

2012

volume two

USRDS Annual Data Report

Atlas of End-Stage Renal Disease in the United States

national institutes of health
national institute of diabetes & digestive & kidney diseases
division of kidney, urologic, & hematologic diseases



volume one

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I come into the presence

of still water.

And I feel above me the

day-blind stars

waiting with their

light. For a time

I rest in the grace of the

world, and am free.

WENDELL BERRY,
“The Peace of Wild Things”

volume two

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program highlights

patients

116,946

number of new ESRD patients, 2010 (Table p.a)

348

adjusted rate of incident ESRD, 2010 (per million population; Figure 1.5)
*white: 275 » black/African American: 924
» Native American: 465 » Asian: 389*

14.6

adjusted rate of incident ESRD in pediatric patients, 2010 (per million population; Figure 8.17)

594,374

number of prevalent ESRD patients, 2010 (Table p.a)

1,763

adjusted rate of prevalent ESRD, 2010 (per million population; Figure 1.13)
*white: 1,311 » black/African American: 5,242
» Native American: 2,565 » Asian: 2,101*

86.4

adjusted rate of prevalent ESRD in pediatric patients, 2010 (per million population; Figure 8.22)

74%

prevalent hemodialysis patients enrolled in Medicare Part D, 2010 (Table 6.c)

56%

prevalent transplant patients enrolled in Medicare Part D, 2010 (Table 6.c)

patient care

55%

patients with hemoglobin <10 g/dl at initiation, 2010 (Table 1.g)

74%

diabetic patients receiving two or more A1C tests, 2009–2010 (Figure 2.8)

59%

diabetic patients receiving two or more lipid tests, 2009–2010 (Figure 2.9)

21%

diabetic patients receiving two or more eye examinations, 2009–2010 (Figure 2.10)

15%

patients using a fistula at first outpatient dialysis, 2010 (Figure 2.12)

outcomes

1.88

adjusted all-cause admission rate, 2009–2010 (admissions per patient year; Table 3.a)
*white: 1.90 » black/African American: 1.93
» other race: 1.52*

520

adjusted cardiovascular admission rate among hemodialysis patients, 2010 (admissions per 1,000 patient years; Figure 3.3)

458 adjusted rate of admission for infection among hemodialysis patients, 2010 (admissions per 1,000 patient years; Figure 3.3)

211 adjusted all-cause first-year mortality among 2009 incident patients (deaths per 1,000 patient years at risk, from day 90; Figure 5.1)
hemodialysis: 225 » peritoneal dialysis: 125 » transplant: 59

198 adjusted all-cause fifth-year mortality among 2005 incident patients (deaths per 1,000 patient years at risk, from day 90; Figure 5.1)
hemodialysis: 236 » peritoneal dialysis: 254 » transplant: 60

0.32 adjusted five-year survival probability among white ESRD patients incident in 2005 (Table 5.a)

0.39 adjusted five-year survival probability among black/African American ESRD patients incident in 2005 (Table 5.a)

transplantation

17,778 total kidney transplants, 2010 (Table p.a)
deceased donor: 11,446 » living donor: 6,273

21.8 rate of deceased donor kidney donation, 2010 (per million population; Figure 7.10)
white: 21.4 » black/African American: 28.1 » Native American: 7.7 » Asian: 8.5

22.3 rate of living donor kidney donation, 2010 (per million population; Figure 7.10)
white: 22.7 » black/African American: 21.9 » Native American: 6.5 » Asian: 11.5

2.4 adjusted rate of deceased donor kidney transplants, 2010 (per 100 dialysis patient years; Figure 7.13)
white: 2.6 » black/African American: 2.0 » Asian: 3.4 » other race: 2.3

1.3 adjusted rate of living donor kidney donation, 2010 (per 100 dialysis patient years; Figure 7.15)
white: 1.9 » black/African American: 0.5 » Asian: 2.3 » other race: 1.0

expenditures

\$33 billion total Medicare ESRD expenditures, 2010 (Table p.a)

\$14.5 billion total non-Medicare ESRD expenditures, 2010 (Table p.a)

\$47.5 billion total ESRD expenditures, 2010 (Table p.a)

