We have known for some time that medical care expenditures are especially high in the last months or year of life. In 1984, I published an article reviewing the available literature on medical care costs of persons who died and found studies as far back as the 1960s showing that patients who died used more medical resources and had higher medical expenses than patients who survived (Scitovsky 1984). Further studies in the 1970s confirmed these early findings and provided additional and more detailed information on the subject. It was not until the early 1980s, however, when the steady rise in national health expenditures (from 5.3 percent of GNP in 1960 to 9.2 percent in 1980) had aroused concern on the part of both policy makers and the general public, that the subject of the disproportionately high medical costs of persons who died attracted general attention. To quite an extent, the increased interest in and concern over what had come to be referred to as "the high cost of dying" (Ginzberg 1980) can be attributed to an article in Inquiry, by Lubitz and Prihoda (1984), which revealed that the 5.9 percent of Medicare enrollees who died in 1978 accounted for 27.9 percent of total Medicare expenditures in that year. This led many to conclude that we are wasting medical resources on the dying and to propose that, if we want to halt the rise in medical care...
costs, our efforts should concentrate on these high-cost elderly patients. For example, in a speech given in early 1984, Governor Lamm of Colorado expressed the opinion that "we've got a duty to die and get out of the way with all our machines and artificial hearts and everything else like that and let the other society, our kids, build a reasonable life" (Lamm 1984). In a similar vein, the ethicist Daniel Callahan, in 1987, proposed that over the next 20 to 30 years we should be prepared to make a "societal decision deliberately to limit life-extending high-technology care for those who have lived out a natural life span," which he set at the late 70s or early 80s (Callahan 1987).

Several other studies published in the 1980s produced much the same findings as the 1984 Lubitz and Prihoda study (Long et al. 1984; McCall 1984; Spector and Mor 1984; Riley et al. 1987; Roos, Montgomery, and Roos 1987; Riley and Lubitz 1989; Scitovsky 1988; Gaumer and Stavins 1992; Temkin-Greener et al. 1992). Most recently, a new study by Lubitz and Riley (1993) provides data on medical costs in the last year of life of Medicare enrollees who died in 1976, 1980, 1985, and 1988. Its principal purpose was to determine whether the proportion of Medicare payments that is accounted for by people in the last year of life had changed over time. If such payments were found to have increased more rapidly than overall Medicare payments, this would indicate that more attention should be given to the care provided to patients in their last year of life. What the data showed, however, was that although Medicare payments per person increased nearly fourfold both among all elderly persons and among decedents between 1976 and 1988, the percentage of total dollars spent for decedents changed little, fluctuating between 27.2 percent (1988) and 30.6 percent (1980), with the percentage of decedents fluctuating between 5.1 percent (1988) and 5.4 percent (1980) of all Medicare enrollees. Thus, to quote Lubitz and Riley, "Apparently, the same forces that have acted to increase overall Medicare expenditures— inflation, new techniques, and greater intensity of care—have affected care both for decedents and for survivors" (1993, 1094).

In this article, I shall discuss what we have learned in the past decade or so about medical care use and costs at the end of life. In particular, I shall discuss what we know about the characteristics of decedents with especially high costs. There are few data on costs at the end of life for persons under 65 years in the United States, largely because—unlike the elderly—they are not covered by a single health insurance program that makes the collection of data comparatively simple. As a result, most of
the data I shall present are limited to the elderly and, in addition, refer to Medicare services only. The fact that they are limited to the elderly is not too serious a problem because just over 70 percent of all deaths in a given year are persons 65 years and older. The fact that they refer only to services paid for by Medicare is a more serious limitation because Medicare covers primarily inpatient hospital care and physician services while paying only a small fraction of nursing-home costs, a limited amount of home health care costs, and nothing for drugs. In 1987, for example, Medicare paid for 69.7 percent of the elderly's expenses for hospital care, 60.6 percent of their expenses for physician services, only 1.7 percent of their nursing-home costs, and 14.7 percent of their costs for other personal health care. Overall, it paid for 44.6 percent of the elderly's total personal health care expenditures (Waldo et al. 1989). These limitations should be borne in mind when evaluating the data that follow.

Medical Care Costs at the End of Life

Review of the Studies

The 1993 Lubitz and Riley study makes a good starting point for the discussion of the medical care costs of the elderly at the end of life. Although Medicare payments per person-year had risen sharply between 1976 and 1988 for both decedents and survivors, the 1988 data show much the same patterns as those for the earlier years. The 5.1 percent of decedents (1.49 million of a total of 29.1 million beneficiaries) who died in 1988 accounted for 27.2 percent of total Medicare payments of $73.5 billion in that year. Medicare payments per person-year were almost seven times higher for decedents in their last year of life than for survivors during that year: $13,316 compared with $1,924. About half of all Medicare costs in the last year of life were incurred in the last 60 days of life, and 40 percent were for the last 30 days. This concentration of medical costs in the last months of life was also found in several earlier studies (Lubitz and Prihoda 1984; McCall 1984; Long et al. 1984; Spector and Mor 1984; Riley et al. 1987).

To examine the data in more detail, table 1 shows Medicare payments per person-year for decedents and survivors by age. While payments for survivors increased with age, those for decedents decreased. Thus the gap between the average payments of the two groups narrowed substantially
TABLE 1
Medicare Payments per PersonYear, by Survival Status and Age, 1988

<table>
<thead>
<tr>
<th>Age</th>
<th>Mean payments per personyear</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Decedents</td>
</tr>
<tr>
<td>65-69</td>
<td>$15,346</td>
</tr>
<tr>
<td>70-74</td>
<td>15,778</td>
</tr>
<tr>
<td>75-79</td>
<td>14,902</td>
</tr>
<tr>
<td>80-84</td>
<td>12,838</td>
</tr>
<tr>
<td>85-89</td>
<td>11,422</td>
</tr>
<tr>
<td>90+</td>
<td>8,888</td>
</tr>
<tr>
<td>Total</td>
<td>13,316</td>
</tr>
</tbody>
</table>


with increasing age: payments for decedents aged 65 to 69 years were almost 11 times higher than those for survivors of the same age, whereas payments for the oldest decedents, aged 90 and over, were only four times higher than those for survivors.

Table 2 shows the percentage distribution of Medicare payments by type of service and age. Payments for inpatient hospital care and for physician services accounted for about 90 percent of payments for both decedents and survivors. Inpatient hospital care, however, accounted for 70 percent of payments for decedents compared with 53 percent for survivors. For both groups, the percentage accounted for by inpatient hospital care was stable up to age 84, but it then rose slightly for enrollees aged 85 years and older. Payments for physician services accounted for 20 percent of payments for decedents and 34 percent for survivors. As in the case of inpatient hospital care, the percentage of payments accounted for by physician services changed little up to age 84; in contrast to inpatient hospital care, however, it declined slightly for the oldest enrollees.

