

End-of-Life Care: An Agenda for Policy Improvement

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Health care in the United States has not adequately addressed the needs of a growing population with serious, eventually fatal chronic illness. In 1982, legislation established Medicare hospice, although experience and research have since highlighted many shortcomings with that program. Hospice is well suited to the care of patients with cancer and people who need support at home for a short time at the end of life. Improving end-of-life care, however, requires changes beyond those that hospice care has accomplished. Comprehensive care needs to start earlier in the illness, and hospice-style care should be available in various settings and to patients with a greater variety of illnesses. Health care reforms must address the care needs of the growing number of citizens who live with serious chronic illness in the last years of life.

The fact that most United States citizens grow old before they become seriously ill and die is a remarkable accomplishment. In contrast with the early twentieth century, many persons and families in the twenty-first century can expect to contend with various serious chronic illnesses before death (Table 1) [3,4]. More than 75% of United States citizens now live past age 65, and 83% die while covered by Medicare [1]. The lifespan in the United States nearly doubled during

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Table 1
Top 10 causes of death, 1900 and 2000

1900	2000
1. Pneumonia	Heart Disease
2. Tuberculosis	Cancer
3. Diarrhea and enteritis	Stroke
4. Heart disease	Emphysema and chronic bronchitis
5. Liver disease	Unintentional injuries
6. Injuries	Diabetes
7. Stroke	Pneumonia and influenza
8. Cancer	Alzheimer's disease
9. Senility	Kidney failure
10. Diphtheria	Septicemia

Data from US Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Healthy people 2010: objectives for improving health, 2000. Available at: <http://www.healthypeople.gov/document/pdf/uih/uih.pdf>. Accessed July 15, 2003; and National Center for Health Statistics. Fast stats A to Z: deaths/mortality 2001. Available at: <http://www.cdc.gov/nchs/fastats/deaths.htm>. Accessed November 12, 2003.

the past century. In 2000, the average life expectancy was 80 years for women and 74 years for men, compared with an average of just 49 years in 1900 [2].

Nearly half of all United States citizens have one or more chronic conditions that require care to prevent or delay disability [5]. Currently, about 40 million people, comprising 15% of the adult United States population, have a chronic health condition that limits activities [6]. Of these, one-twelfth has severe cognitive impairments [7], almost one-third has difficulty walking [8], and one-fifth has impaired vision [9]. With advancing age, the likelihood of disability becomes much greater. After age 85, only one person in 20 reports still being fully mobile [10]. Age and disability are the strongest factors in predicting further declines in functioning, recurrent hospitalization, institutionalization, and death, even after taking into account personal characteristics, such as smoking, obesity, and several specific chronic diseases [11].

An especially important group of chronic conditions are those that regularly worsen and eventually cause death—mostly cancer, organ system failure (primarily heart, lung, liver, or kidney), dementia, and stroke. Nine of 10 elderly people who die while covered by Medicare have one or more of these conditions in the year preceding death [1]. Virtually all United States citizens will have a substantial period of serious illness and disability at some point before death. Cognitive impairment and frailty are rapidly becoming dominant elements in dying in old age, even though they are hard to track because medical records and administrative data do not directly identify these conditions. Half of those who die after the age of 85 (and one-third of the population lives that long) already have major memory loss as part of the final phase of life [12].

Many forces are converging to make good care during fatal chronic conditions a national priority. The cost of chronic illness is certainly a driving concern for government, private insurers, and individuals. Many analyses have found that payments for Medicare-covered services in any year are highly concentrated

among a few beneficiaries who have multiple chronic conditions [13]. Medicare payments average about \$28,000 in the last year of life [14,15], and expenditures vary little in relation to major cause of death and most patient demographic characteristics (other than age). The total costs of care will rise substantially in the next 2 decades, although the sustainability of these costs in the United States is uncertain.

Although large disparities in the availability of services affect health care across the lifespan [16–18], Medicare's expenditures in the last year of life average almost the same for the poor and the rich, for blacks and whites, and for women and men [19]. The equalizing effect may not be a positive finding, as hospice care, for example, is also less likely to be used by poor and minority patients [20]. Additionally, Medicare expenditures do not tell us much about the quality of care provided, and such care appears to have substantial disparities [21,22]. Though research supports patient choice and provider factors in explaining these findings [23], it also suggests that service supply and poverty may promote inequity in access to end-of-life services [24].

