

End-of-Life Care: A Public Health Crisis and an Opportunity for Managed Care

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American society is failing to provide humane care for people who are dying. Unnecessary physical suffering continues even in our most prestigious institutions, and the enormous burden on family caregivers remains unrecognized. The cost of health services and burdensome regulations remain major barriers to improving the quality of care. Healthcare planners and policy makers are gradually awakening to the realities of an increasingly older population and a looming labor shortage of qualified paid caregivers. Several features of palliative care render it attractive within managed care. Evidence is emerging that palliative care, focused on meticulous prospective care planning and coordination, delivers high quality and cost-effective end-of-life care. Innovative demonstration projects around the country are exploring models for integrating palliative care within the routine operational processes and protocols of health systems and are providing examples of feasible "best practices" crucial for raising public expectations and framing possible solutions for policymakers and planners. Ultimately, it will be a marketing asset for a managed care organization to be known as a center of excellence in palliative care, and in some markets it will be a necessity. The goals of managed care and palliative care are already well aligned. Joint efforts among clinicians, provider institutions, insurers, and employee health benefit managers can address the needs and preferences of dying patients and families, while increasing public trust in managed care.

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well as the extensive errors of omission and commission that occur in clinical practice. Collectively, these problems comprise a true public health crisis. By any measure, American society is failing in its responsibility to provide humane care for people who are dying. The deficiencies of care encompass not only significant lapses in medical care for those with serious, chronic illness but also lack of support for their families.

Scope of the Problem

Unnecessary Suffering. Pain and other sources of physical distress among the dying are being inadequately controlled or even addressed, resulting in unnecessary suffering at the end of life. This occurs across the spectrum of healthcare settings, including many of our nation's most prestigious medical institutions.

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) was a prospective cohort study at 5 major university hospitals of outcomes, preferences, and decision making in seriously ill hospitalized adults and their families.² Phase I of this study, which involved 4301 seriously ill patients, showed that 47% of physicians were unaware of their patients' preferences regarding cardiopulmonary resuscitation, 46% of do-not-resuscitate orders were

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Care for people with chronic, incurable, and debilitating illness is a major challenge facing American society today. A recent report, *Approaching Death*, from the Institute of Medicine discusses the severity and pervasiveness of problems involving end-of-life care.¹ The report details the serious deficiencies that exist in medical education, health systems financing, attitudes, and culture, as

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written within 2 days of patients' deaths, 38% of decedents spent 10 or more days in an intensive care unit, and 50% of patients who died in the hospital experienced moderate or severe pain at least half of the time during the last days of life. Furthermore, an intervention consisting of a specially trained nurse who regularly informed treating physicians of patients' prognosis, symptoms, and preferences for care produced no measurable change in clinical outcomes.² In another important study of outpatients with recurrent or metastatic cancer, all under the care of cancer subspecialists at leading medical centers, the authors reported that 42% of patients were not given sufficient basic analgesia.³

The situation is equally troubling in long-term care; Bernabei et al found that 42% of patients with cancer pain residing in nursing homes were inadequately treated.⁴ Other studies among nursing home residents with chronic nonmalignant pain and outpatients with pain due to HIV disease show similar results. Significantly, although these data are derived from US medical centers and nursing facilities, the assessment scale used was the World Health Organization cancer pain guidelines—the same scale used by the WHO to assess adequacy of cancer pain treatment in third world countries.

Financial Burden. The cost of health services remains a major barrier to improving the quality of care. Currently, more than 44 million Americans are uninsured and another 15 to 20 million are underinsured. Roughly two thirds of nursing home residents rely on Medicaid, having had their savings completely depleted during the course of their illness.⁵ Healthcare expenses are growing faster than inflation and are outstripping efforts by managed care organizations and large employers to control soaring costs.^{6,7} Many families of working Americans face financial devastation when a family member develops a chronic, progressive illness or suffers a crippling injury. Statistics from the family impact component of the SUPPORT Study reveal the severe economic burden on families—29% of families reported loss of the major source of income and 31%, loss of most or all of family savings.⁸ Care during the last few months of life typically accounts for a high proportion of total healthcare costs. Routine advance care planning and basic palliative care may lead to fairly significant cost savings.⁹⁻¹¹

