Why We Must Set Limits

Daniel Callahan

In October 1986 Dr. Thomas Starzl of Presbyterian University Hospital in Pittsburgh successfully transplanted a liver into a seventy-six-year-old woman, thereby extending to the elderly patient one of the most technologically sophisticated and expensive kinds of medical treatment available (the typical cost of such an operation is more than $200,000). Not long after that, Congress brought organ transplants under Medicare coverage, thus guaranteeing an even greater range of this form of lifesaving care for older age groups.

That is, on its face, the kind of medical progress we usually hail: a triumph of medical technology and a newfound benefit provided by an established health-care program. But at the same time those events were taking place, a government campaign for cost containment was under way, with a special focus on Medicare. It is not hard to understand why.

In 1980 people over age sixty-five—11 percent of the population—accounted for 29 percent of the total American health-care expenditures of $219.4 billion. By 1986 the elderly accounted for 31 percent of the total expenditures of $450 billion. Annual Medicare costs are projected to rise from $75 billion in 1986 to $114 billion by the year 2000, and that is in current, not inflated, dollars.

Is it sensible, in the face of rapidly increasing health-care costs for the elderly, to press forward with new and expensive ways of extending their lives? Is it possible to hope to control costs while simultaneously supporting innovative and costly research? Those are now unavoidable questions. Medicare costs are rising at an extraordinary pace, fueled by an increasing number and proportion of the elderly. The fastest-growing age group in the United States is comprised of those over age eighty-five, increasing at a rate of about 10 percent every two years. By the year 2040, it has been projected, the elderly will represent 21 percent of the population and consume 45 percent of all health-care expenditures. How can costs of that magnitude be borne?

Yet there is another powerful reality to consider that moves in a different direction: Medicare and Medicaid are grossly inadequate in meeting the real and full needs of the elderly. The system fails most notably in providing decent long-term care and home care. Members of minority groups, and single or widowed women, are particularly disadvantaged. How will it be possible, then, to provide the growing number of elderly with even present levels of care, and also rid the system of its inadequacies and inequities, and yet at the same time add expensive new technologies?

The straight answer is that it will be impossible to do all those things and, worse still, it may be harmful even to try. The economic burdens that combination would impose on younger age groups, and the skewing of national social priorities too heavily toward health care, would themselves be good reasons to hesitate.

BEYOND ECONOMICS: WHAT IS GOOD FOR THE ELDERLY?

My concern, however, extends beyond the crisis in health-care costs. "I want to lay the foundation for a more austere thesis: that even with relatively ample resources, there will be better ways in the future to spend our money than on indefinitely extending the life of the elderly. That is neither a wise social goal nor one that the aged themselves should want, however compellingly it will attract them... Our affluence and refusal to accept limits have led and allowed us to evade some deeper truths about the living of a good life and the place of aging and death in that life" (SL, 53, 116).

The coming economic crisis provides a much-needed opportunity to ask some fundamental questions. Just what is it that we want medicine to do for us as we age? Other cultures have believed that aging should be accepted and that it should be in part a time of preparation for death. Our culture seems increasingly to dispute that view, preferring instead, it often seems, to think of aging as hardly more than another disease, to be fought and rejected. Why does our culture have such difficulty with this question?

Let me start by saying that "the place of the elderly in a good society is a communal, not only an individual, question. It goes unexplored in a culture that does not easily speak the language of community and mutual responsibility. The demands of our interest-group political life constitute another obstacle... It is most at home using the language of individual rights as part of its campaigns, and can rarely afford the luxury of publicly recognizing the competing needs of other groups. Yet the greatest obstacle may be our almost utter inability to find a meaningful place in public discourse for suffering and decline in life. They are recognized only as enemies to be fought: with science, with social programs, and with a supreme optimism that with sufficient energy and imagination they can be overcome. We have created a way of life that can only leave serious questions of limits, finitude, the proper ends of human life, of evil and suffering, in the realm of the private self or of religion; they are thus treated as incorrigibly subjective or merely pietistic" (SL, 220).

In its long-standing ambition to forestall death, medicine has reached its last frontier in the care of the aged. Of course children and young adults still die of maladies that are open to potential cure, but the highest proportion of the dying (70 percent) are over sixty-five. If death is ever to be humbled, that is where endless work remains to be done. This defiant battle against death and decline is not limited to medicine. Our culture has worked hard to redefine old age as a time of liberation, but not decline, a time of travel, of new ventures in education and self-discovery, of the ever-accessible tennis court or golf course, and of delightfully periodic but thankfully brief visits from well-behaved grandchildren. That is, to be sure, an idealized picture, but it arouses hopes that spur medicine to wage an aggressive war against the infirmities of old age.

