

**MEDICARE BENEFICIARIES' COSTS AND USE OF CARE  
IN THE LAST YEAR OF LIFE**

**Final Report**

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## EXECUTIVE SUMMARY

This report is a statistical profile of Medicare beneficiaries' costs and use of care in the last year of life. Information is drawn from various surveys and from Medicare claims and enrollment data. On average, the data reflect costs and practice patterns in the mid-1990s.

Results presented here summarize the first five months of research under a two-year project funded by Agency for Healthcare Research and Quality (AHRQ grant number R01-HC10561-01). Under a cooperative agreement with MedPAC, the AHRQ-funded research term was granted limited access to MedPAC's data resources in exchange for annual reports to MedPAC summarizing significant research findings. This project will run from October 1999 through September 2001.

This initial phase of research looks retrospectively at those who died. This provides basic data and points to issues for further study, but data on decedents' costs can be misinterpreted. The retrospective analysis counts backward from a known date of death, but in fact an individual's date of death is substantially unpredictable. By and large, this report shows the cost of caring for severely ill individuals with unknown life expectancy, not the cost of care delivered in anticipation of impending death. In no sense should the high costs shown here be taken as showing a high degree of wasteful or futile care.

The chapters of the report answer four questions about Medicare decedents: who dies, what diseases are present, where do they die, and how much is spent in the last year of life. Successive sections of the report examine the demographics of Medicare decedents, the mix of diagnoses reported on death certificates and on claims data, site of death as reported in surveys and on claims data, and costs in the last year of life paid by Medicare and by others.

### Summary of Key Findings

Although the report is structured around four broad questions, this summary focuses on a few key populations and measures. Detailed findings are listed in bulleted form at the start of each section of the report.

**Costs in aggregate and by age.** End-of-life costs remained stable as a proportion of total Medicare outlays. Medicare decedents in any year amounted to about 4.7 percent of individuals ever entitled to Medicare during that year. Medicare payments for the last year of life averaged just over \$26,000 (1997 basis), six times the per-capita cost for survivors. Spending for the last year of life was 25 percent of total Medicare outlays. These estimates for decedents' versus survivors' costs just were slightly lower than those calculated for earlier decades (Lubitz and Riley, 1993).

Medicare paid over 60 percent of all costs for Medicare-enrolled decedents, calculated for the calendar year of death. That was modestly higher than Medicare's 54 percent share of all

beneficiaries' costs (Gornick et al. 1996). Direct out-of-pocket spending accounted for 18 percent of decedents' costs, and other insurers and Medicaid paid for the remainder.

**Residence in a facility.** Nearly one-third of Medicare decedents spent all or part of the calendar year of death in a facility (typically, a nursing home), and the annual mortality rate for Medicare-covered facility residents exceeded 20 percent. More than half of decedents who were full-year facility residents were dual-eligible Medicare/Medicaid beneficiaries. For the full-year facility resident population, Medicare covered only about one-third of total health care costs in the calendar year of death, with the remainder split almost equally between Medicaid and out-of-pocket costs. This combination (many decedents in nursing homes, many nursing home residents with Medicaid coverage) may explain the high fraction of all decedents who are dual-eligible (21 percent of decedents versus 13 percent of survivors). About two-thirds of Medicare decedents who were facility residents died in a nursing home.

**Hospice.** Hospice use has become typical for cancer deaths in the Medicare program. Over the entire period (1994-1998), 45 percent of all Medicare cancer decedents used hospice, and by 1998 over half of cancer decedents used hospice. Hospice use was substantially lower for all other types of disease. On average, for this time period, 15 percent of Medicare fee-for-service decedents used some hospice, while 25 percent of Medicare+Choice decedents used hospice. This average masks substantial growth in hospice use, from 11 percent in 1994 to an estimated 19 percent of decedents in 1998.

Hospice largely achieves the goal of allowing patients to die in their own homes. Based either on survey or claims data, about two-thirds of hospice decedents died in a private home, and perhaps 10 percent died in a nursing home. Total costs were only modestly lower for hospice patients who died at home rather than in an inpatient setting.

There was no statistically significant difference in total costs (including all sources of payment) between decedents who did and did not use hospice. Medicare's payments, by contrast, were higher for hospice users. As a result, Medicare paid a significantly higher share of costs for hospice decedents. This simple analysis did not adjust for factors such as diagnosis and patient self-selection as was done for the formal evaluation of the Medicare hospice benefit (Kidder 1992).

Although diagnoses and patient self-selection undoubtedly affect hospice costs, lack of "unexpected" deaths in hospice may also play a part. One-quarter of non-hospice decedents had spending below \$5,000, but only 7 percent of hospice decedents did. Individuals who died without substantial medical care in the last year of life are far less likely to appear as hospice patients.

**Race and ethnicity.** End-of-life costs for Medicare minority decedents were more than 25 percent higher than for others. Among minorities, costs were higher only for African-Americans. Costs for other racial minorities and for individuals of Hispanic ancestry were not significantly different from the remainder of the population.

Minority decedents were more likely than others to have some hospitalization in the last year of life and to die in the hospital. Annual mortality rate, by contrast, was slightly lower for the

Medicare minority population than for others, even after adjusting for the age and entitlement mix of the population.

Nearly 7 percent of deaths in the Medicare minority population were for end-stage renal disease (ESRD), compared to under 2 percent for the remainder of the population. This reflects the high prevalence of ESRD in the minority population. Minorities account for more than 40 percent of ESRD beneficiaries but only 12 percent of the Medicare aged population. ESRD is a costly condition to treat, and the high prevalence of ESRD contributes to (but does not fully explain) the high average costs for minority decedents.

**Site of death.** Site of death was strongly associated with costs in the last year of life, both on a person-by-person basis and when examined across geographic areas. Outside of hospice, individuals who died in inpatient settings covered by Medicare (hospital inpatient and skilled nursing facility) had final-year costs roughly twice as high others. For hospice patients, death in a facility was associated with only modestly higher final-year costs.

**Geography and area characteristics.** Substantial variation in patterns of care was observed across census divisions. Beneficiaries in the West North Central, Mountain, and Pacific areas were less likely to die in a hospital. Two of these three regions also had below-average end-of-life costs.

Medicare spending in the last year of life was higher in urban areas and in areas with many beds and physicians per capita, even after adjustment for geographic differences in Medicare's payments per service. In addition, likelihood of any hospital use and likelihood of dying in the hospital were both positively associated with the number of hospital beds per capita in the beneficiary's county of residence.

Beneficiaries who lived in poverty areas -- ZIP codes with higher poverty rates and lower average incomes -- had higher end-of-life costs and lower likelihood of using hospice. These beneficiaries were also substantially more likely to die in the hospital.

**Diagnosis and disease.** About 17 percent of ESRD beneficiaries die each year. (This category includes all beneficiaries with ESRD, including those entitled to Medicare due to disability or age.) Beneficiaries dying of kidney disease had by far the highest end-of-life costs, nearly two and a half times the average of all others. Almost all of these beneficiaries had at least one inpatient stay in the last year of life, and 60 percent of them died in the hospital inpatient setting. Those dying of cancer had the next-highest Medicare costs for the last year of life, about 20 percent above average.

Beyond these two groups (ESRD and cancer), it becomes difficult to place beneficiaries accurately into a single disease category using information from claims data. Death certificates show that most beneficiaries had multiple significant illnesses at time of death, with an average of three diagnosis codes and two causes of death coded on the death certificate. Cancer decedents had the least complex death certificates (in terms of additional diseases contributing to death), while diabetic decedents had the most complex death certificates, averaging more than two additional diseases listed on the death certificate as contributing to death.



When beneficiaries were categorized by disease accounting for the majority of their Medicare physician costs in the final year of life, the resulting distribution of patients by disease appeared similar to cause-of-death statistics. There were some differences, however. Based on physician claims data, congestive heart failure and Alzheimer's disease appeared as more significant contributors to death than is suggested by single cause of death information from death certificates.

**Health status and restrictions on activities of daily living.** Unsurprisingly, those reporting themselves in poorer health and with restrictions on activities of daily living (ADLs) had higher mortality rates. Those with no ADL restrictions reported in the fall of the prior year had a 2 percent mortality rate, while those with 6 ADL restrictions had a 23 percent mortality rate. Yet, 30 percent of decedents reported no ADL restrictions and 18 percent reported themselves in excellent or very good health in the fall of the year prior to death.

**Physician specialty and hospital discharges.** Physician specialties differed markedly in their involvement in care in the last year of life. Oncologists, pulmonologists, and infectious disease specialists had the highest fraction of billings that are for care in the last year of life. Chiropractic, dermatology, and ophthalmology were among those having the lowest. Cardiologists were squarely in the middle of the listing, despite heart disease being the cause of death for one-third of Medicare decedents.

A similar exercise for hospital payments by diagnosis-related group (DRG) showed parallel results. Cancers, ventilator dependence, and lung and kidney failure were among the DRGs for which the highest fraction of Medicare payments is for last year of life. DRGs for some common low-risk elective procedures, such as transurethral resection of prostate and laparoscopic cholecystectomy, appeared at the bottom of the list.

## **SECTION 1**

### **STUDY OVERVIEW**

#### **1.1 Purpose of the Study**

In 1998 and 1999, the Medicare Payment Advisory Commission (MedPAC) began to examine end-of-life care in the Medicare program. Their reports to Congress emphasized the importance of education and quality issues in this area (MedPAC 1998, MedPAC 1999). MedPAC recommended that the Secretary of Health and Human Services make end-of-life care a national quality improvement priority for both traditional Medicare and for Medicare managed-care plans (MedPAC 1999).

As discussion progressed, MedPAC and others noted the lack of up-to-date, detailed information on use and costs of medical care at the end of life. The pioneering work by Lubitz and colleagues is still cited in most discussions of end-of-life costs in Medicare. Much of that work is based on data now 10 to 20 years old (e.g., Lubitz and Riley 1993). This predates significant changes in practice patterns, such as the growth of hospice, as well as the creation of new Medicare data sources such diagnoses on physician claims and survey information from the Medicare Current Beneficiary Survey (MCBS).

In October, 1999, the Agency for Health Care Policy and Research (AHCPR, now the Agency for Healthcare Quality Research) funded a team based at George Washington University to provide a detailed, up-to-date profile of Medicare end-of-life care. MedPAC, with concurrence from the Health Care Financing Administration (HCFA) and AHRQ, entered into a cooperative agreement to provide access to MedPAC's substantial data resources for this project in exchange for annual reports on findings from the research.

This May 1, 2000 report summarizes results from the first five months of this inter-governmental, public-private research partnership. The primary purpose is to provide a broad-brush profile of Medicare beneficiaries' cost and use of care at the end of life and to suggest avenues for additional exploration. Results are intended to help further timely discussion of Medicare policy options in this area.

#### **1.2 Methods and Caveats for Interpretation**

This work consists entirely of tabulations from existing administrative and survey data, sometimes supplemented with ZIP code- or county-based statistics from Census or Area Resource File data. There was no primary data collection. Methods consist largely of proper application of standard analytical practices, such as weighting survey data to approximate the universe of Medicare beneficiaries.

Five general aspects of the methods require mention because they may strongly effect interpretation of results. **These five substantial caveats should be kept in mind when interpreting the findings of this report:**

- This is a retrospective analysis of those who died, not a prospective study of care delivered in anticipation of death.
- Statistics for individual causes-of-death categories may be misleading because most decedents have multiple medical problems.
- These results are based on small samples of beneficiaries and are subject to sampling, recall, non-response and other types of errors.
- Spending totals will vary depending on time period (last twelve months of life versus calendar year of death) and population (Medicare, Medicare except managed-care enrollees, Medicare except managed-care or hospice enrollees).
- These are simple tabulations of the data and do not necessarily capture cause-and-effect relationships.

**1.2.1 Retrospective analysis of those who died.** This study is a retrospective analysis of costs and service use in the months prior to what is known, after the fact, to have been the beneficiary's date of death. This report is not a study of "end-of-life care," in the sense of care delivered in anticipation of the end of life.

Except for hospice enrollees, there should be no presumption that services and costs tabulated here were delivered with the understanding that the patient would soon die. For hospice, the enrollee must acknowledge that life expectancy is short, and two physicians must certify that life expectancy is less than six months at time of hospice enrollment. For most decedents, life expectancy is unpredictable and mortality can be accurately predicted for individuals in only a small number of cases (Atkinson et al. 1994; Lynn et al. 1997; Fox et al. 1997).

**1.2.2 Cause of death, principal disease, and medically complex beneficiaries** Most elderly decedents have multiple significant illnesses. Official cause-of-death statistics rely on a combination of physician judgement and hierarchical rules to identify a single underlying cause of death for each person. This study, by contrast, examines patterns of spending and diagnoses reported on fee-for-service claims, using a simple algorithm to place each beneficiary into a category based on Medicare claims.

All statistics by diagnosis presented in this report should be interpreted with caution. The degree of certainty in assignment of beneficiaries to diagnosis categories varies widely by diagnosis. Assignment appears most straightforward for beneficiaries dying of cancer or kidney disease, where a single condition tends to account for the majority of care in the last months of life. Assignment is least reliable for slowly debilitating illnesses with high complication rates. These include conditions such as diabetes and Alzheimer's disease. **In cases where cost of treating a complication exceeds cost of treating the underlying disease, the methods used here are likely to categorize the beneficiary by complication rather than underlying disease.** In essence, methods cannot distinguish diabetes complicated by heart disease from heart disease complicated by diabetes, so a patient actively treated for both may end up in either category.

**1.2.3 Samples and survey data.** This is an exploratory analysis using available surveys and small samples of Medicare administrative data. As such, data are subject to the usual types of sampling, recall, and non-response errors. Where possible, appropriate statistical tests have been presented. In some cases, data are blanked where a cell in a table would reflect the experience of fewer than 30 beneficiaries in the underlying survey or sample.

For the Medicare Current Beneficiary Survey, statistical tests were calculated using the replicate weights provided with the survey. This should give unbiased estimates of variances fully accounting for the design effects of the survey. In almost all cases, statistical tests compare the mean for a subpopulation against the mean for the entire population. The variance estimate for this difference of means was calculated simply as the sum of the variances of the means for the subpopulation and the entire population.

**1.2.4 Variation in time period and population studied.** This report analyzes different time periods prior to death, different years of data, and different subsets of the Medicare population. Analyses of Medicare administrative data (claims files) are based on the calendar month of death and prior 11 calendar months, and costs are adjusted to reflect average 1997 spending. Analyses of Medicare Current Beneficiary Survey (MCBS) data, by contrast, are based on calendar year in which death occurred. The resulting spending data will differ substantially. The MCBS data reflect average 1994 spending, and the calendar year basis will capture only about 70 percent of costs incurred during the last 12 months of life.<sup>1</sup>

Estimates may also differ modestly across portions of the report due to variations in the population studied. Complete fee-for-service claims data are available only for those not enrolled in managed care or hospice. At various points in this report, data may refer to the entire Medicare population, Medicare fee-for-service population, or Medicare fee-for-service population other than hospice users. The population definition is typically listed at the bottom of each table.

