

Myths of the High Medical Cost of Old Age and Dying



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by

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The International Longevity Center-USA (ILC-USA)

is a not-for-profit, nonpartisan research, education, and policy organization whose mission is to help individuals and societies address longevity and population aging in positive and productive ways, and to highlight older people's productivity and contributions to their families and society as a whole.

The organization is part of a multinational research and education consortium and includes centers in the United States, Japan, Great Britain, France, the Dominican Republic, India, Sub-Saharan Africa, Argentina, and the Netherlands. These centers work both autonomously and collaboratively to study how greater life expectancy and increased proportions of older people impact nations around the world.

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Myths of the High Medical Cost of Old Age and Dying

MYTH 1

The growing number of older people has been the primary factor driving the rise in America's health care costs.

Fact: Population aging is not the principal determinant of rising health care costs.

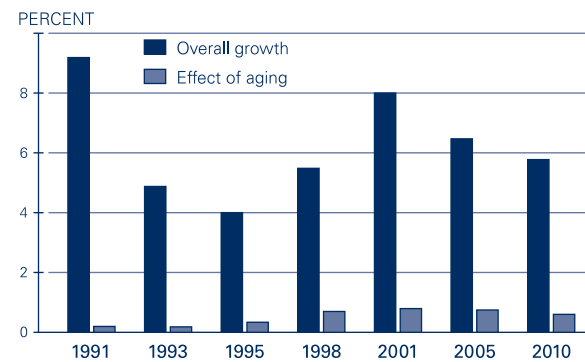
Health care costs in the United States have risen sharply in the past several decades not only in actual dollars but also as a proportion of the gross national product. While the proportion of Americans over age 65 is rising and older adults consume more health care than younger adults, the contribution of aging to rising costs is actually quite limited.

Research conducted by the Center for Studying Health System Change reveals that in 2001, while the annual percentage increase in per capita non-Medicare personal health expenditures was 8.1 percent, less than 10 percent of this (only 0.73 percentage point) was attributable to population aging.¹ Medical care price inflation, greater resource intensity of treatments, including the availability of new technology, and overall population growth have been responsible for the majority of the rise in health care costs.

In a four-part series of articles discussing rising health care costs published in the *Annals of Internal Medicine*, Thomas Bodenheimer, M.D.,

Figure 1

Effect of Aging by Itself on the Growth of Health Care Spending for the Non-Medicare Population, Selected Years 1991–2010



SOURCE: Strunk BC, Ginsburg PB. Aging plays limited role in health care cost trends. *Data Bulletin* (Washington DC: Center for Studying Health System Change), Figure 1.

points out that research consistently shows that the aging population explains only 6 to 7 percent of health expenditure growth, and no significant relationship is found between the percentage of older persons in a nation's population and national health spending.²

Using national household surveys and Centers for Medicare & Medicaid Services National Health Accounts data in an analysis presented in *Health Affairs* in 2004, Ellen Meara and colleagues conclude that population aging accounts for only a small part of medical spending growth since 1970: only 0.2 percentage points of the annual rate of 4.3 percent.³

Even after the baby boom generation begins to reach 65, around the year 2010, the increases in the fraction of the U.S. population age 65 and over will be only a minor determinant of the annual growth in aggregate health care use and spending. This is because the U.S. population age 65 and over will rise ever so gradually, by fewer than ten percentage points between now and 2030.⁴

Thus, to assume that population aging has been the major source of rising health care costs is a mistake and detracts from the more serious determinants of rising costs. As Reinhardt puts it in a study using Medical Expenditure Panel Surveys to evaluate the role of the aging population on health care costs:

Key factors responsible for the growth in health care spending include rising per capita incomes, the availability of promising but costly new medical technology, workforce shortages that can drive up the unit cost of health care, and the asymmetric distribution of market power in health care that gives the supply side of the sector considerable sway over the demand side. These other factors will be the dominant drivers of health spending in the future as well. Blaming Medicare's future economic pressures mainly on demographic factors beyond policymakers' control is an evasion of more important challenges.⁴

MYTH 2

As the population ages, health care costs for older Americans will necessarily overwhelm and bankrupt the nation.

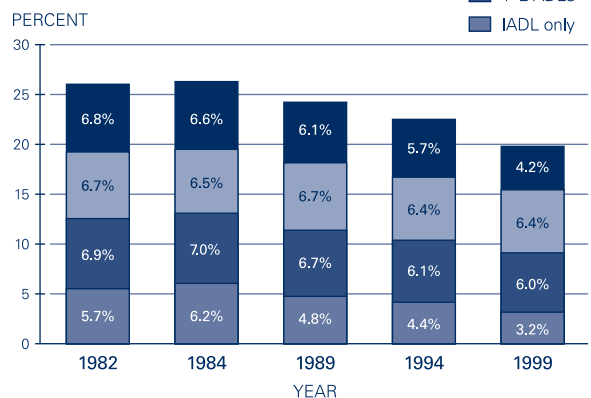
Fact: Population aging need not impose a crushing economic burden, especially if we start now to conduct the necessary research and develop policies on health care at the end of life.