As we have seen, the costs of such a war would be prohibitive. No matter how much is spent, the ultimate problem will still remain: People will grow old and die. Worse still, by pretending that old age can be turned into a kind of endless middle age, we rob it of any meaning.

THE MEANING AND SIGNIFICANCE OF OLD AGE

There are various sources of meaning and significance available for the aged, but it is the elderly's particular obligation to the future that I believe is essential. "Not only is it the most neglected perspective on the elderly, but it is the most pertinent as we try to understand the problem of their health care. The young—children and young adults—most justly and appropriately spend their time preparing for future roles and developing a self pertinent to them. The
mature adult has the responsibility to procreate and rear the next generation and to manage the present society. What can the elderly most appropriately do? It should be the special role of the elderly to be the moral conservators of that which has been and the most active proponents of that which will be after they are no longer here. Their indispensable role as conservators is what generates what I believe ought to be the primary aspiration of the old, which is to serve the young and the future. Just as they were once the heirs of a society built by others, who passed on to them what they needed to know to keep going, so are they likewise obliged to do the same for those who will follow them.

"Only the old—who alone have seen in their long lives first a future on the horizon and then its actual arrival—can know what it means to go from past through present to future. That is valuable and unique knowledge. If the young are to flourish, then the old should step aside in an active way, working until the very end to do what they can to leave behind them a world hopeful for the young and worthy of bequest. The acceptance of their aging and death will be the principal stimulus to doing this. It is this seemingly paradoxical combination of withdrawal to prepare for death and an active, helpful leave-taking oriented toward the young which provides the possibility for meaning and significance in a contemporary context. Meaning is provided because there is a purpose in that kind of aging, combining an identity for the self with the serving of a critical function in the lives of others—that of linking the past, present, and future—something which, even if they are unaware of it, they cannot do without. Significance is provided because society, in recognizing and encouraging the aged in their duties toward the young, gives them a clear and important role, one that both is necessary for the common good and that only they can play" (SL, 43).

It is important to underscore that while the elderly have an obligation to serve the young, the young and society have a duty to assist the elderly. Before any limits are imposed, policies and programs must be in place to help the elderly live out a "natural life span," and beyond that to provide the means to relieve suffering.

A "Natural Life Span" and a "Tolerable Death"

Earlier generations accepted the idea that there was a "natural life span"—the biblical norm of threescore and ten captures that notion. It is an idea well worth reconsidering and would provide us with a meaningful and realizable goal. Modern medicine and biology have insinuated the belief that the average life span is not a natural fact at all, but instead one that is strictly dependent on the state of medical knowledge and skill. And there is much to that belief as a statistical fact: Average life expectancy continues to increase, with no end in sight.

There are, moreover, other strong obstacles to the development of a notion of a "natural life span." This notion "requires a number of conditions we seem reluctant to agree to: (1) that life has relatively fixed stages—a notion rejected on the ground that we are free to make of our different stages of chronological age whatever we want; biology presents no unalterable philosophical and moral constraints or any clear pointers; (2) that death may present an 'absolute limit' to life—an idea repudiated because of the ability of medicine to constantly push back the boundary line between life and death; life is an open-ended possibility, not a closed circle; (3) that old age is of necessity marked by decline and thus requires a unique set of meanings to take account of that fact—a viewpoint that must be rejected as part of the political struggle against ageism, which would make of the old a deviant, marginal, and burdensome group; and (4) that 'our civilization' would be better off if it shared some common view of 'the whole of life'—rejected as a politically hazardous notion, more congenial to authoritarian and collectivist cultures than to
those marked by moral and religious pluralism and individualism” (SL, 40–41).

I want to argue that we can have and must have a notion of a “natural life span” that is based on some deeper understanding of human needs and possibilities, not on the state of medical technology. I offer a definition of the “natural life span” as “one in which life’s possibilities have on the whole been achieved and after which death may be understood as a sad, but nonetheless relatively acceptable event.

“Each part of that definition requires some explanation. What do I mean when I say that ‘one’s life possibilities have on the whole been accomplished’? I mean something very simple: that most of those opportunities which life affords people will have been achieved by that point. Life affords us a number of opportunities. These include work, love, the procreating and raising of a family, life with others, the pursuit of moral and other ideals, the experience of beauty, travel, and knowledge, among others. By old age—and here I mean even by the age of 65—most of us will have had a chance to experience those goods, and will certainly experience them by our late 70s or early 80s. It is not that life will cease, after those ages, to offer us some new opportunities; we might do something we have never done but always sought to do. Nor is it that life will necessarily cease to offer us opportunities to continue experiencing its earlier benefits. Ordinarily it will not. But what we have accomplished by old age is the having of the opportunities themselves, and to some relatively full degree. Many people, sadly, fail to have all the opportunities they might have: they may never have found love, may not have had the income to travel, may not have gained much knowledge through lack of education, and so on. More old age is not likely to make up for those deficiencies, however; the pattern of such lives, including their deprivations, is not likely to change significantly in old age, much less open up radically new opportunities hitherto missing” (SL, 66–67).