Stress on Caregivers. Family caregiving remains the backbone of chronic care in America. The annual monetary value of informal caregiving is estimated

at \$196 billion—a figure that dwarfs the combined costs of home care (\$32 billion) and nursing home care (\$83 billion).¹² Care for the chronically ill and frail elderly has traditionally been and continues to be provided by individual networks of relatives and close friends. Approximately 25.8 million Americans spend an average of 18 hours a week caring for frail relatives, and more than half of Americans (54%) anticipate being responsible for the care of an elderly parent or relative within the next 10 years.¹³ Demographic and economic pressures, however, are making it harder for American families to be available when needed. A diminished birthrate, an increased proportion of multiple-job couples, and heightened geographic mobility within American families are all combining to constrict the pool of caregivers.

Presently, family members are poorly rewarded for providing care for chronically ill loved ones. A 1999 study reported the average loss in total wealth due to caregiving at \$566,443 in aggregated wages, \$25,494 in Social Security, and \$67,202 in pension benefits for a total of \$659,139 in average lost wealth.¹⁴ Beyond losses in wages and benefits, family caregivers routinely face out-of-pocket expenses for special food, transportation, medications, assistance with rent or mortgage, and homecare professionals. The average aggregate cost over 2 to 6 years is approximately \$19,525.¹⁴

The stress of caregiving is associated with significant emotional and physical symptoms, and use of health services.¹⁵ A recent study documented a 63% higher mortality risk among caregivers compared with noncaregiver controls during a 4-year period of surveillance.¹⁶ This burden on caregivers is a significant challenge for American businesses, large and small. In one national study, 64% of caregivers were employed, resulting in an estimated cost to US employers of \$11.4 to \$29 billion per year.¹⁷

These sources of stress are critical components of the current context of dying and end-of-life care and must be kept in mind as leaders in healthcare plan for the needs of our population. Managed care cannot offer a panacea, but strain on caregivers can be alleviated with a case or care management approach, identification and application of support services, volunteer support, assistance with transportation and coordination of appointments, and admission to hospice care. The impact of such a comprehensive and prospective approach is worth testing because reduction of stress and illness in caregivers may well lead to resource and financial benefits.

Demographics and the Looming Labor Crisis.

Current population trends project an unprecedented rise in the numbers of the chronically ill and frail elderly over the next few decades. With aging of the 75 million baby boomers, approximately 20% of the US population will be 65 years of age or older by 2030, twice the number as in 1999.¹⁸ Currently, 40 million people are living with chronic illness and some degree of disability, and this number is expected to increase to as many as 120 million by the middle of the 21st century. At present, 1.6 million people live in one of this country's 17,000 long-term care facilities; by 2030, the projected number of nursing home residents is 5.3 million.¹⁹

Who will care for these people? Even today, there is a shortage of qualified paid caregivers. The nursing workforce is aging and the number of new entrants into the profession is inadequate for the demand. Long-term care faces a similar worker shortage. Currently, 1.3 million nursing aides provide 80% to 90% of hands-on care in nursing homes.²⁰ The Bureau of Labor Statistics estimates that 333,000 more will be needed within 7 years. Nursing aides are often paid less than \$8.00 an hour (\$6.25 to \$7.00 per hour is common),²¹ have little training, work under stress, and lack stature in the healthcare profession. These factors contribute to a 93% annual turnover rate among nursing aides in long-term care. The labor shortage worsens during economic boom periods when unemployment is low, wages in retailing and other sectors are higher, and competition for good workers is increased.

Managed care cannot offer quick solutions for this critical labor shortage, but it is well positioned to respond in a creative and constructive fashion. Support for fair labor practices and adequate compensation for paid caregivers is essential. Managed care organizations and providers can model a clinical approach that responds to this predicament on a patient-by-patient basis, through thorough psychosocial and family assessment and meticulous care planning, and whenever appropriate, by encouraging informal caregiving. Patients' families and friends can be supported in this vital work by limited case management that provides care-planning resources and connects people with support networks for volunteer caregivers.²²⁻²⁴ Working with one patient and family at a time will not solve the national crisis, but it can, by example, offer leadership in confronting a problem that affects all of American healthcare.²²

