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Living Long in Fragile Health: *The New Demographics Shape End of Life Care*

by JOANNE LYNN

Not long ago, people generally “got sick and died”—all in one sentence and all in a few days or weeks. The end of life had religious, cultural, and contractual significance, while paid health care services played only a small part. Now, most Americans will grow old and accumulate diseases for a long time before dying. Our health care system will cleverly supplement the body’s shortcomings, making it possible to live for years “in the valley of the shadow of death,” fearing not only death but also all sorts of evil from the regular dysfunctions of our health care and social systems. In a sense, the great success of modern medicine has been to transform acute causes of death into chronic illnesses. Mostly, we do not spend much time or money on cures—these are quick and cheap when they are available at all. Instead, health care now involves substituting better chronic conditions and helping people to live with implacable illnesses, a few of which are stable and many of which are progressive but not life-threatening. However, each of us eventually lives with a set of conditions that are, taken together, progressively worsening and eventually fatal.

This is a very different way of coming to the end of life from that of “the old days,” when people died in childbirth, of occupational hazards, of periodic epidemics, and with the first heart attack. In 1897, Sir William Osler’s *The Principles and Practice of Medicine* noted that the usual adult hospitalized with diabetes would die within a month. Things have changed so much that today we don’t really have the language, the categories, and the stories to help us make sense of our

situation. One hears people say, “He’s not dying yet,” of a person living with fatal lung cancer. Generally, that means he’s not yet taking to bed, losing weight, and suffering from pain, as would be expected when dying is all that he can do. But the category is used as if one is either “temporarily immortal”—which is the usual state of human beings—or “dying,” in which case the person is of a different sort, having different obligations and relationships. “The Dying” are expected to do little but wrap life up and go. But this dominant myth about dying does not fit many people. Many elderly people are inching toward oblivion with small losses every few weeks or months.

If our language does not accommodate the new reality, it is not surprising that our shared social life has not yet taken up the challenge. No characters on evening television are cracking jokes while dealing with Grandma’s wandering and incontinence. No movies show the accommodations needed to live with advanced emphysema. As a patient once told me, “No one in the Bible died like this.” People find little guidance when they look to our ancient texts for comfort and advice on how to live while walking a tightrope of serious illness and frailty, propped up by modern medicine.

That lack of social understanding also shows in the conceptual apparatus we have used in trying to bring reform to what happens in the last part of our lives. Remarkably, we have used the language of decision-making and law more often than that of spiritual journey and psychological meaning. In the 1970s, the issues were framed as “the right to die” or “the right to choose.” The work of the President’s Commission on Ethical Problems in Medicine and Biomedical and Behavioral Research marks a transition to the language of “foregoing life-sus-

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taining treatment.” At that time, widespread reaction to the suffering inflicted on patients by cancer treatments and to mainstream medicine’s inattention to physical pain led to the only widely adopted change in health care delivery in the last half of the twentieth century—hospice programs. Half of Americans use hospice at least briefly before dying. However, most of the time spent living with serious illnesses that will end in death is spent not in hospice care, but in the indistinct zone of “chronic illness” that has no specific care delivery system. Most of us aspire to “healthy aging,” but we should also ensure that we can “live well while very sick and dying.”

In this short essay, I will lay out the framework for a promising approach to reform. First, reformers must understand some core facts about illness, aging, and disability, and the dysfunctions of the categories and language that we have inherited. Second, we should tailor service delivery arrangements to serve the three common trajectories of service needs that people tend to follow in their last phase of life. Third, we should strategize to build the political base to insist upon rapid practical change, starting with family caregivers.

Factors in the End of Life

In the recent past, a number of events have shaped the last part of life. Oregon debated and eventually accepted a process that allows physicians to assist in some deliberate suicides. Most hospitals, including all of the Veterans Health System facilities, are beginning to offer palliative care programs. New drugs and devices often add a little to the time spent living with fatal conditions but also greatly increase costs. Families still provide most of the supportive care without financial compensation, but the effects on family caregivers are becoming more obvious as their numbers, ages, and emotional and financial burdens increase.