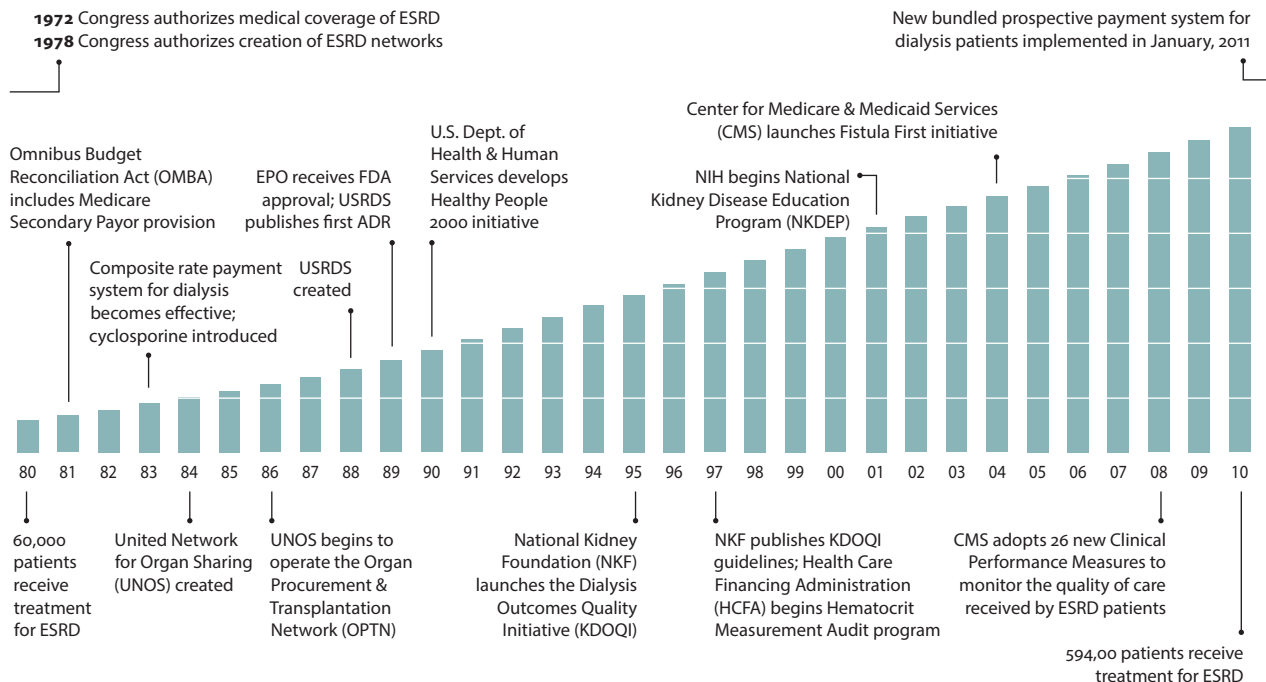
\$87,561 total Medicare expenditures per person per year for hemodialysis patients, 2010 (Table p.a)

\$66,751 total Medicare expenditures per person per year for peritoneal dialysis patients, 2010 (Table p.a)

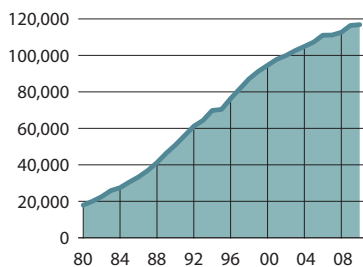
\$32,914 total Medicare expenditures per person per year for transplant patients, 2010 (Table p.a)

\$1.8 billion total estimated net Part D payment for ESRD patients, 2010 (Figure 6.9)
hemodialysis: \$1.43 billion » peritoneal dialysis: \$98 million » transplant: \$306 million

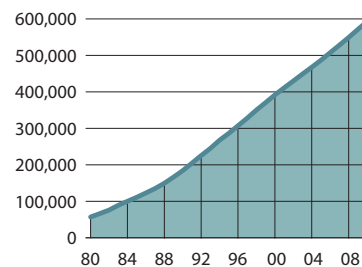
end-stage renal disease (ESRD) IN THE UNITED STATES



New patients Nearly 117,000 people began treatment for end-stage renal disease (ESRD) in 2010.



Total patients Nearly ten times more patients are now being treated for ESRD than in 1980.



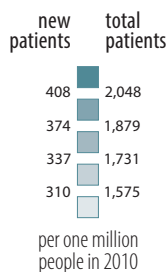
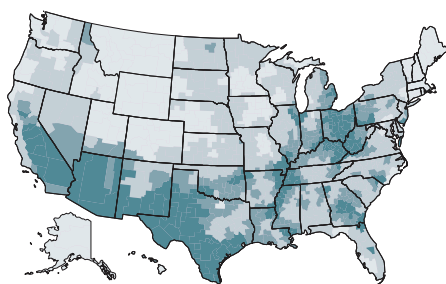
2012
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volume
ESRD