There is good evidence that the health status of older Americans is improving and that longer healthy life may not cause a significant increase in health care spending.¹ A recent analysis using Medicare data showed that for persons who reach the age of 70 in good health and who have several remaining years of life, the cumulative health care expenditures until death are similar to those for persons in poor health at the age of 70. Health promotion efforts in the areas of smoking cessation, diet, and exercise in the younger population that have payoffs in better health and longer life for older persons will keep health care spending from increasing among this older cohort.

Using data from the National Long-Term Care Survey, Manton and colleagues have shown significant reductions over the past two decades in the prevalence of chronic disability among older adults. While the number of older Americans has grown from 26.9 million in 1982 to 35.5 million in 1999, the number of chronically disabled has actually decreased from 7.1 million to 7.0 million. The prevalence of chronic disability declined to 6.5 percent.²

Figure 2

Disability Rates of the Population Age 65 and Older, by Disability Level, 1982 to 1999.³



SOURCE: Manton KG, Gu X. 2001. Changes in the prevalence of chronic disability in the United States black and nonblack population above age 65 from 1982-1999. *Proc Natl Acad Sci USA* 98(11):6354-9.

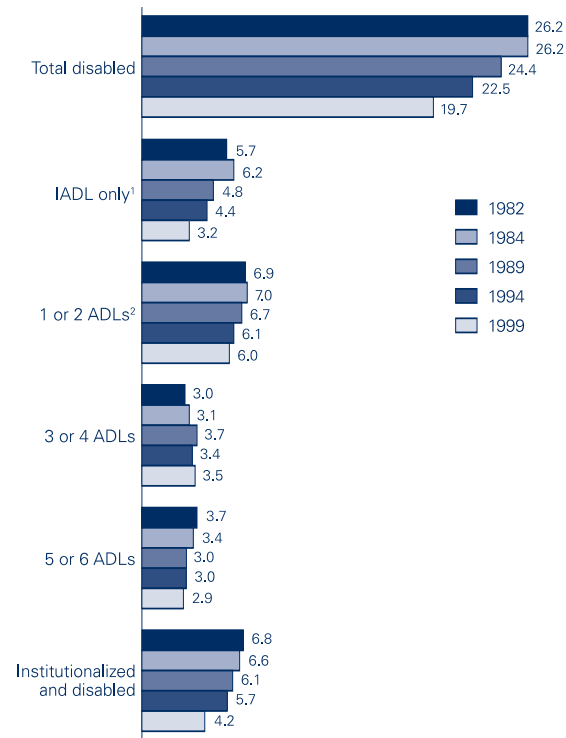
Furthermore, there is reason to believe that the protocol used in this survey overestimated the degree of disability and thus has misclassified survey respondents. In an analysis published in the *Archives of Internal Medicine* in 2005, researchers found the number of chronically disabled older Americans to be about 2.0 million fewer than the 7.0 million published for 1999, suggesting that the burden of chronic disability has been substantially overestimated.⁴

In its report entitled *65+ in the United States: 2005*, the United States Census Bureau describes an increasingly healthier, wealthier, and better-educated

Figure 3

Percent of People Aged 65 and Over With Chronic Disability: 1982 to 1999.

(Age-standardized to 1999 population aged 65 and over)



¹ Institutional activities of daily living.

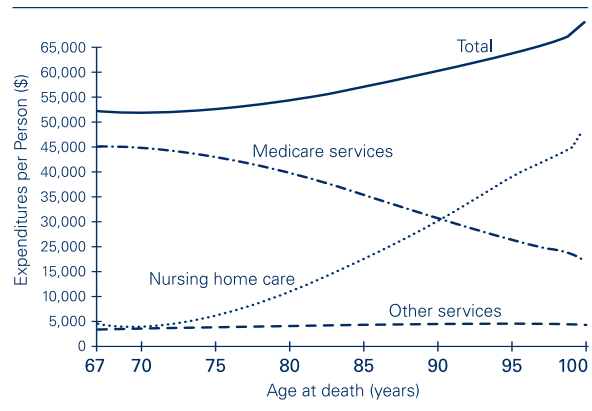
² Activities of daily living.