**1.2.5 Simple tabulations of data, not cause-effect relationships.** Finally, the results shown here are simple tabulations of data, without any adjustment for the multitude of factors that may affect cost and patterns of care. The resulting statistics are meant to provide baseline data and to prompt questions about underlying causes of the differences observed. In general, these results show the extent to which cost and use vary across subpopulations, but do not address the reasons for that variation. Multivariate analysis is required before attributing these differences to any particular causal factors.

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<sup>1</sup> This is calculated from the monthly spending distribution in Lubitz and Prihoda 1984.

### 1.3 Data Sources, Adjustments, and Limitations

Three main sources of patient-level data were used in this analysis. These are:

- Extracts of Medicare claims and eligibility data for a 0.1% random sample of beneficiaries for 1993 through 1998.
- The Medicare Current Beneficiary Survey Cost and Use files for 1992 through 1996.
- The 1993 National Mortality Followback Survey, preliminary version.

**1.3.1 Medicare claims and eligibility data.** In keeping with the exploratory nature of this study, the first step was to construct a one-in-one-thousand (0.1 percent) sample of Medicare beneficiaries, based on terminal digits of the Social Security Number (SSN) or equivalent Railroad Retirement Board number. Medicare Denominator File data were used to identify all beneficiaries in sample for any year 1993 through 1998. Claims data for these beneficiaries were taken from Medicare Standard Analytic files for these years.<sup>2</sup> The result is a sample of roughly 36,000 individuals and 1,700 deaths per year, for the years 1993 through 1998. For some analyses, the first or last years (1993 and 1998) must be dropped out to provide a correct subset of the data. For example, 12 months of claims data are not available for individuals who died in 1993.

Cost data were adjusted for geographic differences in Medicare prices and for growth in spending over time. Costs were adjusted for geographic price differences using Medicare geographic practice cost index and hospital wage index data. To remove effects of cost growth over time, data were inflated or deflated to set each year's average total Medicare cost per fee-for-service enrollee equal to the 1997 average. The result is a data set that can be pooled across areas and years to yield nearly 200,000 person-years of Medicare fee-for-service claims exposure and about 8,000 deaths of Medicare fee-for-service beneficiaries.

Medicare administrative files identify decedents through a variety of channels, primarily but not limited to cutoff of Social Security payments upon death. The administrative data appear to do a very good job of capturing most deaths, matching National Center for Health Statistics (NCHS) vital statistics closely despite the presence of non-Medicare elderly in the vital statistics data (**Table 1-1**). In addition, in any year less than 0.5 percent of beneficiaries in this sample leave the sample without notice of death, probably due to changes in the SSN under which benefits are received. In some cases, the exact day of death is known, but in most cases Medicare administrative data record only the month of death.<sup>3</sup>

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<sup>2</sup> Durable medical equipment (DME) claims processed through the DME carriers were not available for all years and are excluded from all cost estimates. On average, decedents incurred roughly \$600 per person in annual DME costs not included here, survivors incurred roughly \$150.

<sup>3</sup> Thus, last-year-of-life spending in this analysis is, on average, last 11.5 months of life. Based on the distribution of spending by month, this will on average miss about 1.5 percent of total last-365-days-of-life spending.

	Estimated from Medicare Administrative Data for 0.1% Sample of Persons	NCHS Final Deaths Data, 1997
Number of Deaths (thousands)	1,756	1,723
Rate	5.3%	5.1%
Source: Analysis of 0.1% sample of Medicare Denominator File records, 1997, and NCHS vital statistics data (Hoyert et al., 1999).		

**1.3.2 Medicare Current Beneficiary Survey data.** Medicare Current Beneficiary Survey (MCBS) Cost and Use files capture information on a clustered, stratified sample of roughly 12,000 beneficiaries per year for the time period studied, including roughly 700 decedents each year. The principal advantages of the MCBS are that it captures (nearly) all costs (including those not paid by Medicare), and gathers detailed information about health status, living arrangements, prescription drugs, income, and other factors. Health status information for the Cost and Use file is gathered in the autumn prior to the year in which costs were measured.

The main disadvantage of the MCBS for this analysis is the calendar-year orientation of the file. The MCBS is very easy to use for a single calendar year, but fairly complex to use if files must be merged across years and data extracted for part-year periods. There is substantial year-to-year overlap in the panel of beneficiaries across years.

MCBS results presented here reflect the simple pooling of individual calendar years of data 1992 through 1996. There is no attempt to create periods reflecting last 12 months of life (as opposed to calendar year of death), and no adjustments for inflation across years, or for geographic differences in Medicare prices. MCBS spending data cannot be directly compared to the cost estimates from the Medicare claims, but should, within limits, accurately capture variations across types of services and payers.

**1.3.3 National Mortality Followback Survey.** The 1993 National Mortality Followback Survey (NMFS) consists of detailed information for a stratified, clustered sample of roughly 1 percent of all deaths of individuals over age 15 occurring in 1993. Samples are drawn from death certificate data. An interview with next-of-kin or other knowledgeable individual obtains information on the decedent's prior health status, use and cost of care, circumstances of death, health behaviors, and socioeconomic status. Survey information is linked to the death certificate (NCHS 1998). Information on about 8,000 elderly decedents is captured on the 1993 NMFS. For this report, the 1993 NMFS is used to analyze death certificate data, and to provide information on site of death that is not otherwise available through Medicare administrative data. The 1993 NMFS is the sixth and most recent such survey conducted by NCHS (NCHS 1998).

## SECTION 2

### BACKGROUND INFORMATION

This section summarizes the well-recognized facts of end-of-life care and the Medicare program. These include the high proportion of all U.S. deaths that are for Medicare beneficiaries, the main causes of death, and stability of spending patterns for end-of-life care over the past two decades. The main change occurring in the last two decades has been use of hospice, which grew rapidly throughout the 1990s.

Medicare beneficiaries account for between 80 and 85 percent of all deaths in the United States each year. In 1997, roughly 2.3 million Americans died (Hoyert et al.1999). For that same year, approximately 1.9 million Medicare beneficiaries died, consisting of about 1.75 million decedents over age 65 (75 percent of all deaths) and 0.15 million decedents (6.5% of all deaths) entitled to Medicare solely on the basis of disability or end-stage renal disease (ESRD).<sup>4</sup>

National Center for Health Statistics (NCHS) vital statistics data show that heart disease and cancer are the leading causes of death in the elderly, accounting for more than half of deaths in 1997 (**Table 2-1**). These have been the leading causes of death in the United States for at least the last half-century, although their relative importance has shifted somewhat as death rates from heart disease have declined and cancer prevalence has increased (see Hoyert et al., 1999, Chart 4).

Rank	Disease (ICD-9 code range)	Decedents	Rate per 100,000	Percent of Decedents
	All causes	1,728,872	5,074	100%
1	Diseases of heart (390-398,402,404-429)	606,913	1,781	35%
2	Malignant neoplasms (140-208)	382,913	1,124	22%
3	Cerebrovascular diseases (430-438)	140,366	412	8%
4	Chronic obstructive pulmonary diseases (490-496)	94,411	277	5%
5	Pneumonia and influenza (480-487)	77,561	228	4%
6	Diabetes mellitus (250)	47,289	139	3%
7	Accidents and adverse effects (E800-E949)	31,386	92	2%
8	Alzheimer's disease (331.0)	22,154	65	1%
9	Nephritis, nephrotic syndrome, Nephrosis (580-589)	21,787	64	1%
10	Septicemia (038)	18,079	53	1%
	All other causes (Residual)	286,013	839	17%

Source: Taken from Hoyert et al. 1999, Table 8

<sup>4</sup> These figures are calculated from a 0.1 percent sample of Denominator file records.

For less common causes of death, vital statistics data may provide a less reliable picture of underlying prevalence of disease. Official cause-of-death data reflect the information reported by physicians on death certificates, and may to some degree reflect variations and changes in acceptable data reporting practices. For Alzheimer's disease in particular, official sources suggest significant under-reporting on death certificates, although reporting in recent years appears more reliable than in the past (Hoyert and Rosenberg 1999).

The main aspect of the Medicare program specifically addressing end-of-life care is the Medicare hospice benefit. For a beneficiary to elect hospice, a hospice physician and the beneficiary's attending physician (if such exists) must certify that the beneficiary's life expectancy is six months or less. Beneficiaries elect to replace traditional Medicare coverage with the hospice benefit. All care required for the terminal illness is provided by the hospice with minimal beneficiary copayment, while Medicare pays the hospice on a per-diem basis (MedPAC 1999).

Hospice has grown dramatically since 1990, although it still makes up just 1 percent of total Medicare outlays. There were more than 2,200 Medicare-certified hospices in 1998, versus roughly 1,000 in 1991 (NAHC 1999). Medicare hospice payments quadrupled, and hospice users tripled, between FY 1991 and FY 1997 (calculated from NAHC 1999).

Except for the substantial growth of hospice, studies have found stable patterns of spending for Medicare decedents versus survivors over the past two decades. First, costs for decedents have averaged between six and seven times average annual spending for survivors (Riley et al.1987; Lubitz and Riley 1993; Levinsky et al.1999). Second, spending for the last year of life averaged roughly 28 percent of Medicare spending at various points from 1976 through 1988 (Lubitz and Riley 1993). Third, hospital inpatient use is very high in the last 12 months of life, with more than three-quarters of decedents having at least one hospitalization in the last year of life (Riley and Lubitz 1989). The variation in total hospital charges for decedents was found to be stable from 1984-1991 (Riley et al.1987). Fourth, Medicare final-year costs decrease with age (Riley and Lubitz 1989). In 1992 for example, average Medicare expenditure for a decedent aged 65-74 was \$16,700, while for those 85 years or older, the average expenditure was \$10,200. Medicare costs in the last two years of life for those who died in 1992 at age 101 or older were only 37% of those incurred by patients dying at age 70 (Lubitz et al.1995)<sup>5</sup>.

In the past, findings of very high spending for decedents triggered concern that public funds might be expended on "lost causes" (Callahan 1987, Verbrugge 1984). Now, it appears that high final year costs are a stable and expected fact of the Medicare program.

The reasons for high but stable spending for end-of-life care are reasonably easy to grasp: for the typical beneficiary nearing death, health status declines but date of death is largely unpredictable. Most individuals die at the end of a long chronic illness. Increasing costs for decedents are associated with declining functional status, increasing comorbidity, or poorer health (Culler et al.1995; Stump et al.1995; Callahan et al.1998). Only a small proportion have high expenses that would suggest aggressive but futile care, and high cost users are equally likely to survive as not

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<sup>5</sup> This decline in expenditures is unique to those who are dying. Among all of the aged, Medicare per capita payments increase substantially as age increases



(Scitovsky 1994; Roos et al.1989). High spending in the last year of life reflects, in the typical instance, the reasonable response to the decline in health status and function that occurs prior to an unpredictable time of death.

## SECTION 3

### DEMOGRAPHICS OF MEDICARE DECEDENTS VERSUS SURVIVORS

- About 4.7 percent of beneficiaries die each year.
- This varies substantially by entitlement status. About 17 percent of all ESRD beneficiaries, 5 percent of aged beneficiaries, and 2 percent of disabled beneficiaries die each year.
- The oldest old (age 85 and above) comprise 29 percent of decedents, but only 9 percent of survivors in any year.
- Dual eligible Medicare/Medicaid beneficiaries comprise 21 percent of decedents, versus roughly 13 percent of survivors in any year.
- Residents of facilities (mainly, nursing homes) for all or part of the year of death account for 31 percent of Medicare decedents.
- Nearly half of the full- and part-year facility resident population has Medicaid coverage in addition to Medicare.
- The annual mortality rate for Medicare-covered facility residents exceeds 20 percent.
- Medicare-covered minorities have a lower mortality rate than the remainder of the population, reflecting both the enrollment mix (greater proportion enrolled via disability rather than age), but also lower mortality rates within entitlement categories.
- ESRD beneficiaries account for about 7 percent of deaths for Medicare-enrolled minorities, versus 2 percent of deaths for the remainder of the population. That reflects the substantially higher prevalence of ESRD entitlement in the minority population.
- In the fall of the year prior to their death, 18 percent of beneficiaries rated their health as excellent or very good, 30 percent reported no limitations on activities of daily living (ADLs).
- In the fall of the year prior to their death, 60 percent of beneficiaries rated their health fair or poor, and 45 percent reported three or more limitations on activities of daily living (ADLs).
- Beneficiaries reporting no limitations on ADLs had a 2 percent annual mortality rate. Those reporting six ADLs had a 23 percent annual mortality rate.

This section of the report examines demographics of decedents versus survivors in the Medicare program, as well as the self-reported residential and health status of these populations in the fall prior to the year of death. Both claims data and MCBS data are used to profile the population.

**Table 3-1** shows annual mortality rates for segments of the Medicare population.<sup>6</sup> Unsurprisingly, annual mortality rates rise steeply with age, exceeding 14 percent for the oldest old (age 85 and older), and annual mortality rates for women are somewhat lower than average, reflecting their longer average life span.

Mortality rates vary substantially by Medicare entitlement status. Roughly 17 percent of end-stage renal disease (ESRD) beneficiaries die each year, versus only about 2 percent of the

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<sup>6</sup> Annual mortality rate for this calculation is defined as number of decedents in a year divided by the number of beneficiaries ever enrolled in Medicare during the year.

disabled (under age 65).<sup>7</sup> The annual mortality rate for the aged (65 and older) is only slightly above the average for the entire program, unsurprising since the aged account for nearly nine-tenths of the Medicare population.

Mortality rates for Medicare beneficiaries in managed-care plans or with dual Medicare/Medicaid coverage probably reflect differences in health status or risk for those populations. Medicaid's role as payer of last resort after beneficiaries have spent down their assets means that Medicaid coverage may occur as a result of poor health. The HMO-enrolled population, by contrast, appears substantially healthier-than-average by most measures (Riley et al.1996). (The mortality rates shown here are not adjusted for the lower average age of HMO enrollees.)

Population Segment	Percent of Population	Mortality Rate	
All	100.0%	4.7%	
Under Age 65	17.0%	2.0%	*
Age 65 to 74	45.6%	2.7%	*
Age 75 to 84	27.9%	6.3%	*
Age 85 and Older	9.6%	14.4%	*
Race Non-White	14.1%	4.3%	*
Gender Female	56.5%	4.4%	*
Aged, No ESRD	87.3%	4.9%	*
Disabled, No ESRD	12.0%	2.0%	*
All ESRD	0.7%	17.0%	*
Any HMO Enrollment in Year	13.0%	3.7%	*
Dual Eligible Medicaid/Medicare	13.6%	7.2%	*
Source: Analysis of Medicare 1994 through 1998 denominator file records for a 0.1 percent sample of Medicare beneficiaries.			
* Mortality rate difference from remainder of population is statistically significant at p < .05 level, two-tailed t-test.			

The low mortality rate for Medicare-covered minorities requires further explanation. The Medicare minority population is predominantly African-American. For the entire U.S. population, access, outcomes and life expectancy for this population are below average. For the Medicare-only minority population, by contrast, additional factors become important determinants of annual mortality rate. First, a much larger fraction of this population is entitled via disability rather than old age, contributing to a lower average mortality rate. This is only

<sup>7</sup> Throughout this analysis, the ESRD category includes all beneficiaries identified in Medicare enrollment files as having ESRD. This includes those entitled to Medicare solely because they have ESRD and beneficiaries who are entitled to Medicare due to age or disability and who have ESRD. This means that the entitlement categories used throughout include Aged without mention of ESRD, Disabled without mention of ESRD, and all ESRD beneficiaries.

partly offset by the very high rate of ESRD enrollment in the minority population (**Table 3-2**). In addition, for the aged, there is a well-established "crossover" of minority and Caucasian mortality rates around age 75 (Wing et al.1985). For minorities who managed to reach old age, mortality rates are in fact lower than for the Caucasian population, leading to below-average annual mortality rates for the elderly minority population.