Current Barriers to Hospice and Palliative Care within Managed Care

The healthcare industry, particularly long-term care, is mired in excessive regulations that are often antithetical to sound patient care. For instance, in long-term care settings, end-of-life care may seem at odds with a congressionally mandated focus on restoration and rehabilitation with corresponding regulations. A patient who is losing weight, whose function is declining, or whose decubitus ulcer is not healing may attract state surveyors' attention. Many nursing homes fear being cited for deficiencies for not aggressively treating a patient who would otherwise die peacefully and in accordance with the patient's and family's wishes. Additionally, Medicare regulations often make hospice care unavailable to many ill and dying nursing home residents. Only about 1% of nursing home residents receive hospice care because, during at least the first 20 days after hospitalization, Medicare patients and their families must choose between the costs of room and board in the skilled nursing facility or Medicare coverage for hospice care; because of the expense of room and board, few families choose hospice.²⁵

Treating patients with advanced illness and complex needs has become a fiscally risky business because of decreasing Medicare and Medicaid reimbursements, the Balanced Budget Act of 1997, prospective payment arrangements, and lack of adequate risk adjustments in managed care, as well as in long-term care. Cost shifting on a local basis can place physicians, hospice providers, health maintenance organizations, and long-term care institutions at odds over the care of high-cost cases. Pervasive cost cutting has made quality improvement efforts difficult to implement.

Managed care organizations are right to be risk averse in the present healthcare environment. Being known as a referral center for palliative care might well attract a high number of patients with complicated and costly problems, and becoming a center of excellence in end-of-life care could be misconstrued by a cynical public to be a means of cutting services and costs of curative treatments. With public trust in managed care at an all-time low, many patients worry that their health plans and even their own doctors may have financial incentives to not offer the most effective life-prolonging treatments because of their expense.^{6,26-29}

In end-of-life care, consumer demand has not yet caught up with consumer need. Death is an inevitability, regardless of extent of therapy. Palliative care, epitomized by hospice, is exactly the

sort of medical care and individualized care management that patients with complex medical problems and their families need, want, and deserve. Emerging evidence strongly suggests that quality of care and fiscal responsibility can be enhanced within a managed care approach that combines individualized planning, careful surveillance and management of symptoms, coordination, and team-based caring.

Miller and colleagues at Brown University studied the impact of hospice care on quality of care and resource use among nursing home residents.¹¹ A matched control study conducted from 1992 to 1996 involved nursing home residents in 5 states and compared 2644 residents who were served by hospice with 7929 terminally ill residents who were not. Hospice enrollment was associated with a 93% increase in the likelihood that patients experiencing daily pain would have some attempt made at managing their discomfort. In the hospice population, patients in daily pain were twice as likely to receive strong pain relievers, those with persistent depression or anxiety were more likely to receive treatment, and a lower proportion of patients received invasive procedures such as parenteral or tube nutrition or physical restraints. At the same time, utilization data revealed that overall, only 12% of hospice patients were hospitalized for a mean of 1.2 ± 3.5 days, whereas 41.3% of nonhospice patients were hospitalized for a mean of 4.4 ± 7.1 days. Similarly, data for nursing home residents enrolled in hospice during the entire last 30 days of life revealed that 1.8% of hospice patients were hospitalized for a mean of 0.14 ± 1.3 days, whereas 38.3% of

nonhospice patients were hospitalized for a mean of 4.2 ± 7.2 days.¹¹ This study demonstrated it was possible to improve quality of end-of-life care while using less of the most costly services.

Successful End-of-Life Care

Palliative care and hospice are components of effective end-of-life care. A statement by the ethics committee of the American Geriatrics Society provides key categories for assessing the quality of care for patients with advancing, incurable illness (Table 1).³⁰ The Last Acts Task Force on Palliative Care³¹ and other organizations^{32,33} have defined principles and components of effective clinical care for patients and support for families dealing with the progression of eventually fatal illness. Palliative care includes ethical decision making, respect for patient autonomy and the appropriate role of family or legal surrogates, an interdisciplinary team approach to care, effective and (when necessary) intensive symptom management; improving quality of life as a primary goal, recognizing importance of the “inner life” of the person, and bereavement support for family members following a patient’s death (Table 2).

