

# Executive Summary

Since its creation in May 1988 the United States Renal Data System (USRDS) has pursued the collection and analysis of information on the incidence, prevalence, treatment, morbidity, and mortality of end-stage renal disease (ESRD) in the United States. The USRDS is operated by the Coordinating Center (CC) at The University of Michigan, and is funded primarily by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) of the National Institutes of Health with supplementary funding from the Health Care Financing Administration (HCFA). The Health Care Financing Administration, of the U.S. Department of Health and Human Services, participates with NIDDK on the project and supplies expertise and most of the original data. Much of the HCFA data and Special Study data are collected by or through the ESRD Networks.

The present USRDS 1998 Annual Data Report is the tenth volume based on these ESRD data. The annual data reports represent one major vehicle for disseminating information from the USRDS.

The report addresses each of the six goals that are defined for the USRDS. The first three goals are addressed throughout the report: 1) to characterize the total ESRD patient population and describe the distribution of patients by sociodemographic variables across treatment modalities; 2) to report on the incidence, prevalence, mortality rates, and trends over time of ESRD by primary diagnosis, treatment modality, and other sociodemographic variables; and 3) to develop and analyze data on the effect of various modalities of treatment by disease and patient group categories.

The fourth goal is to identify problems and opportunities for more focused special studies of renal research issues. This goal has been addressed with special studies requiring new data collection. A description of these eight special studies is provided in Chapter I, "The USRDS and Its Products." Data collection for the eighth special study, the Dialysis Morbidity and Mortality Study (DMMS), is complete, having begun in March of 1995. Early results from

Waves 2, 3, and 4 of this study are presented in Chapter IV.

Two additional goals were added to the USRDS's mission in 1993 and have been reflected in all subsequent data reports since 1994. Goal five is to conduct cost effectiveness studies and other economic studies of ESRD. Chapter X presents an analysis of the total resource spending for ESRD care in the United States. Chapter X also includes an analysis of Medicare spending by various categories.

Goal six puts new emphasis on supporting investigator-initiated projects to conduct biomedical and economic analyses of ESRD patients. Chapter I of this report describes the USRDS Standard Analysis Files (SAFs) and their availability on CD-ROM. Since 1992, we have supplied our SAFs and custom data files to researchers outside the USRDS, for a total of 52 requests. Chapter I provide a listing of research done by investigators outside the USRDS using USRDS data.

These analysis files are also described in a separate publication, the *Researcher's Guide to the USRDS Database*, which is available through the USRDS Coordinating Center. Essential parts of the Researcher's Guide are available from the World Wide Web as are the full ADR, including the reference tables and color slides of all graphics.

We have provided the complete version of the USRDS 1997 Annual Data Report (including all reference tables) at the USRDS WWW site (<http://www.med.umich.edu/usrds/>) and on CD-ROM and will do the same for the 1998 Annual Data Report. Please contact the USRDS CC for further information if you would like to request a copy of the 1998 ADR on CD-ROM.

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## Changes from Previous Reports and Continuing Notes of Importance

The USRDS has issued nine previous reports, the most recent of which was published in spring of 1997. The current report is based on an update of

biomedical information from HCFA dated September 1997. The USRDS added nearly 60,000 new patients since the last update. In addition to the biomedical information, the Medicare billing data incorporated into the USRDS for 1991-96, which underlie much of the current analyses of cost in Chapter X, consists of over 200 million paid Medicare claims. All of these 1991-96 records are currently on-line, occupying over 20 billion bytes of computer disk storage. Data records for more than 52,000 patients from the eight Special Studies are currently in the database as well.

The ESRD data in this report are current through 1996 for all patient-specific, biomedical, and Medicare payment data; through 1996 for ESRD providers; and into 1997 for the most recent Special Study (DMMS, Chapter IV). Patient-based data are an accumulation of many records for each patient from numerous sources. There is a variable lag time before the patient data are considered complete, and the USRDS generally does not emphasize patient data that occur less than 15 months from the last update. ESRD provider data and much of the payment record data are generally completed within 6 months of the end of the calendar year.

