

Yes - Mutual determination of the earlier declared will (living will) or the presumed will of the patient (physician/caretaker, relatives)

No – Call to order to arrange for a caretaker of the patient

Yes - Mutual determination of the earlier declared will (living will) or the presumed will of the patient (physician/caretaker, relatives)

First accomplish life-supporting measures

Consent

Consent

No – Examination by Court of Guardianship

Yes - Documentation, definition of therapy goal and indication position

Treatment according to patient's will

VI. Literature

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W H I T E P A P E R

RAND

*Living Well at the End
of Life*

*Adapting Health Care to Serious
Chronic Illness in Old Age*

Joanne Lynn, David M. Adamson

RAND Health

The research described in this report was conducted within RAND Health.

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Preface

Most older Americans now face chronic illness and disability in the final years of life. These final years can prove painful and difficult for sick and disabled elderly people, who may have difficulty finding care to meet their needs. This period is often stressful and expensive for families. As currently configured, health care and community services simply are not organized to meet the needs of the large and growing number of people facing a long period of progressive illness and disability before death.

This white paper synthesizes a growing body of research on the issue of chronic illness in the last phase of life. It describes the demographic and cost components of the problem, examines gaps in the current health care system, explores some reform measures that are addressing urgent needs, and outlines a vision for adapting the health care system to confront the new reality. This work has relied heavily upon grant support from The Archstone Foundation, the Milbank Memorial Fund, and The Washington Home and Community Hospices.

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Americans live longer, healthier lives than ever before. However, this longer life span poses a new set of challenges. Nearly all elderly Americans now encounter severe chronic illness and disability in the last phase of life. The problems they face will likely grow as the proportion of elderly increases when the aging baby-boom cohort reaches retirement. Health care and community services currently lack the capacity to provide the care chronically ill seniors need. Compounding the problem: Care for this population is becoming more expensive, and the availability of caregivers is dwindling. The good news is that it doesn't have to be this way: Older people can usually live well with serious chronic illness. America's health care system has adapted to demographic changes before and is capable of doing so again. But adapting will require seeing end-of-life care in new ways and reforming the health care system to deliver and finance the necessary services.

The New Demographic: Aging and Dying in 21st Century America

How Americans live and die has changed dramatically in the past century. In 1900, an American's life expectancy was much shorter: an average of 47 years (1). Illness and disability were more common at every age. Death, when it arrived, came abruptly. The most frequent causes of death in 1900 tended to be "acute": pneumonia, tuberculosis, diarrhea and enteritis, and injuries (2). Few people lingered for many years with worsening disabilities arising from an eventually fatal chronic illness. The time from onset of a serious disability to death was measured in days or weeks, not years. Families bore the bulk of medical expenses, and the main caregivers were family members, especially women—mothers, wives, and daughters. People generally lived their final days at home among family members.

Now, most Americans are healthier in every phase of life and live in good health into old age. In 2000, the average life expectancy for Americans was about 75 years (77 for women and 73 for men) (1). Improved public health and medical treatments have translated into far fewer deaths from acute causes such as childbirth or infections. Currently, the most common causes of death are heart disease, cancer, stroke, chronic respiratory disease, injury, and diabetes (3). Dementia and multi-factorial frailty shape the last years of life for a large part of the population. Medicare pays for most physician and hospital expenses at the end of life, not families (4). Most Americans live out the end of their lives in hospitals rather than at home, and paid professionals provide most of the visible

and costly health care.¹ Americans will usually spend two or more of their final years disabled enough to need someone else to help with routine activities of daily living because of chronic illness (5). See the table to compare changes in the last century.

A Century of Change (6)

	1900	2000
Life expectancy	47 years	75 years
Usual place of death	home	hospital
Most medical expenses	paid by family	paid by Medicare
Disability before death	usually not much	2 years, on average

These improvements in life expectancy and relative freedom from disease and injury in part pay tribute to America's health care system. Indeed, the fatal conditions of 1900 are precisely those that healthier living conditions and better health care have been most effective at averting. As a result, many more Americans survive into old age. However, as we discuss below, the health care system has been slow to adapt to the chronic illness and disability that elderly Americans are likely to face at the end of their longer lives.