Entitlement Status	Non-Minority			Minority		
	% of Persons	% of Deaths	Annual Mort. Rate	% of Persons	% of Deaths	Annual Mort. Rate
Aged, no ESRD	89.3%	93.4%	4.9%	75.2%	83.8%	4.8%
All ESRD	0.5%	2.0%	19.2%	2.0%	6.5%	13.9%
Disabled, no ESRD	10.2%	4.6%	2.1%	22.8%	9.7%	1.8%
All	100.0%	100.0%	4.7%	100.0%	100.0%	4.3%

Source: Analysis of Medicare Denominator Files data for 0.1% sample of beneficiaries, 1994-1998.

**Table 3-3** provides an alternative look at demographic differences by profiling the decedent and survivor populations. This table displays the same underlying information as Table 3-1, quantified differently. On average, decedents are substantially older than survivors, with 29 percent of decedents being age 85 or older. The lower mortality rates for women and Medicare-covered minorities translate to a lower fraction of the decedent population falling into those categories. ESRD beneficiaries make up less than 1 percent of the Medicare population, but account for three percent of deaths. Individuals with some HMO enrollment during the year account for 10 percent of Medicare decedents.<sup>8</sup> Finally, the dual-eligible Medicare/Medicaid beneficiaries make up more than one-fifth of decedents, versus 13 percent of the survivor population.

Demographic Characteristic	Survivors	Decedents
Average Age in Years	70.6	78.3 *
Percent Under 65	17%	7% *
Percent 65 to 74	47%	26% *
Percent 75 to 84	27%	37% *
Percent 85 and older	9%	29% *
Percent Female	57%	53% *
Percent Race non-Caucasian	14%	13% *
Entitlement: Aged, No ESRD	87%	92% *
Entitlement: Disabled, No ESRD	12%	5% *
Entitlement: All End Stage Renal Disease	1%	3% *
Percent with Some HMO Enrollment in Year	13%	10% *
Percent Dual Eligible (Medicare/Medicaid)	13%	21% *

Source: Analysis of Medicare enrollment data for a 0.1 percent sample of beneficiaries, 1994 through 1998

\* Signifies statistically significant difference between decedents and survivors,  $p < .05$ , two-tailed t-test

<sup>8</sup> These individuals will be excluded in later analyses of costs, as no claims data are available for them.

**Table 3-4** demonstrates the importance of the facility resident population in analysis of end-of-life costs. Data from the MCBS show that only about 7 percent of the beneficiary population lived in a facility (mainly, a nursing home) all or part of the year. Yet, the facility resident population accounted for 31 percent of deaths, and in any given year, more than 20 percent of the Medicare-covered facility resident population died.<sup>9</sup>

The link between facility residence and Medicaid coverage likely explains the high fraction of decedents who are dual-eligible. More than half of full-year facility residents (and one-third of part-year facility residents) were dual-eligible (Medicare/Medicaid) beneficiaries. Residents of facilities account for a substantial share of deaths, and Medicaid covers a substantial portion of these individuals.

Place of Residence	% of Population	% of Decedents	Annual Mortality Rate	Memo: % with Medicaid
Community	93%	69%	3%	11%
Facility	5%	23%	21%	56%
Both (part-year)	2%	8%	22%	34%
All	100%	100%	5%	14%

Source: Analysis of 1992 through 1996 Medicare Current Beneficiary Survey Cost and Use files.

MCBS data on health status and limitations on activities of daily living (ADLs) suggest that deaths in the Medicare population reflect both chronic diseases and incidents of fairly sudden onset. Beneficiaries were surveyed in the fall of the year prior to the year of death. As expected, the mortality rate increased with the number of restrictions on activities of daily living noted at that time (**Table 3-5**). Mortality rate for those with no restrictions was 2 percent, rising to 23 percent for those with restrictions in all six ADLs asked on the MCBS.<sup>10</sup> On the other hand, nearly one-third of deaths occurred to beneficiaries who reported no limitations in ADLs in the fall prior to the year of death. Data on self-reported health status tell a similar story. Mortality rate rose as self-reported health status from the prior fall moved from excellent to poor. Yet, nearly 18 percent of deaths were for individuals who reported excellent or very good health in the fall of the year prior to death. Research using other survey sources has shown that one year

<sup>9</sup> Only about 75 percent of facility residents on the MCBS reside in places that were literally termed "nursing homes" by the facility personnel. Almost all of the rest lived in other types of long-term care facilities providing some level of nursing care, including facilities for the mentally retarded, personal care homes, assisted living facilities, and retirement homes. Perhaps as a consequence of this broader definition of long-term care places, the number of full-year facility residents on the MCBS is substantially larger than the number of Medicare-covered nursing home residents estimated from other national surveys. Surveys from the Agency for Healthcare Quality Research and from the National Center for Health Statistics estimate 1.4 million Medicare-covered nursing home residents (Achintya and Dey 1997, Krauss and Altman 1998). The MCBS, by contrast, suggests something closer to 2 million Medicare-covered facility residents at any point in time. Even restricting solely to full-year residents of a "nursing home", the MCBS identifies somewhat more Medicare-covered nursing home residents than are found in the AHRQ and NCHS surveys.

<sup>10</sup> These are: trouble walking, bathing, eating, dressing, toileting, and transferring in or out of bed or chair.

prior to death, the majority of decedents describe their health as good or excellent, have no mobility limitations and are fully oriented (Brock and Foley 1998).

**Table 3-5: Medicare Beneficiaries' Annual Mortality Rate, by Number of Limitations on Activities of Daily Living and Self-Reported Health Status in Autumn of Year Prior to Death**

Number of ADL Limitations At Survey in Fall of Prior Year	% of Population	% of Deaths	Annual Mort. Rate
0	66%	31%	2%
1	12%	14%	5%
2	7%	10%	7%
3	4%	7%	8%
4	3%	7%	10%
5	4%	13%	16%
6	4%	18%	23%
All Beneficiaries	100%	100%	5%
Self-Reported Health Status At Survey in Fall of Prior Year			
Excellent	15.8%	6.0%	1.8%
Very Good	25.2%	11.6%	2.2%
Good	29.9%	23.3%	3.7%
Fair	19.6%	31.3%	7.5%
Poor	9.5%	27.7%	13.6%
All	100.0%	100.0%	4.7%

Source: Analysis of 1992 through 1996 Medicare Current Beneficiary Survey Cost and Use files.

A final way to illustrate the mix of decedents is to combine information on facility residence and restrictions on ADLs. The population of decedents can be broken into three roughly equal segments to show a spectrum of health status in the year prior to death. Almost 30 percent of decedents are community residents with no restrictions on ADLs. Almost a third of decedents reside in facilities at least part of the year in which they die. The remainder of decedents lived in the community and had some restriction on ADLs in the year prior to death. (A negligible portion of the facility resident population reported no ADL restrictions.)

**Table 3-6: Annual Mortality Rates for Medicare Beneficiaries by Facility Residence and Restrictions on Activities of Daily Living**

	% of Persons	% of Decedents	Annual Mort. Rate
Community Resident, No ADL Limitations	67%	28%	2%
Community Resident, Some ADL Limitations	27%	40%	7%
Facility Resident, Full or Part Year	6%	31%	21%
	100%	100%	5%

Source: Analysis of 1992 through 1996 Medicare Current Beneficiary Survey Cost and Use files.

## SECTION 4

### DIAGNOSIS MIX OF DECEDENTS VERSUS SURVIVORS

- Elderly decedents typically have multiple diseases reported at time of death, with three separate ICD-9 codes (and two of the top ten causes of death) reported on the average death certificate.
- The number of diseases reported on the death certificate varies by cause of death. Cancer decedents have the least complex death certificates while diabetes decedents have the most complex.
- Vital statistics data assign individuals to a single underlying cause-of-death category using a combination of physician judgement and coding rules.
- Claims data can be used to assign decedents to "principal disease" categories analogous to the top ten causes of death.
- The aggregate distribution of decedents assigned to "principal disease" is similar to the distribution by cause of death.
- Assignment of complex cases to any one disease category is highly uncertain.
- Classification is more uncertain for diseases with multiple expensive complications (such as diabetes) than for diseases that dominate the course of illness prior to death (such as cancers).
- Different plausible methods for assigning beneficiaries to disease categories often disagree in their assignment of specific individuals to categories.

This chapter examines the diagnoses reported for elderly or Medicare decedents, looking at death certificates, survey data, and Medicare claims data. The purpose is to profile the extent and complexity of decedents' diagnoses and to develop a reasonable method for classifying decedents by disease using claims data. The resulting disease classification will be used subsequently to profile beneficiaries' costs and use of care.

The disease classification system used here was developed in three stages. First, standard NCHS coding for top ten causes of death in the elderly was slightly modified to allow congestive heart failure to be separately identified and to add other types of dementia to Alzheimer's disease. Second, beneficiaries were classified by the disease accounting for the plurality of physician spending in the last year of life. Finally, for hospice patients, principal diagnosis from hospice was allowed to override the diagnosis determined from plurality of physician spending.

#### 4.1 Methods: Cause of Death versus Reason for Medicare Spending

The National Center for Health Statistics (NCHS) compiles information from death certificates and publishes the nation's official cause-of-death statistics. Physicians may report several different medical conditions on the death certificate, using four-digit Internal Classification of Disease (ICD) codes.<sup>11</sup> Physicians' judgement is used to report the codes in a specified order on

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<sup>11</sup> For the data shown here, ninth revision of ICD (ICD-9) was used for death certificate coding. Current death certificates are coded in ICD-10.

the death certificate. From these codes, a single underlying cause of death is identified based on the order in which the codes were reported, applying classification rules developed by the World Health Organization. Individual ICD codes are grouped into standardized disease entities to produce tabulations of the leading causes of death.<sup>12</sup>

Although NCHS cause-of-death statistics are the standard reference, they suffer from four shortcomings for analysis of end-of-life care in Medicare. First, death certificates are gathered by the States and are not routinely matched to Medicare claims data. Performing the match to Medicare claims is difficult both from the standpoint of State privacy laws and in terms of matching the two sources of data, and has been done only rarely by Health Care Financing Administration personnel (Riley and Lubitz 1989).

Second, some diseases important in Medicare end-of-life care are underreported on death certificates or not separately classified. Alzheimer's disease is generally believed to have been substantially under-reported on death certificates, though reporting may be more reliable now than in the past (Hoyert and Rosenberg 1999). Congestive heart failure (CHF) is not separately categorized as a standard cause of death, but instead is classified in an "all other heart disease" category.

Third, for the study of costs near the end of life, it may be more appropriate to focus on the diseases being treated in the last year of life rather than proximate cause of death. Accidents, heart attack, pneumonia, and septicemia reflect common causes of death that may or may not have required substantial treatment prior to death. Cause of death codes may or may not accurately reflect the principal source of illness burden, disability, or Medicare spending in the period prior to death. Even when death certificates are matched to claims data, there is only modest agreement between cause of death and (for example) principal diagnosis for hospitalization (Riley and Lubitz 1989).<sup>13</sup>

Finally, most Medicare decedents suffer from several significant illnesses at the time of death. Any one-dimensional categorization of beneficiaries will necessarily understate the overall burden of illness, and may understate the prevalence of some common conditions that appear on death certificates but are not frequently chosen as underlying cause of death.<sup>14</sup>

**Table 4-1** illustrates these points using a sample of death certificates from the 1993 National Mortality Followback Survey (NMFS). This table shows the top ten causes of death in the elderly, as identified by NCHS. The first two columns of numbers show the number and percent of decedents 65 and older, by cause of death. These are the cause-of-death data as published by NCHS. The next column gives a modified cause-of-death coding calculated from the 1993 National Mortality Followback Survey. This modified categorization breaks out CHF from other

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<sup>12</sup> See Hoyert 1999 for the most recent national mortality statistics and brief description of methods used for cause-of-death reporting. This report may be downloaded from the National Center for Health Statistics website, <http://www.cdc.gov/nchs/releases/99facts/99sheets/97mortal.htm>.

<sup>13</sup> Relevant to this analysis, agreement was highest for cancer decedents, lower for others.

<sup>14</sup> The problem inherent in placing each beneficiary into a single category can be avoided in multivariate models that reflect several diagnoses simultaneously. It is only for purposes of tabulating descriptive data that each beneficiary must be placed into a single category.



types of heart disease, and adds other organic dementia to Alzheimer's disease. (Deaths due to accidents were inadvertently dropped from the file.)

The cause-of-death data – either published NCHS 1997 data or using modified categories calculated from 1993 NMFS – provide essentially the same information. Heart disease accounts for more than one-third of deaths. Within heart disease, CHF is recorded as cause of death for only about a tenth of cases, with the other nine-tenths of heart disease deaths being for other causes, principally heart attack (acute myocardial infarction) and other forms of ischemic heart disease (see Hoyert 1999 for detailed cause-of-death tables).

The final two columns show the extent to which diseases are mentioned on death certificates but not identified as underlying cause of death. The next-to-last column shows the frequency with which diseases were reported anywhere on the death certificate. When all diagnoses were aggregated to the cause-of-death categories shown, the average death certificate for an elderly decedent had just over 2 (2.11) diseases recorded. The final column gives the ratio "any mention" to "cause of death" for each of the diseases shown. When cancer is mentioned on a death certificate, it is almost always identified as cause of death. Heart failure and kidney disease represent the opposite extreme: more than five times as many death certificates have these diseases mentioned somewhere than have them identified as cause of death. These slow, degenerative organ failures diseases are often present but viewed as contributing to death rather than as causing death.

**Table 4-1: Percent of Elderly Decedents with Specified Cause of Death and with Any Mention of Disease on Death Certificate, for Modified Cause-of-Death Categories**

Leading Causes of Death in Elderly	Cause of Death NCHS, 1997		Modified Cause of Death Categories Calculated from 1993 NMFS		
	Number of Persons	Percent of Persons	% of Persons with Cause of Death	% of Persons with Any Mention	Ratio of any Mention to Cause of Death
Diseases of heart	606,913	35%			
Heart – Congestive Heart Failure			4%	18%	4.9
Heart – All Other			34%	52%	1.5
Malignant neoplasms	382,913	22%	23%	26%	1.1
Cerebrovascular diseases	140,366	8%	8%	15%	1.8
Chronic obstructive pulmonary dis	94,411	5%	5%	12%	2.3
Pneumonia and influenza	77,561	4%	4%	11%	2.5
Diabetes mellitus	47,289	3%	2%	8%	3.7
Accidents and adverse effects	31,386	2%			
Alzheimer's and other dementia	22,154	1%	1%	6%	4.0
Nephritis, nephrotic syndrome	21,787	1%	1%	8%	5.4
Septicemia	18,079	1%	1%	4%	4.5
All other causes (Residual)	286,013	17%	16%	53%	3.3
All	1,728,872	100.0%	100%	211.2%	2.1

Source: NCHS 1997 cause of death data taken from Hoyert et al. 1999. Modified cause of death and percent of persons with any mention of disease calculated from: National Center for Health Statistics, National Mortality Followback Survey, Provisional Data – Public Use Data File, 1993

**Table 4-2** shows the overlap between cause of death and secondary diagnoses reported on the death certificate. Each row shows the data for individuals with that cause of death specified on the death certificate, and the columns show the frequency with which other diseases were reported. For example, for all patients with CHF reported as cause of death, 22 percent had some other heart disease also coded.