A longer life does not guarantee a better life. No matter how long medicine enables people to live, death at any time—at age 90 or 100 or 110—would frustrate some possibility, some as-yet-unrealized goal. The easily preventable death of a young child is an outrage. Death from an incurable disease of someone in the prime of young adulthood is a tragedy. But death at an old age, after a long and full life, is simply sad, a part of life itself, what I would call a “tolerable death.”

This notion of a “tolerable death” helps illumine the concept of a “natural life span,” and together these two notions set the foundation for an appropriate goal for medicine in its approach to aging. “My definition of a ‘tolerable death’ is this: the individual event of death at that stage in a life span when (a) one’s life possibilities have on the whole been accomplished: (b) one’s moral obligations to those for whom one has had responsibility have been discharged; and (c) one’s death will not seem to others an offense to sense or sensibility, or tempt others to despair and rage at the finitude of human existence. Note the most obvious feature of this definition: it is a biographical, not a biological, definition” (SL, 66).

THE PRINCIPLES AND PRIORITIES OF A PLAN

How might we devise a plan to limit the costs of health care for the aged under public entitlement programs that is fair, humane, and sensitive to their special requirements and dignity? Let me suggest three principles to undergird a quest for limits:

1. Government has a duty, based on our collective social obligations, to help people live out a natural life span, but not actively to help extend life medically beyond that point. By life-extending treatment, I will mean any medical intervention, technology, procedure, or medication whose ordinary effect is to forestall the moment of death, whether or not the
treatment affects the underlying life-threatening disease or biological process.

“2. Government is obliged to develop, employ, and pay for only that kind and degree of life-extending technology necessary for medicine to achieve and serve the end of a natural life span; the question is not whether a technology is available that can save a life, but whether there is an obligation to use the technology.

“3. Beyond the point of a natural life span, government should provide only the means necessary for the relief of suffering, not life-extending technology” (SL, 137–38).

What would the actual policy look like? “A full policy plan would include detailed directions, for example, for determining priorities within basic biological research, within health-care delivery, and between research and delivery. That I will not try to provide. I can only sketch a possible trajectory—or, to switch metaphors, a kind of likely general story. But if that at least can be done in a coherent fashion, avoiding the most flagrant contradictions, it might represent some useful movement” (SL, 141–42).

Three elements of health policy emerge from my position: “The first is the need for an antidote to the major cause of a mistaken moral emphasis in the care of the elderly and a likely source of growing high costs of their care in the years ahead. That cause is constant innovation in high-technology medicine relentlessly applied to life-extending care of the elderly; it is a blessing that too often turns into a curse. . . . No technology should be developed or applied to the elderly that does not promise great and inexpensive improvement in the quality of their lives, no matter how promising for life extension. Incremental gains, achieved at high cost, should be considered unacceptable. Forthright government declarations that Medicare reimbursement will not be available for technologies that do not achieve a high, very high, standard of efficacy would discourage development of marginally beneficial items” (SL, 142, 143).

“The second element is a need to focus on those subgroups of the elderly—particularly women, the poor, and minorities—who have as yet not been well served, for whom a strong claim can be entered for more help from the young and society more generally. . . . The elderly (both poor and middle-class) can have no decent sense of security unless there is a full reform of the system of health care. It may well be that reforms of the sweeping kind implied in these widely voiced criticisms could more than consume in the short run any savings generated by inhibitions of the kind I am proposing in the development and use of medical technology. But they would address a problem that technological development does nothing to meet. They would also reassure the old that there will be a floor of security under their old age and that ill health will not ruin them financially, destroy their freedom, or leave them dependent upon their children (to the detriment of both)” (SL, 142, 147).

“The third is a set of high-priority health and welfare needs—nursing and long-term care, prevention—which would have to be met in pursuit of the goals I have proposed. . . . Beyond avoiding a premature death, what do the elderly need from medicine to complete their lives in an acceptable way? They need to be as independent as possible, freed from excess worry about the financial or familial burdens of ill health, and physically and emotionally positioned to seek whatever meaning and significance can be found in old age. Medicine can only try to maintain the health which facilitates that latter quest, not guarantee its success. That facilitation is enhanced by physical mobility, mental alertness, and emotional stability. Chronic illness, pain, and suffering are all major impediments and of course appropriate targets for medical research and improved health-care delivery. Major research priorities should be those chronic illnesses which so burden the later years and which have accompanied the increase in longevity” (SL, 142, 149).
Euthanasia and Assisted Suicide