Our objective in preparing this report has been to present data for a span of 10 or more years for biomedical information (5 years for cost information) using consistent definitions, so that valid comparisons can be made across years and among subgroups in the database. Because of year-to-year changes in the data and in the methodologies used, comparisons of data between ADRs should be avoided. We attempt to alert the reader to those cases where changes in the data collection process over the years result in problems in making valid comparisons across years. These warnings appear in the text, in reference table introductions and footnotes, and in Chapter XIII, "Analytical Methods."

The primary methodology and data changes in this report include the following:

### **Data Changes**

**Duplicate Records.** HCFA has implemented a new data system that has substantially improved the timeliness and completeness of much of the patient data. However, the data collected since 1993 represent a transition period and some data may have idiosyncratic characteristics, which vary from year to year. One specific major change this year is in the identification of duplicate records for patients in the USRDS database. This change resulted in reductions in the number of patients, since patients who had been

counted multiple times in prior reports are now counted only once. This had the most impact for patients starting dialysis therapy in recent years, where the most duplication occurred. Consequently, the reported patient counts for some years are somewhat lower in this ADR than they had been in past ADR reports. This is counterbalanced by increases in patient counts due to the late reports for patients that were added to the database this year, even though they were first treated in earlier years. Overall, more than 8,000 patient records were identified as duplicates and only single records were retained for the ESRD patient count.

**Hospitalization Analyses.** In addition, a major change was made this year in the method for counting hospitalizations. This has an impact on the results in Chapter IX. The USRDS uses Medicare billing records to count hospitalization events. A minority of patients (with Medicare Secondary Payer status) have some or all of their hospitalizations paid by other insurance sources, so Medicare billing data would yield undercounts of hospitalization for such patients. In order to limit the hospitalization calculations to those patients whose hospitalizations are likely to be identified by Medicare billing records, the hospitalization tabulations were limited to patients who had Medicare dialysis bills or were identified as being transplant recipients during the time interval of the tabulation. In contrast, all patients who had ever had a Medicare paid dialysis bill were included in the hospitalization tabulations in ADRs in prior years. The criterion used this year means that the results are applicable only to Medicare patients, as before, but gives more interpretable results for those patients because of the increased emphasis on finding Medicare Secondary Payer status. Due to this improved methodology, hospitalization rates reported this year are higher than the rates reported in prior years of the ADR.

**Dialysis Patient Mortality.** A continuing slow decrease in first-year mortality rates is seen for patients incident through 1995. A slow decline in mortality is also seen for prevalent patients through 1996.

**Growth in Incident Patients.** The Annual Facility Survey (AFS), which includes both Medicare and non-Medicare patients, suggests approximately 5 percent growth per year in incidence counts from 1995 to 1996. The USRDS database indicates a growth of about 6 percent for 1996. These data suggest that the United States is possibly seeing some small reduction in the rate of growth in the number of

new ESRD patients in recent years, but the evidence is still not conclusive.

**Medication Use among Dialysis Patients in the Dialysis Morbidity and Mortality Study (DMMS).** Waves 2, 3, and 4 of the USRDS DMMS included special data items concerning medication prescriptions among ESRD patients. Details of these data are summarized in Chapter IV.

**Race Code.** Patient race is determined based on data from the Medicare database, the Medical Evidence Form, and transplant records. Each of these sources uses a different coding scheme. The USRDS combines these sources to determine a race code for each patient. Changes in the coding schemes has resulted in an increase in the number of patients classified as "Other" race.

**Standard Population for Adjustment Across Years.** The adjusted incidence, prevalence, survival, graft survival, and death rates in this ADR now all use one year before most recent year as the standard population for adjustment. For this 1998 ADR, the 1994 Census Bureau population data were used for adjusting incidence and prevalence rates, the 1994 ESRD population was used for adjusting survival rates and the 1993 and 1994 transplant population was used for adjusting graft survival rates.

**Primary Disease Codes.** In 1995, HCFA implemented a new coding scheme for the Medical Evidence (2728) form. All diseases reported prior to that time have been assigned according to the best-fitting code from 1995 on. As a result of grouping diseases in eight primary categories for this report, there is some inconsistency in the way some diseases are grouped before and after the re-codes.

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## Summary Statistics

Selected statistics for the ESRD program for 1996 are shown in Table ES-1. These data provide summary data as a succinct reference for frequently asked questions.