NOTE: The reference population for these data is the Medicare enrollees aged 65 and older.

SOURCE: Manton KG, Gu X. 2001. Changes in the prevalence of chronic disability in the United States black and nonblack population above age 65 from 1982–1999. *Proc Natl Acad Sci USA* 98(11):6354–9.

cohort of older adults reaching retirement age. The report cites an overall improved health expectancy, with more years free of disability.⁵

Figure 4



SOURCE: Spillman BC, Lubitz J. 2000. The effect of longevity on spending for acute and long-term care. *N Eng J Med* 342:1409–15.

Only part of the added life expectancy is spent in good health, and thus it is not surprising that the rate of increase in expenditure for long-term care rises with age at death.⁶ The opposite trend is true of acute-care expenditure for which the rate of increase declines with age at time of death. Future research on compression of morbidity (augmenting the disability-free years among the older population) could stem the increase in long-term care expenditure. Meanwhile, it is not aging as such that creates health care expenditure but services needed when death is imminent.

MYTH 3

Putting limits on health care for the very old at the end of life would save Medicare significant amounts of money.

Fact: The proportion of Medicare spending attributable to beneficiaries in the last year of life has remained stable over the past two decades. Rational political decisions about end-of-life care, integrating respect for human life with quantitative aspects, would prevent this from being an issue.

As life expectancy among older persons improves, so does their health. Those in good health appear to have a longer life expectancy than those in poor health but have similar cumulative health care expenditures until death.¹ For example, in 1998 a person with no functional limitation at age 70 had a life expectancy of 14.3 years and expected cumulative health care expenditures of about \$136,000; a person with a limitation in at least one activity of daily living had a life expectancy of 11.6 years and expected cumulative health care expenditures of about \$145,000 (in 1998 dollars). There are greater costs when older people are institutionalized. Those who were institutionalized at the age of 70 had cumulative health care expenditures that were much higher than those who were not institutionalized. However, over three-fifths of the cost of institutional care is paid by individuals and state and local government, rather than by Medicare (see Figure 5).

Spillman and Lubitz analyzed the effect of longevity on spending for acute and long-term

care.² They examined data from Medicare, the National Mortality Followback Survey, and the National Medical Expenditure Survey to estimate total national expenditures for health care according to the age at death. They found that people who die at an older age do incur higher expenditures overall but actually cost Medicare less. Acute care expenditures, principally for hospital care and physicians' services, increase at a *reduced* rate as the age at death increases. The increases in cost are primarily in long-term care, which is significantly paid for by state/local funds and out-of-pocket funds.³ Overall, the proportion of Medicare spending attributable to beneficiaries in the last year of life has remained stable at approximately 25 percent over the past two decades and is not disproportionately responsible for the Medicare spending increase.⁴

Yang et al. concur that aging accounts principally for higher long-term care costs, but that increased time to death is the main reason for higher inpatient care expenditures.⁵ Both of these expenditures

Figure 5

Sources of Nursing Home Care Payments, 1960–1995 (in percent). (Latest data available.)

Calendar Year	Out-of-Pocket Payments	Private Health Insurance	Other Private	Federal Spending	State and Local Spending	Total Expenditures (in millions)
1960	77.9	0.0	6.4	7.9	7.8	848
1965	60.1	0.1	5.7	15.0	19.0	1,471
1970	53.5	0.4	4.9	24.8	16.4	4,217
1975	42.6	0.7	4.8	30.5	21.3	8,668
1980	41.8	1.2	3.0	31.8	22.2	17,649
1985	44.4	2.7	1.8	29.8	21.2	30,679
1990	43.6	3.7	1.8	30.8	20.0	50,928
1991	40.9	3.6	1.8	32.2	21.5	57,164
1992	39.1	3.4	1.9	34.5	21.2	62,301
1993	37.4	3.3	1.9	36.8	20.7	67,029
1994	37.1	3.3	1.9	37.1	20.6	72,446
1995	36.7	3.3	1.9	37.6	20.5	77,877

SOURCE: Committee on Ways and Means, U.S. House of Representatives. 1997 Medicare and health care chartbook. Feb 27, 1997. U.S. Government Printing Office, Washington, DC. <http://www.gpo.gov/congress/house/ways-and-means/sec1.pdf>

will likely increase due to the increase in the absolute number of older people, as well as increasing longevity. But it is important to remember that population aging is not the principal determinant of rising health care costs (refer to Myth 1). The RAND Future Elderly Model points out that new technologies add to spending because the costs of the new technologies, and the health care costs during the added years of life they bring, outweigh reductions in annual spending from better health.⁶

