



Redefining and Reforming Health Care for the Last Years of Life

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During the last century, the average life span of Americans nearly doubled, from just 49 years in 1900 to nearly 80 years in 2000. Americans today can expect longer and healthier lives, but most of them will spend their last few years living with disabilities or chronic illnesses.

These changes are straining the U.S. health care system, which did not develop in the context of needing to serve large numbers of chronically ill and disabled elderly individuals. RAND researcher Joanne Lynn looked at the health care available to Americans in the final years of life, the demographic trends that will increase the need for end-of-life care, and the methods available to address effectively the growing need for health care at the end of life. Lynn concludes that appropriate reforms will require several changes.

- The end of life must be understood as a period that typically spans years, not just weeks or months.
- End-of-life care should be organized according to the kinds of services that groups of people need, rather than by disease diagnosis or where the patients receive care.
- Palliative care and conventional medical treatment should be thoroughly integrated rather than viewed as separate entities.

Key findings:

- Increased life expectancy and advances in U.S. health care mean that Americans now live longer, but with increased chronic illness at the end of life.
- These changes will likely increase the need for end-of-life care and strain the existing health care system.
- To respond to the changing demands, the U.S. health care system will need to change the way it provides health care to older Americans in their last years of life.
- The needed reforms will require deliberate efforts from policymakers, health care providers, insurers, consumers, and family caregivers.

- Policymakers, health care providers, insurers, consumers, and family caregivers must work toward deliberate reforms, rather than simply assuming that better care will emerge to meet the growing needs.

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Corporate Headquarters
1776 Main Street
P.O. Box 2138
Santa Monica, California
90407-2138
TEL 310.393.0411
FAX 310.393.4818

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This Highlight summarizes RAND Health research reported in the following publications:

Lynn J. *Sick to Death and Not Going to Take It Anymore! Reforming Health Care for the Last Years of Life*, Berkeley, Calif.: University of California Press, 2004.

Lynn J, Adamson DM. *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*, Santa Monica, Calif.: RAND Corporation, WP-137, 2003.

Agging Boomers Will Increase the Demand for End-of-Life Care

The baby-boomer generation will be old enough to begin having high rates of late-life disabilities and progressive chronic illness between 2020 and 2030. In 2030, 22 percent of Americans (80 million) will be over 65, and 2.5 percent (9 million) will be over 85. This far exceeds the numbers for the 1960s, when only 9 percent (17 million) of the population was 65 or older, and only 0.5 percent (1 million) was older than 85. The effects of these changing demographics will be substantial. The Congressional Budget Office forecasts that the cost of long-term care will reach \$207 billion in 2020 and \$346 billion in 2040. Furthermore, the health care system will require many more caregivers to provide hands-on attention for the millions who will need it.

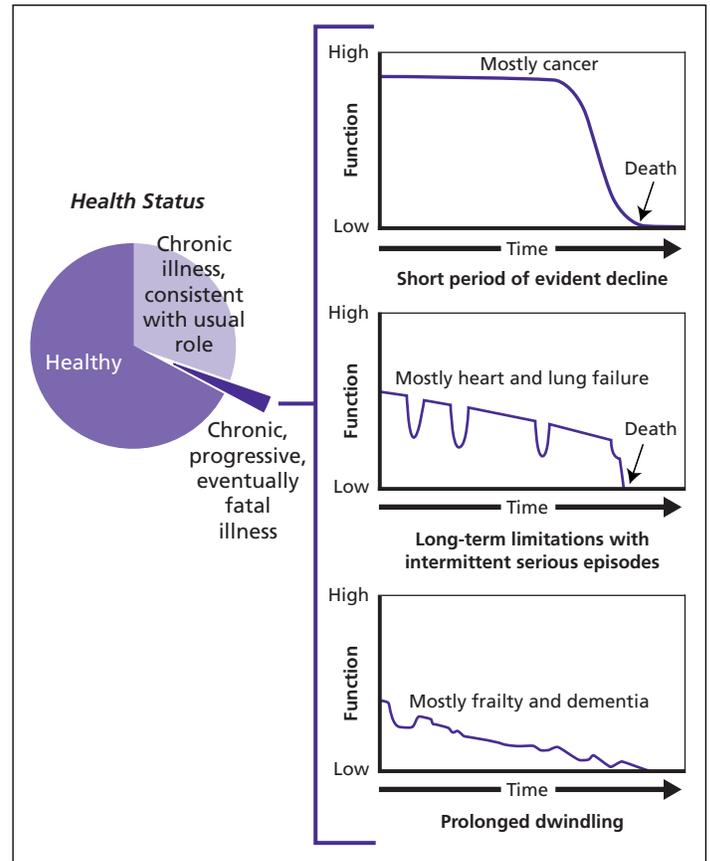
Effective, Efficient End-of-Life Care Should Be Organized by Need

The existing health care system generally classifies patients by disease and setting of care, but this method is becoming less effective because it works poorly for the increasing number of elderly individuals who have multiple diseases and need care in more than one setting. Lynn provides a framework, shown in Figure 1, that groups the entire population according to their health status, which predicts the types of services they are likely to need.

- Healthy people and people with acute, time-limited conditions.
- People with stable or early chronic illness that is consistent with their usual social role and long life.
- People with chronic, progressive, eventually fatal illness.