Management of symptoms is the first priority of palliative care. With the advances in medicine over the past 20 years, including advances in diagnostics, evidence-based disease management, and analgesia, there is no reason for patients to suffer physical agony as they die. However, successful symptom management may occasionally require extraordinary measures and a high level of commitment on the part of caregivers. On occasion, patients may have to accept diminished alertness, or even sedation, to achieve physical comfort, but relief from severe physical distress is always achievable.³⁴

Although symptom management is a critical and essential first step, it is not the ultimate goal of palliative care, which recognizes that dying is more than a set of medical problems to be solved. The fundamental nature of dying is not medical; rather, it is personal and experiential. If dying is a part of living, then care that preserves a person’s quality of life would be deemed excellent. Such care helps patients identify, say, and do the things that are of importance to them. In addition to providing physical comfort, the goal of palliative care is to preserve the opportunity for dying patients and their families to achieve a sense of completion in their lives. With skillful, energetic management of symptoms, this opportunity can be preserved; and with skillful, confident counseling, opportunity can be facilitated.^{35,36}

Table 1. Domains of Quality at the End of Life

<ul style="list-style-type: none"> ■ Physical and emotional symptoms: Support of function and autonomy ■ Advance care planning ■ Aggressive care near death: site of death, cardiopulmonary resuscitation ■ Patient and family satisfaction ■ Global quality of life ■ Family burden ■ Survival time ■ Provider continuity and skill ■ Bereavement

Adapted from reference 30.

Palliative Care within Managed Care

Potential for Synergy. A number of features make palliative care an attractive offering within capitated managed care for patients with progressive, debilitating, or incurable conditions. Indeed, hospice, the best developed and most familiar form of palliative care in the United States, can be thought of as a sub-component of palliative care—a programmatic model for delivering palliative care that focuses on home care for patients with an estimated prognosis of 6 months or less. Hospice was the first system in this country to operate in a per diem manner under Medicare. Within existing fiscal arrangements and regulations, Medicare hospice is a form of managed care. The best hospice programs have proven adept at managing costs by expertly practicing secondary prevention, comprehensive planning, and case management, and avoiding hospitalizations and use of expensive life-prolonging treatments when they are not consistent with patients’ goals and plans of care.

Patients with advanced, progressing, or incurable illness are, by definition, among the sickest patients in the healthcare system, and their care is inherently complex and inevitably expensive. It is in the care of such patients that quality and cost efficiency converge. Individualized communication about a patient’s condition and treatment options, clear identification of the person’s values and goals, and meticulous, prospective care planning can all contribute to positive outcomes and high satisfaction with care. It is often possible to anticipate potential problems and either prevent them or create plans for dealing with potential crises. Emergency ambulance transports to the emergency department and admissions to the hospital or intensive care unit can often be avoided by adequately addressing problems at home or in a nursing home. The savings more than offset the cost of patient communication, education, anticipatory guidance, and care planning.

Putting Theory into Practice: Models of Palliative Care. Demonstration projects are crucial for formulating policy and allocating public resources. They provide examples of what is feasible, establish “best practices” that can raise expectations, and provide benchmarks by which other programs can be gauged. Around the country, a number of innovative demonstration projects are exploring models for integrating palliative care within the routine operational processes and protocols of health organizations and are providing examples of successful outcomes at the health system and community level. If successful, the impact of these projects will extend beyond their local systems

and communities to influence policy-makers and planners.

An important group of demonstration projects is being supported by Promoting Excellence in End-of-Life Care, a national program of the Robert Wood Johnson Foundation (www.promotingexcellence.org). This grant and technical assistance program funds model projects that provide interdisciplinary palliative care in clinical contexts and to defined populations for which access to hospice care has been limited. Barriers to accessing hospice care have most significantly been encountered by children; people of color; non-English-speaking people; individuals residing in poor urban or isolated rural areas; people living in nursing homes; people with non-cancer diagnoses (such as acquired immunodeficiency syndrome, emphysema, congestive heart failure, kidney failure, amyotrophic lateral sclerosis, and dementia); people with long-standing, serious psychiatric illness and those with human immunodeficiency virus (HIV) disease and coexisting psychiatric illness or addiction disorders; and aging, ill, or dying prison inmates. These challenging contexts and special populations provide opportunities for innovation in palliative care.