For the above reasons, even if physicians and hospitals could predict which patients were near death, limiting acute care would not save the amount of money that many assume. The larger problem is that Medicare as a reimbursement structure has not built in a cost-reduction incentive. Some programs within Medicare, such as the hospice benefit, may provide some cost control because of the capitated payment structure.⁷ However, there are no recent or definitive studies examining this issue. Existing data, mainly from the 1980s, suggest that hospice and advance directives can save between 25 and 40 percent of health care costs during the last month of life, with savings decreasing to 10 to 17 percent over the last six months of life and decreasing further to 0 percent to 10 percent over the last 12 months of life.⁸ These savings are less than most people anticipate. Nevertheless, they do indicate that hospice and advance directives should be encouraged because they do not cost more and they provide a means for patients to exercise their autonomy over end-of-life decisions.

More recently, the Dartmouth Atlas Project 2006, which reports on the care of patients (Medicare enrollees) with severe chronic illness during the last two years of life, has provided important insights.⁹ This project found that there are tremendous regional and state variations in the management of patients with serious chronic illnesses, including mean number of doctor visits in the last six

months of life, percentage of deaths occurring in the intensive care unit setting, percentage of decedents enrolled in hospice, and amount of Medicare spending in the last six months of life. They found that regional differences in Medicare spending are largely explained by the inpatient-based and specialist-oriented pattern of practice (as opposed to primary care) observed in high-spending regions. More resource use did not result in better outcomes or satisfaction with care, and, indeed, regions with greater care intensity had increased mortality rates.^{10,11}

In summary, acute care for the very old at the end of life does not appear to be a major item in the nation's health care bill nor a potential area for large savings. As Scitovsky states, "Curbing the rise in medical care costs will require basic changes in the physician-patient relationship and in our attitude to death."¹² We as a nation need to rethink, retool, and reprioritize the way we deliver care, especially in the face of increasing numbers of older persons living with chronic illnesses.

MYTH 4

Aggressive hospital care for the aged is futile; the money spent is wasted.

Fact: Many older people who receive aggressive care survive and do well for an extended period.

One of the most common myths surrounding health care in old age is that aggressive treatment is too often "wasted" on patients who, because of age, cannot benefit from it. The facts are that many older people do benefit from aggressive care, and age alone is not the major determinant of who will benefit.

Several measures have been used to study the impact of aggressive care on the outlook for older

persons. These include the high cost itself, admission to intensive care, the length of stay in intensive care, the number of people receiving certain high-cost procedures, as well as the cost of receiving care in teaching hospitals.

The benefits of aggressive care for older persons are demonstrated by Medicare data showing that among beneficiaries who incur high costs, there are about as many who survive as who die in the course of a calendar year. For instance, among those who cost Medicare more than \$20,000 in 1978, 24,000 died and 25,000 survived in that year.¹ In four other years, the percent of Medicare enrollees who incurred the highest costs were divided about equally between those who survived and those who died in the course of the year.² These data suggest, retrospectively, that high-cost (or aggressive) care has benefits for people age 65 and over about half the time, if one accepts survival as an indication of benefit.

Since then, many studies have attempted to address the question of whether age should determine the aggressiveness and intensity of inpatient care provided to older adults. Although some studies have suggested that older adults in intensive care have higher mortality rates,^{3,4} many other studies have concluded that age itself is not the most significant predictor of outcome in the intensive care unit.⁵⁻⁸

One study suggests that although older patients admitted to intensive care tend to have a decrease in general level of activity including specific activities of daily living from baseline one year after their ICU stay, the cumulative mortality at 12 months was only 25 percent. More importantly, the self-perceived health status of the very old (75 and over) increased over the course of the year, and about 70 percent of all patients discharged were living at home at 12 months.⁹

Another study involving older adults (70 years and over) with a longer than 30-day stay in the ICU showed similar results. Despite a sicker group of older adults requiring a longer ICU stay, the survival rate was 67 percent in the ICU and 47 percent in the hospital, comparable to the Medicare estimates described earlier. Once again, although independence in activities of daily living (except for feeding) was significantly decreased after the ICU stay, their perceived quality of life remained good, and most remained independent with the possibility of returning home.¹⁰

These studies, along with the Medicare data, support the fact that aggressive care has benefited older adults about half the time by extending their lives. But is survival the endpoint of any medical care? Many would argue that with the increasing medical costs that face our nation today, the benefit of aggressive ICU care cannot be measured by life extension itself. Other clinically valuable endpoints such as perceived quality of life and functional status need to be considered.