What matters, of course, is not costs but the quality of services and the perception of value (eg, cost-effectiveness). Especially because most end-of-life care is funded by the government, the public should be confident that health care is of high quality and that costs are reasonable. Evidence indicates, however, that overuse and underuse of Medicare services are widespread [25–27] and that areas of high use of services have worse health-related outcomes than lower-use areas [28,29]. Even the use of hospice services appears to be uneven across the nation [30]. Thus, total costs for care in the last years of life are high, but they may not be yielding reliable and high-value care.

Currently, hospice is the only Medicare program tailored to the end-of-life. Hospice enrolls only patients who have reliably poor prognoses. Hospice arose as a community-based voluntary service to the dying about 3 decades ago and became a regular Medicare benefit in 1982. Only limited rigorous research has addressed the effects of hospice care [31–34]. Hospice programs serve patients near the end of life whose families can provide most care at home. From inception, hospice has been limited to patients with a prognosis of 6 months or less. This prognostic requirement means that hospice serves mostly cancer patients [13]. For various reasons, hospice serves patients when they are near death; median length of stay in hospice was only 26 days in 2002 [35]. Hospice programs generally do not provide costly disease-modifying treatments [36], so most patients consider hospice only when they have given up on other approaches.

Because hospice has been able to serve only a limited population, and because hospitals and nursing homes have substantial problems with quality and reliability in end-of-life care [37], many hospitals and some other health care programs have developed palliative care consultation services, inpatient units, and other programs. These programs do not require that the prognosis be short, and the patient can usually continue to receive any other appropriate treatment. Palliative care programs do not require a reliably short prognosis, as hospice

does. Unlike hospice, however, palliative care programs have no dedicated or tailored payment and usually require subsidization to survive.

Qualifying for special end-of-life care on the basis of need

An alternative to the prognosis-based approach of hospice is to identify patients on the basis of severity of illness as characterized by particular physiological or functional stages of advanced illness. Considering the patient and family's current situation rather than a prognosis of death within 6 months identifies a population on the basis of care needs without regard to the length of time that those needs persist. Because most illnesses have uncertain prognoses even within a few weeks of death [38], this approach requires building flexible service arrangements that are tailored to serving patients and families living for many months with advanced disease, as well as responding effectively to rapid decline and death.

Some interventions, such as appointing a durable power of attorney for health care decisions, are relevant whenever patients are living with a fatal condition. Advanced symptom management and bereavement support eventually become relevant for almost every patient and family. Studies demonstrate that these challenges are common in serious illness even though their exact nature, timing, and relative importance vary [39–42]. Therefore, the “severity of illness” approach to defining a population includes all who are living with specified stages of advanced illnesses. Such an approach would allow flexibility and the opportunity to serve people who have persistently uncertain prognoses. As a practical approach, many clinical teams have found that it works well to identify those patients who are sick enough that death can be expected within a few months [43].

Earlier in life, a health care system that is focused on prevention and cure of illness suffices for most people and situations. However, for persons living with chronic disease who are approaching the end of life, neither prevention nor cure is ordinarily possible. Instead, in the last years of life many of us will have a period of living with worsening chronic illness. In this phase of life, health care must serve additional goals. Expert groups have endorsed important domains of end-of-life care that include these aims [44,45]. These goals are also generally consistent with recent research findings [46–50]. These core considerations include pain and symptom management; communication about diagnoses, prognoses, and alternative treatment plans; treatment decision-making consistent with patient and family preferences; support for addressing existential and spiritual concerns and completion of life tasks; continuity and coordination of services; and support for families and caregivers.

The burden faced by families deserves special comment because the United States health care system often marginalizes the role of families in care. Caregiving is often a 24-hour-a-day activity [51], and the health care system offers little to reduce the burden of that care. Caregiving is often stressful, as the

cost. The baby boom generation is not likely to accept the shortcomings of the current system. First as caregivers, and then as aging and dying people, this group is likely to rally political support for more reliable care.

Near-term opportunities for reform

Policy changes

- Modify reimbursement policy so that provider communication with patients and their families is rewarded.
- Pay better when physicians regularly provide continuity care for patients with serious chronic illness. This could be part of the current interest in “paying for performance.”
- Create opportunities for more demonstrations in the integration of Medicare and Medicaid services to encourage more coordination across the many providers of end-of-life care.
- Encourage technological innovation that supports coordination of care, such as electronic medical records and other expanded information systems.
- Make family caregiving a priority in policy making. Increase allocations through the Older American’s Act to support local caregiving activities. Make respite care, financial support, and health insurance more readily available.