A key criterion in selecting proposed projects for funding was their potential to leverage change broadly. Using comprehensive hospice care as a benchmark, the projects are designed to test strategies for expanding access to and quality of palliative and end-of-life care in settings as diverse as National Cancer Institute regional comprehensive cancer centers, large managed care organizations, academic medical centers, dialysis units, isolated rural communities, inner cities, and even state departments of corrections. Successful demonstration projects will

Table 2. Precepts of Hospice and Palliative Care

- Ethical decision making that respects patient autonomy and role of family or legal surrogates
- Interdisciplinary team approach to care
- Patient and family as the unit of care
- Effective and (when necessary) intensive symptom management
- Dying understood as a time of life; improving quality of life is a primary goal
- Recognizing importance of the “inner life” of the person
- Bereavement support to family during initial period of grieving

then serve as model care programs that can be replicated in similar health systems or communities or that can advance a specific approach that could positively impact care for people elsewhere.

In each project supported by this initiative, clinician-researchers are evaluating the effects of the program on patients' physical comfort, satisfaction, and subjective quality of life, as well as the experience of family caregivers. Assessment focuses on feasibility and acceptability, as well as on measures of clinical effectiveness and impact on lengths of stay in hospital and hospice and utilization of resources. Because of the importance of measures in health systems, significant emphasis has been placed on instrument development and refinement. In establishing the psychometric validity and reliability of measures and in demonstrating their utility it is hoped that in future such measures may be applied within routine quality improvement programs of institutions and health systems.^{37,38} An overall goal of these efforts is to "raise the bar" for health planners and decision-makers regarding access to and standards of palliative and end-of-life care.

A Strategic Plan for Improving Palliative and Terminal Care

Building programs of excellence in care for terminally ill patients and their families and providing qualitative and quantitative descriptions of their operations and outcomes can establish new benchmarks for quality. This, in turn, can help raise expectations among key stakeholders and generate the critical support required to conduct significant quality improvement within health systems. To capitalize on this commitment, relevant data must be made available to system managers in a manner that fosters, rather than inhibits, quality improvement. Stakeholders need information that is accurate, reliable, and meaningful within carefully defined parameters of quality. Optimal quality measures are sensitive to change, valid, reliable across the entire spectrum of the domain being assessed, and not overly burdensome to clinicians, managers, or patients and their families.

Institutional and clinical standards of care are being developed based on consensus of experts and on evidence of need and best practices. Measures of experience and care that have been developed through research can become tools for oversight and accountability of programs and health systems and can also be used to test and refine clinical and systems interventions. In the years ahead, we can expect that education and training of clinicians and

healthcare administrators will integrate these emerging best practices in clinical care and program management. It can be anticipated that as baby boomers struggle with the demands of caregiving and themselves gradually experience illness, increasing public expectations and heightened consumer advocacy will drive policymakers to adopt enhanced standards of care.

Common Elements of Integrated Palliative Care:

Early Lessons

Although the clinical and health system strategies being explored vary significantly, some common features are being discerned among the different model projects seeking ways to improve palliative and end-of-life care for the people they serve.

Lesson 1: The Basics are Necessary. For quality improvement in palliative and end-of-life care to succeed, a well-functioning local healthcare system needs to be in place. It is simply not feasible to build models of integrated, excellent care at any point during the course of illness or phase of life within a deficient and dysfunctional health system. Palliative care can achieve excellence and be valued only if it occurs within a medical center or local healthcare system that delivers high quality curative and life-prolonging care. One basic element is reliable 24-hour availability of scheduled medications such as narcotic analgesics and anxiolytic drugs unimpeded by system policy restrictions or local outpatient pharmacy formularies.

Even in health systems that fully integrate palliative care, there will remain a need for occasional specialty consultation and for special teams to serve patients and families having difficulty with symptoms or adjusting to advancing illness and approaching death. Inpatient and outpatient palliative care consultation for difficult-to-control symptoms and psychosocial distress, and a well-functioning hospice program to follow patients and families at home or in long-term care settings must be available within the health system's operating environment. With this foundation in place, each effective model provides 2 key interventions—advance care planning and individualized care management—in a variety of ways.

Lesson 2: Admission Criteria. Programs focusing on improving care for patients with "advanced, incurable illness" require some method of determining which patients fall into this category. Hospice admission criteria in the United States have focused on prognosis, typically 6 months or less, which reflects statutory requirements of eligibility for

Medicare hospice benefits. Prognostication, however, is notoriously difficult, and the 6-month criterion for hospice admission is widely considered to be a major factor in late referrals.³⁹⁻⁴¹ Although Congress intended patients to receive months of hospice care, the current median length of stay nationally is less than 20 days. Complex, cumbersome, or stringent criteria for beginning palliative care services may exclude from service many patients and families who would benefit and whose care in the absence of such service may involve costly, yet unwanted, interventions. On the other hand, with broader eligibility criteria there is a risk that limited service capacity may be overwhelmed or that the costs of a palliative care program may become prohibitive to the institution or local health system.