A review of the literature on outcomes of aged survivors of intensive care gathered from 1990 to 2003 looked specifically at this question. What the researchers found was that in most studies, critically ill older patients have good functional status and/or health-related quality of life, they were satisfied with their life, and there was little change from their premorbid health-related quality of life following discharge from the ICU.¹¹

It is clear from all these various sources that many older adults would benefit from aggressive treatment. If it were possible, prospectively, to identify patients who would benefit and patients who would not, physicians and patients together could choose care accordingly. At present, physicians do not have a reliable way to predict the outcome of

treatment in older patients or, with the exception of terminal cancer, to predict with much accuracy how long a patient has to live. Even the use of complex scoring formulas that take many factors into account fail to yield precise predictions of life expectancy in critically ill patients. The APACHE model (Acute Physiology, Age, Chronic Health Evaluation) has improved the accuracy of predictions in groups of patients but has not proved useful in predicting which individual patients will die.¹² The SUPPORT (Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment) prognostic model found that seven days before death, patients had a median 51 percent likelihood of surviving two months. Even one day before death, the median likelihood of surviving two months was 17 percent.¹³ What this demonstrates is that although available clinical information can provide some long-term survival estimates, the best estimate is probably that which combines the objective prognosis from these models with a physician's clinical estimate.¹⁴

One clear fact that does emerge from studies of prognostic models is that age alone is not a good predictor of whether treatment will be successful. Both the APACHE III and the SUPPORT model include age as one prognostic element, along with physiologic and other variables. In neither case, however, does age appear to play a major role compared to other variables.^{14,15} A study looking at the long-term outcome of critically ill older patients requiring intensive care further supports this by showing that age alone was neither an adequate predictor of long-term survival, nor was it an adequate predictor of patients' quality of life 12 months after hospital discharge.⁶

In summary, the common assumption that "intensive care for the elderly is futile" is not borne out by the evidence. Age alone is not a good basis for making

prognoses, nor should it be the only determinant used to restrict aggressive medical care. Because the outcome of any aggressive treatment is hard to predict, any decisions to limit aggressive treatment of older adults should take into consideration not only age, functional status, and health-related quality of life but also other factors, including societal values. One of the pressing needs in end-of-life care is the development of better models to enable physicians to give patients and their families reliable prognoses, and particularly, to let them know when further treatment will indeed be futile.

MYTH 5

It is common for older people to receive heroic, high-tech treatments at the end of life.

Fact: Only a fraction of people over age 65 receive aggressive care at the end of life. The older people are, the less likely they are to receive aggressive care when dying.

A terminally ill 90-year-old lives out his last weeks connected to tubes and a ventilator, his dying prolonged by a health care system infatuated with technology and insensitive to human suffering: This is a familiar image, one that haunts many people on a personal level and appears often in media coverage of death and dying.

It is easy to assume from this image that a high-tech, senselessly prolonged dying process is common in old age and that it is a major reason for rising Medicare costs. But are such deaths common? In fact, there are various ways to measure the aggressiveness of care for older persons, and all cast doubt on this assumption.

One measure of the aggressiveness of care is cost. Data from the Health Care Financing Administration show that about 6 to 8 percent of Medicare

enrollees die each year, and they account for about 27 to 30 percent of annual Medicare expenditures.^{1,2} About half of Medicare costs in the last year of life are incurred in the last 60 days and about 40 percent in the last 30 days.² These figures have strengthened the belief that older persons frequently receive intensive futile hospital care.

But a closer look at the Medicare data shows otherwise. While hospital care at the end of life does account for a large portion of Medicare costs, spending for aggressive care is not a major component of these costs. In fact, only about 3 percent of Medicare beneficiaries who die incur very high costs of the kind that suggest aggressive care.^{1,2}

In 1990, the Congressional Research Service reviewed existing studies and concluded that “analysis of expenditure patterns lends little support to the assertion that high technology medical care for the terminally ill contributes disproportionately to expenditures for those who die or to the argument that overall spending at the end of life is inordinately high and could be reduced.”³ The conclusion reached by analysts of the late 1980s and early 1990s that “the high cost of dying” is *not* the major reason why health care spending is increasing still appears to be true.^{2,4} This is evidenced by the fact that the portion of Medicare expenditure for patients in the last year of life has been stable for the last two decades.⁵

Figure 6

Estimated Total Costs and Length of Stay According to Age Group in Nonteaching vs. Teaching Hospitals

Age Group (Years)	NONTEACHING HOSPITALS		TEACHING HOSPITALS		Difference in Mean Total Cost Between Hospitals (Percent)
	Mean Total Costs (\$)	Mean Length of Stay (Days)	Mean Total Costs (\$)	Mean Length of Stay (Days)	
60–69	6,030	7.0	10,524	7.8	42.7
70–79	6,406	8.3	11,542	9.2	44.5
80–89	6,177	9.4	9,499	9.5	35.0
90–99	5,616	9.5	7,338	9.0	23.5
>100	5,330	9.8	6,198	8.3	14.0