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## Chapter I. The USRDS and Its Products

Regular readers of these Annual Data Reports will find this chapter a very familiar description of the USRDS and its products. It does discuss the following new features:

- The USRDS World Wide Web site.

- The USRDS will produce a third round of facility-specific mortality and hospitalization reports, which will be distributed to dialysis units through the ESRD Networks in the Late Spring.

This chapter describes the various products available to the researcher who wants to work with USRDS data and the recent utilization of USRDS data and methodologies by independent researchers. The Standard Analysis Files (SAFs) developed by the USRDS make the database available to researchers in an easy to use and well documented format. This approach reduces production costs and the cost to researchers. These analysis files have patient-specific information, but patient and facility identifiers are encrypted. Sharing of USRDS data has allowed more investigators to pursue independent research and assist the renal community through responses to specific questions.

More than 1500 copies of a CD-ROM edition of the 1997 USRDS ADR were distributed, starting at the ASN meetings in early November, 1997. This CD contains the full text and graphics of the ADR, the ADR graphics as Microsoft PowerPoint slides, and the Researcher's Guide. A similar CD will be produced for the 1998 ADR.

Usage of the USRDS Standard Analysis Files continued to grow. In 1997, 170 CDs were supplied to 25 researchers. The pricing of the USRDS SAFs has been simplified, and the claims data SAFs for individual years now can be purchased separately.

The USRDS has developed several methodologies such as the Standardized Mortality Ratios (SMR), Standardized Hospitalization Ratios (SHR), and Standardized Transplantation Ratios (STR). Each of these methods allow comparison to national data, while adjusting for differences in age, sex, race, and cause of ESRD distribution in the study population. This method has been employed for research, quality improvement, and other purposes on a dialysis facility level, at a state or ESRD Network level and in dialysis chains.

Shorter requests for data were filled in large numbers. During 1997, approximately 3 requests were filled per working day. There has been a seasonal increase in requests around the American Society of Nephrology meeting.

The *Researcher's Guide to the USRDS Database* and the entire USRDS Annual Data Report, including 400 pages of reference tables and color slides of all

Summary Statistics on Reported ESRD Therapy in the U.S., 1996<sup>a</sup>

Patient Characteristic	ESRD Incidence		December 31 ESRD Point Prevalence				Medicare Kidney Tx Performed by		ESRD Deaths <sup>f</sup>
	Count <sup>b</sup>	Adjusted Rate <sup>c</sup>	Count <sup>b</sup>	Adjusted Rate <sup>c</sup>	Counts By Modality <sup>d</sup>		Donor Type <sup>e</sup>		
					Dialysis	Tx	CAD	LRD	
<b>Age<sup>g</sup></b>									
0-19	1,129	13	5,180	64	1,738	3,495	366	389	89
20-44	12,622	117	73,734	692	38,839	35,728	3,746	1,743	4,184
45-64	25,417	542	109,834	2,280	78,075	33,501	3,744	1,105	14,356
65-74	19,456	1,144	58,549	3,518	53,588	5,609	506	112	16,824
75 plus	14,467	1,079	36,635	2,715	36,465	477	15	*	16,309
<b>Race</b>									
White	46,102	199	173,443	754	115,515	60,230	5,630	2,547	34,967
Black	21,808	829	91,580	3,404	77,924	14,057	2,224	605	14,149
Asian/Pacific Islander	2,408	354	9,863	1,291	7,434	2,665	339	86	1,380
Native American	1,279	817	4,504	2,761	3,620	889	103	42	713
Other	1,339		3,124		4,212	969	60	63	353
Unknown	155		1,418		w/other	w/other	21	0	200
<b>Sex</b>									
Male	39,256	325	153,381	1,233	108,472	47,042	5,079	1,935	27,477
Female	33,835	225	130,551	883	100,233	31,768	3,298	1,416	24,285
<b>Primary Disease</b>									
Diabetes	30,933	113	92,211	339	76,950	16,651			21,199
Hypertension	18,844	70	69,538	256	59,322	10,877			15,098
Glomerulonephritis	7,882	29	50,378	185	29,022	22,154			4,818
Cystic Kidney Disease	1,796	7	13,454	50	7,100	6,493			1,102
Urologic Diseases	1,467	5	5,547	21	3,846	1,787			848
Other Known Cause	8,212	30	32,301	119	21,057	11,525			5,493
Unknown Cause	2,866	10	14,209	52	9,119	5,263			2,312
Missing Data	1,091	4	6,294	19	2,289	4,060			892
<b>Total</b>	<b>73,091</b>	<b>270</b>	<b>283,932</b>	<b>1,048</b>	<b>208,705</b>	<b>78,810</b>	<b>8,377</b>	<b>3,351</b>	<b>51,762</b>
<b>Unadjusted Rate<sup>h</sup></b>		<b>268</b>		<b>1,041</b>		<b>Total Tx<sup>i</sup></b>	<b>11,728</b>		