156

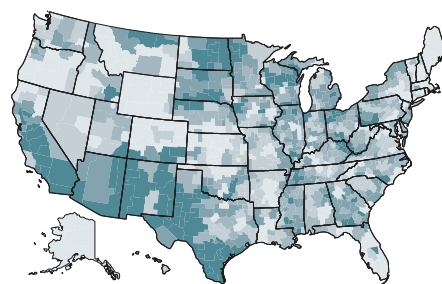
1980 U.S. patients newly diagnosed with ESRD
1 in 11,600

2010 1 in 2,900



1980 U.S. patients being treated for ESRD
1 in 3,450

2010 1 in 570



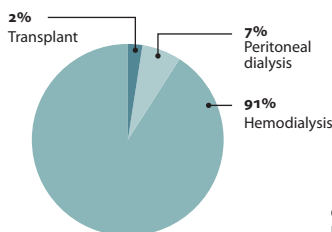
Graphs: Figure 1.1
Rates of new & existing patients: Figures 1.5 & 1.13
Maps: Figures 1.3 & 1.11

44% of new ESRD cases have a primary diagnosis of **DIABETES**;
28% have a primary diagnosis of **HYPERTENSION**

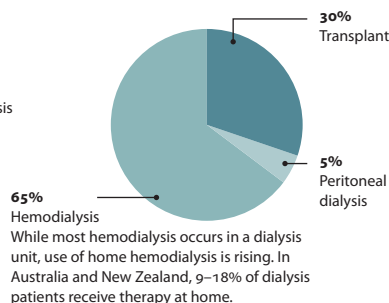
The rate of new ESRD cases is **3.4 TIMES HIGHER**
among **AFRICAN AMERICANS**
than among whites

Renal replacement therapy

Most new patients begin therapy on hemodialysis.



And in the entire ESRD population, 3 in 10 patients have a kidney transplant.



23,000

number of adult patients waiting for a kidney transplant in 1995

86,000

number waiting in 2010

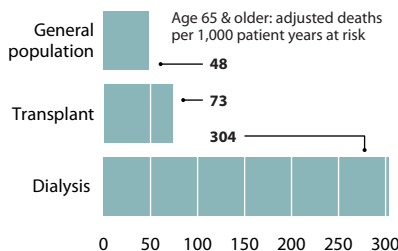
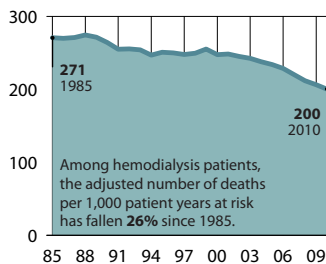
2.6 years

median time on transplant wait list (adults)

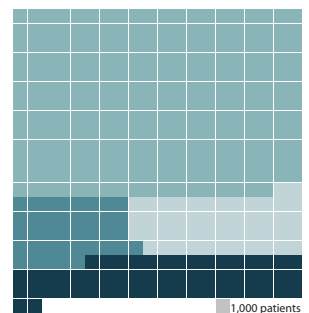
Mortality

People are surviving longer on dialysis than in the past.

But mortality for dialysis patients is still far higher than in the general population.



Dialysis unit ownership

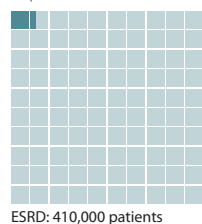


6 in 10

dialysis patients are treated in units owned by **FRESENIUS** or **DAVITA**

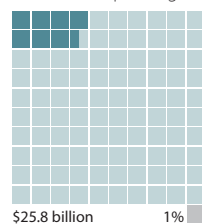
Costs of caring for patients with ESRD, 2010

1.3% of Medicare patients have ESRD



ESRD: 410,000 patients

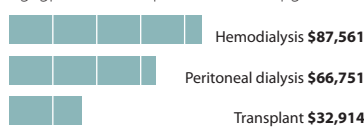
They account for 7.5% of Medicare spending



\$25.8 billion

TOTAL MEDICARE SPENDING
\$343 BILLION

Medicare spending per patient year, by type of renal replacement therapy



\$47.5 BILLION

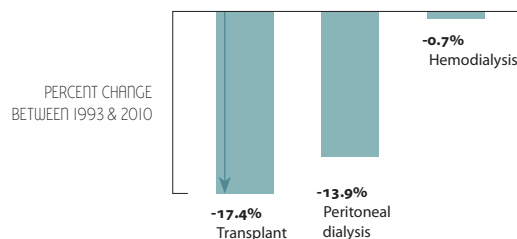
total costs per year for ESRD patient care

hospitalization and part D use IN THE ESRD POPULATION

Hospital days per year Patients with ESRD are now spending fewer days each year in the hospital.