This table illustrates how medically complex most elderly decedents are, even when viewed through the abbreviated diagnosis coding on the death certificate. For example, of all patients who died with diabetes as cause-of-death, more than half also had heart disease coded, one quarter had stroke recorded, and one quarter had kidney disease recorded. Heart disease other than CHF is a common complication for almost all causes of death. Heart failure (CHF), kidney failure, and COPD form a trio of conditions that often occur together with sufficient severity to warrant recording on the death certificate as having contributed to death.<sup>15</sup>

The sum column shows, on average, how many additional diseases (of the top ten causes) are listed on the death certificate as contributing to death. Here again, those who died from cancer and diabetes show the range of variation. The typical elderly cancer decedent had an average of 0.84 additional diseases reported on the death certificate. Elderly persons dying of diabetes had an average of 2.13 additional diseases coded on the death certificate.

<b>Table 4-2: Percent of Decedents with Diseases Reported on Death Certificate, by Cause of Death</b>												
Cause of Death on Certificate	Sum Across Row	Percent of death certificates with any mention of specified disease										
		CHF	H-OTH	CAN	STRK	COPD	PNEUM	DIAB	ALZH	KIDNY	SEPTIC	RESID
Heart – CHF	121%		22%	7%	7%	20%	12%	1%	0%	5%	0%	47%
Heart - Other	105%	23%		3%	9%	7%	4%	8%	4%	5%	2%	40%
Cancer	84%	4%	17%		2%	10%	7%	2%	2%	4%	0%	37%
Stroke etc	144%	9%	31%	5%		3%	7%	11%	8%	3%	5%	61%
COPD	156%	21%	32%	6%	5%		18%	5%	3%	4%	1%	60%
Pneumonia/flu	147%	17%	33%	3%	6%	4%		5%	16%	1%	13%	49%
Diabetes	213%	16%	56%	4%	23%	6%	10%		3%	28%	4%	61%
Accidents												
Alzheimer's	136%	6%	31%	12%	11%	9%	23%	0%		0%	5%	39%
Nephritis etc	168%	37%	61%	5%	1%	0%	6%	12%	0%		7%	40%
Septicemia	121%	9%	17%	1%	10%	1%	8%	10%	8%	16%		42%
Residual	99%	10%	31%	3%	9%	5%	6%	5%	7%	13%	10%	

Source: Analysis of: National Center for Health Statistics, National Mortality Followback Survey, Provisional Data – Public Use Data File, 1993

#### 4.2 Methods: Classifying "Principal Disease" Using Diagnoses on Claims

<sup>15</sup> This table presents a simplified picture of all comorbidities reported on the death certificate because it only captures interactions between cause of death and secondary diagnoses, ignoring overlaps among secondary diagnoses. If all pairs of diagnoses are tabulated, the results are qualitatively similar but show substantially greater overlap among diseases.

The goal of this section is to develop an analog of NCHS cause-of-death data that can be calculated from claims or other administrative or survey data sources. The resulting patient classification will be used in the remainder of the report.

There are two immediate methodological challenges. First, most Medicare claims sources allow multiple diagnoses to appear with multiple services on a single bill, with no unique crosswalk from diagnosis information to volume and intensity of services. Medicare hospital discharge data, for example, provide fields for principal and nine secondary diagnoses, with no obvious way to apportion spending on the bill across the diagnoses reported. Second, many common diagnoses on Medicare bills are not valid (or common) causes of death. For example, cataract surgery is the highest-dollar-volume procedure paid under Medicare Part B, making cataract the (dollar-weighted) most common diagnosis on Medicare physician claims. Yet cataract is not a plausible candidate for cause of death.

For this report, beneficiaries were assigned to the disease accounting for the plurality of physician spending in the year of death, with some modifications. For two reasons, plurality of physician spending provides a reasonable way to assign patients to disease categories. First, physicians must give a unique diagnosis code for each item billed, so these dollars reflect the diseases that physicians said they were treating. Second, Medicare physician payments in large part reflect an estimate of physician effort, so this method tends to allocate beneficiaries to the disease that accounted for the majority of physician effort in the year of death.<sup>16</sup>

Two major modifications were required to obtain results analogous to cause-of-death data. First, diagnoses that are common on Medicare bills but are highly infrequent causes of death were removed from the analysis. This was done by restricting valid diagnoses to those that define the top ten causes of death, plus all others that account for at least 5000 deaths in the elderly each year, as estimated from the 1993 NMFS. In particular, diagnoses for cataract and high blood pressure were lumped into an "all other" category, as these are extremely common diagnoses in the Medicare claims but rare causes of death.<sup>17</sup> Second, for hospice patients, principal diagnosis on hospice bills was used to override diagnosis determined by plurality of physician spending. Principal diagnosis for hospice admission seemed a plausible candidate for cause of death. In keeping with the goal of identify disease categories analogous to NCHS cause-of-death categories, hospice diagnosis takes preference over other diagnoses.<sup>18</sup>

Before overriding the physician-based diagnosis with the hospice diagnosis, this method defines an aggregate patient distribution similar to that of the NCHS cause-of-death statistics (**Table 4-**

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<sup>16</sup> This is more a theoretical than practical distinction. If lab tests are excluded, a simple count of line items (rather than dollars) gives roughly the same distribution of physician effort across diseases. If lab tests are included, diabetes becomes much more important in the overall distribution of claims by disease.

<sup>17</sup> One further exception was to drop transient ischemic attack (ICD codes beginning with 435) from the "Stroke" cause-of-death category for this classification. Physicians may rarely (but properly) certify ICD-9 codes in this range as cause of death, but physician bills for treatment of TIA, in the absence of other information, should probably not be taken as evidence that an individual was likely to have died from stroke.

<sup>18</sup> This differential assignment of hospice patients is a possibly questionable step in the methods and may somewhat distort statistics on hospice use. Certain diagnoses are difficult to find on physician claims (and hence are under-counted by this method), but are clearly identified on hospice bills (and over-reported among hospice patients). This may matter significantly for Alzheimer's disease (typically not the most expensive condition treated for a decedent), and may result in an over-estimate of the proportion of Alzheimers' deaths occurring in hospice.

3). Heart disease and cancer still appear as the principal causes of death in this population, while no other identified cause of death exceeds 10 percent of decedents.

The heart disease category identified via claims is somewhat smaller than identified from death certificates, while the mix of heart disease cases shifts from one-tenth CHF to one-third CHF. This plausibly reflects true underlying differences between reasons for spending (claims) and cause of death (death certificates). Heart attack, for example, may result in death without substantial physician spending.<sup>19</sup>

The other major difference between the principal disease identified from claims and the NCHS cause-of-death distribution is the much larger "residual" category under the claims-based approach. This is not unexpected: almost every death certificate must list a valid cause of death, but that restriction does not apply to physician claims. The "other" category consists of 23 percent of the population where plurality of physician spending was for some potentially valid as a cause of death, as well as 6 percent with either no physician claims or no diagnosis that would be a valid cause of death.

Before overriding the physician diagnosis with hospice diagnosis, patterns of average spending and hospice use reflect some independently verifiable attributes of the beneficiary population. First, beneficiaries entitled through ESRD account for 3 percent of deaths and have very high costs, a very good match to the kidney disease category identified via physician claims. Second, hospice use is known to be highest among cancer patients, evident in these data as well.

Agreement with these aggregate benchmarks masks substantial uncertainty that exists when placing medically complex beneficiaries into single disease categories. Research using matched death certificate and claims data demonstrated only modest agreement between cause-of-death data and diagnoses reported on hospital inpatient claims. For beneficiaries who died of heart disease or stroke and were hospitalized, only about half were hospitalized with principal diagnosis matching ultimate cause of death. For cancer decedents, by contrast, more than three-quarters of those hospitalized had principal diagnosis of cancer.<sup>20</sup> Similarly, when these diagnosis categories based on physician spending were compared to hospice principal diagnosis, concordance was only fair. Hospice cause of death and physician-assigned cause of death agreed only about 60 percent of the time, with the rate of agreement highest for cancer cases.

The uncertainty and bias in assignment of beneficiaries to these "principal disease" categories increases with the medical complexity of the typical decedent. Cancer patients appear to be identified fairly well, based on their relatively non-complex death certificate diagnosis and the good match to the known facts regarding incidence and costs in the Medicare population.

For diabetics, by contrast, the population identified by this method is almost certainly very different from the population with "diabetes" coded as cause of death on the death certificate.

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<sup>19</sup> A separate analysis of Medicare hospital outpatient department claims provide some evidence of a substantial number of rapid heart attack deaths in this population. Of all Medicare outpatient claims in which discharge status indicated that the beneficiary died during the outpatient visit, more than 40 percent had a principal diagnosis of cardiac arrest or heart attack.

<sup>20</sup> These ratios are calculated from Table 4 in Riley and Lubitz 1989.

The high average medical complexity from death certificate data is at odds with the low average costs for those identified via physician claims. The reason for this is fairly clear. The physician claims method probably places complex diabetes cases into the category of their most expensive complication, while only relatively uncomplicated diabetes cases end up in the diabetes category. In short, for the typical patient with serious diabetes and serious heart disease, the physician claims method used here is more likely to classify as heart disease with complication of diabetes than it is to classify as diabetes with complication of heart disease.

**Table 4-3: Contrasting NCHS Cause-of-Death Data with Assignment of Decedents to Principal Disease Categories Using Diagnoses Reported on Medicare Physician Claims Data**

Leading Causes of Death in Elderly	Cause of Death NCHS, 1997		Principal Disease (Disease Accounting for Plurality of Beneficiary's Physician Costs)			
	Number of Persons	Percent of Persons	Persons in Pooled Sample	Percent of Persons	Mean Medicare Spending	Percent with Any Hospice
Diseases of heart	606,913	35%		27%		
Heart – Congestive Heart Failure			726	9%	\$25,830	10%
Heart – All Other Causes			1418	18%	\$24,799	6%
Malignant neoplasms	382,913	22%	1569	20%	\$31,357	40%
Cerebrovascular diseases	140,366	8%	524	7%	\$20,946	9%
Chronic obstructive pulmonary dis	94,411	5%	331	4%	\$21,687	13%
Pneumonia and influenza	77,561	4%	371	5%	\$26,015	11%
Diabetes mellitus	47,289	3%	209	3%	\$14,714	7%
Accidents and adverse effects	31,386	2%	2	0%	\$3,049	0%
Alzheimer's disease/dementia	22,154	1%	224	3%	\$10,632	8%
Nephritis, nephrotic syndrome	21,787	1%	242	3%	\$55,136	10%
Septicemia	18,079	1%	59	1%	\$23,685	7%
All other causes (Residual)	286,013	17%	1805	23%	\$31,641	12%
Claims Data Only:						
No Valid Dx			248	3%	\$3,676	7%
No Physician Dx Data			238	3%	\$2,894	8%

Source: NCHS 1997 cause of death data taken from Hoyert et al.1999. Physician diagnosis data calculated from Medicare Standard Analytic File Physician/Supplier data for the last 12 months of life, for a 0.1 percent sample of beneficiaries, pooling 1993 through 1998 data.

Overriding the diagnosis category assigned from physician billings with the hospice principal diagnosis provides a modestly different picture of diagnosis mix and hospice use. On net, patients are moved from the heart disease, diabetes, pneumonia, and septicemia categories into other categories, most notably cancer and Alzheimer's disease. Using this approach to categorization, nearly half of decedents with cancer use hospice, and 20 percent of decedents with identified Alzheimer's disease or other organic dementia use hospice.

Disease Category	Decedents in Sample	Percent of Decedents	Mean Spending Last Year of Life	Standard Error of Mean	Percent with Any Hospice
Heart – Congestive Heart Failure	725	9%	\$25,502	\$908	10%
Heart – All Other Causes	1368	17%	\$24,918	\$845	3%
Malignant neoplasms	1711	21%	\$30,631	\$650	45%
Cerebrovascular diseases	530	7%	\$21,414	\$884	10%
Chronic obstructive pulmonary disease	340	4%	\$24,253	\$1,435	15%
Pneumonia and influenza	335	4%	\$25,124	\$1,340	2%
Diabetes mellitus	198	2%	\$14,455	\$1,540	2%
Accidents and adverse effects	2	0%	\$3,049	\$624	0%
Alzheimer’s and other dementia	257	3%	\$12,085	\$910	20%
Nephritis, nephrotic syndrome	245	3%	\$54,920	\$2,567	11%
Septicemia	58	1%	\$26,125	\$3,074	5%
All other causes (Residual)	1977	25%	\$28,088	\$813	8%
No Physician Claims Data	220	3%	\$1,668	\$576	0%

Source: Analysis of Medicare 0.1 percent sample of beneficiaries, 1993-1998

Finally, assignment of medically complex beneficiaries to a single principal disease will always understate the total disease burden present near death. Three sources of data provide broader measures of disease prevalence (**Table 4-5**). Diagnoses on claims, survey responses from the MCBS (in fall of year prior to death), and survey responses from next-of-kin (in year following death) provide a reasonably consistent view of total burden of disease in those cases where similar questions were asked across all three data sources.

Looking at total prevalence of disease in the decedent population, heart disease and cancer still have the highest prevalence, as cause-of-death data suggest. Other diseases have substantially higher prevalence than cause-of-death data alone suggest. About one-quarter of decedents have had a stroke at some point in their lives, roughly 20 to 25 percent have had diabetes, roughly the same proportion have some form of lung disease, and about 15 percent had Alzheimer's or other dementia prior to death.

**Table 4-5: Percent of Elderly Decedents with Selected Diseases Present, as Reported in Claims and Survey Data**

Disease	Percent of Decedents
<b>From Claims: Any mention of diagnosis on any claims during last year of life</b>	
Heart Disease – All	66%
Heart – Congestive Heart Failure	36%
Heart - All Other Causes	59%
Malignant neoplasms (exc skin)	31%
Cerebrovascular diseases	23%
Chronic obstructive pulmonary dis	26%
Pneumonia and influenza	29%
Diabetes mellitus	19%
Accidents and adverse effects	1%
Alzheimer's/other dementia	14%
Nephritis, nephrotic syndrome	12%
Septicemia	10%
<b>From Current Beneficiary Survey: Ever been told by physician that surveyed person had disease</b>	
Heart Diseases (all)	55%
Cancer (except skin)	25%
Stroke	24%
Emphysema, COPD	19%
Diabetes	24%
Alzheimer's/other dementia	16%
<b>From National Mortality Followback Survey: Response by next-of-kin whether decedent had disease</b>	
Heart attack or chest pain	40%
Cancer (all)	32%
Stroke	24%
Lung disease (exc. Asthma)	18%
Diabetes	19%
Alzheimer's/other dementia	16%

Source: Analysis of Medicare Standard Analytic File and Denominator File data for a 0.1 percent sample of beneficiaries 1994-1998; analysis of 1992 through 1996 MCBS Cost and Use files; analysis of National Center for Health Statistics, National Mortality Followback Survey, Provisional Data – Public Use Data File, 1993

## SECTION 5

### SITE OF DEATH AND DETERMINANTS OF SITE OF DEATH

- Claims data and survey/death certificate data provide essentially the same distribution of site of death, with the understanding that home and nursing home deaths are "unknown" sites of death from the standpoint of Medicare claims data.
- At least two-thirds of hospice patients die at home. A further 10 percent die in the nursing home.
- About two-thirds of full-year nursing home residents die in the nursing home.
- Other than hospice users, between 41 and 46 percent of Medicare decedents die in the hospital inpatient setting.
- About 7 percent of all Medicare decedents (8 percent of non-hospice decedents) die during a Medicare covered SNF stay.