**Total Spending for ESRD in 1996: All sources: \$14.6 Billion Medicare: \$11.0B Non-Medicare \$3.6B**

Change in Medicare Spending 1996 vs. 1995: Total 13%; Per patient year 5%; Adj. for Inflation 1.2 to 1.5%

Medicare \$/patient year 1996: ESRD \$ 44K; HD \$55K; PD \$48K; Tx \$18K<sup>j</sup>

<sup>a</sup> USRDS Patient Database Updated from HCFA PMMIS September 1996, Quality Control Filters Applied. Includes only ESRD patients reported through HCFA as receiving renal replacement therapy for ESRD, or approx. 93 percent of the total number U.S. ESRD patients. See Chapter XIII,

"Analytical Methods: Technical Notes," for discussions of the database and of the methodologies used.

<sup>b</sup> Incidence = new patients starting ESRD therapy during 1996. Incidence and prevalence counts and rates include residents of the 50 states and the District of Columbia only. All other data in this table (modality, transplant, and death counts) include residents of Puerto Rico and U.S. Territories.

<sup>c</sup> Rates were adjusted for age, race, and/or sex using the July 1, 1995 U.S. resident population as the standard population. All rates are per million population. Rates by age were adjusted for race and sex. Rates by sex were adjusted for race and age. Rates by race were adjusted for age and sex. Rates by disease group and total adjusted rate were adjusted for age, race and sex. Adjusted rates do not include patients with other or unknown race.

<sup>d</sup> Patients were classified as receiving dialysis or with a functioning transplant. Those with treatment modality unknown on December 31 were assumed to be receiving dialysis.

<sup>e</sup> Kidney Tx Performed = number of transplants performed during 1996.

<sup>f</sup> Deaths = number of ESRD patient deaths during 1996.

<sup>g</sup> Age was computed at start of therapy for incidence, on 12/31 for point prevalence, at time of transplant for transplants, and on date of death for death.

<sup>h</sup> Unadjusted total rates include all ESRD patients in the 50 states and the District of Columbia.

<sup>i</sup> Source: 1996 HCFA Facility Survey.

<sup>j</sup> Excludes cost of organ procurement.

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Table ES-1

ADR graphics are available electronically on the Internet at:

<http://www.med.umich.edu/usrds/>

The USRDS continued to reach users throughout the United States and around the world through the USRDS Web Site. The number of data requests filled by USRDS CC staff grew dramatically, in part because of exposure through the Web site and the USRDS booth at the ASN meetings. The USRDS WWW site is accessed from around the world more than 1,000 times each month, and more than 600 megabytes of data are downloaded from the site each month.

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## Chapter II. Incidence and Prevalence of ESRD

This ADR continues the practice, first adopted in the 1997 ADR, of reporting data updated within less than 1.5 years of the ADR year (i.e. this 1998 ADR contains data through 1996). Recent experience has shown that incidence counts increase by approximately 5 percent between this update and one that is delayed by 1 year. As of the last database update, 283,932 patients were treated for ESRD and 73,091 new patients started ESRD treatment in 1996. The 1996 incidence rate is currently estimated at 268 per million and the prevalence rate at 1,041 per million. After adjusting for the expected lag in reporting new ESRD cases, the estimated rate of growth of new ESRD is 6-7 percent per year. Although some slowing trends have been suspected, there is currently no conclusive evidence that the rate of growth of ESRD incidence is slowing. There is some uncertainty in these estimates in part because the reporting of non-Medicare patients has been included in the database in recent years.