1993		2010
8.6	Transplant	5.5 days per year
18.1	Peritoneal dialysis	11.9
14.8	Hemodialysis	12.1

Hospitalization Rates And all-cause hospitalization rates have fallen since 1993.



But **INFECTION** remains a major cause of **HOSPITALIZATION** among patients with ESRD

Since 1993, the rate of hospitalization due to **INFECTION** has increased **31%** overall

Admissions for infection, per 1,000 patient years

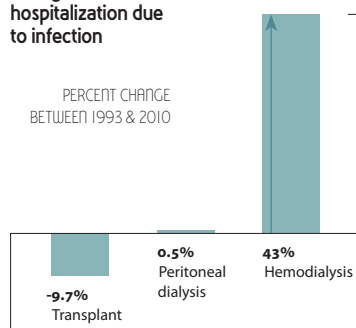
219
transplant

558
peritoneal dialysis

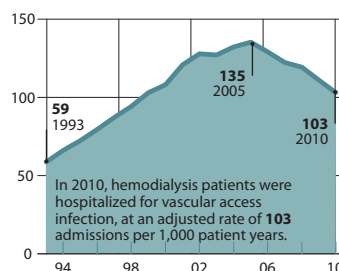
458
hemodialysis

Change in rates of hospitalization due to infection

PERCENT CHANGE BETWEEN 1993 & 2010



The rate of hospitalization for vascular access infection in hemodialysis patients remains 75 percent higher than in 1993.

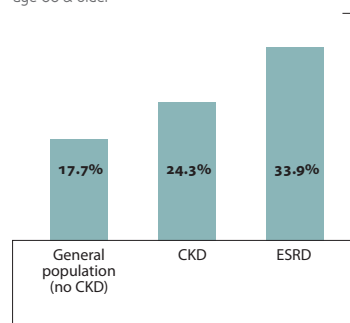


ESRD patients also face a high risk of **REHOSPITALIZATION** after discharge from the hospital

Patients rehospitalized within 30 days of a live hospital discharge

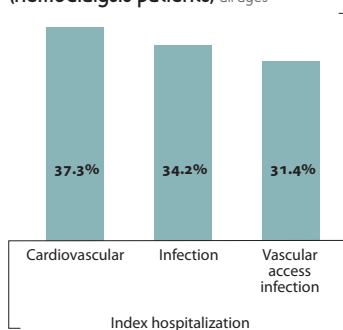
All-cause rehospitalization

age 66 & older

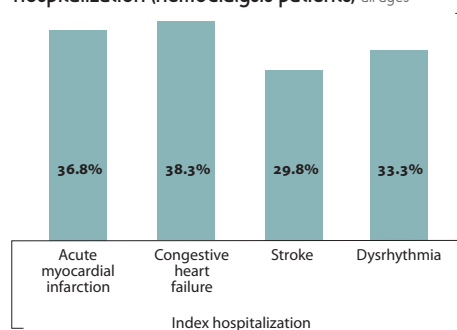


All-cause rehospitalization (hemodialysis patients)

all ages



Rehospitalization after a cardiovascular index hospitalization (hemodialysis patients)



JANUARY 1, 2006: MEDICARE PART D GOES INTO EFFECT

to help subsidize the costs of prescription drugs in Medicare beneficiaries

DAYS SUPPLY top three drug classes used by Part D enrollees on **dialysis**

35 million	8.2%
phosphate binder agents	
27 million	6.3%
calcium channel blockers	
24 million	5.9%
statins	
	20.4%
	of total Medicare Part D drug use in 2010

COSTS top three drug classes used by Part D enrollees on **dialysis**

\$419 million	29.5%
phosphate binder agents	
\$259 million	18.3%
calcimimetic agents	
\$65 million	4.6%
insulin	
	52.4%
	of total Medicare Part D drug costs in 2010

NET PART D COSTS FOR MEDICARE **DIALYSIS** PATIENTS IN 2010

\$1.52 BILLION

DAYS SUPPLY top three drug classes used by Part D enrollees with a **transplant**

9.3 million	7.4%
statins	
8.4 million	6.8%
calcium channel blockers	
8.3 million	6.6%
beta blockers	
	20.8%
	of total Medicare Part D drug use in 2010

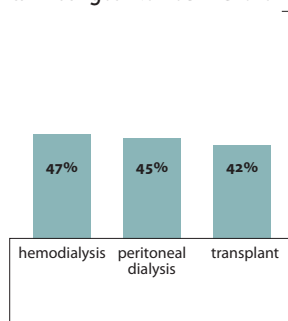
COSTS top three drug classes used by Part D enrollees with a **transplant**

