Words were medicine; they were magic and invisible. They came from nothing into sound and meaning. They were beyond price; they could neither be bought nor sold.

N. Scott Momaday, House Made of Dawn
The economics of ESRD constitute a major public policy issue for Medicare, state Medicaid programs, and other private insurers. The 1972 amendment of the Social Security Act, giving Medicare entitlement to individuals under age 65 with ESRD, was the first and at that time the only program to be defined by a specific rare disease. No one anticipated the success of renal replacement therapy, nor the improvements in care and outcomes (illustrated in Chapter Six) for this once universally fatal disease. Because consolidated data files do not exist for years prior to 1991, when Medicare created the current Standard Analytical Files, long-term financial trends in the ESRD program are difficult to illustrate. We are able, however, to track program costs for the past 11 years. In 1991 Medicare expenditures were $5.8 billion, and non-Medicare costs from health plans and other coverage were $2.2 billion—a total, then, of $8.0 billion from all sources (see Figure p.6 on page 17). By 2001, costs of the program had reached $22.8 billion, almost triple the earlier level of expenditures—this is in contrast to the overall Medicare budget, which, over the same period, only doubled. Medicare’s portion of the ESRD program currently consumes 6.4 percent of the entire Medicare budget of $242 billion, a 33 percent increase over the last 11 years. The Balanced Budget Act of 1997 extended the application of Medicare as secondary payor provisions for the ESRD population to 30 months, a provision applying to individuals in employer health plans. Increasing numbers of patients are now covered by private insurers for at least the first three years of treatment. Assessing this element of the economic burden shows that non-Medicare expenditures have grown from $2.2 billion in 1991 to $7.4 billion in 2001—a 237 percent increase. From this perspective, Congress did achieve its objective of reducing the burden of younger ESRD patients on the Medicare program by having the private sector address an increased proportion of the patients younger than 65. The shortage of available organs, however, which could be used to transplant this younger population and provide ESRD care at a lower cost with improved patient outcomes, has meant that dialysis therapy needs to be provided to ever-increasing numbers of new and prevalent patients. In the past three years the total program and per patient per year expenditures have been increasing at rates not seen since the early 1990s. From 2000 to 2001, total ESRD expenditures grew 11.5 percent—6 percent after adjustments for inflation (see Table p.a on page 16).
In this chapter we have carefully defined the components of these increases. Over the last three years, outpatient expenditures for dialysis and other care have consistently exceeded inpatient expenditures, and the gaps are increasing, a pattern not previously seen in the program (see Figures p.13–14 on page 21). The components of these expenditures include EPO, IV vitamin D, IV iron, and other intravenous injectables such as antibiotics and L-carnitine. Trends clearly show the rise in EPO expenditures, although at a slower rate in the last three years, and rapid growth in expenditures for IV vitamin D in 2000–2001 and IV iron in 2001. These trends in outpatient expenditures appear to have had an impact across all payor groups. The increased proportion of non-Medicare patients has been accompanied in the last three years by an equally steep increase in expenditures. For the Medicare program there was actually a steady slowing in the total and per patient per year expenditures from 1991 to 1998. Total Medicare expenditures appear to have grown in 1999, but only on the basis of an increased number of patients entering treatment, rather than on a per patient basis. Total costs and costs per patient year have been steadily increasing since that time. Both the aging of the ESRD population and its improved survival rates (noted in Chapters Two and Six) have led to increasing program costs, with this growth led by proportionate increases in expenditures for patients age 45–64 and age 75 and older. These changes are also driven by greater survival in the minority populations, particularly in blacks, who have disproportionately higher program expenditures compared to the white population. In addition, patients whose ESRD is caused by diabetes are consuming an increasing part of ESRD program expenditures. From the perspective, then, of projected trends in both the general and ESRD populations over the next 30 years, the economics of the ESRD program are going to be a critical challenge for all payors.
From 1991 to 1996 the annual growth in Medicare payments was 10–17 percent; growth declined to only 1.8 percent between 1997 and 1998, then increased to 4.2, 8.1, and 11.5 percent in each of the following three years (Figure 11.4).

Medicare HMO expenditures for ESRD have grown 18–44 percent per year, with the lowest positive growth—8.2 percent—occurring in 1998 (Figure 11.3). In 2001, however, the HMO program experienced a decline in the number of enrollees, with the total expenditures attributed to this type of insurance coverage falling 13.1 percent. This finding is consistent with the general decline in Medicare HMO enrollment. On a per patient per year basis, annual costs actually declined in 1998 and 1999 before accelerating in 2000 and 2001, a rapid increase present across all age, gender and racial groups (Figures 11.6–8). The reasons for these changes are discussed on page 170.

