have reached out to providers in other settings and created bridges to understanding and acceptance. Despite its successes, hospice continues to face persistent challenges about the association of hospice with death, resulting in provider reluctance to refer and patient and family reluctance to accept hospice until very late in the illness. Emerging models of care, such as hospital-based palliative care, and comprehensive geriatric case management may be viewed by hospice providers as threats to their referral base. Numerous other factors in the current environment will challenge hospice in the coming years. Key issues are summarized here.

Broadening Hospice to Include Palliative Care Programs

Increasing access to nonhospice

palliative care in home or other residential settings has been slower to evolve than home hospice, principally because there is no direct reimbursement for these services. Nevertheless, many hospices and some other home-based providers have developed palliative care programs, sometimes referred to as *prehospice* or *supportive care programs*, as an outreach to patients who are seriously ill but either not eligible or not willing to enroll in hospice. Unless the hospice is also licensed or certified to provide home-care services, programs delivered in these nonhospice programs are frequently fee for service or unreimbursed. Hospices that develop palliative care programs must balance outreach to patients who need and use their services with compliance, according to the federal anti-kickback statute and the civil monetary penalties (CMP) statute, which prohibit unlawful inducement of referrals. That is, hospices may be in violation of these statutes if, for example, they develop a palliative care program that provides services at no charge and the intent of the program is to gain favor with referral sources and thereby capture potential hospice referrals.¹² Many hospice experts argue that, as the “gold standard” for palliative care, hospices are the ideal provider base from which to expand palliative care services at home. They make the case for removing prognosis barriers (ie, eligibility requirement of a 6-month prognosis) to meet many more patients’ needs for palliative care.

Payment for hospice is largely government funded through Medicare and state Medicaid programs and, while the hospice service bundle would surely benefit patients with advanced stages of chronic illnesses as well, the cost is viewed by many policy analysts as unsupportable. Further, others argue that simply removing the prognosis requirement still leaves hospices with public relations and social mar-

keting challenges. For example, does the frail older adult diagnosed with heart failure (or his family) want to receive disease management and support services from an end-of-life care provider? Further, are hospice providers prepared to support patients with chronic but not imminently terminal illnesses to navigate the healthcare maze? New models are needed to meet the needs of frail older adults with 1 or more chronic illnesses. The hospice model of service delivery and care management should inform innovation in home-based care delivery to chronically ill elders.

Hospice Rule Changes

The current atmosphere at CMS has been described as a “mission to scrutinize the hospice industry.”¹³ Two issues are driving the increased scrutiny: (1) dramatic growth in CMS payments to hospice and (2) suspected fraud and abuse in the hospice industry. The Medicare Hospice Benefit (MHB) has been in place with relatively few changes since 1983. The proposed revision to the Medicare Conditions of Participation for hospice was published in May 2005, and the final rule was published in the Federal Register on June 5, 2008. The intent of this rule revision is to bring the MHB into alignment with changes that have already been made in other CMS-regulated settings, such as hospital, nursing home, and home care. Most significant among the changes are (1) an increase in emphasis on quality assessment and performance improvement, which is a first step toward what experts agree will be a public reporting initiative (similar to “Nursing Home Compare” for example) and eventually, a pay for performance (P4P) scheme for hospice reimbursement, (2) a new emphasis on quality and safety oversight by the hospice’s governing body, and (3) tighter coordination of individualized assessment, planning, evaluation, and ongoing reassessment/care plan updates.