\$35 million	13.5%
immunosuppressive agents	
\$27 million	10.6%
insulin	
\$19 million	7.2%
cytomegalovirus agents	
	31.3%
	of total Medicare Part D drug costs in 2010

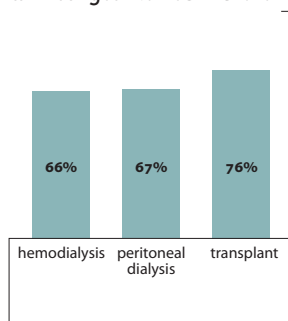
NET PART D COSTS FOR MEDICARE **TRANSPLANT** PATIENTS IN 2010

\$306 MILLION

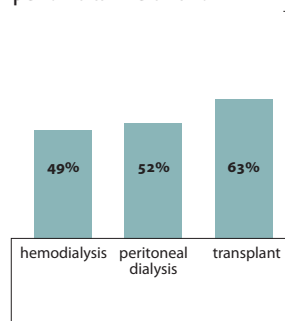
ACEI/ARB use among patients with congestive heart failure



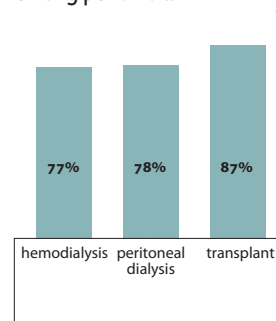
Beta blocker use among patients with congestive heart failure



Statin use among patients with a stroke



Beta blocker use among patients with AMI



This is the twenty-fourth annual report on the end-stage renal disease (ESRD) program in the United States, and the thirteenth in

our atlas series, which provides an in-depth, graphic presentation of data spanning the last quarter century.

As noted in the introduction to Volume One, this year's report incorporates the theme of conservation and preservation, using images from America's national parks. The often harsh realities of the varied landscapes across our parks symbolize the challenges faced by those living with kidney disease. At the same time, the biodiversity of the many ecosystems present in these environments is akin to the versatility of people affected by this disease. Kidney disease has a unique and profound impact on the populations it touches. It creates daily challenges, yet we continue to be amazed at the ways in which patients adapt, and at the work done to preserve both life and its quality in this vulnerable population.

Volume Two continues to focus on ESRD, and on the historical surveillance data that were the basis of the first USRDS reports. We summarize the ESRD program in the United States, and examine public health issues such as changing trends in disease rates, treatment modalities, and morbidity and mortality in the first year of therapy — an area in which there has been some recent progress. This year we show that first-year

survival continues to improve, in parallel to improved survival after the first year of treatment, something we have observed for many years.

At the end of 2010, 594,374 (table p.a) dialysis and transplant patients were receiving treatment for ESRD — a 4 percent increase from 2009. There were 116,946 new cases of ESRD reported, 0.47 percent more than in 2009, and among the smallest increases since 1988. Growth in the incident population should, however, be viewed with caution, as it may take several years to determine whether any changes are sustained. Late reporting of data is always an issue, as complete and stable incident counts sometimes take several years to be finalized.

In this year's program highlights (pages 154–155), infographics (pages 156–159), and Précis we again provide an overview of ESRD patients in the U.S., their care, and their expenditures. We examine pre-ESRD care, reported on the Medical Evidence (ME) form (2728) used to register all ESRD patients. We also look at dialysis modality use, the transplant wait list, and indicators of quality of care, and illustrate recent changes in hospitalization rates, mortality rates, and five-year survival in the dialysis population. Prevalent death rates have been falling for a number of years, and mortality in the first year of dialysis has, since 2004, continued to decline, reaching rates which are the lowest in 30 years and down 17.8 percent from just a decade ago.



Figures on ESRD expenditures show per person and total costs in the program. Total Medicare expenditures for separately billed intravenous medications have been stable since 2004, reflecting changes in payment policies implemented by CMS. The new “bundled” payment system was introduced in 2011; data from the transition are highlighted in Chapter Ten of this year’s ADR as well.

Next we provide a full layout of the Healthy People 2020 goals related to kidney disease. Many of the goals were introduced to the chapter in the 2011 ADR; in consultation with the HP2020 group at DHHS and the CDC, we will further develop related data in upcoming reports. Some goals have already been met, and new targets will be developed in the mid-course assessment of progress in 2013 and 2014.