Changes in the way Americans die are mirrored in health care cost patterns. The overwhelming preponderance of U.S. health care costs now arise in the final years of life. Indeed, if one were to estimate costs across a life span, the shape of the expenditures reflects the new health and demographic circumstances. Figure 1 presents a rough estimate of health care costs distributed across the average American's lifetime. The final phase of life, when living with eventually fatal chronic illnesses, has the most intense costs and treatments. A similar curve for the U.S. population in 1900 would have been flatter, both because serious illness was more common throughout life and because death often occurred suddenly. Neither clinical services delivery nor Medicare has kept pace with the changes in the pattern of needs that underlie these costs.

¹In this paper, we use the terms "medical care" and "health care" to refer to professional, usually paid services. We use the term "care" alone to refer to the supportive services that chronically ill elderly people often need, typically provided by family, friends, or other non-professionals and often given without payment.

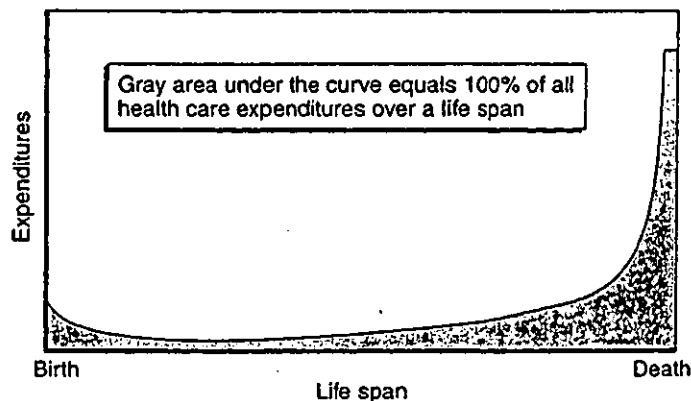


Figure 1. Americans' Current Health Care Expenditures Are Concentrated in the Final Part of the Life Span

So, although the overall health picture for Americans has improved dramatically, health problems have become clustered in the last years of life. In effect, the average American now lives a long, healthy life, with only intermittent health problems or chronic conditions that are compatible with normal life. However, increasingly fragile health and complicated care needs ordinarily mark the years just before death.

Here Come the Boomers

In the next 30 years, the number of older Americans will continue to grow at an accelerating rate. In 2000, 4.2 million Americans were 85 or older. By 2030, the baby-boom cohort of the 1950s will begin to hit age 85 and faces the prospect of substantial disability. At that time, nearly 9 million Americans will be over 85 (7).

While there has been some evidence that the prevalence of disability in old age (8, 9) and the number of years of disability in old age (5) are both declining a little, a lengthy period of disability is still in store. The rising number of people who will be facing old age by 2030 makes it likely that supporting elderly persons with serious chronic illness will be a dominant challenge for health care in the next half-century.

The looming financial consequences of this aging tide are also worrisome. In fiscal year 2000, Medicaid paid for 45 percent of the \$137 billion annual cost of "formal long-term care" (paid care that does not include volunteer services by family members) (10). The U.S. government forecasts that the cost of long-term care will reach \$379 billion, in current dollar values, by 2050 (11). Medicaid spending (on health care and supportive services for the poor) is now outpacing Medicare spending (on health care for the elderly and disabled); Medicaid

spending has become the second largest expenditure for states, behind education, and is projected to continue growing rapidly.

At the same time, caregivers for the elderly are becoming scarce. Paraprofessional workers provide more than three-quarters of care in nursing homes and more than 90 percent of care at home (12). By 2010, when the baby boomers start to retire, the pool of middle-aged women who staff most of these positions will be substantially smaller than it is now (13). Likewise, family caregiving—long the backbone of long-term care—will be heavily burdened. Smaller family sizes and changed family structures are leaving a smaller potential group of family caregivers (14). Longer durations of illness and greater numbers of women working outside the home also place greater burdens on the pool of potential caregivers. Meeting the need for caregivers may prove even more difficult than the financial strain imposed by the aging baby boomers.