Table 3 shows Medicare payments by payment intervals and illustrates the very different cost patterns of decedents compared with survivors. Only 3.1 percent of decedents had no Medicare payments in their last year of life compared with 22.9 percent of survivors. Payments for decedents were concentrated in the $5,000 to $20,000 payment class (43.7 percent), whereas those for survivors were concentrated in the $1 to $1,000
### TABLE 2
Percentage Distribution of Medicare Payments by Type of Service, Survival Status and Age, 1988

<table>
<thead>
<tr>
<th>Type of service</th>
<th>Age and survival status</th>
<th>Inpatient hospital</th>
<th>Physician</th>
<th>Skilled nursing</th>
<th>Home health</th>
<th>All other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total 100.0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>65 and older, all</td>
<td>70.3</td>
<td>20.2</td>
<td>1.8</td>
<td>2.5</td>
<td>5.1</td>
</tr>
<tr>
<td>Survivors</td>
<td>53.2</td>
<td>34.1</td>
<td>1.1</td>
<td>2.5</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>65-69</td>
<td>69.8</td>
<td>20.6</td>
<td>0.8</td>
<td>2.1</td>
<td>6.8</td>
</tr>
<tr>
<td>Survivors</td>
<td>53.3</td>
<td>34.7</td>
<td>0.4</td>
<td>1.5</td>
<td>10.2</td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>70-74</td>
<td>70.2</td>
<td>20.8</td>
<td>1.2</td>
<td>2.2</td>
<td>5.7</td>
</tr>
<tr>
<td>Survivors</td>
<td>53.2</td>
<td>34.8</td>
<td>0.6</td>
<td>1.9</td>
<td>9.5</td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>75-79</td>
<td>70.0</td>
<td>20.5</td>
<td>1.6</td>
<td>2.6</td>
<td>5.3</td>
</tr>
<tr>
<td>Survivors</td>
<td>52.7</td>
<td>34.6</td>
<td>0.9</td>
<td>2.6</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>80-84</td>
<td>69.8</td>
<td>20.2</td>
<td>2.3</td>
<td>2.9</td>
<td>4.8</td>
</tr>
<tr>
<td>Survivors</td>
<td>52.5</td>
<td>34.0</td>
<td>1.6</td>
<td>3.3</td>
<td>8.6</td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>85-89</td>
<td>71.5</td>
<td>19.1</td>
<td>2.8</td>
<td>2.9</td>
<td>3.7</td>
</tr>
<tr>
<td>Survivors</td>
<td>54.7</td>
<td>31.4</td>
<td>2.4</td>
<td>3.9</td>
<td>7.6</td>
<td></td>
</tr>
<tr>
<td>Decedents</td>
<td>90 and older</td>
<td>71.7</td>
<td>19.0</td>
<td>3.2</td>
<td>2.9</td>
<td>3.3</td>
</tr>
<tr>
<td>Survivors</td>
<td>56.3</td>
<td>29.2</td>
<td>3.3</td>
<td>4.5</td>
<td>6.6</td>
<td></td>
</tr>
</tbody>
</table>

* Percentages may not add to 100.0 because of rounding.


class (48.9 percent). However, only a small proportion of decedents had the kind of high expenses that would suggest aggressive, high technology medical services such as the use of intensive care units (ICUs) or respirators (or, alternatively, several hospitalizations) in their last year of life. If we assume that per capita Medicare payments of $40,000 per year (roughly three times the average last-year-of-life Medicare payment) or more represent this type of care, only about 73,000 decedents, or 4.9 percent of all decedents, had such high costs. Moreover, it should be
TABLE 3
Percentage Distribution of Medicare Enrollees and Medicare Reimbursements in the Last Year of Life, by Survival Status and Reimbursement Level, 1988

<table>
<thead>
<tr>
<th>Reimbursement Level (dollars)</th>
<th>Decedentsa</th>
<th></th>
<th></th>
<th>Survivorsa</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Enrollees 100.0 (n = 1.49 million)</td>
<td>Reimbursements 100.0 (n = $19.9 billion)</td>
<td></td>
<td>Enrollees 100.0 (n = 27.61 million)</td>
<td>Reimbursements 100.0 (n = 53.6 billion)</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3.1</td>
<td>0.0</td>
<td></td>
<td>22.9</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>1–999</td>
<td>14.5</td>
<td>0.4</td>
<td></td>
<td>48.9</td>
<td>6.9</td>
<td></td>
</tr>
<tr>
<td>1,000–4,999</td>
<td>18.7</td>
<td>4.7</td>
<td></td>
<td>17.5</td>
<td>22.4</td>
<td></td>
</tr>
<tr>
<td>5,000–9,999</td>
<td>20.9</td>
<td>12.2</td>
<td></td>
<td>5.5</td>
<td>19.7</td>
<td></td>
</tr>
<tr>
<td>10,000–19,999</td>
<td>22.8</td>
<td>26.4</td>
<td></td>
<td>3.5</td>
<td>24.9</td>
<td></td>
</tr>
<tr>
<td>20,000–29,999</td>
<td>10.7</td>
<td>20.7</td>
<td></td>
<td>1.1</td>
<td>12.9</td>
<td></td>
</tr>
<tr>
<td>30,000–39,999</td>
<td>4.5</td>
<td>12.4</td>
<td></td>
<td>0.4</td>
<td>6.4</td>
<td></td>
</tr>
<tr>
<td>40,000–49,999</td>
<td>2.3</td>
<td>8.3</td>
<td></td>
<td>0.2</td>
<td>3.4</td>
<td></td>
</tr>
<tr>
<td>50,000–59,999</td>
<td>1.1</td>
<td>4.7</td>
<td></td>
<td>0.1</td>
<td>1.6</td>
<td></td>
</tr>
<tr>
<td>60,000–69,999</td>
<td>0.7</td>
<td>3.6</td>
<td></td>
<td>&lt;.1</td>
<td>1.7</td>
<td></td>
</tr>
<tr>
<td>70,000–79,999</td>
<td>0.2</td>
<td>1.1</td>
<td></td>
<td>&lt;.1</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>80,000 and over</td>
<td>0.6</td>
<td>5.5</td>
<td></td>
<td>&lt;.1</td>
<td>0.7</td>
<td></td>
</tr>
</tbody>
</table>

a Percentages may not add to 100.0 because of rounding.


noted that almost the same number of survivors—about 70,000—also had such high Medicare payments. It is easy enough in retrospect to regard those who died as terminal or dying patients. It is a different matter, however, to do so prospectively. Despite the enormous advances in medical technology (or possibly because of them), medical prognosis in most serious illnesses is still highly uncertain. Except in the case of cancer patients, predicting imminent death is often possible only a few days before death, while predicting death with any degree of certainty weeks or months before death is almost impossible.

The data also show that decedents under age 80 received a disproportionate share of Medicare payments. Although 49.7 percent of decedents were less than 80 years old, they accounted for 59.9 percent of payments. Decedents under age 80 also were disproportionately represented among high-cost decedents, constituting 74.0 percent of decedents with Medicare payments of $40,000 or more. The percentage of under-80-year-old,
The cost of dying goes up as the payment threshold is raised. For example, of decedents with Medicare payments of $50,000 or more, 75.3 percent were less than 80 years old. These findings are another way of revealing the decline in the intensity of medical care with increasing age of persons who die that was illustrated by the data in table 1. By contrast, the data for survivors show (as did the data in table 1) that the intensity of medical care increases with age. Although constituting only 23.5 percent of all survivors, those aged 80 years and older accounted for 30.1 percent of all Medicare payments for survivors.

The Lubitz and Riley article does not give data on Medicare payments in the last year of life by cause of death. However, an earlier article provides detailed information on this subject for 1979 (Riley et al. 1987). Table 4 presents an abbreviated version of one of the tables in this article.