Chapter One consolidates information on incidence, prevalence, patient characteristics, and modalities of therapy. As in prior years, we illustrate trends in incidence and prevalence by age, gender, race, and ethnicity, and present data on modality use and insurance coverage. We compare trends in the incidence of ESRD due to diabetes and hypertension for younger and older age groups, showing that in those older than 60, rates of ESRD due to diabetes have substantially narrowed between blacks/African Americans and whites, a finding not evident in the younger populations. We examine nephrology referral prior to ESRD, and look at levels of estimated kidney function at initiation, using the CKD-EPI formula. And we present data on the degree of anemia at initiation, on pre-ESRD treatment with erythropoiesis stimulating agents (ESAs), and, from the most recent version of the ME form, on serum albumin, hemoglobin, cholesterol, triglycerides, and hemoglobin A1c levels in those with diabetes at initiation.

Chapter Two, on clinical indicators of care, assesses dialysis adequacy, vascular access, anemia treatment, anemia correction in the first months of ESRD, IV iron therapy, and preventive care in the diabetic and general ESRD populations, and illustrates the marked differences in vascular access complication rates associated with the use of fistulas, catheters, and grafts.

Data on hospitalization are presented in Chapter Three. In the prevalent hemodialysis population, the continued high rate of hospitalization due to infection needs to be addressed by providers; the rate is now 43 percent greater than it was in 1993.

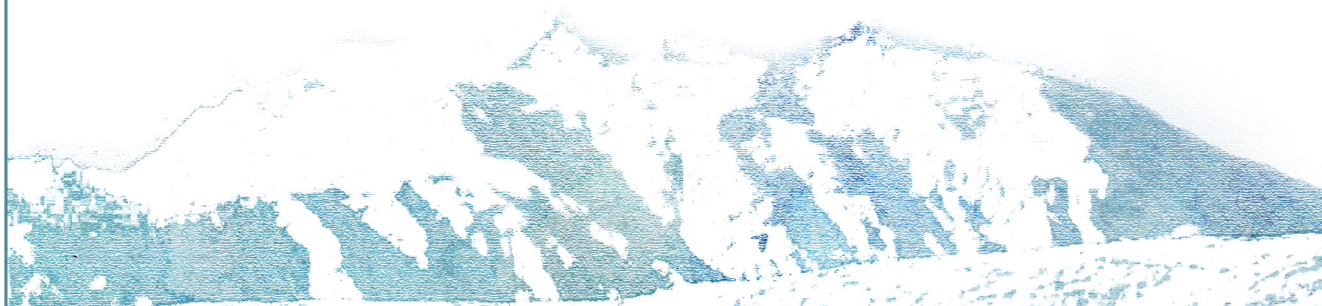
Rates of hospitalization for vascular access infection have declined, but those due to bacteremia/sepsis have increased, possibly due to a changing classification of these complications based on hospital billing practices. A concurrent decrease in access infections in the peritoneal dialysis population suggests that these trends may be affected by factors outside of the dialysis populations themselves, but may also reflect the use of hemodialysis catheters in peritoneal dialysis patients whose peritoneal dialysis catheter has failed and who are waiting for placement of a new one in order to resume therapy.

This year we present expanded data on rehospitalization after a prior discharge. Thirty-six percent of hemodialysis patients, for instance, are rehospitalized within 30 days of discharge — a number substantially higher than the rates of 17.7 and 24.3 percent noted for the general Medicare and CKD populations. We also look at data by organ system of the index event, comparing causes of the repeat and index hospitalizations, and at outcomes 30 days after discharge.

We conclude the chapter with another new analysis, looking at hospitalizations and causes of death in the hemodialysis population by interdialytic interval. This analysis is similar to that published by the USRDS in the *NEJM*, but is applied here to a larger cohort. The long two-day interval is associated with the highest rates of hospitalization and mortality, with the risk declining throughout the week until rising again with the longer interval.

In Chapter Four we examine cardiovascular disease in ESRD patients, beginning with data on cardiovascular mortality, presenting a new method to define sudden cardiac death (SCD), and examining rates of SCD over time and within the first year of therapy. We revisit the use of cardiac defibrillators and resynchronization devices, and look at the newer, wearable cardioverter-defibrillators. Data on cardiovascular event and procedure rates include AMI, stroke, heart failure, percutaneous interventions, and CABG procedures over time. We conclude by looking at the use of cardiovascular drugs in 2006 and 2010, and examining the relationship of medication use to survival in CHF and AMI patients.

We begin Chapter Five, on mortality, by highlighting trends in the first and subsequent years on ESRD therapy. Data now show similar reductions in mortality rates among patients of



all vintages, and there is continued progress in the first year of hemodialysis therapy. Mortality rates for dialysis patients, however, remain eight times greater than those in the general Medicare population.

Figures on mortality during the first year of hemodialysis illustrate a sharp increase in all-cause rates in month two of treatment, following by a steady decline during the rest of the year. These rates are defined from the first ESRD service date, with no 90-day waiting period. Survival in the first six months of treatment has improved for the peritoneal dialysis and transplant populations; for hemodialysis patients, in contrast, the rates since 1997 have shown little change.

