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united states renal data system

National Institutes of Health
National Institute of Diabetes & Digestive & Kidney Diseases
Division of Kidney, Urologic, & Hematologic Diseases

This 18th annual report of the United States Renal Data System is produced by the USRDS Coordinating Center, operated under NIH contract No1-DK-9-2343 by the Minneapolis Medical Research Foundation.
From the outside looking in, it is difficult to comprehend the enormous burden carried by today’s ESRD patients as they strive to cope with the problems confronting them in their daily lives. It is to these patients, and to the clinicians who care for them, that we humbly dedicate this 2006 USRDS Annual Data Report.

Suggested citation for this report

Publications based upon USRDS data reported here or supplied upon request must include this citation and the following notice:

The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author(s) and in no way should be seen as an official policy or interpretation of the U.S. government.
And so the root
Becomes a trunk
And then a tree
And seeds of trees
And springtime sap
And summer shade
And autumn leaves
And shape of poems
And dreams—
And more than tree.

Langston Hughes

“For Russell & Rowena Jelliffe”
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This is the eighteenth annual report on the end-stage renal disease program in the United States, and the seventh in our atlas series, which provides in-depth graphic presentation of data spanning the last two decades. This ADR also presents information on patients with chronic kidney disease—the precursor of ESRD—and assesses care of at-risk populations and international comparisons of ESRD. This book has traditionally focused on the ESRD program, a central public health initiative begun in 1972 with the granting of Medicare coverage to ESRD patients. Since 2003, however, we have also devoted considerable attention to CKD, adding a chapter on the disease in 2004.

At its inception, the ESRD program was expected to plateau at 40,000 prevalent patients—a number passed more than 20 years ago. ESRD was at first considered a rare disease, as defined by the Orphan Drug Act of 1983 and its subsequent amendments, but that definition also became outdated when the prevalent population exceeded 200,000—the threshold defined by the act—in 1990. At times during the past 20 years the ESRD program appeared limitless, with incident rates rising 8–14 percent per year. But in the late 1990s this growth began to slow, and in the past five years rates appear to have stabilized and, in some groups, actually declined.

A detailed assessment of incident rates reveals some dramatic progress, with rates in several populations returning to levels of a decade ago. Among young whites with diabetes as the primary cause of ESRD, for example, the incidence of ESRD has fallen 47 percent. These findings are not, however, present in young African Americans, in whom rates continue to rise, sharpening the already wide disparity in ESRD rates between whites and African Americans.

Incident rates in 2004 are more than 15 percent lower than those projected five years ago by the USRDS—a major achievement in public health that merits recognition for efforts by the provider community, CMS, the CDC, state departments of health, and the NIH. In addition, growth in the prevalent population exceeded projections by 1–2 percent in 2004, suggesting that the mortality rates anticipated in the original projections have declined. The ESRD program is, then, moving toward the objectives put forth by the Healthy People 2010 program, with reduced rates of ESRD incidence, of incidence due to diabetes, and of mortality due to cardiovascular disease.

These improvements have coincided with significant progress in care consistent with clinical practice guidelines from the National Kidney Foundation, the American Diabetes Association, and the American Heart Association. The initial NKF guidelines covered anemia, vascular access, and dialysis adequacy. Subsequent guidelines address bone and mineral disease, cardiovascular disease, lipid disorders, hypertension, and a CKD classification system which defines stages of progressive dysfunction.

Reductions in ESRD, morbidity, and mortality rates during the last ten years have paralleled the establishment of renoprotective therapy with ACE inhibitors and ARBs, and the growing beneficial impact of beta blocker treatment on rates of heart failure...
and sudden death. The lowering of the cardiovascular death rate among ESRD patients has brought the rate toward the HP2010 target—an outcome considered unreachable just five years ago—and is consistent with a similar trend in the general population, recently reported by the National Center for Health Statistics, which may be having an impact on the ESRD population as well.

Since the early 1990s, incident cohort survival in the 2–5 years after initiation has been steadily improving. And in this year’s ADR we show that even prevalent mortality rates in the first year on dialysis—relatively flat over the last 6–7 years—have fallen. But in the past decade there has been no progress in the first-year death rates of the incident hemodialysis population, suggesting a need for greater attention to morbidity and mortality in the first year of treatment.