Figure 7

Average Estimated Total and Ancillary Costs per Discharge to Age Group and Survivor Status at Discharge*

Age Group (Years)	DECEDENTS			SURVIVORS		
	Number of Patients	Total Costs (\$)	Ancillary Costs (\$)	Number of Patients	Total Costs (\$)	Ancillary Costs (\$)
60–69	7,387	16,886	9,463	201,939	6,981	3,705
70–79	13,467	14,917	8,059	241,820	7,163	3,470
80–89	12,887	10,557	4,654	157,481	6,492	2,622
90–99	4,050	6,977	2,737	34,866	5,784	2,044
>100	145	6,523	1,660	857	5,313	2,499

* P < .0001 for differences between decedents and survivors; for both total and ancillary costs, except for the age group of 100 or more years. Source: Perls TT, Wood ER. 1996. Acute care costs of the oldest old. Arch Intern Med 156:759.

Aggressiveness of Care vs. Age

Some of the data on this issue come from a long-term study of treatments and decision making for seriously ill hospitalized patients called SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment). The largest study ever to look at the care of critically ill and dying patients, SUPPORT collected data over a period of five years on 9,105 adults hospitalized with one or more of nine life-threatening diagnoses in five medical centers across the country. This study found that compared to patients who are younger than age 50, patients over 80 years of age are less likely to undergo three procedures representing aggressive care—major surgery, dialysis, and right heart catheter placement.⁶ This finding persisted even after adjusting for patient preferences for life-extending care. By a second measure—the overall intensity of care—older SUPPORT patients received fewer invasive procedures and fewer aggressive, resource-intensive, and costly care.

In fact, older patients may receive less aggressive care even when severity of illness and prior functional status are comparable to those of younger patients. One SUPPORT analysis found that “do not resuscitate” orders were written earlier (in the course of the study) for patients age 75 and older regardless of prognosis.⁷ These findings suggest, as the researchers note, that “physicians may be using age in a way that is inconsistent with the reported association between age and survival.”

Other researchers have looked at the question of age and aggressiveness of care from different perspectives and come up with similar conclusions. A preliminary study analyzing 0.1 percent of all Medicare claims for the years 1993 to 1998 showed that Medicare spending in the last year

of life is strongly associated with age. Medicare expenditures were 70 percent higher for those who were 65 to 69 compared to those who were 85 or over.⁸ In fact, the reported expenditures for younger decedents (65 to 69) was twice that of the oldest decedents (85 or over) for inpatient care and two and a half times for outpatient services. A different study examined the cause of this phenomenon and found that the decrease in expenditure for those 85 or over is due to the fact that the aggressiveness of medical care in the last year of life decreases with increasing age, as judged by less frequent hospital and intensive care unit admissions and by the markedly decreased use of cardiac catheterization, dialysis, ventilators, and pulmonary artery monitors, regardless of the cause of death.⁹

A study of Massachusetts hospital patients found that those age 90 and over tended to have conditions that involved less acute care than people in their sixties.¹⁰ Regardless of diagnosis, the oldest people in this study had lower rates of aggressive care than people ages 60 to 69. For example, they had lower ancillary charges (charges other than those for the hospital room, such as use of the operating room and radiology services). In addition, people age 80 and over in this study were less likely to be admitted to teaching hospitals and more likely to enter lower-cost community hospitals (Figures 6 and 7). Again it appears, as the SUPPORT researchers noted, that some informal age-based rationing of hospital care is in effect.

Functional Status vs. Age

Who receives aggressive, high-technology care at the end of life? A study of 261 patients in a group practice in Palo Alto, California, showed that high-tech care more often went to people with

good functional status (ability to carry out basic activities such as dressing and bathing) 12 months prior to death. In other words, quite reasonably, aggressive care was going to “the kind of patients a physician would not feel justified in not treating aggressively.”¹¹

Although total expenses did not differ substantially for the different functional groups in this study—the unimpaired, partially impaired, or totally impaired—costs by type or service did differ strikingly. Regardless of age, average hospital expenses were much higher for the unimpaired (\$18,000) than for the totally impaired (\$3,000) and the partially impaired (\$11,600). Physician costs for the totally impaired were about a third of those for the unimpaired. On the other hand, nursing home and home health care costs were sharply higher for the totally impaired than the unimpaired, offsetting their lower hospital and physician costs.¹¹

Finally, there is no evidence that aggressive care at the end of life is increasing, nor is there evidence that the cost of dying is growing and will overwhelm the health care system. What researchers did find suggests that physicians and hospitals are not blindly ordering heroic measures to prolong dying. Perhaps much of what was thought to be the “high cost of dying” was just the cost of providing regular care to those with severe illness and functional impairments.⁵ Providing care to the very sick is expensive. The more crucial issues for policymakers center on supportive care for the aged who are close to death. How should clinical decisions be made regarding when such care is appropriate, and how and when they should be provided? The increasing availability of palliative care programs in hospitals may provide valuable services to clinicians caring for seriously ill persons.