#### 5.1 Introduction and Literature Review

The site of death – home, hospital, nursing home, or elsewhere – occupies a central role in the analysis of end-of-life care, touching on issues of patients' preferences, cost of care, and approaches to innovation in end-of-life care. The number of individuals who say they would prefer to die at home substantially exceeds the number who actually do so (Pritchard et al.1998; Banaszak-Holl and Mor 1996). The hospice movement arose in large part as a way to allow individuals to die at home if they wished, and home death remains a cornerstone of the hospice approach to end-of-life care (NAHC 1999). Finally, facility costs account for the majority of all costs in the last year of life, and dying in a facility greatly increases total facility spending.

A substantial literature examines site of death and the determinants of site of death. About half the elderly die in the hospital, although the proportion of hospital deaths varies by diagnosis, region, and patient sociodemographic factors (Polissar et al.1987; Berry et al.1994; Mann et al.1993; Merrill and Mor 1993; Pritchard et al.1998). Various analyses have suggested that individuals diagnosed with vascular disease and early stage cancers, those over 85 and living at home, and elderly (>85) nursing home residents of African American descent are more likely to die in the hospital. Total hospital days per 1,000 persons, which varies by region of the country, is most strongly associated with hospital deaths (Pritchard et al. 1998).

Nursing homes and the patient's home are the next most common sites of death. In addition to diagnoses and patient sociodemographic factors, functional status and social support have been found to influence the variations in proportion of private and nursing home deaths (Polissar et al.1987; Merrill and Mor 1993; Brock et al.1996; Fried et al.1999; Moinpour and Polissar 1989). Because the oldest old (>85) are more likely to reside in nursing homes, these two factors (age and nursing home residency status) are the strongest determinants of nursing home deaths (Merrill and Mor 1993; Brock et al.1996). Selected categories of impaired functional status (i.e., physical disability and incontinence) are also found to be important predictors of admission to a nursing home and ultimately dying there (Brock et al.1996). Dementia and cerebrovascular diseases, which are known to affect functional status, were more prevalent among nursing home



decedents (Polissar et al. 1987; Brock et al. 1996). Similar types of diseases and functional status influence home deaths as well. Individuals with late stage cancer, chronic obstructive pulmonary disease and coronary artery disease were more likely to die at home (Fried et al.1999). Presence of an informal caregiver as well as participating in a hospice program are particularly important predictors of home deaths (Fried et al. 1999; Moinpour and Polissar 1989).

Historically, the least common program at the time of death for all terminally ill patients is hospice (Brock et al.1996; Fried et al.1999). Hospice patients may die at home, in the nursing home, or in an inpatient palliative care unit. Since the advent of the Medicare hospice benefit in 1986, the proportion of deaths occurring in hospice programs has increased, with cancer remaining the most prevalent diagnosis. Women and minorities are more likely to die in hospice programs serving persons in nursing facilities (Scitovsky 1988).

## **5.2 Analysis of Site of Death from Survey and Administrative Data**

Two distinct sources of site-of-death information are available from survey and administrative data. First, the 1993 NMFS has information on site of death as recorded on the death certificate and as reported by next of kin. This provides detail on all sites of death, but cannot be linked to Medicare claims data. Second, Medicare institutional claims provide information on death in hospital, skilled nursing facility, and hospital outpatient department, for patients who expire while being treated at those sites. This information is not available for Medicare hospice patients. Instead, hospices report whether the beneficiary died at home or in an institutional setting.

These two sources – death certificates and Medicare claims – provide a similar picture of the site of death for Medicare beneficiaries. **Table 5-1** tabulates site-of-death information from the 1993 NMFS, for decedents age 65 and older, separately for those with and without any mention of hospice use by next of kin. By this estimate, about two-thirds of elderly hospice decedents die at home, 17 percent die in a hospital inpatient setting, and ten percent in a nursing home. Outside hospice programs, 46 percent are reported to have died in the hospital inpatient setting, 26 percent in the nursing home, and 16 percent at home.<sup>21</sup>

Although these numbers indicate general patterns, some cautions are in order. First, the hospital outpatient department (OPD) captures a wide variety of sites of death. Deaths in that site capture individuals who died elsewhere or emergency cases entering the hospital near or soon after death. In particular, one-third of individuals with hospital OPD assigned as the site of death were said by next-of-kin to have died at home. Second, even for the other sites of death, data sources often substantially disagree. For hospital inpatient, for example, next of kin agreed with the death certificate in only 85 percent of cases.

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<sup>21</sup> The data for hospice users must be interpreted with caution. Use of hospice is based on recall by next-of-kin, and the reported rate of hospice use among elderly decedents in the NMFS is only about half that calculated from Medicare bills.

**Table 5-1: Site of Death for Decedents 65 and Older, by Hospice Use, from Death Certificate and Survey Data in the 1993 National Mortality Followback Survey**

Site of Death	Any Hospice Use	No Hospice Use	All
Hospital, inpatient	17%	46%	44%
Hospital OPD and others	1%	10%	9%
Nursing home	10%	26%	24%
Home	68%	16%	20%
Other	4%	2%	2%
Missing	0%	1%	1%
Total	100%	100%	100%

Source: Analysis of National Center for Health Statistics, National Mortality Followback Survey, Provisional Data – Public Use Data File, 1993

**Table 5-2** gives site of death (from death certificates) based on residence status as reported by next of kin, from the 1993 NMFS. Based on this source, elderly individuals living at home die predominantly in the hospital inpatient setting. Full-time nursing home residents, by contrast, die in the nursing home about two-thirds of the time. Site of death distribution for individuals identified by next-of-kin as part-year facility residents lies between that from home and nursing home residents.<sup>22</sup>

**Table 5-2: Distribution of Site of Death for Elderly Decedents, by Residence Status in Year Prior to Death, from Death Certificate and Survey Data in the 1993 National Mortality Followback Survey**

Site of Death	Residence Home	Residence Nursing Home Full-year	Residence Nursing Home Part-year	Residence Other	Total
Hospital, inpatient	52%	28%	35%	37%	44%
Hosp OPD and others	13%	3%	6%	6%	9%
Nursing home	2%	67%	48%	40%	24%
Home	30%	1%	10%	13%	20%
Other	2%	1%	1%	3%	2%
Missing	1%	1%	1%	0%	1%
Total	100%	100%	100%	100%	100%
Memo: Percent of Elderly Decedents According to 1993 NMFS	59%	22%	16%	3%	100%

Source: Analysis of National Center for Health Statistics, National Mortality Followback Survey, Provisional Data – Public Use Data File, 1993

Site of death can also be approximated from discharge status on various types of Medicare claims. This is important because the claims data provide information on patterns of care and spending, and extracting reasonable site of death information from claims allows analysis of

<sup>22</sup> Compared to the MCBS, the NMFS shows roughly the same proportion of full-year facility residents, but nearly twice as many part-year facility residents. This may be a result of a difference in time frames over which the residence question was asked. In any year of MCBS data, part-year facility residents are identified only when facility status changes during the calendar year of death. For NMFS, by contrast, the question captures moving in or out of the nursing home any time in the 12 months prior to death.

Medicare costs by site of death. The comparison across sources (claims data versus the combination of death certificate and next-of-kin reporting) is an important step prior to the analysis of costs.

**Table 5-3** shows the distribution of site of death as identified from Medicare claims data. Here, for all decedents who have no Medicare+Choice enrollment in the year of death, discharge status on claims was tabulated separately for hospice users and others.<sup>23</sup> Medicare claims data show a pattern of site of death qualitatively similar to that reported on the NMFS. For hospice beneficiaries, both the NMFS and Medicare claims data suggest that about two-thirds died at home. For non-hospice beneficiaries, 46 percent die in the hospital inpatient setting according to NMFS, and 41 percent die in that setting according to Medicare claims data. Medicare claims show fewer persons dying in the hospital outpatient department, but that might be explained by the high proportion in that category in the NMFS who were reported by next-of-kin actually to have died at home.

Hospice site of death		Percent of Hospice Deaths	
Facility			21%
Home			66%
Unknown			14%
			100%
Non-Hospice site of death		Percent of Non-Hospice Deaths	
Hospital Inpatient			41%
Hospital OPD			6%
Skilled Nursing Facility			7%
Unknown			47%
			100%

Source: Medicare Current Beneficiary Survey Cost and Use files, claims data for 1992, 1994, 1995, 1996.

Finally, **Table 5-4** shows site of death from Medicare claims, versus residence status as reported on the MCBS. For residence status, the MCBS does not contain enough cases to allow a separate analysis of hospice users who are residents in facilities.<sup>24</sup> For decedents who did not use hospice, the patterns of site of death by residence status are similar to those noted in the NMFS. About half of community-dwelling residents died in the hospital, versus roughly one-quarter of full-year facility residents. Because this analysis of site of death is based on Medicare

<sup>23</sup> Medicare+Choice enrollees must be omitted here because Medicare does not collect claims-type information on these beneficiaries.

<sup>24</sup> Based on the pooled MCBS sample used here, about 75 percent of hospice decedents were community residents, 15 percent full-year nursing home residents, 10 percent part-year nursing home residents. Even with the pooled sample, there were typically fewer than 20 cases in each site-of-death cell. In general, the MCBS data suggest that perhaps half of hospice deaths with facility site and one-third of hospice deaths with unknown site are for nursing home (full year and part year) residents.

bills, deaths that occur in the nursing home (other than Medicare SNF stays) are part of the "unknown" site-of-death category.

Site of Death	Residence Status			All
	Home	Nursing Home, Full-Year	Nursing Home Part-Year	
Hospital inpatient	50%	23%	16%	41%
Hospital Outpatient	6%	6%	*	6%
Skilled Nursing Facility	4%	7%	36%	7%
Unknown	40%	64%	46%	47%
All	100%	100%	100%	100%

Source: Analysis of fee-for-service beneficiaries with no use of hospice, 1992, 1994, 1995, 1996 MCBS Cost and Use Files.

\* Fewer than 30 cases in the pooled 1992, 1994, 1995, 1996 MCBS files.

## SECTION 6

### COSTS IN LAST YEAR OF LIFE AND IN CALENDAR YEAR OF DEATH

- Last-year-of-life costs remain stable as a fraction of all Medicare spending.
- The oldest decedents have the lowest Medicare costs and lowest likelihood of dying in the hospital inpatient setting.
- Minority decedents have significantly higher costs in the last year of life. This is due to high costs for African-Americans. Costs for other minorities and for those of Hispanic ancestry are not significantly different from the average.
- ESRD decedents' costs are more than twice the average. Almost all ESRD decedents have at least one hospitalization in the last year of life, and 60 percent die in the hospital inpatient setting.
- Over this period, about 15 percent of decedents in the traditional Medicare fee-for-service program used hospice, while 25 percent of decedents enrolled in Medicare+Choice plans did so.
- Nearly half of Medicare cancer decedents used hospice in the year prior to death.
- Hospice decedents' costs are somewhat higher than others. This may be explained, in part, by the very small portion of hospice users with "economically unanticipated" deaths (last year costs under \$5,000).
- For those using hospice, site of death (home versus institution) has only a modest effect on final year costs.
- For those not using hospice, site of death has a strong association with costs. Those who die in inpatient settings (hospital or SNF) have costs about twice as high as others.
- Costs were substantially higher for those who died of kidney disease, and modestly higher for those who died of cancer.
- Those identified with principal disease of Alzheimer's disease were the least likely to die in the hospital.
- End-of-life costs show substantial geographic variation by census division, with total costs and likelihood of dying in the hospital lowest in the West North Central and Mountain divisions.
- High poverty and low income in an area were associated with higher costs and higher likelihood of dying in the hospital.
- Costs were higher in urban areas and in areas with more physicians and beds per capita.
- Likelihood of dying in the hospital was highest in areas with the most hospital beds per capita.
- Medicare covers 61 percent of decedents' costs in the calendar year of death. For those living in the community, Medicare covered 71 percent of costs in the calendar year of death. For those in living in facilities, Medicare covered 30 percent.
- About 18 percent of costs in the calendar year of death are paid directly out-of-pocket. The out-of-pocket percentage is highest for facility residents and the oldest old.
- Use of hospice was associated with a higher proportion of total costs being paid by Medicare.
- Based on this analysis, both Medicare costs and total costs in the calendar year of death decline with age.

This section of the report examines aggregate measures of cost of care in the year prior to death (claims data) or in the calendar year of death (MCBS data). The first part of this section looks only at Medicare costs, using claims data to examine how Medicare reimbursements vary with the characteristics of individuals. The second part of this section uses MCBS data to look at costs and payments outside the Medicare program for the calendar year in which death occurred.

A condensed description of Medicare decedents' costs was provided in Section 2 of this report, including high costs, high use of inpatient care, and declining costs with age. This section largely validates those earlier findings using more recent data.

## 6.2 Medicare Costs in the Last Twelve Months of Life

**Table 6-1** provides a contrast between average spending for decedents (last year of life) and survivors (calendar year). Medicare outlays in the last year of life for all decedents averaged a bit over \$26,000. For comparison, costs for all survivors averaged \$4,400. (These costs are normed to a calendar year 1997 average, and omit costs for durable medical equipment.) The ratio of decedents' costs to survivors' costs was almost exactly six to one, which is at the low end of estimates from the literature.<sup>25</sup> Compared to survivors, decedents' expenditures were concentrated more heavily in inpatient care and less heavily in physician and outpatient spending.

	Decedents		Survivors	
	\$ Per Person	Percent of Total	\$ Per Person	Percent of Total
Home Health	\$2,100	8%	\$450	10%
Hospice	\$1,000	4%	\$20	0%
Inpatient	\$15,900	60%	\$2,120	48%
Hospital OPD	\$1,600	6%	\$500	11%
Physician/Supplier	\$3,700	14%	\$1,070	24%
SNF	\$2,100	8%	\$230	5%
Total	\$26,300	100%	\$4,400	100%

Source: Analysis of Medicare Standard Analytic File and Denominator File data for a 0.1 percent sample of beneficiaries, 1994 – 1998. Managed-care enrollees are excluded.

**Table 6-2** provides some measures of cost and use of care in the last year of life for various subsets of beneficiaries. This table demonstrates many of the principal facts of end-of-life care and provides some additional insights into differences across beneficiary groups.