Chronic Illness Among the Elderly

Most elderly people experience some chronic conditions. In planning for health care, we may usefully split these conditions into three categories: nonfatal chronic illness, serious and eventually fatal chronic illness, and frailty.

Nonfatal Chronic Illness

Common nonfatal chronic conditions include arthritis and hearing or vision problems. Most elderly people live for many years with these conditions, which gradually worsen but seldom pose a threat to life. These chronic conditions can contribute substantially to disability and health care costs.

Serious, Eventually Fatal, Chronic Conditions

An important subset of chronic conditions, however, tends to worsen and eventually cause death. The common fatal chronic conditions are cancers, organ system failures (including those affecting the heart, liver, kidney, or respiratory system), dementia, and strokes. Nine out of ten elderly who die when covered by Medicare have one or more of these conditions in their final year of life (4). While most older people eventually have to live with one of these, probably only about one-quarter of the elderly are actually ill or disabled by their eventually fatal chronic conditions at any given time. While no research yet has directly estimated this rate, the fact that 40 percent of the years past age 65 include some disability (5) provides an upper limit. Conversely, our recent work on Medicare

claims shows that most elderly decedents were already sick with their eventually fatal conditions three years before death (15). With a life expectancy of about 15 years past age 65, the lower bound of the estimate would be 20 percent. Thus, two apparently contradictory statements are true: Most elderly people are relatively healthy; however, nearly all can expect to be chronically ill for an extended period at the end of their lives.

Frailty

Frailty is the fragility of multiple body systems as their customary reserves diminish with age and disease. Frailty may already be a major path through the end of life, but the standard classifications of illness often fail to recognize it. Therefore, persons in a general state of decline are often misleadingly labeled with “heart failure” or some other specific manifestation of their more general decline. In a sense, fatal chronic conditions are those that occur when the rest of the body’s systems have substantial reserves. In contrast, frailty is a fatal chronic condition in which all of the body’s systems have little reserve and small upsets cause cascading health problems.

Shortcomings in the Current System

America is still learning how to think about and respond to these changes in living at the end of life. Shaped largely in the two decades after World War II, the U.S. health care system is designed mainly to prevent illness and to engineer dramatic rescues from injury or illness—mostly with surgery and medication. This concept works well for younger, basically healthy people. Indeed, its success has contributed to the dramatic improvements in American life expectancy.

However, the system has been slow to adapt to the new challenge of chronic illness in old age. Commonplace experience, buttressed by studies of current care arrangements for the chronically ill elderly, suggests that these patients must navigate a fragmented care system, offering them a patchwork of uncoordinated services that do not meet their needs. Indeed, the experience of an increasing number of families confirms the point that health care arrangements for persons with chronic illness often do not work smoothly, reliably, or well.

Our current health care delivery system is organized by setting: nursing home, hospital, home, and doctor’s office. This setup determines how insurance pays bills, providers meet patients, and regulations are applied. Each care provider generally works in only one setting. Patients needing chronic care change

settings often and may do so for several years; however, they have an overriding need for continuity of care, both across settings and across the changing challenges of worsening illness.

Likewise, much of how doctors and nurses think is organized around diagnosis, and this drives the course of care and treatment. However, chronically ill people coming to the end of life ordinarily have multiple diagnoses, none of which may be particularly revealing about aggregate severity of illness. Furthermore, a specific diagnosis may not shed light on their needs. For example, a person may have greater need for help in daily functioning—grocery shopping or in-home supervision—than for a particular course of medical treatment.

For elderly people, living with chronic conditions can resemble walking at the edge of a cliff. The slightest blow—such as a cold or the flu—will stress their already fragile systems and might push them over the edge. Very often, the health care system will label this final blow the cause of death, when the *cause* was more accurately the cumulative effect of illnesses or frailty. However, predicting the timing of the “big fall” is often difficult. Those with serious chronic illness may live reasonably well for many years or succumb quickly to early complications.