This issue of early survival clearly merits increased attention, and the role of infectious complications — particularly those related to dialysis catheters — needs to be addressed. Perhaps the changing incentives in the new bundled payment system, directed at lowering costs and complications, will translate to reductions in the use of dialysis catheters and to a focus on preventive care.

Chapter Six looks at Part D prescription drug coverage. We show, for example, that CKD, dialysis, and transplant patients are quite different from those in the general Medicare population in their use of the low income subsidy (LIS), and that heavy use among ESRD patients is reflected in the proportion who reach the coverage gap. The chapter includes data on Medicare costs for the Part D benefit, on out-of-pocket expenditures for enrollees, and on the most frequently used and most expensive drugs.

As we illustrate in Chapter Seven, the number of transplants from deceased donors, which had declined in the past few years, has now returned to the peak level seen in 2006, reaching 10,891 in 2010. Transplants from living donors have also rebounded, reaching 5,898 in 2010, just below the 6,172 reported for 2004. Waiting times, however, continue to grow, due to the continued shortage of donated kidneys. And death with a functioning graft continues to be a concern, with cardiovascular disease accounting for 30 percent of deaths with a known cause. The rate of influenza vaccinations among transplant patients is still far lower than that in the dialysis population, with very little progress since 1991.

Chapter Eight, on the pediatric ESRD population, begins with data on rehospitalization within 30 days of a discharge.

Rates have changed little over the past decade, and are similar to those for adult patients. A comprehensive table then reports the causes of ESRD in the pediatric population, and figures on hospitalization compare rates by modality, with particular focus on infections. Rates of influenza vaccinations among these patients, as reported in claims data, continue to be low, despite high rates of pneumonia and other respiratory infections. And, as noted in past ADRS, five-year survival among children with ESRD has not improved in more than a decade.

New this year are figures comparing the pediatric ESRD populations in the United States and Canada, using data from CORR, the Canadian Organ Replacement Registry.

In Chapter Nine, The Nutrition Special Studies Center presents data from the Comprehensive Dialysis Study (CDS), while the Rehabilitation/Quality of Life Special Studies Center evaluates patient awareness of peritoneal dialysis and kidney transplantation as treatment options. Conditions of coverage for dialysis unit certification require that patients be made aware of their treatment options.

The landscape of dialysis providers continued to evolve in 2010, with growth in some of the smaller dialysis organizations (SDOs) as well as the large dialysis organizations (LDOs). The LDOs now treat 64 percent of dialysis patients in the United States; SDOs account for 12.1 percent, hospital-based units 9.4 percent, and independently owned units 14.2 percent.

New this year is an evaluation of the major changes that have occurred after the start of the bundled prospective payment system, introduced in January of 2011. Preliminary data was first reported by the USRDS at the 2012 National Kidney Foundation spring clinical meeting. Here we present more complete data based on claims between September 2010 to September 2011, looking at providers switching to the new payment system, changes in the use of EPO, IV iron, and vitamin D, changes in hemoglobin levels, and trends in transfusion events. The chapter concludes with comparisons of standardized hospitalization and mortality ratios across provider groups.

Chapter Eleven, on expenditures related to ESRD, begins with data on dialysis expenditures by payor. Medicare paid claims accounted for 62.2 percent of total ESRD spending in 2010, up from 57.6 percent the previous year. The chapter then presents updated data on the overall costs of ESRD and



injectables, looks at differences in costs by race and in matched and unmatched dialysis populations, and examines Medicare Part A, B, and D costs.

In Chapter Twelve we summarize data from the international community, and present a map of ESRD incidence worldwide. We are, as always, grateful to the registries providing this information, allowing us to see the U.S. ESRD community through a wider lens.

Most of this ADR contains data through December 31, 2010; data on patient characteristics, obtained from the Medical Evidence form, are complete through June, 2011. Current estimated incident and prevalent counts can be found on the USRDS website.

RENDER & the Researcher's Guide

Our real-time online query system allows users to build data tables and maps. The Renal Data Extraction and Referencing System (RENDER) can be accessed on our website.

To assist users of USRDS data, the Coordinating Center (CC) annually updates the Researcher's Guide, which provides information on all analytical methods used by the CC, along with a detailed index of files and variables in the USRDS researcher datasets. It is available on our website in PDF format.