In the models being developed by the Promoting Excellence in End-of-life Care demonstration projects, criteria for patient inclusion tend to be more sensitive to capturing patients who need and would benefit from palliative services. Typical criteria may include patients with (1) any cancer that is known to be incurable at diagnosis or any Stage IV carcinoma; (2) New York State Heart Association class III or IV congestive heart failure or an ejection fraction less than 30%; or (3) chronic respiratory disease who require 24-hour supplemental oxygen. Operational mechanisms for identifying patients vary and include routine screening by palliative care clinicians at oncology, pulmonary, or cardiac outpatient clinics, use of electronic medical records to sort for clinical criteria, or review of pharmacy databases to identify medication doses that correlate with advanced, incurable illness. Once screening identifies an at-risk patient pool, individual case review follows.

Lesson 3: Advance Care Planning. The process of advance care planning begins at the time that eligibility is confirmed and continues over the course of illness. Advance care planning involves the patient, often with close family members, and either the treating physician or a member of the health-care team. The purpose is to provide information about the illness, help clarify the patient's and family's values and goals, and present a full range of treatment options, from aggressive life-prolonging treatments, including any experimental protocols for which the patient may qualify, to purely palliative and supportive care. Optimally, this process is convened and facilitated by a clinician who is impartial, not overly directive, and capable of responding to the values and goals of the patient and family. Some form of advance care planning is a feature

common to many different models of care delivery. Although clinicians or clinical teams that have incorporated advance care planning in practice may view this process as just good communication, from a quality improvement and systems perspective, advance care planning is a distinct process that is carefully charted and that guides the therapeutic plan of care. The initial advance care planning sessions may culminate in completion of an advance directive such as a living will or durable power of attorney that can provide legally valid direction regarding future treatment preferences and surrogacy authority.

Subsequent advance care planning sessions may take place at planned intervals, perhaps every 6 months during times of relative stability, and also during episodes of complications or periods of significant functional decline. The purpose is to revisit goals of care, present treatment options, clarify preferences for care, and revise or update formal advance directives.

Lesson 4: Care Coordination. Care coordination is the second key intervention of palliative care that is also initiated once eligibility has been determined (**Figure**). This term refers to an array of services that were once identified as case management—a term, seldom used in this context now, that has been usurped by some health plans and insurers to connote utilization review and viewed by patients as a process for denying requests for services.

Care coordination, which may be provided by a nurse, social worker, or patient advocate, assists patients and families identify and access goods and services of value within the healthcare system and the local community environment—medical specialists who make home or nursing home visits, occupational, physical, and restorative therapists, assistive devices and durable medical equipment providers, special transportation services—and, in addition, help coordinate appointments and services. The purpose of care coordination is to facilitate the delivery and receipt of care, to minimize domination of the patient's and family's life by medical care, and to maximize the quality of their life.

An integrated approach to advance care planning can have a significant impact on hospitalization, resource use, and cost. Molloy and colleagues conducted a study of 1292 nursing home residents in 6 Ontario facilities. Advance directives that provided a range of healthcare choices for life-threatening illness, cardiac arrest, and nutrition were completed by 49% of the competent residents and 78% of the next-of-kin of incompetent residents, with a total of

527 participants. Over an 18-month period, intervention sites had fewer hospitalizations (mean of 0.27 for intervention sites versus 0.48 for nonintervention sites; $P = .001$) and an average cost reduction of \$1749 (Canadian).¹⁰

Lesson 5: Ownership of Financial Risk and Alignment of Incentives. An observation emerging from the Promoting Excellence in End-of-Life Care program is that the receptivity of local health systems to developing new models for integrating palliative care is influenced by the organization's ownership of financial risk. In situations in which the health system owns all the financial risk of healthcare for a population, innovative approaches tend to be embraced. This explains the high receptivity to comprehensive palliative care in such surprising host institutions as Veterans Administration hospitals, correctional health systems, a state department of mental health, an urban health system serving an indigent and dually diagnosed population of patients with advanced HIV disease and mental illness or addictive disorders, and a public health system serving isolated rural areas. There are no opportunities for cost shifting in these situations, and incentives support individualized, prospective planning and comprehensive team-based approaches that can maximize efficiency of services in complex cases. If valid, this observation implies that the larger the share of total financial risk owned by a managed care organization, in terms of duration and

stability of subscribers, as well as proportion of relatives (by extension, family caregivers) who are covered by the health plan, the more readily a palliative care program will be received.