**TABLE 4**

Medicare Payments per Enrollee, per Survivor, and per Decedent in the Last Year of Life, by Selected Causes of Death and Age, 1979

<table>
<thead>
<tr>
<th>Survival status and cause of death</th>
<th>Total</th>
<th>65-74</th>
<th>75-84</th>
<th>85 and older</th>
</tr>
</thead>
<tbody>
<tr>
<td>All aged</td>
<td>$ 989</td>
<td>$ 817</td>
<td>$1,192</td>
<td>$1,398</td>
</tr>
<tr>
<td>All survivors</td>
<td>772</td>
<td>662</td>
<td>919</td>
<td>1,015</td>
</tr>
<tr>
<td>All decedents</td>
<td>5,191</td>
<td>6,114</td>
<td>5,310</td>
<td>3,833</td>
</tr>
<tr>
<td>Malignant neoplasms</td>
<td>8,021</td>
<td>8,335</td>
<td>7,873</td>
<td>5,670</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>5,634</td>
<td>6,063</td>
<td>5,535</td>
<td>4,991</td>
</tr>
<tr>
<td>Major cardiovascular diseases</td>
<td>4,112</td>
<td>4,429</td>
<td>4,366</td>
<td>3,464</td>
</tr>
<tr>
<td>Diseases of heart</td>
<td>4,018</td>
<td>4,172</td>
<td>4,263</td>
<td>3,499</td>
</tr>
<tr>
<td>AMI</td>
<td>3,170</td>
<td>3,134</td>
<td>3,286</td>
<td>2,998</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>4,324</td>
<td>5,343</td>
<td>4,533</td>
<td>3,393</td>
</tr>
<tr>
<td>Atherosclerosis</td>
<td>3,874</td>
<td>5,529</td>
<td>4,542</td>
<td>3,007</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>5,005</td>
<td>7,133</td>
<td>5,471</td>
<td>3,685</td>
</tr>
<tr>
<td>COPD</td>
<td>7,044</td>
<td>7,973</td>
<td>6,819</td>
<td>4,761</td>
</tr>
<tr>
<td>Chronic liver disease</td>
<td>7,111</td>
<td>7,547</td>
<td>5,722</td>
<td>- ^a</td>
</tr>
<tr>
<td>Nephritis</td>
<td>8,362</td>
<td>12,360</td>
<td>7,735</td>
<td>5,031</td>
</tr>
<tr>
<td>Accidents</td>
<td>4,508</td>
<td>4,236</td>
<td>4,777</td>
<td>4,512</td>
</tr>
</tbody>
</table>

^a An estimate is not given owing to small sample size.

Abbreviations: AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease.

cle. Like the other studies of costs in the last year of life, it shows that Medicare payments per enrollee were substantially higher for decedents than for survivors, the average payment per decedent being $5,191 compared with $772 for survivors.

Of the decedents with above average Medicare payments, those dying of nephritis rank first, with average Medicare payments of $8,362, or 61 percent more than the average for all decedents. This high payment is partly due to the fact that about 7 percent of these decedents were end-stage renal disease (ESRD) patients. Beneficiaries who died of malignant neoplasms had the second highest per capita payments: $8,021, or 55 percent more than the average. Other decedents with above-average costs were those dying of chronic obstructive pulmonary disease (COPD) and chronic liver disease. At the opposite end of the scale, beneficiaries dying of heart disease, cerebrovascular disease, and atherosclerosis had below-average payments ($4,018, $4,324, and $3,874, respectively). Beneficiaries dying of acute myocardial infarction (AMI) had the lowest per capita Medicare payments, $3,170, due in part to the many sudden deaths in this group. Beneficiaries who died as a result of accidents also had below-average costs, $4,508, probably because of deaths that occurred before they reached the hospital.

Decedents who died from the causes that were associated with the highest per capita costs also represented an above average portion of high-cost users. Defining payments of $10,000 as the high-cost threshold, 17 percent of all decedents were high-cost users, compared with only 1 percent of survivors. By cause of death, the percentage of decedents whose costs exceeded $10,000 was 29 percent for those dying of malignant neoplasms and of nephritis and 24 percent for those dying of COPD and chronic liver disease.

Like the data on total Medicare payments per decedent by age, the data by cause of death in general also show a decline with age. Overall, payments per decedent in the youngest age group (65 to 74 years) were 60 percent higher than those for decedents in the oldest age group (85 years and over). For a few causes the differences were substantially larger. For example, in the case of deaths from nephritis, the youngest decedents had two-and-a-half times the average Medicare payments of the oldest group; the very high costs of the youngest group ($12,360 per decedent) suggest that this group may have included the majority of the ESRD decedents. To give another though less striking example, decedents in the youngest age group dying of pneumonia had payments that
The High Cost of Dying Revisited

were about twice those of the oldest age group. By contrast, for a few causes the differences were small. In the case of deaths from heart disease, payments for decedents in the youngest age group were only 19 percent higher than those for decedents in the oldest group. For deaths from accidents, costs of the oldest age group were somewhat higher than those of the lowest group.

Finally, the data—like data from other studies—show that Medicare expenses in the last year of life are heavily concentrated in the last weeks. For all decedents, about 36 percent of expenses in the last year were incurred in the last 30 days, 14 percent in days 31–60 before death, and 9.4 percent in days 61–90. Despite the substantial differences in expenses in the last year of life among the major causes of death, there was little difference in the distribution of expenses by time before death. (It should be noted, as the authors point out, that although on a per capita basis death from cancer was almost twice as expensive as death from heart disease, expenses for all deaths from heart disease—because of their greater number—accounted for 8.2 percent of total Medicare expenses in 1979 compared with 7.2 percent for cancer.)

The studies discussed so far have focused on Medicare payments in the last year of life. To gain a broader perspective, a few studies have explored medical care costs over a longer time period before death. In fact, the 1984 Lubitz and Prihoda study included data not only for the last year of life (1978) but also for the second-to-last year (1977). If Medicare payments for the two years are combined, the ratio of average payments per decedent to payments per survivor drops to 4.4, from 6.2 in the last year of life. Put differently, the 5.9 percent of Medicare beneficiaries who died in 1978 and who accounted for 27.9 percent of Medicare payments in that year accounted for only 21.5 percent of Medicare payments in the two years. Thus, even extending the time span by just one year results in a somewhat lower concentration of expenditures on a small fraction of the population.

Data on medical care use over a longer time span before death reduces the concentration of expenses still further. Roos, Montgomery, and Roos (1987) examined medical care utilization for four years before death of 4,263 decedents aged 45 years and older covered by Manitoba's comprehensive provincial health insurance system who died between July 1974 and June 1976. They found that although the decedents' health care utilization, compared with that of the general population and with that of survivors (i.e., the general population minus decedents), was substan-
tially above average in all four years before death, the differences were
greatest in the year prior to death but declined with each additional year
before death. For example, in the year prior to death, decedents spent
11 times as many days in the hospital as the general population and 23
times as many days as survivors, whereas in the fourth year before death
decedents spent only two-and-a-half times as many days in the hospital
as the general population and five-and-a-half times as many days as sur­
vivors. The steepest rise occurred in the year before death for all age
groups and both sexes. The patterns of nursing-home use and of physi­
cian services are similar though much less dramatic than the pattern of
hospital use.