One element that has influenced the course of reforms in care for the last part of life has been some data-driven insights from the SUPPORT project. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments, or SUPPORT, enrolled more than 10,000 seriously ill patients in five hospitals from 1989 to 1994. The project initially aimed to understand and improve decision-making for these patients through better information about outcomes and better support for those making decisions. Since SUPPORT enrolled people who had one of nine serious illnesses, or were old and had a nonelective admission, a great many patients died during data collection. While the population is not representative and the data arose fifteen years ago, the SUPPORT project illuminated a number of facts that otherwise had been overlooked or had never before been substantiated. For example:

1. Many patients suffer substantially in the time before dying.
2. The patients, their families, and their professional caregivers did not see adverse symptoms or aggressive treatment as serious shortcomings of care.
3. Statistical models could accurately predict the likelihood of survival for two or for six months, both for individual patients and for groups of patients.
4. Knowing reliable predictions concerning survival did not affect patients, family members, physicians, or nurses: they continued to follow usual treatment patterns.
5. Prognoses remain ambiguous even very close to death. For example, the median person dying of heart failure today had a 50-50 chance yesterday to live another six months. Good care for the dying requires taking care of many who will live for a long time with their serious illnesses.
6. Counseling about the possible alternatives for care and encouraging decision-making that implemented patient preferences among available options had no effect upon patterns of care.
7. The course of care is much more strongly associated with the service supply and habit patterns of the local care system than with the particular preferences or prognoses of the individual patient.

Several other facts also shape the possibilities for reforms. First, despite our cultural (and perhaps our universally human) distaste for the fact of finitude, American society is gradually learning to expect disability in old age and to accept that serious illness and death are inevitable. Thirty years ago, hospital staff attempted resuscitation on nearly every person whose heart stopped. Now, only a small minority of patients, mostly those with some real chance to benefit, undergoes resuscitation. In a similar vein, the U.S. Preventive Services Task Force has started including some “upper limits” on the ages at which screening tests make sense.

Second, the costs and burdens of care are highly concentrated in the last years of life, especially when one accounts for long-term disability. One recent study found that, for those alive at age eighty-five, one-third of lifetime health costs are still ahead.

Third, knowledge about the body has been organized by disease and organ system, and claims about quality or costs of care have been organized by program and setting (nursing home or intensive care unit, for example). Those who are very sick over a substantial time before death,

Society could build care arrangements around the major patterns of decline and dying. For any population, one could estimate the care needs and arrange to have them available at the right time. This approach conceives of the challenge of end of life care as a problem of system design.

who routinely have more than one illness, and who need many care settings challenge the care system design. Instead of noticing only virtuoso medical interventions, society is beginning to value continuity and comprehensiveness, or even just reliability. Nevertheless, initial contemplation leaves one overwhelmed by the infinitely varying arrays of physiological dysfunctions, personal preferences, family situations, and other aspects of a person's circumstances as they become ill "through to death." Some have contended that the proper course requires the care system (and the family and community) to discern and create the strategies needed to support each patient's individual situation. At the least, this view contends that patients should get to choose from among available options and craft their own end of life. While this approach has substantial appeal, it entails remarkable inefficiency and quickly reaches its limits when the services that would best serve a particular patient could be available only if they served a substantial number of patients in an area.

Trajectories of Decline

This conundrum leads to the very creative interface of seeking opportunities for "mass customization," which is how most successful product or service suppliers match their goods to the needs of important subsets of their potential markets. The reform agenda has focused on crafting patient-centered care around each individual patient or, in contrast, on altering major elements of the entire care system, such as payment policy or standards for care settings. Mass customization instead aims to define manageable populations with similar needs and then engineers services that match the size of that population and its predictable needs. This endeavor has found its anchor in the observation that most people follow some fairly stereotyped courses in those last months and years. The most common three trajectories of care needs over time are these:

1. Long maintenance of good function despite known fatal illness, with a few weeks or months of rapid decline as the illness becomes overwhelming and leads to death. While many diagnoses can lead to this course, the major

cancers are the typical cause. Probably about 20 percent of Americans follow this course.

2. Slow decline in physical capacities punctuated by serious exacerbations, with death often coming rather suddenly. If patients survive an episode, they may well return home without much worsening of their everyday limitations; but at some point, rescue attempts fail. Although many diagnoses can lead to this course, chronic heart failure and emphysema are the most common; about 25 percent of Americans follow this course.

3. Long-term dwindling of function, needing years of personal care. Although half of this population has serious cognitive failure as part of the disease course, half maintain cognitive function, at least when not stressed by illness. Dying often follows a physiological challenge that would have been a minor annoyance earlier in life—influenza, urinary infection, pneumonia, or a broken bone. Approximately 40 percent of Americans follow this course.