There has been an effort to reduce the use of dialysis catheters, which are associated with significant morbidity and mortality from infectious complications. CMS’s Fistula First program appears to be having a positive impact, as the percent of prevalent patients using fistulas rose from 28 in 1998 to 39 in 2003. But the use of fistulas as the first vascular access in incident patients has been relatively flat, reaching only 36.3 percent, compared to far higher rates in Japan and Europe. Recent reductions in catheter placement rates were encouraging, but the apparent reversal of this trend in 2004 needs to be monitored closely.

These reductions in catheter placement rates, however, have not yielded anticipated changes in first-year mortality rates. Perhaps it is too early to see changes in the morbidity and mortality associated with catheter use, or perhaps other factors should be considered. There is certainly evidence that the incident hemodialysis population is aging, and carrying greater comorbidity, but even with these differences taken into consideration, first-year death rates are unchanged.

This raises the possibility that other factors, not yet given careful consideration, may be at play. In this year’s ADR we present data on trends in higher hemoglobin levels and the likelihood of providers overshooting a target hemoglobin of 12 g/dl. Incident hemodialysis patients now reach the initial target level of 11 g/dl faster than in any prior year, and receive intravenous iron at a higher rate. There has been considerable debate over the clinical impact of large doses of IV iron and their potential to promote infectious complications. Rising hemoglobin levels, and the frequent surpassing of the target—up to 40 percent of patients reach a hemoglobin level of greater than 14 g/dl in the first six months—may also be a concern, given results of the higher hemoglobin arm of the Normal Hematocrit Trial (Besarab et al.) and recent initial results from the CHOIR trial, assessing a target hemoglobin of 13.5 g/dl versus 11.3 g/dl in a CKD population. Hemoglobin levels of less than 11 g/dl have been a concern as well, challenging providers to hit a 1 g/dl hemoglobin window. There is a suggestion that natural variability precludes providers from hitting this target, but clearly some providers have greater degrees of success than others, indicating that provider practices are at play. These and other observations suggest that there should be more targeted investigations to determine if certain provider practices may enhance or be adversely associated with outcomes in the first year of treatment.

Outcomes in the second and subsequent years do show steady improvement, paralleling improvements in other aspects of care. Dialysis adequacy is at an all-time high, as are hemoglobin levels. And as noted above, following publication of the guidelines, fistula placement rates have doubled over the last nine years. The rate of actual functioning fistulas in prevalent patients has grown at a more modest pace, but it too is increasing, approaching the initial 40 percent target set by the NKF K/DOQI guidelines. More complete data on trends in hospitalizations for vascular access infections show that the rate of increase has slowed, but point to no clear evidence of a sustained reduction. Changes in bone and mineral metabolism treatment have also been marked since 2000, meriting a more complete evaluation.

Such data do provide evidence of continued progress in ESRD patient outcomes. Overall, it is still difficult to reconcile improving survival rates, along with the quantifiable increase in care that follows clinical practice guidelines, with the lack of efficacy recently noted in trials on dialysis therapy and flux, on the use of statins to reduce cardiovascular events, and on anemia correction to reduce the progression of left ventricular hypertrophy. It may be that general improvements in care—as opposed to specific interventions in the dialysis population—are a factor in the improving rates. In addition, earlier initiation of dialysis may create a lead-time bias that makes it appear that patients are surviving longer, and improved care in the CKD population may bring to dialysis patients whose comorbidity is better managed. There is little doubt, for instance, that the number of cardiovascular procedures to treat ischemic heart disease...
has grown, and that survival after these interventions has improved. Or perhaps the consolidation of dialysis providers by the large chains has brought more consistent care.

We are left with the simple observation that mortality is down, patients are living longer, the prevalent population is growing faster than anticipated, and there are fewer patients coming to ESRD. Perhaps the magnitude of the disease burden in the CKD and ESRD populations is so large, as demonstrated by the wide range of adverse cardiovascular and infectious events, that classic single intervention trials are unable to show effects. By all classic standards, the lack of efficacy noted in most ESRD trials on mortality should lead to little or no improvement in overall outcomes of the entire population. While this is of particular concern in the first year on hemodialysis, overall progress is unmistakable, so we must conclude that something is improving in this very complex population. The USRDS will continue to explore a number of areas to try and shed light on potential factors associated with these improvements, and to address areas of concern.

chapter overview

In the Précis we provide an overview of the ESRD program, beginning with statistics on patient counts and rates, modalities, and costs. We look at modality use over time and across the country, at the transplant wait list, at indicators of quality of care (vascular access use, dialysis adequacy, anemia treatment, diabetic preventive care, and prescription drug therapy), and at trends in hospitalization and mortality rates. And we examine expenditures—those related to ESRD, and those for patients in the Medicare and EGHP populations who have chronic kidney disease.