A study of longitudinal patterns of Medicare use by cause of death
tracked Medicare utilization and expenses retrospectively to 1974 for a 5
percent sample of Medicare beneficiaries aged 65 years and older who
died in 1979 (Riley and Lubitz 1989). Findings are reported for all dece­
dents and for those who died of the specific causes selected in the 1987
study by Riley et al. "Reimbursement ratios," which are the ratios of av­
erage cause-of-death-specific reimbursements to average reimbursements
for all beneficiaries (survivors and decedents) in each year, were calcu­
lated for each of the six years. A ratio above 1 indicates that per capita
reimbursements for a given cause of death were above the Medicare aver­
age in that year.

Table 5 shows the findings for all decedents. In the last calendar year
of life, reimbursement ratios of all decedents rose from 1.02 in the fifth
year before death (not significantly different from average Medicare pay­
ments) to 4.31 in the year of death. Patterns of expense varied considerably
over time among the various causes of death. For example, reimburse­
ment ratios for malignant neoplasms were highest in the year of death
(6.62) and the first calendar year prior to the year of death (3.92), but
decreased rapidly for preceding years. By contrast, persons dying of dia­
abetes, COPD, pneumonia, chronic liver disease, and nephritis showed a
pattern of high use of services over a longer period. For example, the re­
imbursement ratio of persons dying of diabetes was 1.62 in the fifth year
before death; it rose slowly to 4.66 in the last year. The most costly
causes of death on a per capita basis over the entire six-year period before
death were the same ones that were found to be the most costly in the
year before death; this finding applies to the least costly causes of death
as well.
The most recent study on this subject is a 16-year longitudinal study that follows three age cohorts of Medicare beneficiaries (aged 65, 75, and 85, respectively, in 1974) and examines separately those who died during this period and those who survived (Gornick, McMillan, and Lubitz 1993). Comparing Medicare payments for decedents in the 65-year cohort who died in 1989 (i.e., decedents who were alive all 16 years) with those for survivors in this cohort, the authors found that per capita Medicare payments (adjusted to 1989 dollars) over this period were $44,434 for beneficiaries who died compared with $20,897 for survivors, or a ratio of 2 to 1. The study also showed that, among decedents in this cohort, the distribution of beneficiaries by level of lifetime Medicare payments was less skewed compared with that of payments in the terminal 12 months of life. About 30 percent of decedents had lifetime payments under $10,000; about 63 percent, payments under $30,000; about 82 percent, payments under $50,000; and about 92 percent, payments under $75,000.

It should be noted that although a decedent-to-survivor expenditure ratio of 2 to 1 over a 16-year period is considerably less than the ratio of about 7 to 1 found in studies that compare Medicare payments for dece-
dent in the last 12 months of life with payments for survivors, it is still a substantial difference. Moreover, the study showed that for members of the 65-year cohort who died in 1989, per capita payments as far back as 1975 were already higher than for those still alive in 1989; the authors estimate that costs in the final 12 months accounted for 33 percent of this cohort's lifetime Medicare payments.

Limitations of the Studies

These are the principal studies of the use and costs of medical services in the last year or years of life of the elderly that have been published in the past 10 years. They have two major limitations: (1) With the exception of the studies by Roos, Montgomery, and Roos (1987) and by Scitovsky (1988), all are based on Medicare data and therefore cover primarily hospital inpatient care and physician services but practically no nursing-home care; and (2) none provide any information that would permit an evaluation of the appropriateness of the services rendered.

Exclusion of Services Not Covered by Medicare. Although the authors of the various studies have been careful to stress that the data refer to the use of Medicare-covered services only, there has nevertheless been some tendency to conclude that total medical care costs of elderly decedents decrease with age. A small number of studies, however, which provide some data on all medical care at the end of life, have shown that this is likely to be a misconception.

Roos, Montgomery, and Roos (1987), in the study referred to earlier, based on data for decedents covered by Manitoba's comprehensive provincial health insurance system, estimated that in the four years before death, decedents aged 85 years and older had health expenditures that were 29 percent higher than those of decedents aged 75 to 84 years, 74 percent higher than those of decedents aged 65 to 74 years, and twice those of decedents aged 45 to 64 years. Although the authors warn that the dollar estimates may overstate expenditures, especially those of the oldest group, the data on the use of different medical services clearly indicate that death at older ages is likely to be more rather than less costly. The use of hospital services was somewhat lower for those aged 85 years and over than for decedents aged 75 to 84 years (a mean of 88.7 days compared with 89.9 days), but higher than for those aged 65 to 74 years (78.2 days) and 45 to 64 years (65.2 days). The mean number of physician visits decreased steadily with age, from an average of 29.0 visits for
the youngest group (45 to 64 years) to 19.6 for the oldest (85 years and over). Nursing-home care, however, increased dramatically from a mean of 22.6 days for decedents aged 45 to 64 years to 55.7 days for those aged 65 to 74 years, to 181.8 days for those aged 75 to 84 years, to 419.3 days for those aged 85 years and over. The corresponding figures for use of services in the last year of life, calculated on the basis of detailed tables by age and sex in the article, are (in the order by age groups 45–64 years, 65–74 years, 75–84 years, and 85 years and over): hospital services (mean days): 31.4, 42.2, 47.4, and 42.2; nursing home (mean days): 8.1, 20.9, 69.5, and 120.6; and physician visits: 9.2, 9.7, 7.8, and 5.8.

Scitovsky (1988) studied the use and costs of all medical services in the last year of life received by 261 patients of a large multispecialty, predominantly fee-for-service group practice who died in the period January 1983 through August 1984; of these, 216 were 65 years or older. The under-65-year old decedents and those aged 65 to 74 years had almost identical medical expenditures in their last year of life. Although, like the study by Roos, Montgomery, and Roos, this study includes nursing-home costs, the data showed that the medical costs in the last year of life of the "old old" (80 years and older) were about 80 percent of the costs of the "young old" (65–79 years). However, the two groups showed a very different pattern of use of different medical services. Whereas the older group’s hospital expenses were 50 percent and their expenses for physician services were 46 percent of the corresponding expenses of the younger group, their expenses for nursing-home and home health care services were 2.5 times those of the younger group.

A more recent study, by Temkin-Greener et al. (1992), compared the use and costs of medical services at the end of life by decedents who were eligible for Medicare only (MO) and decedents who were dually eligible for Medicare and Medicaid (DE). The study population consisted of the 4,349 Medicare recipients who died in 1988 in Monroe County, New York, of whom 3,304 were MO and 1,045 DE.

The study showed that, in the year of death, when decedents had on average six months of exposure, payments declined with age for both the MO and the DE decedents. However, when payments in the year prior to the year of death (1987) are also counted (i.e., payments covering 18 months prior to death), the age differential persisted only for the MO decedents, whereas DE decedents had much the same payments regardless of age: an average of $40,471 for the 65–74 year group, $40,005 for the 75–84 year group, and $40,582 for the oldest decedents 85 years and
older. The principal reason for this difference was the use of nursing-home care by the DE decedents, which rose steeply with age, representing 62 percent of costs of the 85-year-and-older decedents, compared with 24 percent of those of the youngest (65-74 years). Thus the data indicate that the older decedents received largely supportive care, whereas the younger decedents received the generally more intensive care provided by hospitals.

The study also examined annual per capita payments over the four calendar years prior to death and, following the methodology of Riley and Lubitz (1989), compared them with those of the general population and of survivors. The data for both MO and DE decedents showed that higher than average use of services extended well before the calendar year of death, but especially in the case of the youngest decedents (65-74 years). The authors conclude that this higher-cost use of the younger decedents over a longer period of time indicates "either a prolonged spell of illness or a more intensive pattern of use of acute services, compared with persons who die at older ages" (Temkin-Greener et al. 1992, 688), and that the older decedents, although "they may have more disability, as evidenced by their reliance on nursing home care, prior to death than do the younger decedents . . . may have lower rates of acute disease requiring hospitalization" (699). I shall return to this point later.