Reenvisioning Care for Chronic Illness in Old Age

One of the fundamental challenges that chronic illness poses for the current system is the way in which it blurs traditionally distinct concepts of health care. As we have seen, diagnosis and cause of death in the chronically ill elderly have become ambiguous because most people have overall decline and multiple conditions. The value of preventing or curing any one illness diminishes greatly when patients have multiple conditions or face the onset of new symptoms as part of a broad deterioration.

Likewise, the concept of *dying* itself has become less clear. At one time, a person was healthy, then sick, and either recovered or died quickly. Only mental illness and tuberculosis regularly violated this pattern. The recognition in the late 1960s that some patients were “dying” and thus not appropriately treated with aggressive interventions was a radical one in American health care and spawned the hospice movement in the 1970s. However, this model does not apply well to most chronically ill elderly. It presumes a sharp transition in which patients come to be “dying” by becoming “terminally ill,” and thus needing a different type of care from patients who might recover or remain stable (see Figure 2). Many chronically ill elderly people have ambiguous medical prognoses: They may be sick enough to die but could also live for many years. A more useful way

to think about this “near death” condition is to focus on fragility rather than time to death. From this point of view, people living with serious illness at the end of life can be identified not from certainty of timing of death, but from “living on thin ice”—suffering long periods of illness or disability, diminished functioning, and potential exacerbation of symptoms, any of which could prove fatal. They could keep “living on thin ice” for some years, or die in a week.

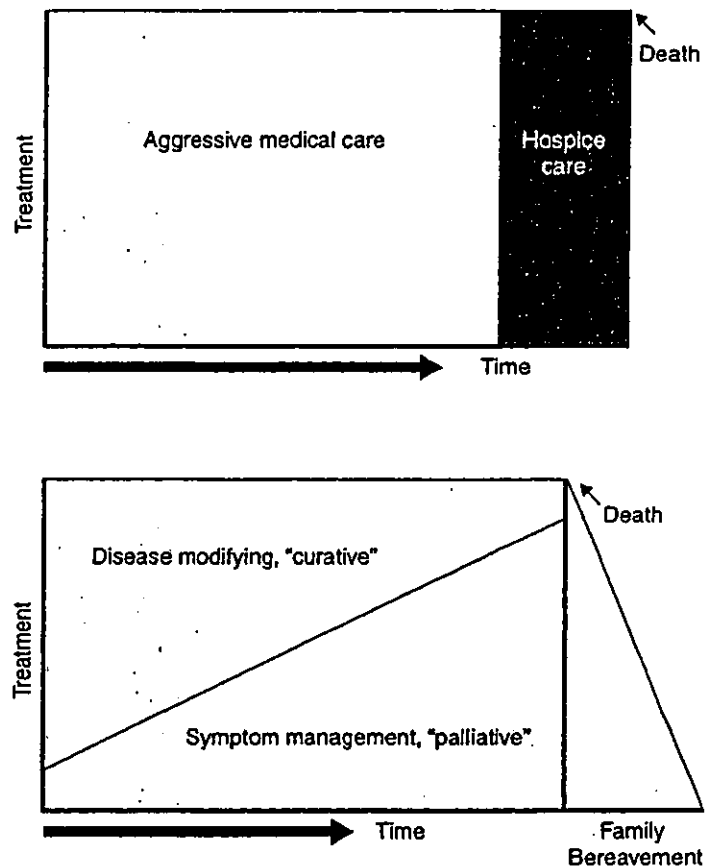


Figure 2. The Older “Transition” Model of Care Versus a “Trajectory” Model

Policymakers and the general public also lack terms to capture the types of care that individuals facing eventually chronic illness may need most. Many in the health care arena talk of end-of-life care as *palliative* or comfort-oriented care, but there is still no widely accepted definition of the term. The language typically associated with palliative care often assumes that it means a turning away from conventional care. However, chronically ill elderly patients routinely blur this distinction by needing a mix of both kinds of care. Early in the course of their illness, many need both curative treatment as well as “palliative” care aimed at treating symptoms; and late in life, some treatments may still stall the

progression of illness, even while most needs are for relieving symptoms and providing support.

