

Living long in fragile health: the new demographics shape end of life care.

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

Joanne Lynn

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**In lieu of** an abstract, here is a brief excerpt of the content:

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

*Joanne Lynn*

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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-sustaining **[End Page S14]** 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...

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

by JOANNE LYNN

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