



PRÉCIS
A Summary of
the United States
ESRD Program

All interest
in disease and
death is only
another
expression
of interest in life.

*Thomas Mann,
The Magic Mountain*

The United States Renal Data System (USRDS) was created in 1988, and manages a comprehensive database on end-stage renal disease (ESRD). Under the direction of the National Institutes of Health (NIH), the USRDS has produced major studies aimed at improving the outcomes of patients with kidney disease.

Five central goals define the mission of the USRDS: to characterize the ESRD population; to describe the prevalence and incidence of ESRD along with trends in mortality and disease rates; to investigate relationships among patient demographics, treatment modalities, and morbidity; to identify new areas for special renal studies and support investigator-initiated research; and to provide data sets and samples of national data to support research by the Special Studies Centers.

There have been eleven previous USRDS Annual Data Reports. This twelfth report, the millennial issue and the first produced by the new Coordinating Center at the Minneapolis Medical Research Foundation, breaks new ground at the USRDS. In the first part of the book we have created an atlas of end-stage renal disease, making the visual display of information our primary focus, and introducing to ESRD research the use of data mapping. We believe that this new focus, which allows us to present more comprehensive data without increasing the number of pages, not only makes the book more interesting and accessible, but presents data that is easier to interpret and more relevant to readers in all parts of the renal community. Most of the text previously found in the chapters has been omitted in favor of succinct chapter summaries and figure captions, and we have moved the data descriptions and the summary of analytical methods to the appendix. The reference sections are comprised of the same tables included in previous editions (with some new tables added), but the order of

the sections now matches that of the chapters, and the tables themselves are more consistent in structure and easier to read.

Both the methods and the format of this atlas of end-stage renal disease are modeled after several publications that use mapping to illustrate geographic differences in national mortality and delivery of care. These include *Atlas of United States Mortality*, published by the Centers for Disease Control and Prevention in 1996, *Atlas of Cancer Mortality in the United States, 1950–1994*, published by the National Cancer Institute and released in December 1999, and *The Dartmouth Atlas of Healthcare in the United States*, published in 1999 by the Dartmouth Center for the Evaluative Clinical Sciences.

The use of maps enables us to present large amounts of data in a form that is particularly easy for readers to interpret. We believe that using geographic illustrations to describe ESRD care in the U.S. will dramatically increase understanding of the disease, allowing researchers, clinicians, policy makers, patients, and the general public to identify and investigate geographic patterns in outcomes and patient populations, and providing benchmarks for comparisons of patient care throughout the country.

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.” These HSAs are defined in terms of access to general health care; in the future, however, the USRDS will investigate whether the creation of HSAs specific to ESRD care, and defined in terms of patient access to both dialysis and transplant facilities, might provide an enhanced view and understanding of the data.

Mapping by these 805 HSAs, rather than on a county level, alleviates most problems in geographic patterns that arise from low patient and population densities. In some instances multiple maps per page are used to present large amounts of data in a small amount of space, allowing readers to make comparisons over time for rates of disease, hospitalization, and mortality.

While this book contains most of the graphs familiar to readers of previous ADRs, we have provided additional detail within these graphs on race, gender, and modality, allowing readers to compare outcomes across many patient groups. The chapter on patient characteristics (with data from the Medical Evidence Form 2728) has been expanded, chapters on patient survival, mortality, and causes of death have been combined, and the hospitalization chapter now includes information on patient morbidity—including infection and cardiovascular disease—and its relation to hospitalization rates. We have also addressed the guidelines set by the National Kidney Foundation’s Dialysis Outcomes Quality Initiative (NKF-DOQI) by adding a new chapter on clinical indicators of care, and have followed the lead set by the National Committee of Quality Assurance (NCQA) by creating a chapter on preventive health care issues of particular relevance to ESRD patients.