Trajectories of Chronic Illness: Service Needs Across Time

One useful way of envisioning care for elderly people who are sick enough to die follows from classifying them into three groups, using the trajectory of decline over time that is characteristic of each major type of disease or disability (16). Each trajectory corresponds to a different rhythm and set of priorities in care. (See Figure 3.)

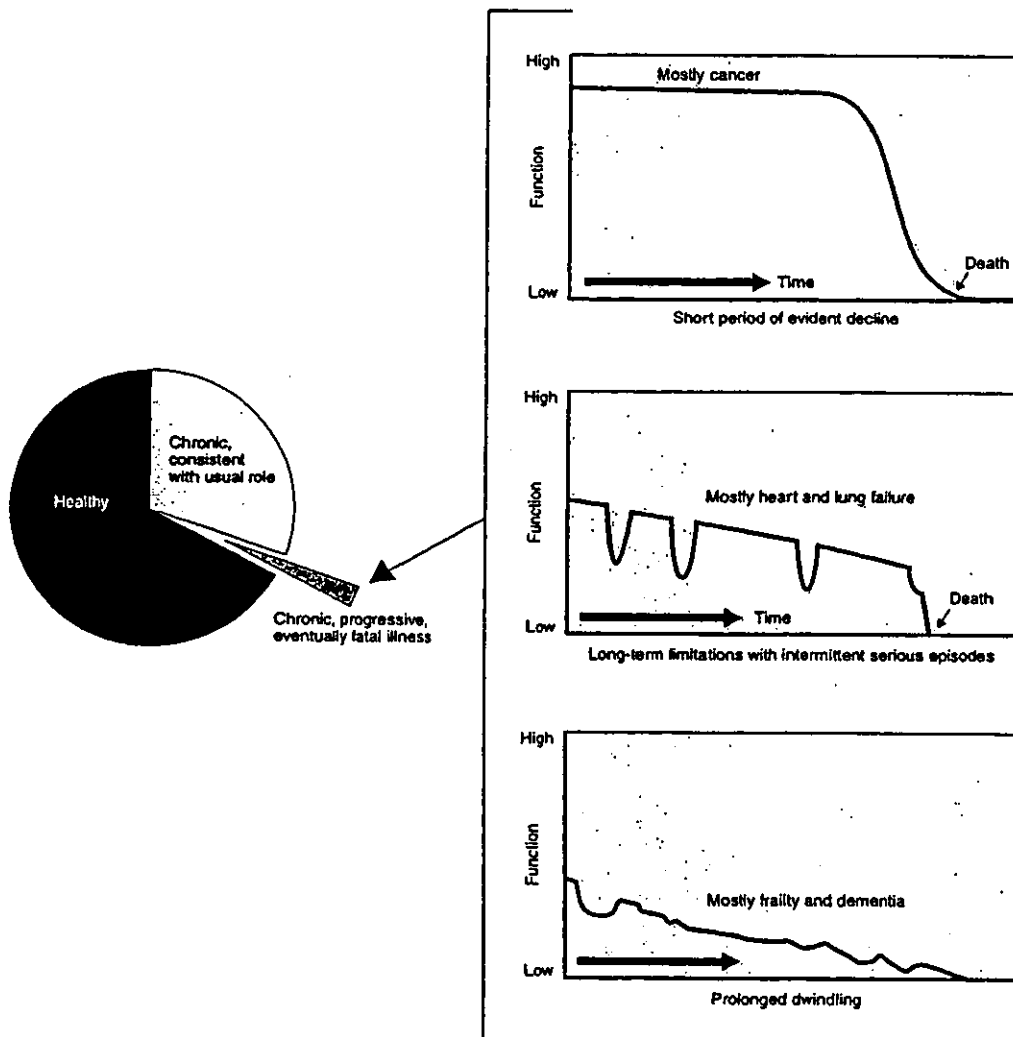


Figure 3. Chronic Illness in the Elderly Typically Follows Three Trajectories

- **Short period of evident decline—typical of cancer.** Most patients with malignancies maintain comfort and functioning for a substantial period. However, once the illness becomes overwhelming, the patient's status usually declines quite rapidly in the final weeks and days preceding death (17). Hospice is an important part of the care for this trajectory.
- **Long-term limitations with intermittent exacerbations and sudden dying—typical of organ system failure.** Patients in this category often live for a relatively long time and may have only minor limitations in everyday life. From time to time, some physiological stress overwhelms the body's reserves and leads to a worsening of serious symptoms. Patients survive a few such episodes but then die from a complication or exacerbation, often rather suddenly. Ongoing disease management, advance-care planning, and mobilizing services to the home are key to optimal care (18).
- **Prolonged dwindling—typical of dementia, disabling stroke, and frailty.** Those who escape cancer and organ system failure are likely to die at older ages of either neurological failure (such as Alzheimer's or other dementia) or generalized frailty of multiple body systems. Supportive services at home, like Meals on Wheels and home health aides, then institutional long-term care facilities are central to good care for this trajectory.

Analyses of Medicare claims show that about one-fifth of those who die have a course consistent with the first group (mostly cancer patients); another fifth share the course of the second group (mostly organ system failure patients); and two-fifths follow the third course (frailty/dementia). The last one-fifth of decedents are split between those who die suddenly and others we have not yet learned to classify (16).

Tailoring Services to Needs

The key point for care across all of these groups, however, is that diagnosis, while it may drive medical care needs, does not necessarily generate all service needs. Needs arise as disabilities and symptoms emerge. The service array should address these emerging practical needs as well as diagnosis.

Tailoring services to match the needs of the last phase of life requires defining that phase in the most relevant ways. Because the phenomenon of a long, healthy life, followed by chronic illness and disability in the last phase, is new in human history, we are just beginning to understand its dynamics. The following are the key points:

- It is possible to live comfortably, even with serious chronic illness. But living with such illness requires planning for the ongoing course so that services match the course of the illness.
- Serious chronic illnesses require continuity and comprehensiveness of care. Care needs generated by symptoms or disabilities are urgent priorities. Flexibility is also important—adjusting care to family and patient resources, to varying needs, and to patient and family preferences.
- The timing of death remains unpredictable until late in the course of serious chronic illness. Therefore, special arrangements for care near the end of life must be triggered by severity of symptoms, rather than waiting for a reliable prediction that death is near.
- The major causes of death are all progressive, degenerative illnesses that leave people in fragile health for a long period of time before death. Programs and policies to improve care for chronic conditions need to accommodate the fact that death is the eventual outcome.
- Designing reliable care systems might best build upon the time course and nature of the service needs of a small number of populations, differentiated by trajectory of disability and symptoms over time, rather than conventional differentiation by care setting (e.g., hospital or home) or diagnosis.

Small-Scale Innovation and Reform

Building on emerging insights into the special needs of chronically ill elderly patients, some health care innovators have launched successful pioneering programs. However, most of these programs are funded and operated on a small scale with limited funds. Notable examples include the following.

Integrating Care: Strengthening Links Across Settings and Types of Care

Several programs have developed ways of improving connections among home health care, disease management, and hospice and palliative care. At Kaiser-Bellflower in Southern California, the hospice and palliative care teams worked with staff members from disease management programs to improve end-of-life care (19). Teaching hospitals have also begun to develop palliative care consultation teams, both to teach health care professionals about end-of-life issues and to improve care delivery.

The Program of All-Inclusive Care of the Elderly (PACE)

The PACE program offers a comprehensive set of services to persons eligible for nursing home care: housing, personal, and health-care services. PACE patients are almost all seriously ill with eventually fatal conditions, mostly in the frailty trajectory. PACE care is not seen as “end-of-life” service; however, most PACE patients are not discharged and thus die while covered by the program. PACE provides a comprehensive range of services whenever needed, including adult day care, nursing, meals, social work, primary medical care by a PACE physician, medical specialists, dentists, podiatry, optometrists, eyeglasses, prescriptions, and hospital and nursing home care. PACE serves less than 7,000 patients at 24 sites, and another 1,100 at nine pre-PACE sites. Formal evaluation of PACE is ongoing, but early reports show good rates of satisfaction and uncertain effects on costs of care (20).