MYTH 6

Medicare covers everything that older adults need in terms of their health care.

Fact: Medicare does not cover several essential components of health care for older Americans.

As a result of technological innovation as well as the advent of myriad treatments for medical illness, life expectancy has grown sharply over the past 50 years. The percentage of older persons within the United States is likely to continue to rise. In fact, it is estimated that the portion of older persons within our population will increase from one in eight in 1994 to one in five by 2030.¹

As our collective population ages, more and more U.S. citizens depend on Medicare as their primary health insurance plan. The vast majority of them, however, incorrectly assume that Medicare will provide absolute financial support for their health care. In truth, Medicare covers only a fraction of the care that they will likely need.

Whereas far below 1 percent of our nonaged population suffers from dementia, approximately 6 to 10 percent of older Americans have dementia.² Thus, one unfortunate consequence of the increase in life expectancy within the United States is that the proportion of our population with dementia is on the rise. Progression of dementia usually goes hand in hand with dependency on others for custodial care. Those without family members willing to provide the needed level of care are compelled to seek out assistance from home health aides and nursing homes. Such assistance can be very expensive; in 2006, the average annual cost of nursing home care within the United States was more than \$75,000.³ The amount spent on home health care in 2002 was over \$26 billion. Seven out of ten patients who receive this care are ages 65 and

older. Nonetheless, Medicare pays for custodial services only in the setting of acute illness; it does not pay for long-term care.

With a growing population of older adults who are living longer with chronic illnesses, our nation will be faced with increasing numbers of older persons who become frail and homebound. When these individuals have an acute decompensation, they can receive home nursing care services. When they are dying (have a less than six-month prognosis), they are entitled to hospice care services. But if they are neither dying nor acutely ill, the frail aged may find themselves falling through the cracks of our health care system. They may not be able to obtain medical care because there are not enough doctors who make home visits. They may not qualify for skilled nursing services under Medicare regulations. This is a serious gap that will require attention. It would be useful to allow patients who are expected to live for 12 months to become eligible for hospice care, and to offer palliative care for the frail and homebound who are not dying.

In addition, the aged are the cohort within our population at highest risk for falling, as well as for sustaining injury from any one given fall. As a whole they have multiple risk factors for falling, including cognitive decline, poor vision, poor hearing, and gait impairment. In fact, balance among the aged population is so poor that 75 to 90 percent of disabled older community-dwelling adults require assistive technology such as canes, walkers, or wheelchairs.⁴ And although Medicare was designed for older Americans, it does not provide for hearing aids, general hearing care, eyeglasses, or eye exams (except for postcataract surgery⁵). Furthermore, Medicare has stringent criteria for coverage of wheelchairs, walkers, or canes under its Durable Medical Equipment (DME) benefits. As a result, more than half of the population of older

adults who require assistive technology for mobility pay for it out of pocket.⁴ And mobility equipment can be expensive; whereas the average cost of a cane was \$52 in 2001, the average power wheelchair cost more than \$6,000.⁴ Nor does Medicare cover routine dental care.

It is incumbent upon Medicare to educate the public about the services it covers as well as those it does not. Insurance coverage for long-term care is too expensive for most people once they reach the status of “older American.” As of now, approximately 16 percent of nursing home residents have been bankrupted by the cost of their care. Whereas at one point they were paying for their care out of pocket, they now rely on Medicaid for nursing home coverage.⁶ It is imperative that we find a way to allow nursing home-dependent, aged individuals to obtain the care they need without compromising all of their life savings. This will not happen unless the general public is apprised of Medicare’s shortcomings.

MYTH 7

If all older patients had living wills or other kinds of advance directives, it would resolve dilemmas of how aggressively to provide care.

Fact: Living wills and other forms of advance directives frequently have little impact on or relevance to end-of-life decision making. And physicians and other health care professionals often lack training to help them to empathically and effectively communicate with patients and family members about the options, potential outcomes, and time-limited trials.