Part of this growth in expenditures is related to growth in the population under care. Although the Medicare ESRD population grew only 4 percent from 2000 to 2001, the number of non-Medicare patients with ESRD increased 8 percent in the same period (Figure 11.5). Direct information on components of the expenditures was not available to the USRDS, but it is reasonable to assume, based on the basic use of non-dialysis services such as injectables, that these costs increased at a comparable rate. The consistent growth in billed services for patients age 0–19, 20–44, and 45–64, which started in 1999, also appears to reflect major, uniform changes in provider billing practices. By primary diagnosis, these recent increases are most pronounced in the diabetic population (14.1 percent), less so for patients with a primary diagnosis of hypertension (11.8 percent), and lowest for patients with glomerulonephritis and other causes of ESRD (7.1 and 8.9 percent, respectively).

*Figure 11.3* Medicare ESRD costs are obtained from claims files, & include all Medicare as primary payor claims as well as amounts paid by Medicare as
secondary payer. Medicare patient obligations are estimated deductibles & copays. HMO costs are estimated as the number of HMO months times the Medicare AAPCC. & organ acquisition costs are estimated as $25,000 per transplant. The non-Medicare estimate includes all non-Medicare patients (using the AAPCC primary payer estimate for Medicare as secondary payer patients), & estimated patient obligations. Figure 11.4 Total Medicare ESRD costs obtained from claims data. Figure 11.5 December 31 point prevalent ESRD patients; non-Medicare status determined from payor sequence. Figures 11.6–8 period prevalent ESRD patients; non-Medicare & MSP patients excluded. As-treated economic model (see Appendix A for a discussion of this model).
ECONOMIC COSTS OF ESRD

PMPM expenditures, by modality & vintage: prevalent patients

Dialysis only
- < 2 years
- 2-<5 years
- 5+ years

Transplant event within year

Functioning graft only

Graft failure within year

PMPM costs (in dollars)

91 93 95 97 99 01

3,000 4,000 5,000 6,000 7,000 8,000

PM PM expenditures, by modality & age: prevalent patients

Dialysis only

Transplant event within year

Functioning graft only

Graft failure within year

PMPM costs (in dollars)

91 93 95 97 99 01

3,000 4,000 5,000 6,000 7,000 8,000

PM PM expenditures, by modality & gender: prevalent patients

Dialysis only
- Male
- Female

Transplant event within year

Functioning graft only

Graft failure within year

PMPM costs (in dollars)

91 93 95 97 99 01

3,000 4,000 5,000 6,000 7,000 8,000

We present here information on per member per month (PMPM) expenditures by patient modality within a calendar year. Overall, PMPM costs fell in 1998 and 1999, consistent with changes in Medicare policies for payments related to home health and skilled nursing services (see Figures p.13–14 on page 21).

Differences in PMPM costs by vintage have remained relatively consistent for dialysis patients, though differences in hospitalization rates for these patients have narrowed (Figure 11.9; see also Figure 6.4). In the Medicare system, hospitalizations are paid on a fixed-rate, DRG basis, so a reduction in the difference in admission rates reduces the differences in Medicare expenditures. Patients with less than two years on dialysis still have a higher payment rate, consistent with early vascular access services.

For patients who receive a transplant, differences by vintage have actually increased, and costs are highest for those with the most time on ESRD. These trends may be associated with longer transplant waiting times, as increased time on dialysis has been linked with higher event rates both on the waiting list and after a transplant. Such differences need more careful assessment to determine if care systems should be altered to address comorbidity development after a transplant (see pages 122–127 in Chapter Seven).
Costs for patients with a functioning graft who have been on ESRD less than two years declined from 1998 to 2000, but rose quite steeply in 2001. And with the exception of a decrease in 1998, costs for the newest patients whose grafts fail during the year have risen quite steadily since 1992.

Racial differences in PMPM expenditures are most pronounced in patients with a functioning graft (Figure 11.12). Costs are considerably higher for black patients, and lowest for patients of races other than white or black.