Quality Improvement

A growing number of provider programs have been recognized for success in improving end-of-life care. An important outcome of these programs has been the gradual circulation of new approaches to pain management, advance-care planning, palliative-care consultation, and family support. Continuous quality improvement has shown that energetic and well-informed efforts, starting small in scale, can make a difference (21).

Diversionsary Reforms

In such a new and complex area—where the need for rapid improvements is becoming apparent—it is worthwhile to distinguish reforms that deserve strong support from those that are counterproductive or simply irrelevant. With regard to eventually fatal chronic illness, a number of proposals have attracted great interest. Dozens of states have considered legalizing physician-assisted suicide. Nearly every provider group has an agenda for increasing revenues. Some feel that conventional education for physicians and nurses would make all the difference. The only “modernization” of Medicare in the 2000–2002 congressional session was a failed effort to cover all prescription drugs. Some advocates spend a substantial effort in making “palliative care” into a specialty parallel to cardiology or vascular surgery.

Reformers should be concerned that these are low-leverage changes. Accomplishing all of them would not greatly improve end-of-life care. Few want,

and given good care fewer would want, suicide. Better payment for current providers alters neither the incentives nor the dysfunctions. Teaching practitioners about good care may be essential, but it does not actually implement good care.

Addressing the Challenge of Sustainable Health Care Reform

Clearly, the health care system faces major challenges. These are opportunities as well—to design a response to an emerging challenge before it leads to more harmful dysfunctions.

Address the Shortage of Caregivers

To begin, the system must address the looming imbalance between the number of chronically ill elderly and available caregivers. If very sick elderly people cannot receive competent and caring day-to-day assistance, other health care reforms are unlikely to have much impact. Caregivers for this population, whether paid attendants or family “volunteers,” generally face poor working conditions, low wages, isolation, and few opportunities for advancement or professional development (22). Little wonder then that this important occupation is not attracting a large pool of candidates.

Specific reforms to improve the availability and working conditions of caregivers may include the following:

- Offer health, disability, and retirement benefits for caregivers.
- Increase wages for professional caregivers and offer a career ladder for experience and skills.
- Pay family caregivers, at least those with low incomes.
- Encourage family caregiving through graduated tax credits.
- Make adequate training available and provide at-home support.
- Tie family caregivers together via newsletters, online conversations, political agendas, and organizations.

Reform Federal Finance Policy

Federal dollars pay for most health care costs in the final years of life.

Unfortunately, current federal payments are not designed to promote continuity

of care over the long term. Federal payments also do not cover supportive home health care, prescription medication, symptom control, family and caregiver support, or even professional services meant to reduce the rate of decline in patient function. Medicaid does cover nursing home care for those who are utterly impoverished and quite disabled.

Medicare is the main financing mechanism for medical services in the last phase of life. Medicare covers 83 percent of all who die in the United States (4). Under the usual fee-for-service program, doctors, hospitals, and other service providers are paid for each billed service, although hospitalization services are mostly packaged and paid with one fee for the entire hospitalization. This arrangement encourages billable services, but not continuity of care. No coverage is ordinarily available for caregiver training, classroom education of patients, on-call advice, bereavement support, or spiritual counseling, so they are ordinarily unavailable as well. Medicare managed care has generally not paid enough to cover the high costs of the seriously ill; thus most managed care programs cannot capitalize on their potential to provide good care. Attracting members who are already very sick would be financially disastrous.

What are some incentives that could help align Medicare coverage more closely with needed care?

- Medicare payment could require specific performance criteria for key elements of care such as continuity, symptom relief, and advance-care planning.
- Payment for Medicare's managed care benefit could be higher for those who are more seriously ill, in addition to the current adjustments for age, gender, region, and diagnosis.
- Hospitals could be paid much less for second admissions for the same serious chronic condition in a patient who had no advance-care planning during the first hospitalization.