By age group, Medicare costs were lowest for the oldest decedents. Medicare last-year-of-life spending for those 85 and older was more than a third lower than for those age 64 to 75. About

<sup>25</sup> A totally accurate comparison should account for the missing "half-month" of costs for decedents, because costs were summarized on a calendar-month basis. On average, because costs are so strongly concentrated in the last months of life, adjusting for the missing last half of the 12<sup>th</sup> month prior to death increases decedents average costs by just 1.5 percent.

one-quarter of those over age 85 had less than five thousand dollars in Medicare spending in the last year of life.

Medicare minorities' end-of-life costs were substantially higher than for others. This appears to reflect a true underlying difference in treatment patterns, and is only partially explained by differences in entitlement (more ESRD), age, and cause of death (multivariate analysis not shown).

ESRD beneficiaries' costs in the last year of life were more than two and a half times the average. Almost all of these individuals were hospitalized at some time in the last year of life, and 60 percent of them died as non-hospice hospital inpatients. The level of copayment and deductible liabilities (out of pocket liabilities for Medicare-covered services) was correspondingly large, estimated at \$10,000 for 1997.

**Table 6-2: Profile of Medicare Last Year of Life Costs by Beneficiary Characteristics**

Population	Percent of Pop.	Avg Mcr. Cost LYOL	Any Use of Hospice	Any Hospitalization LYOL	Avg. Copay/Deduct. LYOL	% Non-Hospice Inpatnt. Death (See Note)	AGE	Pct w/ Costs, \$5K	Pct w/ Costs \$5K to \$25K	Pct w/ Costs >\$25K
All Decedents	100%	\$26,000	15%	74%	3300	35%	78	22%	39%	38%
Age < 65	7%	\$31,000 *	13%	67% *	3700	36%	54 *	32% *	27% *	41%
Age 65-74	25%	\$32,000 *	18% *	78% *	3900 *	40% *	70 *	19% *	35% *	46% *
Age 75-84	37%	\$28,000 *	16%	78% *	3400	36%	80 *	19% *	40%	42% *
Age >84	30%	\$19,000 *	13% *	69% *	2500 *	28% *	90 *	28% *	45% *	27% *
Caucasian	87%	\$25,000	16%	74%	3200	34%	79 *	23%	40%	37%
All Other Races	13%	\$32,000 *	14%	76%	3800 *	40% *	75 *	20%	34% *	46% *
Male	46%	\$27,000	15%	75%	3400	36%	76 *	22%	39%	39%
Female	54%	\$26,000	16%	74%	3200	34%	81 *	22%	40%	38%
Aged, no ESRD	92%	\$25,000 *	16%	74%	3100 *	34%	80 *	22%	41%	37%
Dsbl'd no ESRD	5%	\$27,000	15%	65% *	2900 *	32%	53 *	35% *	30% *	35%
All ESRD	3%	\$69,000 *	7% *	92% *	10000 *	60% *	67 *	3% *	8% *	89% *
Medicaid	22%	\$27,000	11% *	73%	3700 *	32% *	79	25% *	36% *	38%

Source: Analysis of Medicare Standard Analytic File and Denominator File data for a 0.1 percent sample of beneficiaries, 1994 – 1998. Managed-care enrollees are excluded.

NOTES: For this table, hospital inpatient death refers to the proportion of the entire decedent population that is not in hospice and dies in the hospital. LYOL is last year of life, Mcr is Medicare.

\* Signifies statistically significantly different from the average of all decedents,  $p < .05$ , two-tailed t-test.



**Table 6-3** profiles last year of life costs by selected other characteristics. Decedents who had some use of hospice had higher costs in the last year of life. Many factors, including patient selection and preferences, might explain this, but the right-hand columns on the table suggest one potential source. Hospice deaths tend to be anticipated, while the non-hospice category contains a substantial fraction of individuals who died without receiving significant amounts of medical treatment. One-quarter of non-hospice decedents had last-year-of-life costs below five thousand dollars, while only 7 percent of hospice decedents did.

Site of death (as determined by claims) had a strong and obvious relationship to Medicare costs in the last year of life. For non-hospice decedents, those who died in the hospital inpatient or SNF setting had costs roughly twice as high as those who died in the hospital OPD or at a site not captured in Medicare claims (largely, home or nursing home). The spending distribution (right-hand columns) largely explains why. Nearly half of those non-hospice patients who expired in the OPD or at unknown location may have had relatively unexpected deaths, with total Medicare spending in the last year of life below \$5,000, versus only three percent of those non-hospice patients who died in an inpatient facility setting. For hospice patients, by contrast, death in a facility was associated with only modestly higher total costs than was death at home. This may reflect, in part, the higher Medicare per-diem payments to the hospice provider for days in which the patient is in the facility.

As noted in the earlier section, the statistics by disease category must be treated with caution. These are not cause-of-death categories, but reflect the diagnosis for which the plurality of physician costs were incurred in the year prior to death, modified by the principal hospice diagnosis for those with hospice. For some categories, such as cancer deaths and deaths due to kidney disease, the assignment of patients to diagnosis categories appears reasonably straightforward. For others such as diabetes, where the typical patient has many significant and costly complications, the disease category probably reflects primarily those cases with relatively few costly complications.<sup>26</sup>

Given that caveat, the most interesting finding by disease is probably that 45 percent of decedents identified as cancer patients had some use of hospice in the last year of life. With the upward trend in hospice use, 51 percent of 1998 cancer decedents used hospice (not shown). Thus, hospice has become the norm for elderly cancer decedents. A secondary finding for cancer patients is their disproportionately high out-of-pocket costs. Upon analysis, this appears to be due largely to chemotherapy costs. These are typically incurred in hospital outpatient departments, where the effective beneficiary copayment rate is roughly 50 percent of costs (MedPAC 1999a, p. 102).

The only trend identified in this analysis was the rapidly rising use of hospice care. In 1994, 11 percent of decedents were estimated to have had some hospice use in the last year of life. By 1998, that had risen to 19 percent. A second finding is that average last-year-of-life costs for decedents did not change over this period. (Costs in this database were adjusted so that average

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<sup>26</sup> For example, a diabetic undergoing bypass surgery in the year of death would likely be categorized as a heart disease patient if the physician costs for the surgery exceeded the costs during the year that were attributed directly to treatment of the underlying diabetes.

costs for all beneficiaries in each year matched 1997 average costs. Thus, last-year-of-life costs have risen only in proportion to the increase in average costs for all beneficiaries.)

**Table 6-3: Profile of Medicare Last Year of Life Costs by Hospice Use, Site of Death, Disease, and Year**

Population		Pct. Of Decedents	Avg Mcr. Cost LYOL	Any Use of Hospice	Any Hospitalization LYOL	Avg. Copay/ Deduct. LYOL	% Non-Hospice Inpatnt. Death (See Note)	Age	Pct w/ Costs <\$5K	Pct w/ Costs \$5K-\$25K	Pct w/ Costs >\$25K
All Decedents			\$26,000	15%	74%	3300	35%	78	22%	39%	38%
Any Hospice	No	85%	\$26,000	0%*	74%	3300	41%*	79	25%*	39%	36%*
	Yes	15%	\$30,000*	100%*	76%	3400	0%*	78*	7%*	42%*	51%*
Site of Death	Hospice, Facility	3%	\$32,000*	100%*	76%	3700	0%*	80	6%*	39%	55%*
	Hospice, Home	10%	\$28,000*	100%*	75%	3300	0%*	77*	7%*	45%*	48%*
	Hospice, Unknown	2%	\$34,000*	100%*	79%	3500	0%*	77*	6%*	37%	57%*
	Not Hospice, Hosp Inpatient	35%	\$37,000*	0%*	99%*	4100*	100%*	77*	3%*	46%*	51%*
	Not Hospice, Hospital OPD	5%	\$17,000*	0%*	51%*	2700*	0%*	76*	45%*	32%*	23%*
	Not Hospice, SNF	8%	\$34,000*	0%*	97%*	4500*	0%*	82*	3%*	48%*	48%*
	Not Hospice, Unknown	37%	\$15,000*	0%*	49%*	2300*	0%*	79*	48%*	30%*	21%*
Disease (See Text For Important Caveats)	HEART-CHF	9%	\$26,000	10%*	84%*	3000	34%	82*	15%*	46%*	39%
	HEART-OTHER	17%	\$25,000	3%*	73%	2800*	42%*	79*	27%*	38%	35%*
	CANCER	21%	\$31,000*	45%*	82%*	4100*	27%*	76*	8%*	41%	50%*
	STROKE	7%	\$21,000*	10%*	82%*	3000*	43%*	80*	17%*	49%*	34%*
	COPD	4%	\$24,000	15%	73%	3000	30%	76*	25%*	40%	36%
	PNEUMONIA	4%	\$25,000	2%*	93%*	3000	46%*	81*	8%*	57%*	35%
	DIABETES	2%	\$14,000*	2%*	50%*	2100*	26%*	79	50%*	30%*	20%*
	ALZHEIMER'S	3%	\$12,000*	20%*	47%*	1900*	11%*	85*	48%*	33%*	19%*
	KIDNEY	3%	\$55,000*	11%*	91%*	7800*	57%*	72*	3%*	24%*	72%*
OTHER	28%	\$25,000	7%*	66%*	3000*	34%	79	32%*	34%*	34%*	
Year of Death	94	20%	\$26,000	11%*	75%	3200	36%	78	23%	38%	39%
	95	21%	\$26,000	15%	73%	3200	35%	78	23%	39%	38%
	96	19%	\$27,000	15%	75%	3300	35%	79	21%	40%	38%
	97	20%	\$27,000	18%*	74%	3300	33%	79	22%	38%	39%
	98	20%	\$27,000	19%*	74%	3400	34%	79	22%	40%	37%

Source: Analysis of Medicare Standard Analytic File and Denominator File data for a 0.1 percent sample of beneficiaries, 1994 – 1998. Managed-care enrollees are excluded.

NOTES: For this table, hospital inpatient death refers to the proportion of the entire decedent population that is not in hospice and dies in the hospital. LYOL is last year of life, Mcr is Medicare. **SEE TEXT FOR IMPORTANT CAVEATS REGARDING DISEASE CATEGORIES.**

\* Signifies statistically significantly different from the average of all decedents, p < .05, two-tailed t-test.

The analysis can be repeated by geographic region and by characteristics of the beneficiary's county or ZIP code of residence (**Table 6-4**). Geographic differences in Medicare prices were removed (to the extent possible) from the underlying cost data. The differences shown below largely (but not entirely) reflect underlying differences in use of care.<sup>27</sup>

There were few notable differences by urbanicity and region. Total cost and hospice use were lower in rural areas (counties not in Metropolitan Statistical Areas). This may reflect supply factors, such as the lower likelihood of having a hospice provider in a rural area. The cost data largely reflect differences in utilization, but may also reflect certain types of (primarily urban) non-patient-care hospital costs that were not removed from the data.

Regionally, there were substantial differences in site of death. The West North Central, Mountain, and Pacific areas had substantially lower proportion of decedents who died as hospital inpatients. Of those areas, two of the three also had last year of life costs that were substantially below average. In the Mid-Atlantic and East South Central regions, by contrast, hospice use was low and probability of dying in the hospital was well above average.

The ZIP-code-based income and poverty statistics suggest the role of local wealth and poverty in determining last-year-of-life care. (Note that these two sets of statistics are ordered differently – the *first* line for income and the *last* line for poverty reflect low-income, high-poverty areas.) Low area income and high area poverty were associated with higher last-year-of-life costs, lower use of hospice, and greater likelihood of dying in the hospital outside of the hospice setting. These area income and poverty characteristics are likely strongly correlated with the findings by race shown in **Table 6-2**.

Area supply characteristics were also associated with hospital use and overall costs in the last year of life. Decedents in areas with the highest number of short-term hospital beds per capita had a higher likelihood of some hospitalization in the final year and of dying as hospital inpatients. Physicians per capita and hospital beds per capita were strongly positively associated with costs in the last year of life, not surprising as these two measures tend to be strongly correlated with the urban/rural differences noted above.<sup>28</sup>

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<sup>27</sup> One exception is teaching and disproportionate share costs in hospitals. These payments are made largely to urban hospitals. Deflating total hospital costs by the appropriate wage index data does not remove the effects of these costs.

<sup>28</sup> Number of hospital beds per capita was calculated from American Hospital Association annual survey data as summarized on the Area Resource File (ARF). Hospital-based long-term beds removed *when those were separately reported by the hospital*. To the extent that hospitals only reported total beds, the beds per capita data may include some mix of long-term and short-term beds.

**Table 6-4: Profile of Medicare Last Year of Life Costs by Characteristics of Beneficiary's County and ZIP code of Residence**

Geographic		Pct. Of Decedents	Avg Mcr. Cost LYOL	Any Use of Hospice	Any Hospitalization LYOL	Avg. Copay/Deduct. LYOL	% Non-Hospice Inpatnt. Death (See Note)	Age	Pct w/ Costs <\$5K	Pct w/ Costs \$5K-25K	Pct w/ Costs >\$25K
Urban	Non-Metro	26%	\$23,000*	13%*	73%	3000*	33%	79	24%	41%	34%*
	Metro	74%	\$28,000*	16%	75%	3400	35%	78	22%	38%	40%
Census Region	New England	6%	\$25,000	11%*	72%	3400	34%	80*	23%	41%	36%
	Mid Atlantic	16%	\$28,000	13%*	75%	3500	40%*	79	22%	38%	40%
	East North Central	19%	\$25,000	16%	75%	3300	33%	78	23%	41%	37%
	West North Central	8%	\$21,000*	15%	71%*	2900*	27%*	80*	27%*	43%	31%*
	South Atlantic	19%	\$27,000	17%	76%	3300	37%	78*	20%*	40%	40%
	East South Central	7%	\$28,000	12%*	80%*	3300	44%*	78	18%*	39%	44%*
	West South Central	10%	\$31,000*	17%	77%	3500	35%	77*	19%*	37%	44%*
	Mountain	4%	\$22,000*	17%	69%*	3100	26%*	79	27%	41%	32%*
	Pacific	10%	\$26,000	16%	70%*	3200	26%*	79	27%*	35%*	37%
ZIP Code Median Income	1 LOWEST 10 PCT	7%	\$31,000*	14%	78%	3600	40%*	77*	21%	35%*	44%*
	2 10 TO 25 PCTILE	12%	\$27,000	12%*	76%	3300	37%	78	21%	38%	41%
	3 25 TO 50 PCTILE	24%	\$25,000	13%*	75%	3300	35%	78	22%	41%	37%
	4 50 TO 75 PCTILE	24%	\$26,000	16%	74%	3100	33%	79	23%	40%	36%
	5 75 TO 90 PCTILE	15%	\$27,000	17%	73%	3300	33%	79	23%	37%	41%
	6 ABOVE 90 PCTILE	10%	\$26,000	18%	73%	3500	32%	80*	22%	39%	39%
ZIP Code Pct in Poverty	1 LOWEST 10 PCT	7%	\$23,000*	18%	73%	3100	34%	80*	24%	40%	36%
	2 10 TO 25 PCTILE	16%	\$26,000	18%*	74%	3300	33%	79	22%	40%	38%
	3 25 TO 50 PCTILE	23%	\$26,000	16%	73%	3200	32%*	79*	23%	41%	36%
	4 50 TO 75 PCTILE	25%	\$26,000	14%	74%	3300	35%	78	23%	39%	38%
	5 75 TO 90 PCTILE	14%	\$27,000	11%*	76%	3300	38%	78*	22%	38%	40%
	6 ABOVE 90 PCTILE	8%	\$33,000*	15%	78%*	3700*	40%*	77*	20%	34%*	46%*
Short-term Hospital Unit Beds/Capita In County	Lowest QUARTILE	25%	\$24,000*	0.16	72%*	3200	30%*	78	25%*	39%	36%*
	2ND QUARTILE	24%	\$25,000	0.15	72%	3200	33%	79	24%	39%	37%
	3RD QUARTILE	25%	\$28,000*	0.16	75%	3400	37%*	79	21%	38%	41%
	Highest QUARTILE	24%	\$29,000*	0.14	79%*	3500	38%*	79	19%*	40%	41%*
Active MD/DO Per Capita In Cnty of Residence	< 1 per 1000	19%	\$24,000*	12%*	75%	3100	33%	78	23%	41%	36%
	1-2 per 1000	28%	\$25,000*	16%	74%	3300	33%	78	23%	41%	36%
	2-3 per 1000	26%	\$28,000*	16%	75%	3400	36%	78	21%	39%	40%
	>3 per 1000	25%	\$29,000*	16%	75%	3400	36%	79*	22%	36%*	42%*

Source: Analysis of Medicare Standard Analytic File and Denominator File data for a 0.1 percent sample of beneficiaries, 1994 – 1998. Managed-care enrollees are excluded.