Finally, the data showed that almost 46.8 percent of the MO decedents and 70.5 percent of the DE decedents had no hospitalization in their last calendar year of life, and that their cost of care was only 60 percent higher than the cost for the general elderly population. This suggests that a substantial proportion of elderly decedents make relatively small demands on the health care system in their last year of life.

The authors warn that the findings for the DE decedents cannot necessarily be generalized to all elderly decedents because the DE elderly have been shown to have greater health needs than other elderly persons. However, in view of their finding that Medicare reimbursements for the DE and MO decedents were similar, they suggest that the medical care use and cost patterns of DE decedents may not be too different from those of other elderly decedents.

Because these last three studies suggest that the decline in per capita Medicare payments for decedents with increasing age is at least to some extent attributable to the program's exclusion of most nursing-home costs, I have made an attempt to estimate what the national distribution of costs in the last year of life by age group would be if noncovered
nursing-home costs were included. My estimates are in terms of charges because data on costs or expenditures by type of service and age of decedent are not available. My estimates of the number of elderly with a nursing-home stay, their age distribution, and their length of nursing-home stay are based on data from the 1986 National Mortality Follow-back Survey (U.S. Department of Health and Human Services 1992), and my estimate of nursing-home charges derived from data in "Nursing Home Utilization by Current Residents: United States 1985" (U.S. Department of Health and Human Services 1989), which were inflated to 1988 prices by using the medical care component of the Consumer Price Index. Data on Medicare payments for skilled nursing-home care were obtained from the Health Care Financing Administration (Gerald Riley: personal communication). Per capita Medicare payments were converted into charges on the basis of data on decedents' liability for coinsurance and deductibles from the 1984 article by Lubitz and Prihoda.

The results, presented in table 6, show that, when nursing-home charges are included, differences between the three age groups disappear, and, if anything, are reversed, with per capita charges rising slightly with age. As the share of primarily acute-care services covered by Medicare declines, the share of nursing-home charges rises from 6.6 percent for decedents aged 65 to 74 to 40.4 percent for those aged 85 and older.

It must be emphasized that these are very rough estimates, both because of the nature of the data on which they are based and because of the factors that are omitted. For example, with regard to the latter, the estimates of Medicare charges do not include possible charges of hospitals, and especially physicians, above the Medicare-approved amounts. The estimates also do not include charges for other goods and services not covered by Medicare, such as drugs. Nevertheless, both these estimates and the studies cited above suggest strongly that, when all medical services are included, it is unlikely that costs at the end of life are significantly lower for the very old than for the younger old.

Lack of Information on Appropriateness of Care. The other major limitation of the studies conducted to date is that they do not provide any information that would permit an evaluation of the appropriateness of the care received by elderly patients who died. Only one rather small study addressed this issue. In my study cited earlier (Scitovsky 1988), I obtained (in addition to data on total medical care expenditures of the 261 decedents in my study) data on the functional status over the course of the last 12 months of life of the 216 decedents who were 65 years old
TABLE 6
Estimated per Capita Medical Care Charges in the Last Year of Life
Including Nursing-Home Charges, by Age Group, 1988

<table>
<thead>
<tr>
<th></th>
<th>65–74 years</th>
<th>75–84 years</th>
<th>85 and older</th>
<th>All 65 and older</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Estimated nursing-home charges excluding Medicare skilled nursing-home payments(^a)</td>
<td>$1,215</td>
<td>$3,417</td>
<td>$7,561</td>
<td>$3,987</td>
</tr>
<tr>
<td>2. Medicare payments(^b)</td>
<td>15,632</td>
<td>13,887</td>
<td>10,208</td>
<td>13,316</td>
</tr>
<tr>
<td>3. Estimated Medicare approved charges(^c)</td>
<td>17,226</td>
<td>15,303</td>
<td>11,249</td>
<td>14,674</td>
</tr>
<tr>
<td>4. Estimated total charges (1 + 3)</td>
<td>18,441</td>
<td>18,720</td>
<td>18,810</td>
<td>18,661</td>
</tr>
</tbody>
</table>

\(^a\) Estimated on the basis of utilization data from the "National Mortality Follow-back Survey: 1986 Summary" (U.S. Department of Health and Human Services 1992) and on charge data from "Nursing Home Utilization by Current Residents: United States, 1985" (U.S. Department of Health and Human Services 1989). Per capita Medicare skilled nursing payments were $158 (age 65–74), $269 (75–84), $304 (85 and older), and $245 (all 65 and older) (Gerald Riley: personal communication).

\(^b\) Lubitz and Riley (1993).

\(^c\) Based on data on Medicare decedents’ amounts of liability for coinsurance and deductibles in their last year of life (Lubitz and Prihoda 1984). These data showed that liability for coinsurance and deductibles were the equivalent of 10.2 percent of total Medicare payments for decedents. Because the data were not available by age group, we have increased each group’s per capita Medicare payment by 10.2 percent. It should be noted that these figures are not estimated total charges for Medicare services because patients may have had to pay more than their share for Medicare services, especially for physician services.

or older. This information was obtained in personal interviews with the decedents’ next of kin. To measure functional status, the study used the standard questions on activities of daily living (ADL), instrumental activities of daily living (IADL), and cognitive status. On the basis of this information, decedents were grouped into three categories: (1) unimpaired all 12 months, (2) partially impaired all or part of the 12 months, and (3) totally impaired all 12 months. The unimpaired decedents were defined as those who could perform all functions of the ADL without help all 12 months before death (or until their final hospitalization if they died in the hospital), the totally impaired were those unable to perform any of these activities all of the 12 months, and the partially impaired were all others. (The answers to the ADL were used in the final
analysis because the other two measures resulted in much the same grouping of the decedents.) About one-fourth of the decedents fell into each of the two extreme groups (unimpaired and totally impaired); the rest belonged in the partially impaired group.

Mean medical expenditures in the last 12 months of life of decedents in the three groups were surprisingly similar: $23,000 for the unimpaired, $22,000 for the partially impaired, and $21,400 for the totally impaired. However, they differed widely in the distribution of expenditures by type of service. Hospital care represented 78 percent of the total costs of the unimpaired, 53 percent of those of the partially impaired, and only 17 percent of those of the totally impaired. By contrast, nursing-home and home health care accounted for less than 1 percent of the costs of the unimpaired, 22 percent of the costs of the partially impaired, and 70 percent of the costs of the totally impaired. In other words, the intensity of care as represented by hospital care declined steeply with declining functional status—although this did not result in any substantial cost savings because the increase in the use of nursing-home and home health care consumed most of the savings from reduced hospital use.

When the data for the three groups were broken down into two age groups, those 65 to 79 years old (the “young old”) and those 80 years old and older (the “old old”), they showed that the most expensive decedents were the unimpaired and partially impaired “young old,” with mean expenditures of $26,200 and $26,600, respectively, and the totally impaired “old old,” with mean expenditures of $24,000, the former because of their high hospital expenses ($21,000 and $16,000, respectively), the latter because of their high nursing-home and home health expenditures ($18,000). It is of interest to note that, whereas the intensity of care as indicated by hospital expenditures was very much less for the unimpaired and partially impaired “old old” than for the “young old,” hospital expenditures for the totally impaired younger and older decedents were virtually identical (about $3,000).

