

United
States
Renal
Data
System



2002 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

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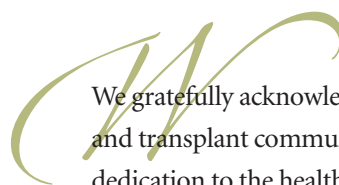
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T In order to arrive there,
To arrive where you are, to get from where you are not,
You must go by a way wherein there is no ecstasy.
In order to arrive at what you do not know
You must go by a way which is the way of ignorance.
THOMAS STEARNS ELIOT, "East Coker"

above



We gratefully acknowledge the members of the dialysis and transplant communities, and their remarkable dedication to the health and welfare of the patients they serve. And we thank our patients for the daily strength and courage with which they face their illness, and assure them that through our research efforts we will continue our quest to improve their quality of life.

THE ATLAS

In the 2002 USRDS Annual Data Report we have again worked to improve the visual display of information on ESRD, taking as our model the conference poster with its succinct summary of methods, data, and results. Each spread—two facing pages—of the atlas section now focuses on one topic, or story. All figures or tables on a spread contribute to that story, and expanded space for text allows us to discuss more thoroughly both our methods and the implications of the data. On the last page of each chapter we have also added a summary in which we present the patient cohorts and analytical methods used in the chapter, along with what we view to be the chapter’s central points. A detailed discussion of the analytical methods used throughout the book is again presented in Appendix A.

We have also worked to expand the breadth of data presented in the ADR. The Précis, for example, no longer contains a sample of figures taken from the rest of the book. We have instead used this chapter to present new information on trends in the ESRD program, looking in particular at pre-ESRD patients and at chronic kidney disease in the general population.

Information related to Healthy People 2010, a program sponsored by the Department of Health and Human Services, is now presented in its own chapter. The HP2010 objectives related to kidney disease include reducing the incidence of ESRD overall and of kidney disease caused by diabetes. To address such issues we have used additional data from the five percent Medicare file (available to researchers), which provides information on the general Medicare population, and which we also use later in the book to analyze hospitalizations and preventive health care services.

Disease-specific information in the ADR has traditionally centered on the broad categories of diabetes, hypertension, glomerulonephritis, and cystic kidney disease. Hoping to increase the data available on less common diseases,

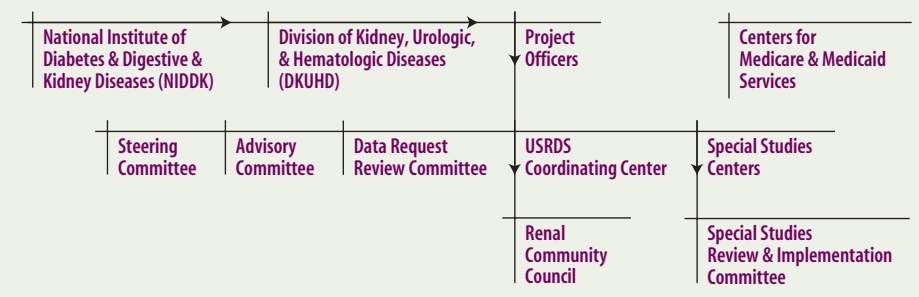
we have this year added data on IgA and IgM nephropathy, Goodpasture’s syndrome, systemic lupus erythematosus, scleroderma, multiple myeloma, and AIDS, among others. The chapters on incidence and prevalence, patient characteristics, hospitalization, and mortality contain spreads on these diseases, and we hope that the data presented will prompt new awareness of patients affected by less common causes of ESRD.

The revised Medical Evidence form (2728), introduced in April 1995, includes information on clinical markers at initiation such as glomerular filtration rate, hematocrit, and albumin. In this year’s ADR we have used these data to conduct risk factor analyses for the likelihood of hospitalization and mortality. We have also created several new analyses of the associations between patient insurance at initiation and later clinical care, using an intent-to-treat approach. The impact of the uninsured and under-insured is shown with particular reference to anemia treatment, a service whose potential lack of coverage may significantly influence both patients and providers.