NOTES: For this table, hospital inpatient death refers to the proportion of the entire decedent population that is not in hospice and dies in the hospital. LYOL is last year of life, Mcr is Medicare. Data (not shown) are missing for between 2 and 7 percent of observations due to non-matches across sources of data or missing source data.

\* Signifies statistically significantly different from the average of all decedents,  $p < .05$ , two-tailed t-test.

Hospice use is the one area for which Medicare administrative data provide some comparison between beneficiaries in traditional fee-for-service Medicare and those enrolled in Medicare+Choice plans. Medicare makes a separate payment to the hospice provider when a Medicare+Choice enrollee chooses hospice. One-quarter of all Medicare+Choice decedents chose hospice, based on analysis of hospice bills, versus 15 percent of decedents enrolled in the traditional Medicare fee-for-service program (**Table 6-5**).

	Beneficiaries Enrolled in Traditional Medicare at Time of Death	Beneficiaries Enrolled in Medicare+Choice at Time of Death
Decedents in Sample	8404	924
Pct. Using Hospice	15%	25%

Source: Analysis of Medicare hospice claims and enrollment files for a 0.1 percent sample of all beneficiaries, pooled 1994 through 1998 data.

### **6.3 Payments by Medicare and Others in the Calendar Year of Death**

Medicare program outlays are only one part of the total cost of care provided to Medicare beneficiaries at the end of life. Other payers – notably Medicaid, but also secondary insurers and direct out-of-pocket costs – cover a substantial portion of the bill.

Readers should note two important caveats. First, this section does not address informal caregiver costs. Family members caring for homebound terminally ill individuals devote substantial time that may substitute for formal (paid) caregivers. One recent study of elderly disabled community dwellers found that working (employed outside the home) caregivers averaged more than ten hours of care weekly, nonworking caregivers averaged almost 20 (Doty, Jackson, Crown, 1998). These unpaid hours increased substantially as the level of disability increased, with nonworking caregivers devoting nearly 70 hours weekly in cases where the disabled family member had five restrictions on activities of daily living (Doty, Jackson, Crown 1998). By focusing only on paid caregivers, this analysis ignores significant labor input.

Second, this section shows costs in the calendar year of death, not costs in the last twelve months of life. The figures will reflect an average of six months' costs for decedents. Data from this section should not be compared to data from the other sections of this report. The reason for the change in the time period of analysis is purely technical. The MCBS is arranged as a series of calendar year files, weighted to give a very accurate portrayal of the cross-section of beneficiaries. In principle, many individuals on the MCBS can be linked across years, and event-by-event detail could be used to construct totals for the last 12 months of life. In practice, this greatly complicates the analysis. Analysis of MCBS calendar year data should give a good qualitative portrait of end-of-life spending because about 70 percent of Medicare last-year-of-life

spending occurs in the calendar year of death.<sup>29</sup> On net, the additional accuracy gained from constructing a twelve-months-prior-to-death series did not seem to merit the substantial additional complication this would entail.

**Table 6-6** shows payments by Medicare and others in the calendar year of death. These payments reflect a simple pooling of MCBS data from 1992 through 1996 Cost and Use files, and so on average reflect typical spending circa 1994. These are costs in the calendar year of death, with no adjustments for changes in spending over time or for geographic differences in Medicare prices.

For all decedents, Medicare covered more than 60 percent of total health care costs. This compares with about 54 percent of costs for all beneficiaries (Gornick et al. 1996). The difference is largely attributable to the high use of hospital inpatient care, for which Medicare covers a high proportion of all spending (not shown).

Even with this relatively small sample of decedents, many aspects of this table dovetail with previous analyses. Medicare program payments were lowest for the oldest old (85 and older), and Medicare's share of total payments was also lowest for this group. But, where other studies have found that total payments are roughly equal across age groups, this analysis of MCBS data suggests that total payments were lowest for the oldest old. In part, that may be due to the use of calendar year data, which increases the importance of acute care costs occurring at the very end of life relative to ongoing monthly nursing home expenditures. The oldest old also had the highest proportion of spending directly out-of-pocket, and the lowest proportion covered by private insurance and similar sources.

Race and gender differences in spending patterns were not large. As was true in the previous analysis of Medicare-only costs, minorities had somewhat higher average spending (although that difference does not reach statistical significance in this analysis). The proportion of spending paid out-of-pocket was somewhat lower for minority decedents. Men had a lower proportion of costs paid by Medicaid, women had a lower proportion paid directly out-of-pocket. This may reflect the higher proportion of oldest old, poor, and facility residents among the female Medicare decedent population.

As was shown in the prior analyses, ESRD decedents were substantially more expensive than others. Dual eligible (Medicare/Medicaid) beneficiaries obviously have a different fraction of total costs paid by each payer than does the remainder of the beneficiary population. For these beneficiaries, Medicare covered a bit over half their costs, Medicaid covered a third, and out-of-pocket and other insurer payments made up the remainder.

Payer mix by residential status shows the differential financing of acute versus long term care. Medicaid covered about one-third of total health care costs for full-year facility residents who died, but covered only a trivial portion of costs for community dwellers and a small portion for those making the community/facility transition then dying. Total costs were highest for those

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<sup>29</sup> James Lubitz of the Health Care Financing Administration (HCFA) suggested a method for calculating this figure from published data on spending in the last months of life. The figure of 70 percent of Medicare last-year-of-life spending occurring in the calendar year of death was calculated from the monthly spending data developed by Lubitz and colleagues (Lubitz and Prihoda 1984).

who made a community/facility transition then died, probably reflecting the cost of at least two acute episodes (one prompting entry to a facility, the other at death).

Finally, hospice users' costs total costs were not significantly different from costs of beneficiaries who did not use hospice. Medicare covered a higher proportion of total costs for hospice users than for other decedents, while Medicaid and out-of-pocket costs were lower for that group.

**Table 6-7** shows the mix of services (spending) for these decedent populations. Across age categories, the data demonstrate the substitution of long-term care for acute care in the oldest old population. For that population, nursing home spending was substantially above average, while hospital inpatient spending was below average. Nursing home costs were lower for men, reflecting their lower age at time of death. Facility residents not only had below-average hospital costs, they also had below-average physician spending. The low drug costs for facility residents are an artifact of the MCBS survey itself, as the MCBS does not separately recognize a cost category for the institutionalized corresponding to the outpatient prescription drug costs captured for the remainder of the population.



Population		Wgtd % of Population	Total Health Care Pmts	Medicare Program Pmts	Medicare % of Total Pmts	Medicaid % of Total Pmts	Out of Pocket % of Total Pmts	All Other Payers % of Total Pmts
All Decedents		100%	\$22,000	\$15,000	61%	10%	18%	12%
Age lt 65		6%	\$27,000	\$19,000	62%	10%	14% *	15%
Age 65-74		26%	\$24,000	\$18,000 *	67% *	5% *	14% *	15% *
Age 75-84		36%	\$22,000	\$16,000	64% *	8% *	16% *	12%
Age > 84		32%	\$21,000 *	\$11,000 *	52% *	17% *	23% *	8% *
Caucasian		86%	\$22,000	\$15,000	60%	10%	18%	12%
Minority		14%	\$24,000	\$18,000 *	67% *	12%	12% *	9% *
Male		47%	\$23,000	\$16,000	63% *	6% *	16%	15% *
Female		53%	\$22,000	\$14,000	59% *	14% *	19%	9% *
Aged no ESRD		93%	\$22,000	\$15,000	60%	10%	18%	11%
Disabled no ESRD		5%	\$24,000	\$17,000	60%	11%	15%	15%
All ESRD		2%	\$57,000 *	\$42,000 *	76% *	6% *	6% *	12%
Medicaid		24%	\$25,000	\$15,000	54% *	32% *	10% *	4% *
Residential Status	Community	67%	\$20,000	\$17,000	71% *	3% *	13% *	14% *
	Facility	24%	\$24,000	\$9,000 *	30% *	32% *	32% *	6% *
	Both	8%	\$35,000 *	\$24,000 *	66% *	7% *	17%	11%
Any Hospice Use in CY	No	89%	\$22,000	\$15,000	59%	11%	18%	12%
	Yes	11%	\$23,000	\$16,000	74% *	5% *	12% *	9% *

Source: Analysis of 1992 – 1996 MCBS Cost and Use Files

Note: See text for explanation of methods used for statistical tests

\* Difference between average for group and average for all beneficiaries statistically significant at p<.05, two-tailed t-test.

**Table 6-7: Total Payments in Calendar Year of Death, by Type of Service, by Selected Beneficiary Characteristics**

Population		Wgtd % of Population	Total Health Care Pmts	Dental	Facility (Nursing Home)	Home Health	Hospice	Inpatient	Institution	Medical Provider (Physician)	Hosp. OPD	Drugs
All Decedents		100%	\$22,000	\$40	\$3,900	\$1,000	\$400	\$11,000	\$1,100	\$3,800	\$950	\$290
Age lt 65		6%	\$27,000	\$40	\$2,200 *	\$600 *	\$400	\$16,000 *	\$600 *	\$4,900 *	\$2,190 *	\$460 *
Age 65-74		26%	\$24,000	\$40	\$1,800 *	\$700 *	\$500	\$14,000 *	\$600 *	\$4,800 *	\$1,260 *	\$390 *
Age 75-84		36%	\$22,000	\$50	\$3,000 *	\$1,100	\$400	\$11,000	\$1,400	\$3,800	\$870	\$300
Age > 84		32%	\$21,000 *	\$10 *	\$7,000 *	\$1,100	\$400	\$7,000 *	\$1,400	\$2,800 *	\$550 *	\$180 *
Caucasian		86%	\$22,000	\$40	\$4,100	\$900	\$400	\$11,000	\$1,200	\$3,800	\$950	\$290
Minority		14%	\$24,000	\$20	\$2,800 *	\$1,100	\$300	\$14,000 *	\$1,000	\$4,100	\$990	\$300
Male		47%	\$23,000	\$40	\$2,400 *	\$800	\$400	\$12,000	\$1,100	\$4,200	\$1,120	\$320
Female		53%	\$22,000	\$40	\$5,300 *	\$1,100	\$500	\$10,000 *	\$1,200	\$3,400	\$810	\$260
Aged no ESRD		93%	\$22,000	\$40	\$4,100	\$1,000	\$400	\$10,000	\$1,200	\$3,500	\$720 *	\$270
Dsbl'd no ESRD		5%	\$24,000	\$60	\$2,200 *	\$600 *	\$500	\$14,000	\$500 *	\$4,300	\$1,260	\$460 *
All ESRD		2%	\$57,000 *	\$30	\$1,700 *	\$800	\$100 *	\$30,000 *	\$1,200	\$13,400 *	\$9,380 *	\$610 *
Medicaid		24%	\$25,000 *	\$0 *	\$7,700 *	\$800	\$400	\$10,000	\$1,300	\$3,200 *	\$1,040	\$200 *
Residential Status	Community	67%	\$20,000	\$50	\$0 *	\$1,200 *	\$400	\$12,000 *	\$500 *	\$4,200 *	\$1,030	\$400 *
	Facility	24%	\$24,000	\$0 *	\$13,800 *	\$100 *	\$300	\$6,000 *	\$1,200	\$2,100 *	\$700 *	\$0 *
	Both	8%	\$35,000 *	\$30	\$6,700 *	\$1,100	\$1,000 *	\$14,000 *	\$5,700 *	\$5,400 *	\$1,060	\$280
Any Hospice Use in CY	No	89%	\$22,000	\$40	\$4,000	\$1,000	\$0 *	\$11,000	\$1,200	\$3,800	\$940	\$280
	Yes	11%	\$23,000	\$20	\$3,100	\$800	\$4,100 *	\$8,000 *	\$900	\$4,200	\$1,100	\$370 *

Source: Analysis of 1992 – 1996 MCBS Cost and Use files

Note: See text for explanation of methods used for statistical tests

\* Difference between average for group and average for all beneficiaries statistically significant at p<.05, two-tailed t-test.

The findings on the higher costs of minority decedents appear contrary to expectation and require, at the minimum, additional analysis to distinguish among minorities. Given the relatively small sample sizes for this analysis, only the largest groups could be separately identified. **Table 6-8** shows that, of minority Medicare beneficiaries, only African-Americans had above-average final year costs. Costs for other minorities and for those of Hispanic ancestry are not significantly different from the average.

<b>Table 6-8: Payments in the Calendar Year of Death, by Race and Hispanic Ethnicity</b>				
Population	Wgt'd % of population	Total Health Care Pmts	Medicare Program Pmts	
All Decedents	100%	\$22,000	\$15,000	
<b>Race</b>				
Caucasian	88%	\$22,000	\$15,000	
African-American	10%	\$26,000 *	\$20,000 *	
Other Minority	3%	\$21,000	\$16,000	
<b>Hispanic Ethnicity</b>				
Non-Hispanic	96%	\$23,000	\$15,000	
Hispanic	4%	\$21,000	\$16,000	
Source: Analysis of 1992-1996 MCBS Cost and Use File				
Note: See text for explanation of methods used for statistical tests.				
* Difference between average for group and average for all beneficiaries is statistically significant at p<.05, two-tailed t-test.				

## SECTION 7

### LAST YEAR OF LIFE AS A FRACTION OF ALL MEDICARE OUTLAYS

- Beneficiaries in the last year of life accounted for 25 percent of total Medicare program payments.
- Last year of life costs account for a higher fraction of inpatient care (hospital and SNF) than outpatient care (hospital OPD and physician).
- Last year of life spending accounts for only 77 percent of hospice costs, with the remainder spent prior to the last year of life. This ranged from a high of 83 percent for hospice enrollees with principal diagnosis of cancer, to a low of 45 percent for enrollees with Alzheimer's disease.
- Last year of life costs differ substantially across physician specialties; highest for oncologists, lowest for chiropractic, physical therapy, allergy, dermatology, ophthalmology.
- Diagnosis Related Groups (DRGs) that occur primarily in last year of life are those for cancer and ventilator dependence.