Consider the Cost-Effectiveness of Treatment

The escalating cost of treating illness at the end of life raises a thorny issue that few Americans have been willing to confront: The value of giving expensive new treatments to people whose life expectancy is drastically limited, even with the treatment. Some other countries have begun to base coverage decisions, in part, on how many years of life a treatment is expected to produce (23). However, even raising the subject of conditioning access to life-extending treatment on anything (costs, effects on life span, or effects upon quality of life) in the United

States may provoke controversy. An easier course is to cut back on other services that are hard to track or whose benefit is not so apparent. The challenge is to establish a method by which the federal budget for care of those with fatal chronic illnesses can match the dominant problems and concerns of the chronically ill elderly and families, even if this framework means that very costly treatments are sometimes not readily available to some chronically ill elderly who might benefit.

The following are some possible approaches to making this happen:

- Tailor services to evidence about what the covered population values.
- Consider competing co-morbidities and shortened life expectancy in decisions about treatment of individuals.
- Require consideration of competing co-morbidities, life span, and quality of life with treatment in guidelines for Medicare coverage and professional usage of treatments that will be heavily used for persons with serious chronic illness.
- Authorize Medicare and Medicaid to develop methods for weighing merits among beneficial treatments and services.

Reevaluate Life Possibilities for Dementia

As many as half of those over age 85 have a cognitive deficit before they die (24). With substantial dementia, the patient cannot serve his or her usual role of being the arbiter of decisionmaking. For adults, we are generally willing to allow each person to make his or her own choices about what is important and how to make trade-offs among alternatives throughout life. However, such choices become impossible for those who cannot remember their own past, apply their own values, and envision possible alternatives for the future. For this group, society needs to develop a shared understanding of how to proceed in evaluating the merits of prolonging life with serious and progressive dementia and what latitude of choices can be built into advance planning.

Possible approaches to this issue include

- reworking our language toward accurate descriptions of trade-offs among fatal illnesses and frailty as dominant causes of death
- building a public discourse about the nature and value of lives with severe dementia
- testing strategies to limit use of high-cost but somewhat effective treatments

- shaping financing and regulation to allow trials of warranted reforms.

Plan Strategically

Efficient reform depends on designing and pursuing high-leverage strategies and avoiding low-leverage ones. Crystal balls are notoriously foggy for such prognostications. Nevertheless, reformers in this arena could undoubtedly do better with regard to strategic planning.

Some possibilities that might improve on the current uncoordinated efforts include

- convening stakeholders and others experienced in reform efforts to consider options and identify a short list of priority agendas for all to endorse
- conducting regional and statewide trials of major innovations
- simulating the effects of innovations in model systems.

Building a Care System That Works

A reliable care system that helps the chronically ill elderly live well at the end of life would make seven promises: correct medical treatment, reliable symptom relief, no gaps in care, no surprises in the course of care, customized care, consideration for family situation, and help as needed to make the best of every day. (See Figure 4.) One approach to engineering a reliable care system uses the three trajectories described earlier. Each can provide an organizing framework for care and simplify the task of tailoring services so that people with fatal chronic illnesses can count on good care.

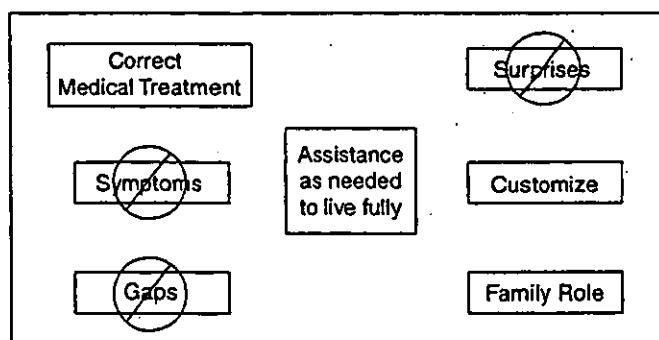


Figure 4. A Reliable Care System Would Honor Several Promises to the Chronically Ill Elderly