Beyond Healthcare

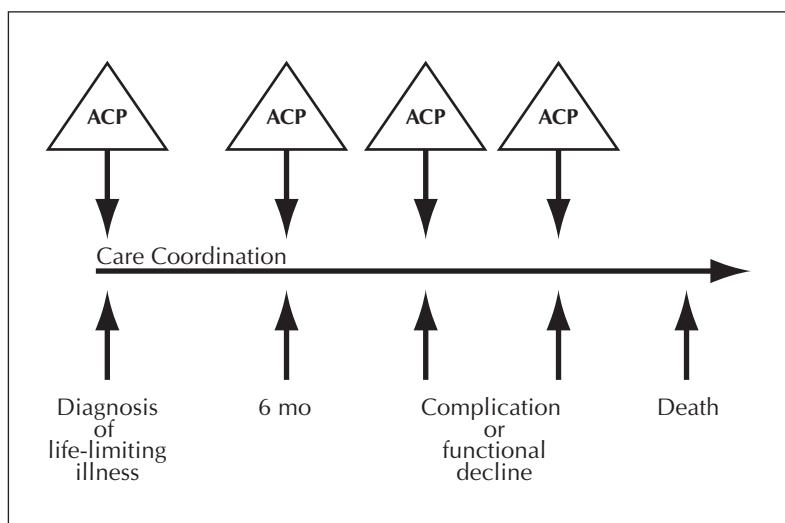
Social experimentation related to the graying of our nation with an accompanying increase in chronic illness and challenge of caregiving can be observed in other arenas of American life. New models of caring and ways for people to live together in community, helping one another live well, age well, and die in place are springing up around the country. Some involve geriatric case management practices, whereas others are faith-based senior and assisted-living communities and parish nursing or block nursing programs. Some involve the service and travel industry, such as assisted living facilities and programs of certain hotel corporations. Many others are community-based, intergenerational programs, such as service learning programs in schools, elder-to-elder volunteer programs, and communal living. These creative efforts deserve careful attention, as they may provide valuable strategies for responding to the challenges of caring over the next few decades.

Reclaiming Life's End

The public is slowly beginning to comprehend the crisis in end of life care but has yet to grasp the extent of the problem. Dying Americans remain neglected, and as a group, their pain is undertreated, their access to services is limited, and their preferences for care are often ignored. Patients are too sick and their families often too confused, frustrated, and overwhelmed to complain. The movement to legalize assisted suicide has been the only apparent avenue for bold social action. Although this issue continues to be hotly debated, there is agreement by both sides that legalizing physician-assisted suicide must not become an apology for failed healthcare and lack of basic social support.

As the baby boomer generation ages and finds itself caring for elderly relatives, consumers are increasingly demanding access to comprehensive home care, hos-

Figure. Advance Care Planning (ACP) and Care Coordination: Key Elements of Palliative Care Through the Course of Illness.



pice, and palliative care. Current clinical, health system, and social-community models being developed should be available for adoption, adaptation, and expansion when the crisis of caregiving receives full attention from American society.

The goals of incurably ill patients, their families, and the providers and payers of healthcare are well aligned to provide excellent palliative care. Joint efforts among clinicians, provider institutions, insurers, and employee health benefit managers can address the needs and preferences of customers, while reducing public suspicions about managed care. A commitment to excellence in palliative care offers managed care organizations, employers, and payers of healthcare a chance to raise standards of care without raising healthcare costs. Ultimately, it will be a marketing asset for a managed care organization to be known as a center of excellence in palliative care, and in some markets it will be a necessity. Clinicians, health systems, and payers can help restore belief in the dignity of dying and value of caregiving among the American people and make it possible to envision an American society of the future in which high-quality, comprehensive palliative care is accessible to all, families are extended support for their caregiving, and dying people are helped achieve a sense of life completion and life closure.

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