This section of the report looks briefly at last year of life outlays as a fraction of all Medicare spending, at various levels of disaggregation. In addition to comparing results against earlier studies by Lubitz and colleagues, these tables provide additional characterization of the types of Medicare-covered services and physician specialties that are and are not important in the provision of care at the end of life.

#### 7.1 Last year of life spending as a fraction of all Medicare spending

Lubitz and colleagues have established that spending for those in the last year of life has held fairly steady as a proportion of all Medicare outlays. Except for hospice, the results here offer few surprises.

About 25 percent of Medicare spending was estimated to be for last year of life (**Table 7-1**). This is only slightly lower than the range estimated by HCFA staff, who found that last-year-of-life costs accounted for between 26.9 and 30.6 percent of Medicare spending, depending on the particular year studied (Lubitz and Riley 1993). Several factors might account for that, including exclusion of most durable medical equipment claims from this analysis, variation in methods used to adjust for regional differences in Medicare prices, and differences in methods for counting the last 12 months of life. As was noted in prior studies, last year of life spending accounts for a higher share of inpatient and SNF payments, and a lower share of outpatient and physician payments.

The main surprise of Table 7-1 is that 23 percent of hospice spending occurs prior to the last year of life. A separate analysis of 1995 MCBS data (not shown) similarly found that 28 percent of all months of hospice enrollment were prior to the last year of life. Thus, while most hospice

patients have a relatively short stay just prior to death, a substantial fraction of hospice payment was for care delivered prior to the last year of life.<sup>30</sup>

<b>Table 7-1: Last Year of Life as Fraction of Total Medicare Person-Months of Entitlement, Program Costs, and Copayment/Deductible Liabilities</b>	
	Last Year of Life As Fraction of Total
Person-Months	5%
Medicare Outlays:	
Hospital Outpatient	14%
Physician	15%
Home Health	20%
Hospital Inpatient	29%
Skilled Nursing Facility	37%
Hospice	77%
Total	25%
Memo: Beneficiary Coins/Deduct	19%
Source: Medicare Standard Analytic File and Denominator File data for a 0.1% sample Medicare beneficiaries. Managed-care enrollees excluded.	
Note: Costs for durable medical equipment billed through DME carrier are omitted.	

Detailed analysis of hospice spending shows substantial variation by diagnosis. Cancer patients were the most likely to die within a year of admission to hospice. For those patients, only 17 percent of hospice spending occurred outside the last year of life. For patients with principal hospice diagnosis of Alzheimer's Disease or Stroke, by contrast, roughly half of hospice spending occurred prior to the last year of life. This almost certainly reflects, in part, the greater difficulty in predicting life span for patients with these conditions.

<b>Table 7-2: Hospice Spending in the Last Year of Life as Percent of All Medicare Hospice Spending, by Patient's Principal Hospice Diagnosis</b>	
Principal Diagnosis on Hospice Bill	Last Year of Life Hospice Spending as Percent of Total Hospice Spending
Cancer	83%
Heart – Congestive Heart Failure	80%
Heart – Other	76%
Chronic Obstructive Pulmonary Disease	63%
Stroke	56%
Alzheimer's Disease/Dementia	45%
Source: Analysis of 1994 – 1998 Medicare hospice bills and enrollment data for a 0.1 percent sample of fee-for-service enrollees	

<sup>30</sup> Prior to the Balanced Budget Act of 1997 (BBA97), beneficiaries could only elect hospice a maximum of four times, with the fourth period being of unlimited duration. The BBA changed that to allow an unlimited number of hospice elections of 60 days each. This change in statute may have affect hospice spending in ways not identifiable from the historical data.

Detailed analysis of physician spending by specialty shows the types of services used in the last year of life and the physician specialties whose work was concentrated in care at the end of life (Table 7-3). This table shows all Medicare physician billings (except anesthesia services), by physician specialty. All specialties with less than \$50,000 in allowed charges were summarized in the "all other" line. Specialties are sorted by the fraction of their billings that were for beneficiaries in the last year of life.

To a large degree, the top-listed specialties offered few surprises. They were concentrated in oncology, critical care, and infectious disease. The contrast between pulmonology and cardiology, however, may be of some interest. Although heart disease is the most common cause of death in the elderly, cardiologists' revenues were not concentrated in patients in the last year of life. Pulmonologists, by contrast, appeared near the top of this listing, showing their heavy involvement with patients nearing the end of life. The bottom of the listing demonstrates the types of services not utilized by those near the end of life: chiropractic, physical therapy, allergy, dermatology, and ophthalmology.

Specialty	LYOL as % of Specialty Total	Specialty LYOL as % of LYOL Total	Specialty	LYOL as % of Specialty Total	Specialty LYOL as % of LYOL Total
Hematological Onc.	42%	5.8%	Endocrinology	13%	0.4%
Medical Oncology	41%	2.1%	(Physician Assistant)	13%	0.1%
Critical Care	40%	0.4%	Clinical Psychiatry	12%	0.5%
Hematology	40%	0.3%	Clinical Socl. Worker	12%	0.0%
Infectious Disease	39%	1.0%	Clinical Lab	11%	3.4%
Pulmonary Disease	36%	4.8%	Colorectal Surgery	11%	0.1%
Radiation Onc.	34%	2.7%	Plastic Surgery	11%	0.3%
Nephrology	31%	3.3%	Gynecological Onc.	10%	0.0%
Emergency Medicine	22%	2.5%	All Other Specialties	10%	0.1%
Surgical Oncology	22%	0.1%	Physio lab	10%	0.3%
Interventional Rad.	21%	0.4%	Nuclear Medicine	9%	0.1%
Gastroenterology	20%	3.4%	Podiatry	9%	1.3%
Peripheral Vascr Dis.	20%	0.1%	Urology	9%	2.3%
Geriatrics	19%	0.2%	Otolaryngology	8%	0.6%
Neurological Surgery	19%	1.0%	Psychiatry	8%	1.2%
Diagnostic Radiology	19%	7.7%	Pediatric	8%	0.1%
Internal Medicine	18%	15.3%	Orthopedic Surgery	8%	2.4%
Multispec grp	18%	4.1%	Hand Surgery	7%	0.0%
General Surgery	18%	5.6%	Rheumatology	6%	0.2%
Thoracic Surgery	17%	1.7%	Manip. Therapy	6%	0.0%
Neurology	17%	1.7%	Oral Surgery	6%	0.0%
Pathology	17%	1.4%	Optometry	6%	0.2%
Vascular Surgery	16%	0.6%	Ob-Gyn	5%	0.3%
Phys. Medicine/Rehab	15%	0.7%	Ophthalmology	4%	2.2%
Cardiology	15%	8.0%	Dermatology	4%	0.6%
Family Practice	14%	5.5%	Allergy	4%	0.1%
General Practice	14%	2.2%	Physical Therapy	2%	0.1%
Cardiothoracic Surgery	13%	0.6%	Chiropractic	2%	0.1%
(Continued)			Total	15%	100.0%

Source: Analysis of Standard Analytic File data for 0.1% sample of Medicare fee-for-service beneficiaries, 1994-1997. Managed-care enrollees excluded.

Finally, a detailed analysis of hospital spending by Diagnosis Related Groups (DRGs) tells much the same story. Cancer discharges and ventilator dependence dominated the top of the list (**Table 7-4**). The bottom of the list was substantially more mixed, but contained two common low-risk procedures in Medicare (transurethral resection of prostate and laparoscopic cholecystectomy), elective procedures not likely to be performed on frail beneficiaries.

**Table 7-4: Common Diagnosis Related Groups with High and Low Proportion of Medicare Reimbursements for Last Year of Life, 1993-1997**

DRG	Bills in Sample	LYOL as % of Reimbursement	Label
123	232	100%	CIRCULATORY DISORDERS W AMI, EXPIRED
203	151	94%	MALIGNANCY OF HEPATOBILIARY SYSTEM OR PANCREAS
082	380	89%	RESPIRATORY NEOPLASMS
010	100	88%	NERVOUS SYSTEM NEOPLASMS W CC
172	180	80%	DIGESTIVE MALIGNANCY W CC
403	214	76%	LYMPHOMA & NON-ACUTE LEUKEMIA W CC
483	210	75%	TRACHEOSTOMY EXCEPT FOR FACE, MOUTH & NECK DIAGNOSES
475	460	67%	RESPIRATORY SYSTEM DIAGNOSIS WITH VENTILATOR SUPPORT
202	118	60%	CIRRHOSIS & ALCOHOLIC HEPATITIS
076	207	55%	OTHER RESP SYSTEM O.R. PROCEDURES W CC
087	381	54%	PULMONARY EDEMA & RESPIRATORY FAILURE
398	103	54%	RETICULOENDOTHELIAL & IMMUNITY DISORDERS W CC
205	118	53%	DISORDERS OF LIVER EXCEPT MALIG, CIRRH, ALC HEP A W CC
416	970	51%	SEPTICEMIA AGE >17
316	373	50%	RENAL FAILURE
079	1092	50%	RESPIRATORY INFECTIONS & INFLAMMATIONS AGE >17 W CC
296	1084	45%	NUTRITIONAL & MISC METABOLIC DISORDERS AGE >17 W CC
410	492	45%	CHEMOTHERAPY W/O ACUTE LEUKEMIA AS SECONDARY DIAGNOSIS
127	3567	43%	HEART FAILURE & SHOCK
239	304	43%	PATHOLOGICAL FRACTURES & MUSCULOSKELETAL & CONN TISS MALIGNA
***	***	***	***
218	120	7%	LOWER EXTREM & HUMER PROC EXCEPT HIP, FOOT, FEMUR AGE >17 W CC
005	411	7%	EXTRACRANIAL VASCULAR PROCEDURES
065	173	7%	DYSEQUILIBRIUM
430	2018	6%	PSYCHOSES
257	116	6%	TOTAL MASTECTOMY FOR MALIGNANCY W CC
125	305	5%	CIRCULATORY DISORDERS EXCEPT AMI, W CARD CATH W/O COMPLEX DI
435	210	5%	ALC/DRUG ABUSE OR DEPEND, DETOX OR OTH SYMPT TREAT W/O CC
142	160	5%	SYNCOPE & COLLAPSE W/O CC
183	309	4%	ESOPHAGITIS, GASTROENT & MISC DIGEST DISORDERS AGE >17 W/O C
494	115	3%	LAPAROSCOPIC CHOLECYSTECTOMY W/O C.D.E. W/O CC
134	154	3%	HYPERTENSION
278	141	3%	CELLULITIS AGE >17 W/O CC
337	215	3%	TRANSURETHRAL PROSTATECTOMY W/O CC
215	175	2%	NO LONGER VALID
258	106	2%	TOTAL MASTECTOMY FOR MALIGNANCY W/O CC
359	136	2%	UTERINE & ADNEXA PROC FOR NON-MALIGNANCY W/O CC
437	101	2%	ALC/DRUG DEPENDENCE, COMBINED REHAB & DETOX THERAPY
358	125	2%	UTERINE & ADNEXA PROC FOR NON-MALIGNANCY W CC
356	147	1%	FEMALE REPRODUCTIVE SYSTEM RECONSTRUCTIVE PROCEDURES
245	100	1%	BONE DISEASES & SPECIFIC ARTHROPATHIES W/O CC

Source: Analysis of Medicare Standard Analytic File data for a 0.1 percent sample of Medicare beneficiaries, 1993-1997. Managed-care enrollees excluded.



## SECTION 8

### SUGGESTIONS FOR FURTHER RESEARCH

This report summarizes the first five months' research under a two-year project to examine Medicare beneficiaries' costs and use of care at the end of life. It provides a reasonably comprehensive descriptive profile of the Medicare decedent population, using survey data and administrative data for small samples of beneficiaries.

Descriptive analyses often raise as many questions as they answer. In large part, this study has identified differences within the decedent population but has not addressed the causes of those differences. Further research might reasonably include investigation of at least these topics:

- **Prospectively-identified cohorts** A major analytical challenge will be to shift the focus from retrospectively-identified cohorts (those who died) to prospectively-identified cohorts (those at high risk of death). Medical and policy decisions can only be made prospectively, based on some judgement of severity of disease and likelihood of survival. Identifying the most seriously ill and quantifying likelihood of death are necessary steps to identify groups most likely to benefit from targeted end-of-life policies.
- **Race, poverty, and end-of-life care** The findings for minority decedents and for residents of low-income and poverty areas warrant further investigation. Do these beneficiaries receive more of their care from teaching hospitals? Are they less likely to have a regular source of care? Is the driving factor the beneficiary's own income or the average income in the area of residence? What happens in the years prior to death, where spending for these populations is known to be below average?
- **Facility population** The finding that nearly one-third of Medicare decedents resided in a facility all or part of the year prior to death has significant implications for federal payment policy. It fundamentally involves Medicaid in discussions of financing, and shows that policies affecting facilities and facility residents may be important for discussions of Medicare end-of-life care. Substantially more information is available on this population from the MCBS, from AHRQ and NCHS surveys, and from other sources. A more detailed analysis of characteristics of this population is feasible and clearly warranted.
- **Hospice use and spending** The descriptive analysis showed that total costs for hospice users are no different from other decedents, but that Medicare's share of costs is higher. A substantially more careful analysis of hospice use and costs is possible using existing data sources, including adjustment for mix of diagnoses and other factors likely to affect costs.
- **Medicare+Choice** The finding of higher hospice use by Medicare+Choice enrollees merits further investigation. To what extent does this reflect the location of these plans (in areas with generally high hospice use), the diagnosis mix of enrollees, or other measurable factors? Beyond this, MCBS data can be used to contrast the costs and use of care by Medicare+Choice enrollees versus beneficiaries remaining in the traditional fee-for-service program.

- **Continuity of care** This study made little use of claims-level detail available from Medicare data. In particular, Medicare claims allow individual physicians to be identified via the Unique Provider Identification Number (UPIN), and they allow some tracking of beneficiaries transferred among sites of care using admission and discharge source on facility claims. A study of continuity of care – continuity in the attending physician, and continuity in the site of care – could be done from existing data.
- **Disease categories** There is a high degree of uncertainty in assignment of medically complex beneficiaries to a single disease categories. For risk adjustment in Medicare, that problem has been avoided by a multivariate approach, allowing a single beneficiary to trigger multiple disease categories. Application of standard risk adjustment models to the decedent population seems a reasonable next step in the analysis of costs and patterns of use.
- **Durable medical equipment** Durable medical equipment (DME) data were not included in this analysis due to incomplete files. DME claims capture a significant amount of information that may flag frail beneficiaries, such as purchase of canes, walkers, wheelchairs, oxygen, hospital beds, and enteral/parenteral nutrition supplies. DME data have seldom been used analytically and may provide a source of information that is particularly relevant to a frail elderly population.
- **Clinical detail** Medicare physician bills provide substantial detail on the type and number of services provided to beneficiaries. Almost none of that information was used for this analysis. At the least, Medicare bills could be used to quantify the major types of services delivered by cause of death. For example, what fraction of cancer decedents received chemotherapy in the last year of life, and how does this vary by region?
- **Area resource supply** This analysis used readily-available data on physicians and hospital beds per capita. A more detailed analysis would also factor in area capacity in terms of long-term care beds, skilled nursing facility beds, and the number and size of home health and hospice providers in the area.

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