All data underlying the maps and figures in this book, along with the reference tables, are available on the USRDS website (www.usrds.org), both in an easily printed PDF format and in ASCII files for downloading and working with the data. The site will be updated throughout the year, enabling users to access the most current information on ESRD. Taking advantage of the web’s unique ability to fulfill individual requests, we will also be adding an interactive component to the website which will enable users to create

maps on particular topics and geographic areas and to download customized aggregated datasets. We see the printed ADR and the website as complementary—related to and at times echoing one another, but serving distinct functions. This book is for people to keep on hand, to use as an immediate reference and learning tool. We hope, for instance, that the book will be used by unit staff to examine quality of care issues, to compare outcomes in their region to those in the rest of the nation, and so on. Because most unit staff currently have limited computer time and access, we assume that researchers will at first be the primary users of the website, looking for both the tables traditionally included in the ADR and the data behind the maps and graphs, and expecting that data in a form that can be easily manipulated for their own analyses. Ultimately, however, we hope that both researchers and clinicians will find the website to be a valuable resource for customized, aggregated data on both a nationwide and regional level.

In the remainder of this chapter we have selected maps from the ADR that we believe to represent the current state of the ESRD population, to introduce the mapping strategies used throughout our analyses, and to serve as a visual overview of and introduction to the ADR itself. Further detail on these maps, along with graphs of related data, may be found in the body of the book.

It is our hope that this new approach to presenting data on ESRD patients will gain the interest of readers throughout the renal community, help clinicians and policy makers identify areas of the country in which patient outcomes do not meet expectations, prompt discussions on regional differences in the delivery of care, and trigger epidemiological studies and quality improvement initiatives that will continue to improve the quality of care for renal patients in the United States.

Table p.1
Summary statistics on reported ESRD therapy in the United States
 1998, completed as of May 2000

Recent rates of growth in the ESRD population have varied across patient groups. While the overall annual increase in the incident rate from 1994 to 1998 is similar to that in the previous five-year period of 1990–1994, the average annual percent change has declined for hypertensive patients on all modalities, with the sharpest decrease seen in the hemodialysis and transplant patient populations. The percent change in the rate of diabetes, in contrast, has increased for dialysis patients. In the prevalent patient population, the average annual percent change in rates per million decreased across all races, primary diagnoses, and modalities.

Adjusted incident and prevalent rates continued their increase in 1998, 308 and 1,160 per million population, respectively.

Total cadaveric transplants for Medicare patients were up 4% from 1997, while transplants from living donors were up 12%.

Medicare expenditures for ESRD rose from \$11.76 billion in 1997 to \$12 billion in 1998, with non-Medicare expenditures increasing from \$3.88 billion to \$4.7 billion. Total spending for all ESRD in 1998 was \$16.7 billion. Expenditures per patient year of exposure were down 3.8 to 5.7% compared to 1997, paralleling a decrease in the number of hospitalizations and increases in dialysis dose and hematocrit levels.

See Appendix A for discussions of the database and analytical methods used to construct this table. The economics section of Appendix A includes an explanation of the methods used to calculate the data on Medicare and non-Medicare spending.

The data in this table are updated for completeness through May 2000, with more detailed accounting of duplicate patients. The data in the remainder of the ADR are less complete than the data used in this table, and are updated through December 1999.

