The costs of caring: who pays? Who profits? Who panders?

by Leonard H. Fleck

Avastin, a widely used colon cancer drug manufactured by San Francisco-based biotech company Genentech, has proven a somewhat effective treatment for lung and breast cancer when administered at twice the normal dose. In February, the New York Times carried a story about Avastin's extraordinarily high price when used in this alternative way: $100,000 for one year's treatment—a figure fully twice the price of the normal dose, even though producing the higher dose costs the company little additional money. And the treatment yields only an average gain in life expectancy of five months—very modest relative to the cost.

What garnered media attention, however, was Genentech's novel justification for the price: "the inherent value of these life-sustaining technologies." (1) Rather than making the usual appeal to high research costs, the company cited the pricelessness of human life, implying a moral reason for the pricing decision. I will pass in silence over the obviously self-serving disingenuousness of this appeal. The fact is that many in our society—and perhaps a substantial majority—think human life should be thought of as priceless. That assertion can be taken in three very different ways.

We can take the pricelessness of human life to mean that the social worth of an individual (their social status or contribution to the national economy) should be completely irrelevant when it comes to determining how much society should spend to save or prolong that individual's life in the face of a life-threatening illness or accident—a worthy moral principle. Likewise, we should affirm the nonutilitarian view that the cost of saving either a life or a life-year should not determine by itself what will count as a just allocation of limited health resources when we cannot afford to save all the life-years medical technology may salvage. But we need to reject the view that we have a moral obligation to spend any amount of money to save all lives and life-years that medical technology permits. The result of adopting this view would be a gross distortion in our society's health care priorities that would not be just, compassionate, or prudent.

To see why this is true, let us look at some facts and reasonable projections. Health spending in the United States topped $1.8 trillion in 2004, roughly 16.3 percent of our gross domestic product (GDP), compared to 5.2 percent in 1960. Projections to 2015 show us spending more than $4 trillion on health care then—almost 20 percent of expected GDP. (2) Medicare spending in 2005 was about $330 billion. With deployment of the prescription drug benefit in 2006, spending will be about $424 billion—a price tag expected to rise by 2014 to $747 billion. Over the ten-year period ending in 2015, Medicare spending will exceed $4 trillion. (3) These figures are socially and politically problematic, especially in light of growing federal deficits.

Health policy analysts generally agree that emerging medical technologies drive escalating health costs. (4) Yet they and the public feel medical innovation should not be slowed or stopped—a conclusion I endorse as well. However, if we couple this belief with that third sense of the pricelessness of human life, the results are morally and economically disastrous.

The problems posed by pricey medical innovation combined with a belief in the pricelessness of human life began with the passage of the 1972 End Stage Renal Disease (ESRD) amendments to the Medicare program. Those amendments created a program that would pay for renal dialysis or transplant for virtually any U.S. citizen in kidney failure. The program was motivated by the fact that thousands of patients died every year in the late 1960s...
because they could not afford the cost of dialysis (roughly $90,000 a year per patient in 2005 dollars). The rhetoric at the time was that no one should be denied access to effective, life-sustaining medical technology simply because they could not afford it, and society pressured Congress to pass the program quickly. (5) Further, Congress believed that this was a unique medical technology, rather than the headwaters of a torrent, and it expected the program to top out in twenty years at a half billion dollars per year, meaning future costs would be reasonable. Unfortunately, Congress was wrong on all these points.

The dialysis program in 2005 cost about $20.5 billion and sustained the lives of 390,000 patients. Current projections show the program costing about $28.3 billion for 520,000 patients by 2010. Another 180,000 former dialysis patients will be kept alive with even more expensive transplants. (6) That Congress got the numbers wrong is excusable; that it endorsed the rhetoric of the pricelessness of human life is intolerable. The moral framework that should have guided these early decisions was that of health care justice.

Where was the moral mistake? The ESRD program paid for kidney transplants as well as dialysis. These were the early years of transplants; organ rejection problems meant success was spotty. By the late 1970s cyclosporin resolved that problem but created the question of whether to use public funds for other costly organ transplants. Why should renal patients benefit from public largesse, but not patients needing a heart or a liver? Aren't their lives just as priceless? (7)

Hemophiliacs have essentially the same predicament as renal patients: they need Factor VIII--a drug with annual costs in excess of $100,000--to halt bleeding episodes. But the government did not create any special program to save their lives. We can imagine the rationale constructed to defend this lack of response: the needs of hemophiliacs are too heterogeneous; not every bleeding episode is life-threatening; too many complex choices would have to be made among "deserving" and "nondeserving" episodes of bleeding. Government programs need bright lines. This, however, represents a second moral mistake.

Kidney failure draws the bright line that government seeks: dialysis works, sustaining lives otherwise doomed. However, that bright line obscures the morally problematic "ragged edge." (8) The fastest growing segment of the dialysis population are those over age seventy-five. (9) This is not to suggest that age by itself should disqualify anyone from dialysis. The real problem is that dialysis is being used more often to sustain very marginal prolongations of life at very great cost. Behind this is a subtle version of the pricelessness of human life claim.

Dialysis is a paradigm case of "rescue" medicine. Individuals faced with imminent death are given back the rest of their lives--for some, another fifteen to twenty years. But if human life is really priceless, then all prolonging of life through medicine is equally worthy of being supported, whether the gain is ten years or ten days. Likewise, if human life is priceless, then the quality of sustained life is irrelevant. Patients in the end stages of dementia or in a persistent vegetative state would have as much moral claim on prolonging their lives by dialysis as anyone else. (10) In short, the morally problematic syllogism is this: If dialysis is effective in saving life and we have chosen to fund it, then every instance must be covered--no rationing decisions can be made.

The broader consequences of this thinking require our attention. Literally dozens of extraordinarily expensive cancer drugs and medical devices are now entering the market. All of them are "effective"--they prolong life. But the added time is often measurable in weeks and months, not years, which yields very high cost-effectiveness ratios--literally hundreds of thousands of dollars per quality-adjusted life year (QALY). Aggregate costs for all these treatments can quickly mount into the tens of billions of dollars. This has two morally problematic systemic consequences: employers drop or drastically restrict health insurance, (11) and health priorities get skewed in ways that are both unjust and uncaring.