The ESRD Medical Evidence Form (2728) was changed in 1995 to include a more specific and less circumspect list of choices for the cause of ESRD, baseline laboratory values, and comorbid conditions at the time of ESRD initiation. Providers now enter a primary cause of ESRD from a relatively complete and contemporary coded list of 72 diagnoses which are organized into 10 primary disease categories.

Incidence and prevalence rates tended to increase with age and then fall off for the oldest age group. The largest group of patients falls in the 70-74-year age group for incidence and 65-69 for prevalence. The disease was more common in men than women. Individuals classified as Black race constituted 30

percent of treated ESRD patients as contrasted with 12.6 percent of the U.S. population. Diabetes continues to be the most common reported cause of ESRD. The attributed cause of ESRD varies by patient demographics including age, sex, and race.

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## Chapter III. Treatment Modalities for ESRD Patients

The growth of the number of patients has been similar for each treatment modality so that the percent distribution of modalities has remained virtually constant. Although the fraction of patients being treated with peritoneal dialysis has been fairly constant over the past decade, the use of CAPD has declined and the use of CCPD has increased sharply since 1994. The number of patients on the transplant waiting list has continued to show a steep growth, while the number of cadaveric renal transplants performed per year has increased minimally. Thus the gap between supply and demand for organs continues to widen. The number of living related and living unrelated renal transplants performed per year has shown an increase during the last 10 years, but this increase has not been large enough to keep pace with the growing demand for renal transplants.

For hemodialysis patients, the average delivered dialysis dose varies substantially across geographic regions, although no particular pattern is apparent. The majority of hemodialysis patients starting replacement therapy in 1996-97 are treated with synthetic membranes and large unexplained geographic variations in membrane choice are evident. Treatment modality varies a great deal with respect to age and race. For example, transplantation and PD are dominant forms of treatment among pediatric age groups, whereas CAPD and CCPD are utilized to a relatively greater extent among younger adults and White or Asian patients than among older patients and other race groups.

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## Chapter IV. Medication Use Among Dialysis Patients in the Dialysis Morbidity and Mortality Study

The Dialysis Morbidity and Mortality Study (DMMS) is a USRDS Special Study which includes over 20,000 randomly selected dialysis patients. The study included 4 "waves" of data collection over 3 years (Waves 1-4). A standard "core" of data was collected for all patients included in the study to address research questions that require a large sample size. In addition, each separate Wave included a

“non-core” component designed to address additional specific research questions. Wave 1 focused on anemia, nutrition, and vascular access and preliminary descriptive results were reported in the 1996 USRDS Annual Data Report. Wave 2 focused on peritoneal dialysis prescription and delivery, peritoneal dialysis and hemodialysis comparisons, residual renal function, quality of life, pre-ESRD care, and several other topics. Preliminary results were reported in the 1997 USRDS Annual Data Report. Data on medication use were collected for Wave 2 and were also a major focus of Waves 3 and 4.

This chapter reports on descriptive analyses of medication prescription as noted in the medical records of random samples dialysis patients from Waves 2, 3, and 4. Highlights include the following:

Overall, hemodialysis (HD) patients starting dialysis were prescribed a median of 8 medications. Among new HD patients starting dialysis in 1993, 34 percent of patients were prescribed 10 or more medications, and 8 percent were prescribed 15 or more medications. The median number of medications prescribed among prevalent patients established on dialysis in 1993 was 9.

Over 75 percent of new HD and 81 percent of new PD patients were prescribed at least one antihypertensive medication. Calcium channel blockers were the most commonly used antihypertensives, followed by ACE inhibitors, beta blockers, central  $\alpha_2$  receptor agonists, peripheral  $\alpha_1$  receptor blockers, and others. Nitrates were used in 22 percent of new HD and 17 percent of new PD treated patients. Digoxin was used in 11-13 percent of patients. A lipid lowering agent was used in 8 percent of HD and 15 percent of PD patients.