Case: *R.F. is a 90-year-old retired business manager who has an aged wife and no children. He has moderate dementia, physical deconditioning, unsteady gait, and a progressing frailty syndrome. He fell at home*

and was hospitalized for hip fracture repair. He was then sent to subacute rehabilitation but made little progress. He returned to the hospital for urosepsis, acquired hospital-related infections, developed respiratory failure, and was placed on a breathing machine (life support). His kidneys also began to fail, and he received a feeding tube for artificial nutrition. His wife and nephew were told by the physician that there was no hope of his recovery, and R.F. was referred to hospice. During a family meeting, Mrs. F. told the team that R.F. had told her he “never wanted to be sustained by machines.” R.F. even clearly stated these wishes in his living will and health care proxy form. However, Mrs. F. felt powerless to honor these wishes because she felt she would be “pulling the plug” on R.F. With counseling and support from the hospice doctor and her nephew, Mrs. F. decided to stop the breathing machine the next day. The hospital intern and attending did not wish to stop the artificial feeding until the patient was “officially” a hospice patient, even though the patient had clear and convincing wishes and was fluid overloaded and extremely swollen. R.F. died the next day, with all the machines that he did not want.

Faced with medicine’s increasing ability to save and prolong lives with high-technology care, many people have turned to advance directives to guide decisions about use of such care in the event they are unable to make these decisions themselves. The Patient Self-Determination Act (PSDA) in 1990 mandated that health care institutions inquire about and document existing advance directives at the time of hospital or nursing home admission.

Have advance directives fulfilled their promise? Not so far, say researchers who have identified several barriers and challenges to their use. To say the least, advance directives discussions are complex, entailing multiple variables.

One of the barriers appears to be that advance directives are still not well integrated into our

health care system despite the passage of the PSDA. The prevalence of advance directives among the U.S. population varies between 5 percent and 35 percent. This statistic is well documented in SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment), a study that took place between 1989 and 1994 (encompassing the years before and after the passage and implementation of PSDA) and enrolled 9,105 patients who were seriously ill. In a subset of 2,162 seriously ill patients, less than a quarter (23 percent) had discussed preferences regarding cardiopulmonary resuscitation with their physicians; of those who had not had discussions, 58 percent were not interested in doing so.¹ In a study by Goodman et al. of 401 older patients admitted to the intensive care unit between 1992 and 1995, only 5 percent had advance directives.² Another study of critically ill cancer patients found that advance directives were completed in only 27 percent of cases.³ Furthermore, there are considerable variations in the acceptability and execution of advance directives among various ethnic groups, with higher acceptance rates among Caucasians as compared to African Americans, Hispanic Americans, and Asian Americans.⁴

A second barrier occurs even when advance directives are in place. These directives may not necessarily impact care or reduce resource utilization. According to Teno et al. in the SUPPORT study, chart documentation of existing advance directives increased with both the PSDA and the SUPPORT intervention.⁵ However, there was no corresponding change in hospital resource use. As a matter of fact, SUPPORT intervention patients with early documentation of advance directives showed a trend toward greater cost compared with those patients who had no advance directives documentation. In the Goodman study, the level of care delivered to older ICU patients was not affected by the presence or absence of advance directives statements.

For example, CPR was administered to 11 percent of the patients who died with advance directives that specifically stated they did not want CPR. Thirdly, advance directives should be more comprehensive than just the discussion of resuscitation. They need to elicit thinking about what kind of life is worth living and what is not; what are the physical and mental conditions that would impede a meaningful existence; what are the patient's personal experiences and what are the risks and benefits of various interventions. Tools, such as the POLST,⁶ the MOLST,⁷ Five Wishes,⁸ and the Halachic Living Will, are including these higher levels of discussions.⁹

A fourth challenge is improving the system by which hospitalized patients receive and complete advance directives. Currently, a patient is admitted to a hospital or nursing home and receives a package of materials, including advance directives.

Finally, because advance directives state care preferences in the setting of serious illness, all physicians and health care professionals must be trained in communication skills. If physicians and

practitioners cannot guide patients and surrogates in a compassionate and competent manner, offer options and alternatives, and support patients/families through difficult decision making, then all is for naught. Traditionally, medical professionals have not been properly educated about communications that involve goals of care. Adding to this mix is the uncertainty of prognosis in most illnesses, making these conversations all the more challenging.

The issue, in other words, is complex. Simply getting more patients to write advance directives, even getting more hospitals to incorporate them into patient records, may have little impact in the face of the aforementioned challenges and barriers. With the emergence of palliative care consult services in hospitals and long-term care facilities, more meaningful conversations about advance directives that can impact care may take place. Some key focus areas for research and debate are how and whether the improved advance planning tools can make a difference in a patient's clinical experience and whether palliative care consults can impact patients' care.

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