In the next chapter we address the objectives of the Healthy People 2010 initiative that relate to kidney disease. HP2010 is sponsored by the Department of Health and Human Services in partnership with federal agencies, businesses, communities, and other organizations, and aims to improve. Or perhaps the consolidation of dialysis providers by the large chains has brought more consistent care.

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Chapter One presents data on CKD patients. We look at the nationwide prevalence of CKD, then at the likelihood of at-risk patients receiving assessments and preventive care—with new data by industry and union status. We also examine how hospitalization rates in patients with diabetes and hypertension compare in individuals with and without the complicating condition of CKD, and at the associations between a prior history of CKD and outcomes after hospitalization for acute kidney failure. The chapter concludes with data on adherence to prescription drug therapy.

Trends in the incidence and prevalence of ESRD are presented in Chapter Two. We again include an analysis of differences in incident rates by age and race, showing the often
dramatic disparities between blacks and whites and between older and younger patients. Detailed tables show rates and patient distributions for many of the primary diseases causing ESRD. We have brought back information on patients with rare diseases, hoping to focus attention on these patients, and look further at ESRD patients who are age 75 and older.

We begin Chapter Three by examining cardiovascular comorbidity at the start of ESRD, and look at patient compliance with drug therapy during this period. We then describe characteristics of new ESRD patients: hemoglobin levels at initiation and the prior use of EPO, biochemical characteristics, estimated glomerular filtration rates, and body mass indices.

Chapter Four provides data on modalities and the types of patients using each kind of therapy. Tables present data on incident and prevalent counts and rates, while graphs show patient distribution by insurance coverage, and maps illustrate regional variations in rates over time. The chapter also includes updated data on the probability of death or a change in modality during the first five years of therapy, as well as information on patient distribution by provider.

In Chapter Five we examine progress toward guidelines set by the National Kidney Foundation’s Kidney Disease Outcomes Quality Initiative (K/DOQI) and toward other targets for clinical care. We look at trends in vascular access use and in access events and complications, at diabetic care, and at adherence to prescription drug therapy. We have brought back figures on anemia treatment and EPO resistance, and added a new spread on anemia management. The chapter concludes with data on the use of preventive care—glycosylated hemoglobin testing, lipid testing, and vaccinations—in the ESRD population as a whole.

Chapter Six addresses morbidity and mortality. We examine overall and cause-specific hospitalization and mortality rates, including tables of hospitalization rates by patient vintage, maps of admission rates for cardiovascular disease and infection, and maps of mortality rates related to cardiovascular disease, stroke, and bacteremia/septicemia. Three spreads on neuroepidemiology address incident and prevalent stroke, peripheral neuropathy, and dementia.

Chapter Seven addresses the renal transplant population, looking first at the transplant wait list and at wait times for transplantation, at transplant rates, and at kidney donation rates. We also examine patient outcomes after a transplant (graft outcomes, survival, preemptive retransplantation, and return to dialysis), immunosuppression regimens, and post-transplant complications. The chapter concludes with analyses of the listings and use of extended criteria donor (ECD) kidneys and of projected wait times for transplantation.

Information on pediatric patients with ESRD is presented in Chapter Eight, in which we update data on patient characteristics, preventive healthcare, and vascular access,
and add new figures on modality in the first 3–5 years after initiation. We examine differences in hemoglobin levels and anemia treatment by age, gender, and race/ethnicity, look at trends in infectious complications, and present trend data on overall and cause-specific hospitalization and mortality.

In beginning of this year’s Chapter Nine, the Cardiovascular Special Studies Center focuses on acute myocardial infarction, congestive heart failure, and cardiac arrest, showing probabilities of these events in both incident and prevalent CKD and ESRD populations. These data are followed by figures on cardiovascular event rates in dialysis patients, by a spread on sudden cardiac death and the use of implantable cardioverter defibrillators, and by information on the use of cardiovascular procedures—such as stress tests and coronary angiography—in the dialysis population.

Chapter Ten provides data on ESRD providers and the characteristics of the provider community. Figures describe provider growth, provider compliance with care guidelines, and differences in the provision of preventive care. In a new analyses we look at anemia management by unit type and affiliation. We also present data on Bayesian hospitalization and mortality ratios, looking at how these ratios differ by unit affiliation.