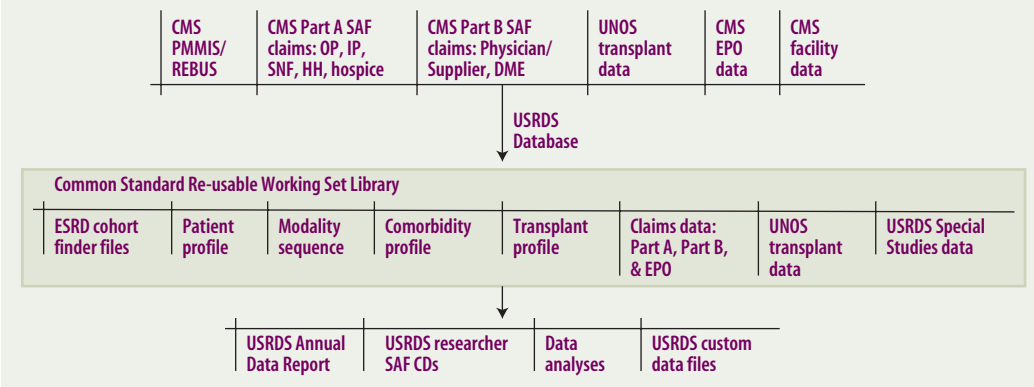
We continue to use our revised methodology to estimate prevalent mortality and hospitalization rates for the calculation of standardized mortality and hospitalization ratios (SMRs/SHRs). Instead of the multiple models previously used to estimate death rates, the USRDS biostatistical group now uses a single model for all interactions of age, gender, race, disease, and modality, and computes the standard errors for these individual cells using the bootstrapping method. Methods for estimating first-, second-, and third-year patient survival and death rates have also been modified. Average coefficients were previously entered into the Cox proportional hazards model for these estimations, but a careful examination suggested that the average output from the model would give a more accurate representation of survival estimates and subsequent death rates. These modifications are detailed in Appendix A.

In our analyses of patient characteristics and therapy outcomes we have added new information on unit ownership, looking at the five chains with the largest numbers of dialysis patients as well as at non-affiliated and hospital-based units. We define a chain-affiliated unit as one of a group of 20 or more dialysis

i.1 • Administrative oversight of the USRDS



i.2 · Structure of the USRDS database



Available on our website, WWW.USRDS.ORG

PDF files of the 2002 Annual Data Report & the *Researcher's Guide*



Powerpoint® slide files of all figures in the ADR, & Excel files of the data underlying the graphs

units owned by a corporation and located in more than one state. Initially available from individual networks and states through FOIA requests, ownership data can now be obtained from the Medicare cost reports submitted to CMS (www.cms.hhs.gov/data/download).

Because the population counts in the 2000 U.S. census are considerably different from those estimated in the 1990 census, and because the most recent census form also introduced a new category for race, any rates using the most recent data would not be comparable to those presented in previous ADRs. We have chosen, therefore, to continue using population estimates based on 1990 census data to calculate all rates which incorporate data on the U.S. population, and will further address the issue of national populations in the 2003 ADR.

To make our presentation of the data more consistent with that of the nephrology journals, we have chosen to present hemoglobin rather than hematocrit levels. These levels have been obtained by dividing hematocrit values by three.

Appendix D contains a new index of all graphs, maps, and tables included in the atlas.

THE REFERENCE TABLES & RenDER

We have again worked to make the format of the data in the Reference Tables more consistent across sections. The layout of Table A.1—with years across the top and age groups (small and large), gender, race, ethnicity, primary diagnosis, and, when applicable, patient residence down the side—is now repeated whenever possible throughout the sections, improving the ease with which multiple tables can be compared and used together.

Supplemental tables are again included on our website; these consist of standard errors for all rate tables, as well

as tables for subgroups of patients. A complete list of these supplemental tables is provided on the first page of the Excel file for each reference section.

Because of interest from CMS and other researchers, we have added to the website a special section

of tables which assess only the Medicare population. These tables parallel the traditional tables in the ADR, and include information on incidence and prevalence, modalities, hospitalization, transplant, mortality, survival, and the costs of ESRD.

We have also supplemented the reference tables with a direct online query system that allows users to build data tables and interactive maps based on query specifications. The Renal Data Extraction and Referencing System (RenDER) can be accessed on the USRDS website.

Most of the 2002 Annual Data Report contains data through December 31, 2000, with certain sections (those with data on patient characteristics from the Medical Evidence form) complete through December of 2001.