The study is a small one, and the predominantly white and middle-class study population is not representative of all elderly decedents in the United States. Nevertheless, as I concluded, it “suggests that despite the generally recognized difficulties of predicting when death will occur, and in the absence of a formal rationing program such as the one suggested by Callahan or institutional constraints on the use of medical resources, high-cost medical services may already be allocated to the el-
...derly in their last year of life in a more rational manner than is generally assumed, with their age and functional status being taken into account" (Scitovsky 1988, 656).

Summary

To sum up, what have we learned in the last decade or so about the "high cost of dying" of elderly patients? Although most of our new information comes from studies based on Medicare data and thus is limited largely to acute care services, certain general statements can be made. (Let me add in parenthesis that a good deal of what we have learned about medical care at the end of life of the elderly probably also holds true for younger decedents.)

1. There is ample evidence that medical care costs in the last year of life are high, with various studies showing that they are about seven times the average annual Medicare payments of beneficiaries who survive; as a result, elderly decedents account for a disproportionate share of total Medicare expenditures. However, their share has remained constant over the past decade or more, at around 27 to 30 percent of the total Medicare budget. In other words, although changes in medical technology and greater intensity of care have contributed to the overall rise in medical care costs, they have not had a greater impact on the costs of elderly Medicare patients who died than on those of beneficiaries who survived. Whether this increased use of high technology is less appropriate in the case of critically ill elderly patients who die than in the case of elderly or younger patients who survive is a question the available data cannot answer. It should be borne in mind, however, that the uncertainty of prognosis makes it difficult in the case of many critically ill patients to determine at which point further treatment is futile.

2. Examining medical care use and costs of elderly decedents over a longer period results in a considerably lower concentration of health care costs on a small fraction of the elderly population. For example, a recent study found that, over a 16-year period, total per capita Medicare payments for decedents were only twice those for survivors. Although this finding does not temper the fact that costs are very high in the last year of life, it does modify the finding that a high proportion of the costs are concentrated in a small proportion of beneficiaries in any one year. According to the authors, "By putting high average costs in the final years of life in the context of a cohort's total lifetime experience, the study..."
shows a leveling of spending over time, resulting in a lower concentra-
tion of health care resources on a small fraction of the population” (Gor-

3. Costs at the end of life vary widely between different causes of
death. Deaths from malignant neoplasms, nephritis, COPD, and chronic
liver disease are the principal high-cost causes of death in terms of per
capita Medicare payments at the end of life. By contrast, deaths from
heart disease and cerebrovascular disease are at the opposite end of the
scale. However, it must be remembered that these data refer to Medicare-
covered services and do not include costs of long-term care. Thus they
show the relative costliness of different causes of death in terms of acute
care services (primarily inpatient hospital care), not in terms of total re-
sources used.

4. The intensity of medical care, as indicated by the use of acute-care
services covered by Medicare, declines with age. In 1988, for example,
Medicare payments for decedents aged 65 to 69 years were 74 percent
higher than those for decedents aged 90 years and older. This has some-
times been interpreted as indicating a compression of morbidity, that is,
as showing that the time between onset of illness and death may be
shorter for older decedents (Lubitz and Prihoda 1984; Roos, Montgom-
ery, and Roos 1987). This conclusion is questionable. Gornick, McMillan,
and Lubitz (1993) suggest that part of the explanation for this difference
may be that the older decedents had had certain surgical procedures such
as cataract surgery and prostatectomies done at an earlier age. Perhaps
more important, nursing-home data show that many of the older per-
sons who died in nursing homes had had a lengthy stay, indicating a
prolonged period of disability. For example, in 1984–85, 15 percent of
the 235,200 nursing-home decedents 80 years old and older had had
stays of five years and more (U.S. Department of Health and Human
Services 1990). Finally, the data from my study suggest (although they
do not prove) that physicians take into account not only the age of their
very sick elderly patients, but also their functional status, treating the
frail “old old” less aggressively than the younger and less debilitated
elderly.

5. Data on the distribution of Medicare payments by payment inter-
vals show that only a relatively small number of decedents had the kind
of high costs that would indicate aggressive, high-technology care. Using
per capita payments of $40,000 a year as the high-cost threshold, only
about 73,000 decedents (or just under 5 percent of all decedents) had
such high costs in 1988. If these patients had been denied all medical
care (something not even the most ardent cost cutters would advocate),
this would have saved about 23 percent of Medicare payments for dece­
dents but only about 6 percent of total Medicare payments in that year.

6. The data on the distribution of Medicare payments by payment in­
tervals also confirm (what has already been shown by the data on per
capita payments by age) that it is the younger decedents who receive the
more intensive care. While decedents aged 65 to 79 years represented
just under 50 percent of all decedents in 1988, they accounted for just
under 60 percent of all payments for decedents. They also accounted for
74 percent of decedents with per capita Medicare payments of $40,000
and more and for 75 percent of those with payments of $50,000 and
more.

7. The few studies that are not limited to Medicare-covered services
but that include data on all or most medical services at the end of life
show that, unlike per capita Medicare payments, total per capita costs do
not decline significantly with age. They show that nursing-home costs
increase substantially with age, and that this increase makes up, or more
than makes up, for the decline in hospital costs.

8. Finally, one small study suggests that functional status (in addition
to age) plays an important role in determining the intensity of care in
the last year of life. It showed that the decedents who got aggressive care
were the younger (under 80 years) decedents who were in good func­
tional condition, whereas the frail older old were given mainly support­
ive care.

9. To sum up, the studies conducted in the past decade or more do
not support the hypothesis that it is high-cost, high-technology treat­
ment of patients who die that has driven up medical care costs. The use
of new, more expensive technologies and greater intensity of care appear
to have affected the costs of care of both decedents and survivors. How­
ever, with the exception of my study (Scitovsky 1988), the studies do not
shed light on the appropriateness—or lack of it—of the use of medical
resources for the elderly at the end of life. There is likely to be a certain
amount of medical care of patients who die that, at least in retrospect,
appears inappropriate or excessive—just as there is a certain amount of
medical care in general that is likely to be inappropriate (e.g., too many
cesarean sections and hysterectomies, procedures of dubious value such
as routine electronic fetal monitoring during delivery). In the case of
critically ill patients, the problem of the appropriateness of treatment is
complicated by the uncertainty of prognosis. As I mentioned earlier, of the Medicare beneficiaries with Medicare payments of $40,000 or more in 1988, 73,000 died and 70,000 survived. We do not know how many of the decedents had been expected to survive and how many of the survivors had been expected to die, but undoubtedly there was considerable uncertainty about the outcome of treatment of many of these patients, decedents and survivors alike.

Methods to Reduce Costs and Assure More Appropriate Care at the End of Life

The problem of medical care at the end of life has raised concern, not only because of the high costs of care, but also because it is feared that some of the care may be inappropriate for many critically ill elderly patients—that in many cases it prolongs dying rather than living and makes death more painful. To address this dual concern, two methods have been introduced in the past decade or two: (1) hospice care as an alternative to conventional care at the end of life, and (2) advance directives for medical care, specifying the patient’s preference for the kind of care desired if critically ill and unable to give instructions at that time.