PMPM expenditures by primary diagnosis are, not surprisingly, greatest for patients whose ESRD is caused by diabetes—in dialysis patients, for example, costs are almost 30 percent higher than in patients with a primary diagnosis of glomerulonephritis, and 12.4–13.8 percent higher than in patients with hypertension or other causes of renal failure (Figure 11.13). For patients with a functioning graft these differences are even more pronounced, with costs for diabetics being 43, 66, and 82 percent higher than in those with hypertension, other primary diagnoses, and glomerulonephritis, respectively. Diabetic patients experiencing a graft failure during the year also have markedly higher expenditures.

Overall PMPM costs by modality demonstrate the major financial incentives for transplanting as many patients as possible, as their costs are one-fourth to one-fifth those of patients on dialysis at any time during the year (Figure 11.14). As expected, a

\[\text{Figures 11.9–14}\] period prevalent ESRD patients. As-treated model; patients with Medicare as secondary payor are excluded. Modalities determined using methods from the HCFA Research Report on End-Stage Renal Disease (publication number 03393); see Appendix A for further details. ■ Figure 11.10 data for transplant events, functioning grafts, & graft failures in patients age 75 & older are not reported due to small sample sizes.
Medicare risk patients

In the 2002 ADR we presented new information on the number of ESRD patients treated under the Medicare+Choice HMO care system. We also reported that general enrollment in the program had declined from its peak in 1999. As private health plans withdraw from participation because of low payment rates, Medicare HMO group enrollment continues to fall (Figure 11.15). Many health plans had previously offered generous packages, which included prescription drug coverage and little if any costs for copayments and deductibles. Cost pressures and payment rates are now, however, part of the discussions which have led to a new proposed payment system based on the number of chronic diseases patients carry.

Geographic patterns in the percent of Medicare risk patients have changed since 1991 (Figure 11.16). Florida and states on the West Coast continue to have the highest proportions of Medicare risk patients. Since 1996, growth has occurred in New England and the South Atlantic.

The declines noted last year in the general Medicare+Choice program are now apparent in ESRD enrollment as well. Peaking at 30,400 individuals in 2000, enrollment fell to 29,100 in 2001. The top 25 MSAs now account for 64 percent of all ESRD enrollees in Medicare+Choice programs (Figure 11.18). Almost one-third of all patients are located in California—10 percent in the

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**Metropolitan statistical areas (MSAs) with the greatest numbers of Medicare risk patients**

1. Los Angeles/Long Beach CA
2. Philadelphia PA
3. New York NY
4. Riverside-San Bernardino CA
5. Phoenix AZ
6. Oakland CA
7. Miami FL
8. Chicago IL
9. San Diego CA
10. Pittsburgh PA
11. Orange County, CA
12. San Francisco CA
13. Ft Lauderdale FL
14. Boston MA
15. Sacramento CA
16. Portland OR
17. Denver CO
18. Tampa-St. Petersburg FL
19. San Jose CA
20. San Antonio TX
21. St Louis MO
22. Palm Beach FL
23. Cleveland OH
24. Washington, DC
25. New Orleans LA

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### Table 11.a - Distribution of Medicare risk patients, by ESRD network, diabetic status, age, & race