Some might view my position as an endorsement of euthanasia and assisted suicide. My position “is exactly the opposite: a sanctioning of mercy killing and assisted suicide for the elderly would offer them little practical help and would serve as a threatening symbol of devaluation of old age. Were euthanasia and assisted suicide to be legalized, would there be a large and hitherto restrained group of elderly eager to take advantage of the new opportunity? There is no evidence to suggest that there would be, in either this country or in any other. But even if there might be some, what larger significance might the elderly in general draw from the new situation? It would be perfectly plausible for them to interpret it as the granting of a new freedom. It would be no less plausible for them to interpret it as a societal concession to the view that old age can have no meaning and significance if accompanied by decline, pain, and despair. It would be to come close to saying officially that old age can be empty and pointless and that society must give up on elderly people. For the young it could convey the message that pain is not to be endured, that community cannot be found for many of the old, and that a life not marked by good health, by hope and vitality, is not a life worth living.

“What do we as a society want to say about the elderly and their lives? If one believes that the old should not be rejected, that old age is worthy of respect, that the old have as valid a social place as any other age group, and that the old are as diverse in their temperaments and outlooks as any other age group, an endorsement of a special need for euthanasia for the old seems to belie all those commitments. It would be a way of legitimizing the view that old age is a special time of lost hopes, empty futures, and personal pointlessness. Alternatively, if it is believed that old age can have a special value, that it can—with the right cultural, economic, and political support—be a time of meaning and significance, then one will not embrace euthanasia as a special solution for the problem of old age, either for the aged as individuals or for the aged as a group. It would convey precisely the wrong symbolism. To sanction euthanasia as a special benefit for the aged would signal a direct contradiction to an effort to give meaning and significance to old age” (SL, 194, 196, 197). We as a society should instead guarantee elderly persons greater control over their own dying—and particularly an enforceable right to refuse aggressive life-extending treatment.

Conclusion

The system I propose would not immediately bring down the cost of care of the elderly; it would add cost. But it would set in place the beginning of a new understanding of old age, one that would admit of eventual stabilization and limits. The elderly will not be served by a belief that only a lack of resources, better financing mechanisms, or political power stands between them and the limitations of their bodies. The good of younger age groups will not be served by inspiring in them a desire to live to an old age that maintains the vitality of youth indefinitely, as if old age were nothing but a sign that medicine has failed its mission. The future of our society will not be served by allowing expenditures on health care for the elderly to escalate endlessly and uncontrollably, fueled by the false altruistic belief that anything less is to deny the elderly their dignity. Nor will it be aided by the pervasive kind of self-serving argument that urges the young to support such a crusade because they will eventually benefit from it.

We require instead an understanding of the process of aging and death that looks to our obligation to the young and to the future, that recognizes the necessity of limits and the acceptance of decline and death, and that values the old for their age and not for their continuing youthful vitality. In the name of accepting the elderly and repudiating discrimination against
them, we have succeeded mainly in pretending that with enough will and money the unpleasant part of old age can be abolished. In the name of medical progress we have carried out a relentless war against death and decline, failing to ask in any probing way if that will give us a better society for all.

"There is little danger that the views I advance here will elicit such instant acclaim (or any acclaim, for that matter) that the present generation of the elderly will feel much of their effect. That could take two or three decades if there is any merit in what I say, and what I am looking for is not any quick change but the beginning of a long-term discussion, one that will perhaps lead people to change their thinking, and most important, their expectations, about old age and death" (SL, 10).

NOTE


Reading 17

Pricing Life

Why It's Time for Health Care Rationing

Peter Ubel

In the United States, people frequently debate the pros and cons of managed care organizations and whether medicine should be a for-profit business. They almost never debate health care rationing. Instead, they mention it only to accuse managed care organizations or for-profit insurance companies of some egregious crime against humanity. Clearly, there are many important issues to debate about managed care organizations and about the rampant corporatization of American health care. But these debates miss the larger issue of the need to ration health care.

Managed care organizations did not create health care rationing. Instead, the need to ration created managed care. In the United States, managed care organizations proliferated largely because of their presumed ability to contain costs. But governments in Europe, Asia, and other parts of North America are also desperate to control health care costs. Outside the United States, the need to ration health care forced governments to devise other ways besides managed care to contain costs. In Canada, patients wait for months for heart bypass surgery, only to be bumped to the back of the line when another patient becomes urgently ill (Naylor, 1991). Indeed, even in the United States, managed care organizations are not the only groups engaged in rationing. Traditional fee-for-service insurance companies hire hordes of utilization reviewers to have patients discharged from the hospital earlier. State governments change eligibility criteria for Medicaid. Hospitals close down trauma centers to avoid uninsured patients. Rationing is ubiquitous. Managed care is not.