These three trajectories are roughly sequential in the ages afflicted, with fatal cancers peaking around age sixty-five, fatal chronic organ system failures roughly a decade later, and frailty and dementia afflicting mostly those who live past their mid-eighties. As science and public health more reliably prevent or delay onset of cancer, emphysema, and heart disease, the proportion of the population facing the third course will increase.

One can see how a society could build care arrangements around these three patterns, following the mass customization approach. Those facing the first trajectory need excellent medical care during the long period of good function, meshed with supportive hospice care for family and patient during the period of rapid decline. Those living with the second trajectory benefit from disease management to reduce the likelihood of exacerbations and to sustain all possible function, along with rapid intervention at the first sign of exacerbation (often in the home rather than the hospital) and good advance care planning directing the eventually overwhelming exacerbation. Those living with the third trajectory need supportive care over many years, including assistance with the ac-

tivities of daily living, housing, and comfort. The core need is to support family caregivers, although they also need reliably paid aides and institutional care. For any population, one could estimate the care needs and arrange to have them available at the right time. Patients, families, and providers would still make small adjustments to fit their capabilities and preferences, but the core arrangements for care would already be in place, rather than being patched together for the first time around each patient.

This conception of the challenge of care for the end of life as a problem of system design reflects a very different concept from “refusing life-sustaining treatment.” Indeed, it is really quite different from imagining that the core problem is decision-making by patient and physician. Those remain important, but this approach does not assume that good care could arise from prudent choices by individual doctors and patients. Rather, it starts from the claim that the care system should be designed to serve the vast majority of patients “on autopilot.” That is, if no one makes any particularly strong choices, still just about the right things will happen for patients because they are “built into the system” and are part of the expected pattern.

This is what happens now in obstetrics. Just a few decades ago, women had to advocate personally for the services each wanted; now nearly everyone is well-served by a care system that supports prepared labor, bonding with the baby, breastfeeding, and other desirable goals. One way to think about the reforms needed in end of life care is to aim for a care system in which almost every patient would get very close to what serves him or her and the family well, without having to advocate for himself or herself.

The Shape of a Reform Agenda

One implication of the SUPPORT findings concerning prognostication and the model involving trajectories is that we cannot build workable care systems that serve only those who will die quickly. Rather than the Medicare hospice program’s approach of conditioning tailored care to the near certainty of death within six months (and thus the median survival of just a few weeks), effective restructuring of care will need to serve populations that include people who end up dying after some years, as well as those who die soon. No strategy is available, for example, that would serve most who die of heart failure without including many who live with those services for years. With most conditions, including heart failure, the timing of death is just too unpredictable to enable good services to be conditioned upon reliable short-term predictions of death.

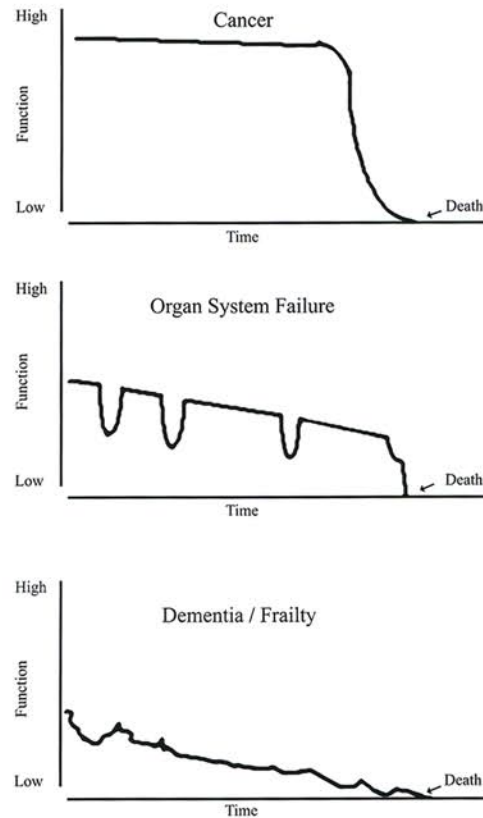


Figure 1.
Three General Trajectories of Function and Well-Being over Time in Eventually Fatal Chronic Illnesses