NEW RESEARCHER'S GUIDE

To assist users of the USRDS data the Coordinating Center has updated and revised 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 will be sent to researchers upon request.

WWW.USRDS.ORG

On the USRDS website users can download PDF files of the printed Annual Data Report, Excel files of the Reference Tables and the data underlying the graphs, and PowerPoint® slides of ADR figures and USRDS presentations. (Because of the size and complexity of the ADR files, downloading time for large portions of the book may be substantial; estimated times using a 56 kbs modem are provided next to the file names.) All data is aggregated in order to comply with USRDS confidentiality policies, and data for cells with fewer than ten patients or five providers are not included.

THE USRDS DATABASE: WHY DO THE NUMBERS KEEP CHANGING?

The Coordinating Center frequently responds to concerns about changes in reported counts of incident and prevalent patients and in patient 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. 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.

To close some of the gaps noted in past ADRs we have collaborated extensively this year with CMS (the Centers for Medicare and Medicaid Services, formerly HCFA) and the ESRD networks. Information obtained from the Medical Evidence form, the Facility Survey form, and the Standard Information Management System (SIMS) database has been reviewed to identify discrepancies.

Because of the expanding population of non-Medicare patients there have been significant problems with the large number of patients classified as lost-to-followup. This year, however, we have used the SIMS files to identify the modalities of these patients on December 31, 2000, enabling us to track the hemodialysis and peritoneal dialysis populations more accurately. This new information has also allowed us to reduce the number of duplicate patients in the database—patients with more than one Medical Evidence form, and with incomplete information in the Medicare Enrollment Database on Social Security numbers and enrollment. CMS and the USRDS are actively working with the SIMS data in order to improve the accuracy of ESRD patient information, and the REBUS group inside CMS will be using the SIMS data as the primary source of information on all ESRD patient forms.

CMS and the USRDS are also sharing additional datasets that will be used to advance research on the ESRD population. Since 1994 CMS has been collecting information on a random sample of dialysis patients through the Clinical Performance Measures Project (CPM, formerly the Core Indicator Project). The data include information on dialysis adequacy, anemia treatment, vascular access, and, more recently, pediatric patients.

The USRDS and CMS have created a joint steering committee to guide this collaborative research, and have developed datasets in a format similar to that of the Special Studies data files, using universal identifiers to link the CPM data to the main USRDS data files. The committee began its work with the files in April 2002, and will make the files available to researchers by April 2003. More information on these new datasets will be distributed on the USRDS website and at the 2002 meeting of the American Society of Nephrology.

MEDICARE & NON-MEDICARE PATIENTS

In previous Annual Data Reports we discussed the difficulties of dealing with combined Medicare and non-Medicare (“ZZ”) patients in the USRDS database. The revised version of the Medical Evidence form requires that all ESRD patients be reported to the ESRD networks, and information on the in-

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i.3 · Departmental organization of the Coordinating Center



creased numbers of reported non-Medicare patients continues to differ considerably from that available on traditional Medicare patients. While deaths of Medicare patients, for example, are reported both on the Death Notification form (2746) and in the Medicare Enrollment Database, deaths of non-Medicare patients are reported only on the 2746 form, which frequently leads to incomplete mortality data for these patients.

Since non-Medicare patients do not submit claims to Medicare, data on hospitalizations and costs of care are not available to the CC. Morbidity analyses in the ADR therefore include only those patients for whom Medicare is the pri-

mary payor. Information on Medicare managed care patients is also limited, since the USRDS does not have access to the claims for services submitted by these risk program patients. The USRDS Special Studies do include supplemental information on certain aspects of the non-Medicare population, and the Coordinating Center continues to advance its efforts to more fully identify non-Medicare patients.