Compression of Reimbursement

Hospices in general are highly dependent on Medicare revenue. Noting the industry’s exponential rate of growth, CMS has signaled that reimbursement reforms such as across-the-board per-diem rate cuts and greater scrutiny of processed claims are on the horizon. Further, increases in the enrollment of longer-stay patients has resulted in some hospices exceeding the annual aggregate per-beneficiary cap on reimbursement (total payments per total number of beneficiaries may not exceed \$21,410 in the year ending October 31, 2007). This trend is likely to contin-

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ue, and no clear “fix” for the cap issue has been identified. The Medicare Payment Advisory Commission (MedPAC) is an independent group of advisors to the Congress established by the 1997 Balanced Budget Amendment. MedPAC’s 17 commissioners are recognized experts in the fields of economics, health policy, and health care who are tasked with analyzing payment in, access to, and quality of the Medicare program. While MedPAC has no authority to create policy, its recommendations are key to Congressional and departmental action concerning Medicare benefit structure and payment across healthcare settings. In a 2007 public meeting, MedPAC commented regarding the MHB: “This is a payment system that is ripe for a major overhaul, and there are many different forms that this overhaul may take. You may wish to start thinking now

strategically about what the hospice payment system should look like in the future and the kind of steps that would need to be taken in order to achieve that vision.”

Hospice-managed Inpatient Units and General Inpatient Care

Once rare, nearly 20% of hospices now own and operate freestanding or co-located facilities or hospice units where they provide residential and acute level care to hospice patients. Most of these facilities and co-located units are appropriately small given (1) the philosophical history and reimbursement structure of hospice in the US as a home care model and (2) the relatively low demand for inpatient hospice care as a proportion of total hospice days on service. As inpatient unit (IPU) development has accelerated, utilization of the general inpatient (GIP) level of the Medicare hospice benefit has increased. While some portion of hospice GIP days is surely justified based on patients’ acute needs, the financial pressure on hospices to fill IPU beds cannot be understated.

CMS is tracking this trend as well and has noted that the greatest growth areas in hospice-related expenditures in the 5 years from 2001 to 2005 were for physician services, continuous home care level of care, and *GIP level of care*.¹⁴ Under the MHB, CMS also caps the number of inpatient care days (at the GIP level) that a hospice may provide to no greater than 20% of its total patient care days. Unlike the daily rate for routine home care, the caps are not adjusted for geographic differences in costs.¹⁵ Hospices should expect to see greater regulatory scrutiny of utilization, which will likely take the form of greater administrative burden (documenting eligibility and per-unit utilization reporting requirements, for example) and claims review.

Hospice in Nursing Homes

Since 1986, hospices have routinely brought the hospice service package

to residents of nursing homes, providing support to the residents' families and nursing home staff in addition to the residents themselves. Although these 2 models of care would appear to integrate well—nursing home residents are, after all, progressing to end of life—hospice and long-term care (LTC) embody different cultures, value sets, regulatory standards, and reimbursement challenges.

The merging of these distinct models has been challenging, and issues of overlap between services and payment have yet to be completely resolved. The nursing home–hospice tension is not new, and continued scrutiny as well as substantial reform is likely. Operation Restore Trust (ORT) in 1997 was the federal government's first major examination of use (and alleged abuse) of hospice benefits in LTC settings. ORT clarified the overlap between nursing home services and hospice services to some degree, particularly in terms of contracting and provision of free services. The Office of the Inspector General (OIG) has indicated that its 2008 work plan includes a review of "the nature and extent of hospice services that are provided to Medicare beneficiaries who reside in nursing facilities and [assessment of] the appropriateness of payments for hospice care for these services."¹⁶

On the Horizon

The needs in the current market are for both high-quality end-of-life care and comprehensive, coordinated supportive care for persons with complex chronic illnesses. Persons in the latter group currently fend for themselves to a large extent—they receive acute care for exacerbations of 1 or more chronic illnesses; they see many specialists; they take many medications; they may receive some support and services depending on availability in their communities (transportation, meals, and personal care, for example); and they frequently find themselves incapable of remaining in their own

homes because of declining functional ability and inadequate, *coordinated* resources to support them in the home environment. These persons need palliative care. They will not be "cured" of their heart failure, chronic obstructive pulmonary disease, arthritis, macular degeneration, diabetes, hypertension, etc. The question becomes, how can the needs of these persons be met by high-quality, community-based providers who provide guidance and care management across time, anticipate and prevent health crises to the greatest possible extent, and permit safe and effective care in the older adult's own home?