<table>
<thead>
<tr>
<th>ESRD Risk Category</th>
<th>Total Medicare pts</th>
<th>Medicare ESRD pts</th>
<th>% of ESRD risk pts in network</th>
<th>% of total Medicare pts</th>
<th>Medicare ESRD risk months</th>
<th>% of total Medicare risk pts in network</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetic</td>
<td>174,812</td>
<td>12,726</td>
<td>7.3</td>
<td>43.7</td>
<td>104,679</td>
<td>6.1</td>
</tr>
<tr>
<td>Non-diabetic</td>
<td>264,167</td>
<td>15,010</td>
<td>5.7</td>
<td>51.6</td>
<td>125,675</td>
<td>100.0</td>
</tr>
<tr>
<td>Unknown</td>
<td>35,967</td>
<td>1,367</td>
<td>3.8</td>
<td>4.7</td>
<td>11,619</td>
<td>3.3</td>
</tr>
<tr>
<td>0-19</td>
<td>7,607</td>
<td>25</td>
<td>0.3</td>
<td>0.1</td>
<td>2,424</td>
<td>0.8</td>
</tr>
<tr>
<td>20-44</td>
<td>99,373</td>
<td>1,347</td>
<td>1.4</td>
<td>4.6</td>
<td>31,114</td>
<td>1.2</td>
</tr>
<tr>
<td>45-64</td>
<td>188,709</td>
<td>5,762</td>
<td>3.1</td>
<td>19.8</td>
<td>51,593</td>
<td>2.3</td>
</tr>
<tr>
<td>65-74</td>
<td>99,947</td>
<td>11,730</td>
<td>11.7</td>
<td>40.3</td>
<td>97,884</td>
<td>10.7</td>
</tr>
<tr>
<td>75+</td>
<td>79,310</td>
<td>10,239</td>
<td>12.9</td>
<td>35.2</td>
<td>79,140</td>
<td>12.9</td>
</tr>
<tr>
<td>White</td>
<td>289,821</td>
<td>20,262</td>
<td>7.0</td>
<td>69.6</td>
<td>166,183</td>
<td>70.6</td>
</tr>
<tr>
<td>Black</td>
<td>151,343</td>
<td>6,605</td>
<td>4.4</td>
<td>22.7</td>
<td>55,516</td>
<td>22.7</td>
</tr>
<tr>
<td>Native American</td>
<td>7,499</td>
<td>143</td>
<td>1.9</td>
<td>0.5</td>
<td>1,236</td>
<td>1.9</td>
</tr>
<tr>
<td>Asian</td>
<td>18,656</td>
<td>1,849</td>
<td>9.9</td>
<td>6.4</td>
<td>16,847</td>
<td>3.2</td>
</tr>
<tr>
<td>Other/unknown</td>
<td>7,627</td>
<td>244</td>
<td>3.2</td>
<td>0.8</td>
<td>2,190</td>
<td>2.0</td>
</tr>
<tr>
<td>All</td>
<td>474,946</td>
<td>29,103</td>
<td>6.1</td>
<td>100.0</td>
<td>241,973</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Los Angeles/Long Beach area alone—and the next largest concentrations of patients occur in Networks 7, 15, and 4 (Table 11.a).

The Medicare+Choice program will certainly undergo more changes under the new risk adjuster system. Demonstration programs are also planned for ESRD patients and those with chronic kidney disease to determine if care systems and payment mechanisms can help improve care and address growth in the costs of these outlier populations. (On June 4, 2003 the demonstration program was announced in the Federal Register, and interested organizations were invited to apply.)
Components of care

Recent growth in Medicare ESRD program expenditures has reversed the lower costs seen in 1998 and 1999, and the increases in 2000 and 2001 appear related to services not currently included in the composite rate (Figure 11.21).

Because we were previously able to track only the total amount paid for an entire claim, the USRDS estimated line level amounts for items such as IV iron and IV vitamin D. We adopted a standard actuarial approach of partitioning the total payment to the percent of the billed amount on the line level. Though our validation of this method, using EPO billing, was found to be within 2 percent, the method is vulnerable to disproportional charges to Medicare net payments. In July 2000, however, Medicare implemented a detailed line level tracking of services, including dollar amount for billed amount, Medicare allowable charges, and the net amount paid by Medicare. This has allowed us to directly determine individual expenditures for each billable line item.

This new detail helps illustrate some substantial changes in PMPM costs, particularly for IV vitamin D and IV iron. Expenditures for IV iron increased almost 16 percent in 2001, in part due to increased use of iron gluconate and iron sucrose. Because the coding system for tracking these medications was not fully implemented until 2001, and codes used prior to this lacked specificity, it is likely that use of these medications was underreported in 2000. This is not true, however, for IV vitamin D, as Zemplar has had a HCPCS code for several years. The 41 and 19 percent increases in IV vitamin D expenditures for the years 2000 and 2001, then, are a direct result of increased billing for Zemplar versus Calcijex.
11.24 · PMPM costs for clinical services, by unit affiliation: prevalent dialysis patients

11.25 · Geographic variations in unadjusted Part A & B costs ($) | prevalent dialysis patients


Unit affiliation
All · All units
Chain 1 · Fresenius
Chain 2 · Gambro
Chain 3 · DaVita
Chain 4 · Renal Care Group
Chain 5 · Dialysis Clinics, Inc.
Chain 6 · Nat’l Nephrology Assoc.
NC · Non-chain units
HB · Hospital-based units
U · Unknown affiliation

11.21 · PMPM costs for clinical services, by unit affiliation: prevalent dialysis patients