Patient characteristics	Incidence ^A		December 31 Point Prevalence				Medicare kidney transplants		ESRD deaths
	Count	Adj. Rate ^B	Count	Adj. Rate ^B	Dialysis ^C	Transplant	Cadaver	Living donor	
Age^D									
0-19	1,196	14	5,935	70	1,850	4,139	356	416	111
20-44	13,209	121	78,853	728	40,252	39,461	3,763	1,997	4,586
45-64	30,009	606	127,592	2,468	87,207	42,215	4,075	1,435	17,750
65-74	22,097	1,314	65,841	4,011	58,758	7,826	683	167	19,493
75+	19,009	1,359	45,600	3,279	45,031	892	43	*	21,213
Unknown					113	289			
Race									
White	53,807	228	194,114	830	126,121	70,379	5,937	3,201	41,136
Black	25,807	962	106,621	3,854	89,587	17,493	2,337	567	18,146
Native American	1,385	858	5,225	3,075	4,142	1,089	103	31	793
Asian/Pacific Islander	2,940	394	11,672	1,403	8,287	3,409	395	115	1,714
Other/unknown	1,581		6,189		5,074	2,452	154	106	1,364
Gender									
Male	45,388	370	175,899	1,382	121,982	56,137	5,362	2,301	32,941
Female	40,132	261	147,922	977	111,089	38,247	3,561	1,726	30,205
Unknown gender					140	438			7
Primary diagnosis									
Diabetes	36,904	133	107,613	386	90,675	18,420	2,493	829	26,656
Hypertension	19,659	71	69,347	250	63,585	11,689	1,456	445	17,228
Glomerulonephritis	10,528	38	61,317	221	29,182	22,844	1,966	1,097	5,102
Cystic kidney disease	2,507	9	18,223	66	6,951	7,236	690	312	1,138
Urologic disease	4,118	15	12,254	44	4,477	1,910	201	129	1,027
Other known cause	3,408	12	12,916	46	23,111	13,425	1,095	693	6,495
Unknown cause	6,734	24	21,275	77	8,951	4,129	312	183	2,514
Missing cause	1,662	5	20,876	70	6,279	15,169	713	339	2,993
Total	85,520	308	323,821	1,160	233,211	94,822	8,926	4,027	63,153
Unadjusted rate ^E		311		1,170		Total Transplants ^F	13,272		
Average annual percent change in rates per million									
	HD		PD		Transplant		Medicare spending		
	1990-94	1994-98	1990-94	1994-98	1990-94	1994-98	Medicare spending for ESRD in 1998 (in billions of dollars)		
Incident patients							SAF paid claims	11.03	
White	6.47	7.47	2.23	4.48	8.12	8.91	2% inflation	0.23	
Black	8.24	6.88	3.59	1.63	7.51	-19.79	HMO	0.58	
N. Am.	8.68	12.64	7.11	6.86	4.46	-3.51	OA	0.20	
Asian	11.91	10.20	30.98	2.58	3.29	0.45	Total Medicare costs	12.04	
Diab.	9.88	11.52	4.34	6.95	6.98	1.32	Non-Medicare spending for ESRD (in billions of dollars)		
HTN	6.94	2.15	1.16	-1.15	6.21	0.88	EGHP (non-Medicare)	0.83	
GN	3.37	4.30	2.03	3.05	2.95	3.15	Patient obligations	2.83	
Cys Kid	3.42	5.91	3.59	6.92	0.00	18.60	Non-Medicare patients	1.04	
All	7.27	7.45	3.27	3.78	-4.18	2.19	Total non-Medicare costs	4.70	
Prevalent patients							Change in Medicare spending (%) from 1997 to 1998		
White	8.43	7.39	8.58	-2.82	9.27	6.41	Total	0.6	
Black	9.94	7.14	11.91	-2.63	10.91	8.38	Per patient year	-2.1	
N. Am.	13.76	10.99	12.93	0.99	12.15	6.70	Adjusted for inflation	-5.7 to -3.8	
Asian	13.40	9.02	23.28	3.53	13.06	10.94	Medicare spending per patient year 1994-1998 (in \$1,000s)		
Diab.	14.44	12.42	12.82	0.71	12.06	8.74	ESRD	43	
HTN	9.89	4.34	10.86	-6.02	10.45	7.69	Hemodialysis	53	
GN	4.78	3.83	7.09	-3.34	8.22	6.17	Peritoneal dialysis	47	
Cys Kid	4.25	3.25	7.86	-2.24	10.62	8.44	Transplant	18	
All	9.28	7.40	9.89	-2.47	9.70	6.92			

A Incidence: new patients with valid birthdates who began ESRD therapy in 1998. Includes only residents of the 50 states and Washington D.C.

B Rates were adjusted for age, race, and/or gender using the July 1, 1998 U.S. resident population as the standard population. All rates are per million population. Rates by age were adjusted for race and gender. Rates by gender were adjusted for race and age. Rates by race were adjusted for age and gender. Rates by disease group and total adjusted rates were adjusted for age, gender, and race. Adjusted rates do not include patients with other or unknown race. Includes only residents of the 50 states and Washington D.C.

C Patients were classified as receiving dialysis or having a functioning transplant. Those whose treatment modality was unknown on December 31 were assumed to be receiving dialysis. Includes all Medicare and non-Medicare ESRD patients.

D Age was computed at the start of the therapy for incidence, on December 31 for point prevalence, at the time of transplant for transplants, and on the date of death for death.

E Unadjusted total rates include all ESRD patients in the 50 states and Washington D.C..

F From the 1998 HCFA Facility Survey.