The emerging competition will likely take the form of nonhospice service models that address similar or identical patient and family needs.

The impact of the aging of the baby boomers will be significant. This cohort is likely to demand new models of care. They are unlikely to be content with the current options (ie, choosing either to discontinue disease-remitting therapies, enroll in hospice, or do without the service package that hospices provide). They will challenge the industry to create programs that provide a continuum of services, support them in their own homes, and are truly seamless as their care needs and expectations change.

The emerging competition will likely take the form of nonhospice service models that address similar or identical patient and family

needs over many months or years, ease illness and care transitions, and allow seniors to age (and die) in place—without an abrupt change in providers late in the illness. Two such examples in the current market are the Program of All-Inclusive Care for the Elderly (PACE), in which hospice is a component of the PACE service bundle, and continuing care at home, which enables seniors to tap into a continuum of services beginning at a time when they are independent and continuing seamlessly across their lives. The latter model is neither licensed nor described as hospice, yet the services provided clearly meet the broadest definition of palliative care.

Conclusion

Most older adults wish to remain independent for as long as they can... living, aging, and ultimately, dying in familiar and comfortable surroundings. Hospices have made significant inroads with patients, families, and physicians to view end of life as an opportunity for comfort and personal healing and growth. Yet, death denial is deeply ingrained in Western society. While progress will continue, it is likely that denial, coupled with advances in technology and availability of new treatments, will continue as barriers to hospice enrollment. Palliative care, like "slow medicine," is a model for care that considers the patient's perspective and preferences in treatment decision making and provides both medical treatment and comprehensive support to meet the patient's goals for care. Many aging adults with 1 or more chronic illnesses could benefit from comprehensive palliative care. Hospice is a palliative care model that has benefited countless patients, families, and communities, but enrollment is typically late in the illness because of prognosis concerns, death denial, and complicated rules that force patients to choose between cure and care. We need a model that combines the lessons learned through the hospice

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same. That is why they don't put a handicap sign on either of the doors because it doesn't matter which restroom you use. Each of the restrooms is accessible.

I visited the dining room on the afternoon of my first day at Any-Home Manor. Thank goodness David waited all day so that I could get settled in. My observations were that someone had tried to make the place look homey, but it did not look like my dining room at home. It was more like a restaurant or David's country club dining room. What I noticed right away was how much room there was between the tables and how the chairs all had arms and were on rollers. I also noticed that the tables had an edge that was a different color of wood. That detail helps me see where the edge of the round table is.

When I first visited my new bedroom and bathroom, I was surprised that it was so plain. The wall outlets were not even at the normal

height on the wall. There was something with a pull cord behind where my bed would be located and another one in my new bathroom. I later learned that the reason that the cords were there was

Someone had tried to make the [dining room] look homey.

for my own safety; I could pull them and a staff member would respond—like room service! The wall outlets were placed at a height for people in wheelchairs or with back problems to easily be able to reach them. The other thing I noticed was that the bathroom was so big, and the floor was an ugly vinyl floor.

Later I found out the reason for this was for the residents who must use wheelchairs to get around. I also had a shower; and there were grab rails everywhere.

I so much wanted my old bathtub back; the one with the claw feet. Unfortunately, I have had to get used to not taking baths. Once I moved my own furniture into the room, and put up my own drapes and photos of my family, I made the space my own. I even found out that the grab bars are dandy places to hang bath towels. I am not handicapped and do not need all these special things, but they make my life easier, and I have come to realize that many of my new friends do need some or all of these special features. ALC

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and palliative care experience with a feasible payment structure that responds to patients' and families' needs over years—not months. As we look to the future and consider how we will provide and pay for services to the burgeoning population who will need support, it is clearly time to bridge the LTC gap. Palliative care is a good place to start. ALC

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