Hospice Care

The hospice model of care emphasizes supportive care and pain relief for terminally ill patients in place of conventional care with its emphasis on cure. It began to spread in the United States in the 1970s and early 1980s, and in 1982 a hospice benefit was added to Part A of the Medicare program. To be eligible for hospice care under the Medicare program, the patient must have a prognosis of death within six months or less. (For non-Medicare hospice patients, the limit of stay varies depending on the patient’s type of insurance.) In 1992, 154,000 Medicare decedents (or about 10 percent of all decedents) used hospice services, but hospice care accounted for less than 1 percent of total Medicare payments (Paul Eggers, Health Care Financing Administration: personal communication, May 1994).

Early evaluations of the cost effectiveness of the hospice model (some based on data from the National Hospice Study, the hospice demonstration program sponsored by the federal government in the early 1980s)
generally showed that terminally ill hospice patients incurred lower costs than those treated in traditional settings, especially patients treated in home-based hospice programs (Spector and Mor 1984; Hannan and O'Donnell 1984; Brooks and Smyth-Staruch 1984; Mor and Kidder 1985; Greer et al. 1986). At least one study, however, found no difference between the costs of hospice and conventional care (Kane et al. 1984).

The latest and most comprehensive evaluation of the Medicare hospice program, by Kidder (1992), compared treatment costs of hospice care with conventional treatment of Medicare beneficiaries who had a diagnosis of cancer. The study showed that, in the first three years of the program, Medicare saved $1.26 for every dollar spent on Part A expenditures (i.e., primarily inpatient hospital services, plus a small percentage—about 6 percent—for home health care and skilled nursing-home services). However, most of the savings were achieved in the last month of life by hospice patients with a stay of less than three months, whereas patients enrolled for more than three months did not save the Medicare program any money, except possibly (and rather oddly) beneficiaries enrolled for six to seven months, the longest enrollment period. Moreover, Medicare hospice expenditures were lower than expenditures for conventional care only in free-standing hospices, whereas they were about the same in home health agency-based hospices and slightly higher than the costs of conventional care in hospital and skilled nursing-home, facility-based hospices. The overall saving attributable to hospice care of $1.26 for every dollar spent on Part A expenditures is due to the fact that most hospice patients were enrolled in the program for one month or less, the period of maximum savings. Even these rather limited savings may be an overestimate. It has been argued that the terminally ill patients who select hospice care are patients who do not want aggressive care and who would have rejected aggressive care even if hospice care had not been available.

The author of this evaluation doubts that the hospice benefit will be "an important tool for containing the costs of terminally ill Medicare beneficiaries" (Kidder 1992, 213). For one thing, hospice reimbursement rates have been raised twice since the program was initiated, narrowing the difference between the costs of hospice and conventional care. For another, there is some evidence that lengths of enrollment have risen steadily, which also lowers or even eliminates the savings from the program. It should also be noted that the vast majority of hospice patients—
78 percent in 1992—were patients with cancer, one of the very few conditions for which impending death can be predicted with a reasonable degree of accuracy. An additional 10 percent had heart-related conditions, and 4 percent had AIDS (National Hospice Organization: personal communication, March 1994). Whether in time patients with other serious conditions will choose hospice care remains to be seen.

**Advance Directives**

The use of advance directives, in which individuals state how they want to be treated if they are critically ill and unable to make their preferences known at that time, has increased in the past decade, in step with the movement for greater patient autonomy, which resulted in the Patient Self-Determination Act of 1991. "Do not resuscitate" (DNR) orders are advocated primarily to protect patients from overaggressive medical care when such care is futile or unlikely to result in a quality of life that is acceptable to them; however, they are also looked to as a way to reduce the high medical costs at the end of life.

There is a considerable body of literature on advance directives, but mostly it deals with patient and physician attitudes toward them, the sociodemographic and clinical characteristics of patients with DNR orders, the different rates of DNR orders in different hospitals, and the extent to which the directives are followed by caregivers, issues that are beyond the scope of this article. Only a handful of studies have explored the question whether advance directives (or DNR orders) lower the terminal medical (usually inpatient hospital) costs of patients who die. To date, however, the findings of these studies are inconclusive. Whereas most studies found no significantly lower terminal costs for patients who had an advance directive, a recent study by Chambers et al. (1994) showed substantially lower costs for them.

This study was based on data for 474 Medicare patients who died in a large, private university tertiary care hospital between January 1 and June 30 in 1990, 1991, and 1992. Patients were defined as having an advance directive if their medical records contained documentation of a discussion of advance directives within the first 48 hours after admission. Of the total study population, 132 patients (28 percent) had such documentation; 16 of these (13 percent of the study population) had a copy of their advance directive in their charts, and 116 (60 percent) had documentation of a discussion regarding advance directives but no document
in their charts. The 16 patients with written advance directives had executed them before their hospital admission, but no records were kept on whether the 116 patients with a documented discussion had had such a discussion before their hospitalization or in the first 48 hours of their hospital admission. For the entire group, mean hospital charges of patients without documentation of advance directives were found to be more than three times those of patients with such documentation, $95,305 versus $30,478; a similar relationship was found in each of the three study years.

Of the studies that found no effect of advance directives on costs, the most detailed is a retrospective one of 852 deaths at a referral medical center in 1990 by Maksoud, Jahnigen, and Skibinski (1993). This showed that 625 patients, or 73 percent, had a DNR order at the time of death. Of those with a DNR order, 107 (or 13 percent of all patients) had executed the DNR order before admission, and 512 (or 60 percent of all patients) had the order written in the hospital. There was no significant difference between the average hospital and physician charges of patients who died with a DNR order and those who died without one. However, mean charges of patients who died with a preadmission DNR order were significantly lower ($10,631) than those of patients with a DNR order obtained in the hospital ($73,055) and those of patients with no DNR order ($57,334). (This last group had comparatively low costs because they had the shortest length of stay, suggesting that they died suddenly and unexpectedly.)

Two other studies (Teno et al. 1993; Schneiderman et al. 1992) also found no difference in the resource use of patients who died with or without a DNR order. To quote from the latter study: "Executing the California Durable Power of Attorney for Health Care and having a summary copy placed in the patient's medical record had no significant positive or negative effect on a patient's well-being, health status, medical treatment, or medical treatment charges" (1992, 599). Two studies actually found that ICU patients with DNR orders used a disproportionate share of ICU resources, but these patients were older and sicker than those without a DNR order (Jayes et al. 1993; Zimmerman et al. 1986).

One explanation for the lack of cost saving attributable to DNR orders written in the hospital may be that most are written very shortly before death. Maksoud, Jahnigen, and Skibinski (1993) found that the median time from the writing of a DNR order to death was two days for all patients, one day for surgical patients, and three days for hematology/on-
The High Cost of Dying
Revisited

A prospective study of 17,440 ICU admissions by Jayes et al. (1993) showed that patients who had a DNR order written within the first seven days of their ICU admission and died had their order written an average of 2.8 days before ICU discharge or death. A more detailed examination of these data shows that, of these patients, 27.2 percent received the order on the day of death; 33.5 percent, on the day before death; and 14.7 percent, two days before death (Douglas P. Wagner: personal communication, February 1994). Two other studies found equally short time intervals between the writing of DNR orders and death: an average of 1.7 days (Zimmerman et al. 1986) and 3.3 days (Gleeson and Wise 1990).