Chapter Eleven addresses the economics of caring for patients with CKD and ESRD. Figures of overall costs are followed by actuarial tables and related figures on components of Part A and B costs, and by a summary of ESRD program expenditures. We update our annual data on per person per year costs, present comprehensive data on components of care, and show costs for vascular access procedures, and conclude the chapter with data on Medicare risk patients.

In Chapter Twelve we again summarize data from the international renal community, with data on incidence, prevalence, ESRD caused by diabetes, dialysis, and transplantation. We are, as always, grateful to the registries who add late information to the database as soon as it becomes available. Delays in the reporting of data are unavoidable, and we add late information to the database as soon as it becomes available.

Most of the 2006 ADR contains data through December 31, 2004; data on patient characteristics, obtained from the Medical Evidence form, are complete through June, 2005.

www.usrds.org
On our website users can download PDF files of the ADR, Excel files of the tables and the data underlying the graphs, and PowerPoint slides of ADR figures and USRDS presentations. Supplemental tables are also included, with standard errors for all rates as well as tables for patient subgroups.

Also available on the website are supplemental tables on ESRD patients covered by Medicare. These tables parallel tables in the printed ADR, and include information on incidence and prevalence, modalities, hospitalization, transplant, mortality, survival, and the costs of ESRD.

RenDER & the Researcher’s Guide
We continue to improve our real-time online query system, which allows users to build data tables and maps based on query specifications. The Renal Data Extraction and Referencing System (RenDER) can be accessed on our website.

To assist users of USRDS data, the Coordinating Center annually updates and revises 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, and a hard copy is sent to researchers who order Standard Analysis Files (SAFs).

USRDS database
The Coordinating Center often responds to concerns about changes in reported counts of incident and prevalent patients and in counts by modality. The USRDS dataset is a living record of ESRD care in the United States, and is continually updated with new information on the ESRD population. Delays in the reporting of data are unavoidable, and we add late information to the database as soon as it becomes available.
available. This information includes data from the Medical Evidence form, claims for hospital and physician services, and updates of the Medicare Enrollment Database that are received after the ADR has gone to press.

administrative oversight
Lawrence Agodoa, MD and Paul Eggers, PhD provide direct oversight of the Coordinating Center and Special Studies Centers, 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 Project Officers, and includes representatives from CMS, the NIH, the CC, and each of 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 Annual Data Report production.

The USRDS External Advisory Committee plays a major role in advising Project Officers on appropriate and necessary special studies, data studies, and analyses. This committee is also responsible for reviewing manuscripts and Annual Data Reports. Members are listed in Table i.d.

The Data Management Advisory Committee (DMAC) includes CMS members, Network Forum representatives, database technical staff, and others appointed by the Project Officers. DMAC addresses the accuracy and completeness of data provided to the USRDS, and works to ensure timely fulfillment of data requests.

The Annual Data Report Committee (ADRC) reviews the data in previous ADRs, proposals for future editions, and ideas for expanded data availability on the USRDS website.

The Information Systems Committee (ISC) reviews hardware requirements, systems configuration, documentation, and performance, and evaluates technical specifications.
nologies that may enhance database structure, function, and management.

The Special Studies Review and Implementation Committee (SSRIC), 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 (DRRC) reviews data requests requiring more than two hours of staff time to fulfill, and makes recommendations to the Project Officers based on the types of datasets requested and the ways in which the CC can improve the availability of data.

The Renal Community Council (RCC), with 30 professional, scientific, and advocacy groups, serves as a significant liaison between the USRDS and the ESRD community.

## reading the maps

The majority of disease mapping within this atlas is by Health Service Area (HSA), a group of counties described by the authors of the CDC Atlas of United States Mortality as “an area that is relatively self-contained with respect to hospital care.”

Maps throughout the ADR present data divided into quintiles. Each data range in a legend contains approximately one-fifth of the data points included in the map. In the sample map here, for example, one-fifth of all data points displayed have a value of 10.8 or above.

To facilitate comparisons of maps that present data for several different years or time periods, we usually apply a single legend to each map in a series, e.g., rates of diabetes in 1990 and 2000. 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 the colors or ranges listed in the legend.

In legends the numbers in parentheses 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.

On the summary page at the end of each chapter we have included several numbers to help you interpret the maps and their relation to other data presented in the ADR. The map-specific mean is calculated using only the population whose data are included in the map itself—i.e., the mean for a state map excludes all patients whose state of residency is unknown. 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 is 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

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