TYPES OF ESRD TREATMENT

The Coordinating Center and the REBUS group at CMS have worked extensively on methods to categorize patients by ESRD treatment modalities. While the Medical Evidence form is the primary source of data on modality at the initiation of treatment, the modality indicated here may be temporary, as patients often change to a new modality within the first 90 days. Methods used to determine modality within this time are significantly influenced by the availability of data. Patients 65 and older have Medicare claims in the first 90 days; these claims contain revenue codes that designate modality. Patients younger than 65 who are in employer group health plans or Medicare risk programs, however, have no claims in

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New to this edition of the Annual Data Report

a chapter on Healthy People 2010



data on less common diseases causing ESRD



comparisons between the ESRD & general Medicare populations



expanded information on transplant patients & on cardiovascular disease



new information on patient demographics & quality of care in chain-affiliated & non-chain providers



newly designed chapters with two-page spreads organized around integrated topics



summaries of each chapter



an index of all figures & tables

this period. A patient's modality may therefore not be determined until Medicare becomes the primary payor at day 91 or, for patients in employer group health plans, at 30–33 months after the first ESRD service date. These limitations influence the CC's ability to determine a patient's exact modality at any one point in time.

Of particular concern are those patients found to have an unstable modality (i.e. they are treated on that modality for fewer than 60 consecutive days) in the first 90 days, and who are therefore not recognized as being hemodialysis, peritoneal dialysis, or transplant patients. These patients tend to have higher death and hospitalization rates, and unless they are identified and assigned to modalities, interpretations of modality-specific outcomes should be viewed with caution. These patients are included in the "all ESRD" category, which provides a more complete view of actual mortality and hospitalization events with the least biasing of the data.

The Coordinating Center and CMS continue working to reconcile the claims and ESRD network census data, reducing the number of patients classified as having unknown or unstable dialysis modalities.

SPECIAL STUDY CENTERS

Contracts for all four Special Study Centers (SSCs) have now been awarded. The Economic SSC is headed by Lawrence Hunsicker and John Brooks at the University of Iowa, the Nutrition SSC by Glen Chertow and George Kaysen at the University of California at San Francisco, the Rehabilitation and Quality of Life SSC by Nancy Kutner and Donna Brogan at Emory University, and

the Cardiovascular SSC by Charles Herzog and Blanche Chavers at the University of Minnesota and the Minneapolis Medical Research Foundation. Table i.a includes contact information for these SSCs, while Figures i.4–7 present the organizational structure of each center.

ADMINISTRATIVE OVERSIGHT OF THE USRDS

Lawrence Agodoa, MD and Paul Eggers, PhD provide direct oversight of the Coordinating Center and Special Studies

i.b · USRDS members

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Centers, and members of CMS, the ESRD networks, and the renal community provide crucial input and feedback through their committee participation.

The Steering Committee functions as the governing body of the USRDS, and 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 Advisory Committee plays a major role in advising the 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 members from CMS, Network Forum representatives, database technical staff, and others appointed by the Project Officers. DMAC addresses the accuracy and completeness of the data provided to the USRDS, and works to ensure timely fulfillment of data requests.

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

The Information Systems Committee (ISC) reviews planned hardware requirements, systems configuration, documentation, and performance, and evaluates new technologies that may enhance the structure, function, and management of the database.

The Special Studies Review and Implementation Committee (SSRIC) serves as the operations committee for SSC proposals and support of CC projects. It 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 data sets 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 interested in ESRD, 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.”

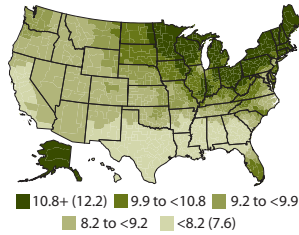
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With the exception of maps that show the location of dialysis units (like those included in Chapter Eleven), maps throughout the ADR present data divided into quintiles. Each data range shown in a legend contains approximately one-fifth of the data points included in the map. In the sample map here, for example, one-fifth of all data points displayed on the map have a value of 10.8 or above.



To facilitate comparisons of maps that present data for several different years or time periods, we have applied a single legend to each of the maps 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 the legends the numbers in parentheses indicate the mean values of the data points in the highest and lowest quintiles. These can be used to calculate the percent variation between these quintiles. For maps with shared legends we have, when possible, 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.

NOTE

The Health Care Financing Administration (HCFA) recently changed its name to the Centers for Medicare and Medicaid Services, and is referred to as CMS throughout this book.

The Annual Data Report 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. Feedback on the ADR and on other work of the USRDS is welcomed, and all comments and requests are reviewed by the Director, Deputy Director, and staff in order to provide the best possible responses, improve future materials, and ensure a strong working relationship between the USRDS and clinicians, researchers, patients, and others involved in ESRD care.