The fact that most DNR orders written in the hospital are written only a few days before death may be explained partly by the reluctance of many physicians to give up, to acknowledge that their therapeutic efforts have failed. The principal reason, however, is likely to be the difficulty of predicting death for any specific patient at an earlier time. It is of interest to note that, as in the case of the hospice program, critically ill patients with cancer also seem to be more likely than most other critically ill patients to be users of advance directives (Gleeson and Wise 1990; Chambers et al. 1994).

To sum up, studies conducted to date suggest that neither hospice care nor advance directives are likely to have a major impact on the costs of dying, except possibly advance directives executed before a patient is admitted to the hospital. Chambers et al., on the basis of their data for patients of whom an (unfortunately) unknown but possibly substantial percentage had expressed a preference for nonaggressive care before being admitted to the hospital, believe that advance directives have a great potential to save costs. Pointing out that approximately 1.2 million Medicare beneficiaries die each year in acute care hospitals, and that most of them do not possess advance directives, they conclude: “If our findings are generalizable to the larger population of Medicare patients in their last hospitalization in the United States, the potential cost savings implications of developing advance directives, therefore, would be enormous” (1994, 545).

By contrast, Emanuel and Emanuel (1994) estimate that in 1988 only $18.1 billion of the $546 billion in total national health care expenditures, or 3.3 percent, would have been saved on the best-case assumptions that each of the 2.17 million Americans who died had chosen hospice care, used advance directives, and refused aggressive, in-hospital
treatment at the end of life. The authors stress that despite the unlikeli­ness of substantial savings in health care costs, hospice care and advance directives should be promoted because they provide very important ben­efits for dying patients: “Respecting patients’ wishes, reducing pain and suffering, and providing compassionate and dignified care at the end of life have overwhelming merit” (1994, 543).

One of the obstacles—in my opinion, the major one—to the greater and more effective use of both hospice care and advance directives is the difficulty of predicting whether a critically ill patient will live or die. In the last decade, various sophisticated models have been developed to im­prove the ability of medical care providers to predict mortality of criti­cally ill patients treated in ICUs. The best known and most widely used of these is the APACHE model (Acute Physiology, Age, Chronic Health Evaluation). Others include PRISM, a model for use in pediatric ICUs; SAPS (Simplified Acute Physiology Score); and MPM (Mortality Probability Models). Although all of them have improved the accuracy of pre­dicting mortality for aggregated groups of patients, they cannot be used to predict which individual patients will die. Nevertheless, despite this limitation, Thibault (1994) maintains: “These clinical predictors are one more piece of information, like any other diagnostic test, to be used in the context of the full clinical picture . . .” when making end-of-life treatment decisions. Further development of such models should thus help physicians to improve their ability to determine when a critically ill patient is unlikely to benefit from further aggressive treatment.

Conclusion

At least at this time neither hospice care nor advance directives promise to have a major impact on medical care costs at the end of life. Do we thus have to conclude that nothing can be done to reduce the cost of dy­ing? I do not think so. We all know of cases where unnecessary and inap­propriate medical care was rendered, and not only for critically ill elderly patients. There is a considerable amount of waste throughout the health care system. The problem of excessive or inappropriate care should be addressed on a national, across-the-board basis rather than selectively on medical care at the end of life because, given our present inability to predict the death of specific patients with reasonable accuracy, the sav­ings in costs would most likely be limited. Greater coordination of a pa-
tient's care (or "managed care") and changes in the financing of health care appear to be the most promising national policies for curbing the rise in medical care costs.

In the long run, however, in order to reduce both overall health care spending and expenditures at the end of life, two, more fundamental changes, are required: a closer patient-physician relationship and a change in our expectations of what medical care can do for us, especially our attitude toward death.

I believe that the lack of a closer patient-physician relationship is a large factor in the overtreatment that occurs in the health care system in general and in the difficulty of treatment decision making at the end of life. Advances in medicine have brought with them increased specialization of physicians so that a patient's medical care is fragmented, and often no single physician has a close relationship with the patient and the patient's family. This is especially true in the case of critically ill patients treated in the hospital, particularly in teaching hospitals and the ICUs of teaching hospitals. In this setting, several specialists, residents, and interns are often involved in a patient's care, all well informed about the patient's clinical condition, but none familiar with the patient's personality and preferences. Under these circumstances, it is not surprising that decisions to forgo further treatment of critically ill patients are difficult to arrive at and are made at a relatively late stage.

Possibly even more important are our expectations of what medical care can do for us, and especially our attitude toward death. The author of a recent book on death and dying points out:

The necessity of nature's final victory was expected and accepted in generations before our own. Doctors were far more willing to recognize the signs of defeat and far less arrogant about denying them. Medicine's humility in the face of nature's power has been lost, and with it has gone some of the moral authority of times past. With the vast increase in scientific knowledge has come a vast decrease in the acknowledgment that we still have control over far less than we would like. . . . The greater humility that should have come with greater knowledge is instead replaced by medical hubris: Since we can do so much, there is no limit to what should be attempted—today, and for this patient! (Nuland 1994, 259)

But the blame is not solely attributable to the physicians. Our society shies from facing death, regarding it as something to be hidden from view. Nuland also says:
Modern dying takes place in the modern hospital, where it can be hidden, cleansed of its organic blight, and finally packaged for modern burial. We can now deny the power not only of death but of nature itself. (1994, xi)

I do not know what the prospects are for a closer patient-physician relationship and a change in our expectations of modern medicine and in our attitude toward death. These are fundamental changes and, if they are realized at all, will not come about overnight.

In conclusion, I would like to make one more point that did not fit into my discussion. In the many studies of medical care costs at the end of life, the emphasis has been almost exclusively on high-cost, high-technology care. Largely ignored has been the problem of patients dying in nursing homes. There are no data on the costs of medical care in the last year of life of such patients, although this situation should change when the data on the institutionalized population covered by the 1987 National Medical Expenditure Survey (NMES) finally are released. However, data from the 1986 National Mortality Followback Survey show that the 516,464 patients aged 65 years and older who had a nursing-home stay in their last year of life had an average stay of about seven months, and that 50 percent of them had a stay of between 9 and 12 months. Assuming an average charge per nursing-home month of about $1,800 in 1988 dollars (the figure we used in our estimate of nursing-home costs), this would mean that the average nursing-home decedent paid about $12,600 a year for nursing-home care alone, and that a decedent who was in the nursing home the whole year spent $21,600. Considering that such patients also have additional medical expenses—for physician and at least some hospital services, and for drugs—it is clear that many patients who die in nursing homes have catastrophic expenses. As the population ages, this group of decedents will become increasingly important and may well pose greater economic problems than the high-cost decedents on whom most of the research to date has focused. Temkin-Greener et al. conclude that their study of the dually eligible Medicare/Medicaid decedents “suggests that excessive, high-technology care for the elderly in their last year of life may be much less of a problem than the overall long-term-care needs of the frail and disabled elderly population in need of chronic, supportive care” (1992, 700). Let me add that I think they not only pose a serious and increasing economic problem, but they also
present ethical problems different from, and possibly more difficult than, those posed by critically ill patients. Chronically ill patients present us with the dilemma not so much of when to forgo "heroics," but rather of when to halt ordinary care (such as treatment with antibiotics in case of infection) and sustenance. This subject is beyond the scope of my article, but I hope that the medical profession, economists, and ethicists will begin to give some attention to this growing group of elderly patients.

References


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Address correspondence to: Anne A. Scitovsky, Senior Staff Scientist (Emeritus), Research Institute, Palo Alto Medical Foundation, 860 Bryant Street, Palo Alto, CA 94301.