Phosphate binders were prescribed in 78 percent of HD and 81 percent of new PD patients. Only a small fraction of patients were prescribed aluminum containing binders. The majority of patients use a calcium containing agent, of which calcium carbonate and calcium acetate each account for approximately one half. Vitamin D was used in 42 percent of HD and 33 percent of PD patients starting dialysis.

With regard to gastrointestinal agents, 30 percent of patients starting HD and 26 percent starting PD were prescribed a proton pump inhibitor. Overall, approximately 13 percent of dialysis patients were prescribed a GI motility agent. This figure was substantially higher among diabetics.

Analgesics were used in 9 (PD) to 12 (HD) percent of new patients. NSAIDs were used in less than 2 percent and narcotics and non-narcotics contributed equally to the remainder. Antidepressants and benzodiazepines are prescribed in approximately 12 percent and 8 percent respectively.

A large fraction of patients with ESRD attributed to diabetes are not on either insulin or an oral hypoglycemic agent and a small fraction of patients with ESRD due to causes other than diabetes are on these medications. Thyroid replacement therapy is prescribed in over 10 percent of patients. Among female HD patients over age 55, 6.6 percent are reported in 1996 to be prescribed estrogen replacement therapy.

As these preliminary results are based on a national random sample of U.S. dialysis patients, the results in this chapter are likely to be a description of patterns of medication use among dialysis patients in the United States. More detailed analyses are planned to determine predictors of and outcomes associated with the prescription of these medications.

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## Chapter V. Patient Mortality and Survival

There are seven major sections in this chapter, which focuses on patient survival among treated ESRD patients. Transplant recipients are included in some of the results, but the primary focus is on dialyzed patients.

An incident cohort consists of patients who started ESRD therapy in a particular year. For the incident patient results, patients are categorized by the calendar year of first treatment for ESRD in all analyses. In selected analyses they are also categorized by the number of years of treatment. Observed differences in mortality among incident cohorts could be due to several factors, such as changes in enrollment criteria for ESRD treatment or in treatment patterns for those cohorts.

A prevalent cohort includes all patients being treated in a particular year, both new and continuing patients, without distinguishing among the patients by the number of years of prior treatment. The calculation of results for prevalent patients is based upon categorizing the years of followup for each patient by calendar year. Differences in mortality among prevalent years would primarily reflect factors, such as innovations in treatment, that tend to affect all patients being treated in that year.

Patients from Puerto Rico and the U.S. Territories are included in results that are derived from the HCFA Annual Facility Survey, but are not included in results derived from the USRDS database. Until 1994, the USRDS data were largely limited to Medicare insured patients, while after 1994, both incident Medicare and non-Medicare patients are included in the database. This change might cause results based on pre-1994 data to differ from results based on post-1994 data.

A progressive improvement in first-year survival among dialysis patients has been observed for each successive year's incident cohort since 1985. This improvement is sustained in the 1995 cohort, and is consistent across subgroups by age, race, sex, and diagnosis. Declining death rates for all prevalent patients between 1989 and 1995 reflect this trend. There have been many changes in dialysis therapy during this time that could be associated with this drop in mortality and which deserves further study.

However, the gains in survival are tempered by two other factors: First, considerable geographic variability exists in adjusted mortality rates. The reasons for this variability have not been explored. Second, the gains in survival are the most dramatic in the first few years of therapy. Although 2-year survival improved by 11.1 percent between 1984 and 1994, the 5-year survival for the period 1981-1991 only improved by 5.3 percent. Furthermore, the expected lifetimes of dialysis ESRD patients are between 17 and 39 percent of those for the age-sex-race matched U.S. population, while lifetimes of all ESRD patients are between 19 and 47 percent of the corresponding U.S. population.

Methods for calculating national death rates. There were no major changes in the analysis methods used for this year. As in the ADR for last year, deaths not plausibly related to dialysis were excluded and a regression model was used to stabilize the year-to-year variation in the death rates for dialysis patients

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## Chapter VI. Causes of Death

This chapter focuses on the specific causes of death for approximately 100,000 ESRD patients, who died during 1994 to 1996 and may serve as a source of information to help decrease the death rates of ESRD patients through further in-depth epidemiological and clinical research. The distributions of specific causes of death categories are analyzed for various subgroups of prevalent dialysis and transplant patients.