Inpatient

Dialysis

EPO

IV iron

IV vitamin D hormones

Other injectables

Laboratory

Unit affiliation
All · All units
Chain 1 · Fresenius
Chain 2 · Gambro
Chain 3 · DaVita
Chain 4 · Renal Care Group
Chain 5 · Dialysis Clinics, Inc.
Chain 6 · Nat’l Nephrology Assoc.
NC · Non-chain units
HB · Hospital-based units
U · Unknown affiliation

Outpatient (non-dialysis)

Part B

Dialysis

Part B

Unit affiliation
All · All units
Chain 1 · Fresenius
Chain 2 · Gambro
Chain 3 · DaVita
Chain 4 · Renal Care Group
Chain 5 · Dialysis Clinics, Inc.
Chain 6 · Nat’l Nephrology Assoc.
NC · Non-chain units
HB · Hospital-based units
U · Unknown affiliation
INTRODUCTION  Figure 11.1  Between 2000 and 2001, total Medicare spending on EPO, IV vitamin D, IV iron, and other injectables increased 9.45, 43, and 6 percent, respectively. Since the introduction of the NKF K/DOQI guidelines in 1998, growth has been 40 percent for erythropoietin, 158 percent for IV vitamin D, 61 percent for IV iron, and 74 percent for other injectables.  Figure 11.2  From 1991 to 2001, the prevalent ESRD population grew 106 percent, the total number of deaths 123 percent, total Medicare expenditures 162 percent, and estimated non-Medicare expenditures 239 percent.  ESRD PROGRAM EXPENDITURES  Figure 11.3  The distribution of ESRD payments has changed since 1991. In 2001, Medicare expenditures were 63 percent of the total, patient obligations 14 percent, HMO costs 3.7 percent, and non-Medicare estimated expenditures 19.4 percent.  Figure 11.4  In 2000 and 2001, increases from the previous year in total expenditures were 8.1 and 11.5 percent, while growth in costs per patient year were 4.2 and 10 percent. The small annual increases in 1998 to 1999 are most closely associated with changes in payment policies for home health services and skilled nursing services.  Figure 11.8  Patients with diabetes consume the greatest amount of resources, though the annual percent growth in the diabetic population has decreased sharply since 1992.  PMPM EXPENDITURES, BY MODALITY  Figure 11.9  Differences in PMPM costs by patient vintage for dialysis patients have remained relatively consistent; they have increased, however, for patients receiving a transplant or with a functioning graft during the year, and for those experiencing a graft failure.  Figure 11.12  Racial differences in PMPM costs are most pronounced in patients with a functioning graft, with costs considerably higher for black patients than for those who are white or of other races.  Figure 11.14  Overall PMPM costs for patients with a functioning graft throughout an entire year are only one-fourth to one-fifth those of patients on dialysis.  MEDICARE RISK PATIENTS  Figure 11.15  The Medicare-Plus Choice program for ESRD patients peaked at 30,400 individuals in 2000, and declined to 29,000 in 2001. The population of the entire program peaked at 6.35 million in 1999, and declined to 5.98 million by 2001.  Figure 11.16  The highest percentages of patients with Medicare+Choice coverage are located in the western and southwestern states.  Figure 11.18  The top 25 metropolitan statistical areas account for almost two-thirds of the Medicare risk ESRD population, with the largest number of patients located in Los Angeles/Long Beach, California.  Table 11.a  Almost one-third of all Medicare risk ESRD patients in the U.S. live in California (Networks 17 and 18), which accounts for the large proportion of Asian patients in the risk population. The Medicare risk population, not unexpectedly, is dominated by patients age 65 years and older.  COMPONENTS OF CARE  Figure 11.21  Since 1991, expenditures have increased more for IV vitamin D, IV iron, and other injectables than for erythropoietin.  Figure 11.22  In 2001, combined IV iron and erythropoietin PMPM expenditures ranged from $434 to $546 between the eastern and western portions of the United States, a 25 percent difference. Expenditures for IV vitamin D and other injectables varied between $59 and $229, a difference of 288 percent between the lowest and highest quintiles.  Figure 11.23  PMPM costs for inpatient expenditures in 2001 varied between $1,268 and $1,785, a 41 percent difference between the lowest and highest quintiles on the map. Geographic patterns for outpatient PMPM expenditures differ from those of inpatient costs, and vary from $1,786 to $2,028, a 13.5 percent difference.  Figure 11.24  Chain-affiliated units tend to receive higher payments than hospital-based units for dialysis, EPO, and other injectables. Erythropoietin expenditures vary between $421 in hospital-based units to $501 in one of the chains.