Palliative care teams trying to achieve quality improvement often find the relevant population by asking what we have come to call the “surprise question.” Instead of asking whether the person has a prognosis of some short limit (such as having a prognosis of six months, which Medicare regulations require if a patient is to qualify for reimbursement of hospice benefits), the clinical team asks, “Is this person sick enough that it would be no surprise for the person to die within the next six months, or a year?” Whether one looks a few months ahead or a year turns out not to matter much; at stake is whether the person is in a fragile enough condition that relatively minor worsening or intercurrent illnesses could spell the end of life. Some of the patients identified by “the surprise question” will end up living for years in a fragile state, and some will die soon, but all typically need the services that are priorities in the last part of life: advance care planning, comfort measures, assistance for daily activities, family support, and so forth. Whether a particular person needs this help for a few weeks or a few years, the social planning requires arranging services that can stay with the person throughout.

One might think that the concentration of suffering and costs would have led to substantial investments in learning how to serve people as they pass through that last part of life. However, investments of this sort have been very slow in coming. While the Soros Foundation's Project on Death in America, the Robert Wood Johnson Foundation, and others did invest during the last decade in building palliative care consultation in hospitals and grassroots citizen action, very few substantial demonstration projects have tested reformed care delivery, very little basic science research has targeted symptoms and disabilities, and few initiatives have started to alter the dysfunctional financial incentives that favor medical, surgical, and pharmacological interventions over reliability, continuity, and comprehensiveness.

I recently participated in a review of the state of the science underlying palliative care. The review was worded as optimistically as possible, but the science was indefensibly inadequate on virtually every issue, from measuring better and worse outcomes of care to assessing the merits of standard therapies. I came away feeling that this must have been the state of science regarding heart disease fifty years ago—when most of the “science” was expert opinion and much of it was inadequate, even erroneous. In twenty years, when the aging of the Baby Boomers doubles the number of people living with serious illness in the last years of life, society will have to focus on generating reliable science and insights about effective care. Otherwise, we are sure to make major errors and incur major inefficiencies in serving the burgeoning population.

What might make the last part of life as comfortable and meaningful as possible, at a cost that the community can sustain? Some elements of the shape of a worthy reform agenda include the following:

1. Articulate thresholds of severity of illness that are also administratively convenient for indicating the onset of serious illness expected to last to the end of life.
2. From that time on, focus on care arrangements that stay with the patient and family across time and settings and that are comprehensive across all care needs.
3. Insist on high standards of symptom prevention and relief, family support, and planning ahead.
4. Pay sustainable salaries and decent benefits for such a system's employees, and discount the costly services that have much smaller expected benefits (often, the high-tech devices or costly drugs).
5. Develop supports for family caregivers, such as health and disability insurance, respite care, and evidence that the community honors and respects their work.

6. Develop adequate supply of all of the critical components of good care—hands-on services for personal care as well as hospital care and good nursing homes as well as on-call nurses to handle crises in home care.

7. Monitor the effectiveness and efficiency of innovative approaches and deliberately replicate proven models, aiming to evolve a highly reliable, sustainable care system within a decade.

In a way, this reform would dramatically expand hospice principles of continuity, patient and family focus in priorities, and encouraging care at home. It would also build on the social supports and endurance of home and institutional long-term care. It would evade the sense that patients must give up on treatment to get good care, but would still make them unlikely to use burdensome treatments of limited value. The costs are probably not greatly different from those of our current approach, but the priorities are.

What gets in the way of doing this?

First, of course, many powerful interests have substantial investments in perpetuating the current dysfunctions. Those who lobbied for a broad prescription medication benefit under Medicare are not likely to have the same interest in lobbying for good working conditions for nursing home aides or for strategies that reduce the use of hospitals. Who could advocate for a more reasonable and balanced approach? The answer, tellingly, is that no strong industry interests are aligned with good care for the end of life. Even the professional trade associations have to look first to the best interests of their particular part of the puzzle, be it hospice programs or nursing careers.

The only group that comes to the fore as a potential powerful force for thoughtful reform is family caregivers. Almost all people have been, will be, or now are family caregivers. They—really, we—could take on an identity as a political force and demand that leadership focus upon these issues. That is a daunting claim—to take a diverse group that now has no particular self-identification, convince them that they have shared interests, and see them forge a political agenda and carry it through. Hope lies in the fact that the alternative is so distasteful—wasteful, unreliable services that also bankrupt the country and demoralize family members—and that all of us face this fate together, across the entire range of wealth and family structures.