Healthy people and those with stable chronic illnesses need mostly preventive and acute-care services, such as routine visits to health care providers for prevention and health maintenance and emergency medical services. However, individuals with serious chronic illnesses have more complicated needs. Patients in this category typically follow one of three patterns over time, as shown in Figure 1. The graph at the top shows the pattern typical for cancer patients, who often live with comfort and normal daily functioning for a substantial period. However, once the illness becomes advanced, the patient's health usually declines rapidly in the final weeks and days preceding death. The second graph shows the trajectory typical of organ system failure. Patients in this category often live for a relatively long time with only minor limitations in everyday life. They are likely to suffer intermittent serious health problems with emergency hospitalizations and to die suddenly from a related complication. The third graph depicts the prolonged dwindling of health

Figure 1
Chronic, Progressive, Eventually Fatal Illness in the Elderly Typically Follows Three Trajectories



that is typical of dementia, disabling stroke, and frailty. These individuals escaped cancer and organ system failure and are likely to die at older ages of neurological failure or frailty caused by multiple factors. The current health care system is poorly prepared to provide appropriate care for the growing numbers of older Americans in this third group, whose period of “dying” may be ambiguously drawn out over years, unlike patients in the first group, for whom the timing of death is sooner and more predictable, and the second group, for whom dying is ordinarily more sudden.

Palliative and Conventional Medical Care Must Occur in Tandem

To address older Americans’ shifting array of health care needs, the health care system needs to change. The existing system generally operates on the assumption that living and dying are discernibly different and that medical practitioners must either (1) apply aggressive conventional medical care to try to extend or save the person’s life or (2) accept death and provide only palliative care.

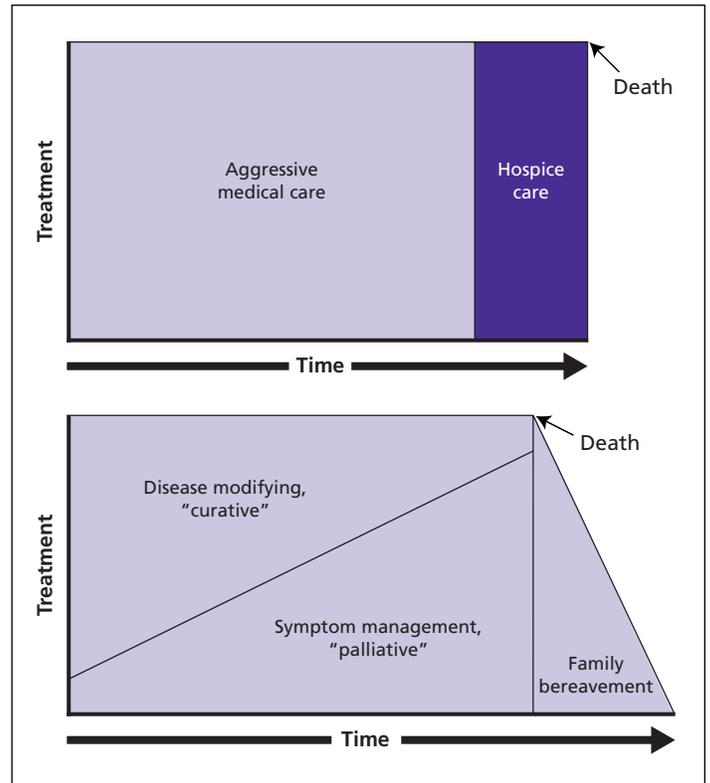
Today, however, health care professionals know that many of the chronically ill elderly have ambiguous medical prog-

noses: They may be sick enough to die from a small complication on any day or they may, instead, live for many years. Therefore, the symptom management and support services of palliative care are no longer restricted to a relatively short and easily recognizable end-of-life period—and it is no longer appropriate to associate the beginning of palliative care with the cessation of conventional medical care. Instead, frail or chronically ill elderly patients nearing the end of life typically require a mix of various kinds of care. The proportion of palliative care services needed gradually increases over time, as the second panel in Figure 2 illustrates.

How to Make Reform a Reality

Changing the U.S. health care system into one that can ably handle older Americans' growing numbers and needs will require deliberate efforts from policymakers, health care insurers, health care providers, consumers, and family caregivers. First, better data about the changing epidemiology of eventually fatal chronic illness are urgently needed to enable policymakers and public health leaders to make prudent decisions about health care programs and budgets. More information about patient comfort and costs in given regions would enable public health leaders to monitor the quality of care and work to improve it. Second, health care insurers, such as Medicare and the Veterans Health Administration, should structure payment systems to ensure that patients living with serious, eventually fatal chronic illness routinely receive comprehensive, coordinated care. In fact, these agencies could design payment systems that discourage the kind of episodic treatment that made sense 40 years ago but no longer works best today. Instead, an elderly person with a serious chronic illness should have a health care team that stays with the patient through the rest of his or her life. That team would provide symptom management treatment, planning for potential complications, self-care education to the patient, support services to the family caregivers, and rapid

Figure 2
The Conventional Model of Care Versus an Improved Model



response to the home when needed. Third, health care organizations and practitioners should measure their service outcomes and use quality improvement to increase the reliability of care. Finally, family caregivers will need to mobilize to place pressure on policymakers to enact successful reforms and on health care providers to make changes. These focused actions could shape the U.S. health care system into one that helps Americans live out their final years comfortably, with a care system that is reliable, cost-effective, and sustainable. ■

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