Research

- Direct the Centers for Disease Control and Prevention and the National Institute on Aging to develop an epidemiology of the last part of life, then map trends and variations across jurisdictions.
- Direct research at National Institutes of Health toward relief and prevention of symptoms.
- Test the effects of alternative strategies for income support, incentive alignment, and community control in services for serious chronic illness.
- Test innovations in organizing nursing and clinical services.

Some of these changes require congressional action, leadership in federal executive agencies, or innovation by organized health care delivery systems. It will take strong incentives to make these parties address the issues. Making small changes is important, not only for improving care but for forming the political will to make more substantial and enduring changes.

One vision of optimal care: MediCaring

The current United States system of care reflects the needs that patients had in the 1950s and 1960s, when the society last reorganized care. Patients then

primarily needed acute care services, curative care, and short-term interventions. An individual can get “911” services almost anywhere in the country; and surgeries, devices, drugs, and hospitals have had ongoing investment and yield profits. However, having a nurse available in the home on a weekend or in the middle of the night to reinsert a catheter for a terminally ill person is nearly impossible. The hopes and fears of elderly ladies living in walk-up apartments and juggling half a dozen medical problems along with small incomes and rising rents are different from the issues that built the care system. For all those elderly women (and a fair number of frail old men, too), endurance and constancy count for a lot, as do concrete services in daily life and respect for the value of home, control, companionship, and meaningfulness. The health and social services designed to support an individual in their preferred setting (ie, home) are not often evident in a plan of care that includes the traditional acute health care system. These services do not attract investment—their funding is usually a welfare or safety net model with a spending cap.

Various clinical service providers around the country are working with a mental model of optimum care, sometimes called “MediCaring,” which aims for more effective organization of care services. The core idea is to identify a time near the onset of substantial disability and suffering from progressive, eventually fatal chronic illness and match the patient to a tailored service array with appropriate funding and regulation. For each of the three major trajectories discussed previously, eligibility would be set by the onset of a specific serious level of the patients’ condition. For example, for persons facing mostly heart failure problems, eligibility might be based on being unable to climb steps due to shortness of breath and having the heart move less than 30% of its volume on each stroke. The eligibility criteria should be replicable and administratively feasible, rather than “accurate.” In general, the eligibility criteria would mimic asking providers: “Would you be surprised if this patient were to die in the next few months?” Services would ensure continuity, advance care planning, family support, and other important elements.

This approach offers the opportunity to blend the interdisciplinary team, continuity, and symptom relief that underlie the effectiveness of hospice with the self-care education, timely reminders for prevention, and advance care planning of successful chronic illness management. The funding that makes sense would be by capitation or budget, probably with separate coverage of occasional costly outliers, such as heart transplants. MediCaring is the kind of major rethinking of health care delivery that offers hope of substantial reform, especially as the providers would have to organize to meet quality standards to be eligible for the increased payments. Not only are there a dozen providers trying out this set of ideas, in settings from veteran’s home care to hospice, but the Medicare Payment Advisory Commission has declared its intention to examine whether disease management programs might target beneficiaries coming to the end of life [84]; similar programs are included in the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 [85].

The following are the basic tenets of MediCaring:

- To reform payment and clinical services array nearly simultaneously.
- To tailor clinical services to care needs as sorted by trajectory, including continuity, services at the patient's home or nursing home, caregiver support, and advance care planning.
- To pay at an appropriate rate and with enough flexibility so that programs can manage a broad range of patients.
- To require nearly all provider arrangements to last through all of serious illness until death (and bereavement).
- To create a structure that can balance the merits of interventions and work within sustainable resource constraints.

This proposal differs from those that add a layer of useful treatment to the underlying care system, such as disease management, and it is different from simply paying for usual care at a discounted risk-adjusted rate. Improved payment should generally be a function of high-value care, so that only providers capable of effective and efficient care can sustain their business model. That is what MediCaring approaches try to do.

Summary

The agenda laid out here is urgent and incomplete. Urgency arises from the mandate created by avoidable current suffering and the prospect of worsening performance of the care system as the population ages. However, data are limited, many conceptual models are new and untested, and the priorities and action steps will require ongoing learning. Perhaps the most important element in reform is to develop ways to garner insight and forge consensus that can fuel the will to make changes happen. Because interpreting facts and generating consensus requires updating with new insights and emerging opportunities, the social structures that can do this work need to be enduring and ongoing. Many advocates and activists are needed to push a shared agenda.

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