USRDS database

The USRDS dataset is a living record of patient care in the United States, continually updated with new data. Delays in data reporting are unavoidable, and we add late information as soon as it becomes available. This includes data from the Medical Evidence form, claims for hospital and physician services, and updates of the Medicare Enrollment Database received after the ADR has gone to press.

administrative oversight

Project Officers (POs) Lawrence Agodoa, MD, and Paul Eggers, PhD, provide direct oversight of the CC and Special Studies Centers (SSCs), and members of CMS, the ESRD networks, and the renal community provide crucial input and feedback through their committee participation.

The Steering Committee, the governing body of the USRDS, is responsible for the operations of the CC and SSCs. It works under the direction of the POs, and includes representatives

from CMS, the National Institutes of Health, the CC, and the SSCs. Its responsibilities include coordination among the centers, study design, project tracking, data management and validation, assurance of data availability for researchers and government officials, and oversight of ADR production.

The USRDS External Expert Committee plays a major role in advising POs on special studies, data studies, and analyses. It is also responsible for reviewing manuscripts and ADRs.

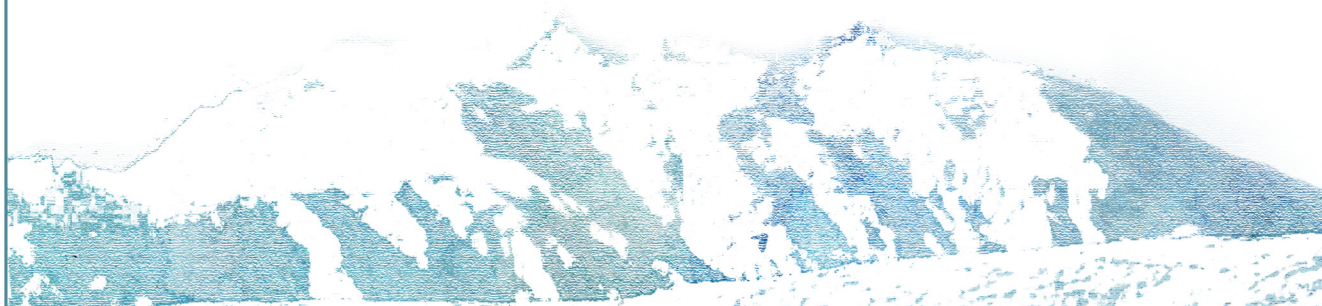
The Special Studies Review and Implementation Committee, the operations committee for SSC proposals and CC project support, is a collaboration of CMS, the ESRD networks, and the providers. The Data Request Review Committee reviews data requests requiring more than two hours of staff time to fulfill, and makes recommendations to the POs based on the datasets requested and the ways in which the CC can improve data availability.

reading the maps

Many maps in the ADR are by Health Service Area (HSA), a group of counties described by authors of the CDC Atlas of United States Mortality as "an area that is relatively self-contained with respect to hospital care."

Maps here present data divided into quintiles, with each range in a legend containing approximately one-fifth of the data points. In the sample map, for example, one-fifth of all data points have a value of 10.8 or above. Ranges include the number at the lower end of the range, and exclude that at the upper end (i.e., the second range in the sample map is 8.2–<9.2). To facilitate comparisons of maps with data for different periods, we commonly apply a single legend to each map in a series. Because such a legend applies to multiple maps, the data in each individual map are not evenly distributed in quintiles, and a map for a single year may not contain all listed colors or ranges.

Numbers in the first and last boxes indicate the mean values of data points in the highest and lowest quintiles; these can be used to calculate the percent variation between quintiles. For maps with shared legends we have provided these values by repeating the legends and inserting the unique quintile values. Mean numbers within the quintiles can be calculated as a simple half-way point.



On the Excel page for each map (found on the website and CD-ROM) we include several numbers to help you interpret the maps and their relation to other data in the ADR. The map-specific mean is calculated using only the population whose data are included in the map itself. This mean will usually not match data presented in tables elsewhere in the ADR, and should be quoted with caution. The overall mean includes all patients for whom data are available, whether or not their residency is known. We also include the number of patients excluded in the map-specific mean, and the total number of patients used for the overall calculation.

acknowledgements

The ADR could not be produced without the extraordinary work of members of the ESRD community — including the staff of CMS and the ESRD networks — and the dedicated efforts of the USRDS staff and investigators. The efforts of the providers themselves are crucial in the collection of data used by the USRDS, and their dedication to this task is greatly appreciated.

We welcome feedback on all elements of USRDS work. All comments are reviewed by the Director, Deputy Director, and staff of the USRDS in order to improve future materials and to ensure a strong working relationship between the USRDS and the clinicians, researchers, patients, and others involved in the care of ESRD patients across the U.S. and throughout the world.

Throughout the ADR, with the exception of NHANES data, CKD cohorts exclude ESRD patients.