Among dialysis patients cardiac causes account for almost half of the reported causes of deaths. In the 45-64-year-old age group deaths due to cardiac causes are somewhat more common for males and Whites than for females and Blacks. Infection accounts for the second largest category and is a more common cause of death for younger, female, and Black patients than for older, male, and White patients. It is also a relatively more common cause for PD than for HD patients among both diabetic and nondiabetic patients.

The distribution of causes of death for transplant patients was analyzed for ages 0-19 years, 20-44 years, and 45-64 years in a similar fashion. A limitation of this analysis is that causes of death are less frequently reported for transplant recipients and there is some uncertainty about the assumption that unreported deaths have a similar cause distribution as those with reports. Cardiac causes accounted for a smaller proportion of deaths for transplant recipients than for dialysis patients. Whites and diabetic patients have a much larger fraction dying of acute myocardial infarction than Blacks and nondiabetics.

Approximately 20 percent of dialysis patients withdraw from dialysis before death. Older patients have a much higher rate of withdrawal than younger patients do. While diabetic patients withdraw at higher rates than nondiabetics, a smaller percentage of diabetic deaths are preceded by withdrawal than nondiabetic patient deaths. Females withdraw at a higher rate than males. Asians, Blacks, and Native Americans are at half to a third the risk of withdrawal compared to Whites. Medical complications and failure to thrive make up the majority of reasons for withdrawal from dialysis. Additionally, access failure and transplant failure (usually refusal to return to dialysis) account for a proportion of withdrawals particularly for pediatric patients.

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## Chapter VII. Renal Transplantation: Access and Outcomes

This chapter provides an overview of the trends in access and outcomes of kidney transplantation in the United States. The Annual Data Report includes both Medicare and beginning in 1995, non-Medicare kidney transplants.

The number of cadaver kidneys transplanted annually ranged from 8,327 in 1994 to 8,526 in 1996, representing an increase of only 100 kidneys per year. In 1996 there were 12,238 renal transplants

performed in the United States. Among these 3,091 (25.3 percent) were from living relatives and 621 (5 percent) from spousal and other biologically unrelated donors. During 1993-96, kidney donation from biologically unrelated donors increased annually by 46.6 percent whereas living-related kidney donation increased annually by 5.4 percent and cadaveric donation showed a minimal increase of 1.6 percent per year.

Rates of cadaveric transplantation (CAD) vary by race, gender, age group, and location of residence. Pediatric patients (ages 0-19 years) received a relatively small number (10.8 percent) of living donor transplants and of CAD renal transplants (3.4 percent), although the rate of CAD and living donor (LD) transplantation was 2 and 3.4 times greater than for young adults (age group 20-34 years). Older age groups had lower transplantation rates (for both LD and CAD) with patients aged 50-65 years having rates of 1.2 and 4.3/100 dialysis patient-years for LD and CAD transplantation, respectively. Given the high incidence and prevalence of ESRD in the 50-65-year age group, they received more than twice as many LD organs than the small pediatric group and more CAD organs than the two younger age groups combined (ages 0-34 years). The CAD transplantation rate was higher in Whites than in Blacks in each of the eighteen ESRD Networks, the racial disparity was more marked in some networks than in others. The geographic differences and the within region racial disparities in CAD transplantation rates are complex and may warrant further study.

In 1994-1995, the difference in 1-year patient survival between diabetic and nondiabetic ESRD patients who received their primary renal transplant from living donors was very small (95.4 percent vs. 96.3 percent). Median primary CAD graft survival improved from 64.5 months in 1986-1987 to 101.8 months in 1992-1993. This substantial increase by 58 percent occurred during these post-cyclosporin years in a steady fashion. Median primary LD graft survival increased by a similar percentage from 116 months in 1986-1987 to 176.5 months in 1992-1993. During this time the improvement in first-year graft survival was near 50 percent as was the second year graft survival, which argues against the prevailing notion that long-term graft survival has not improved as much as the short-term graft survival.

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## Chapter VIII. Pediatric End-Stage Renal Disease

The incidence of treated ESRD is many times higher among adults than among children. A higher ESRD incidence with older age is also found across 5-year age groups within the pediatric cohort when adjusting for differences in sex and race. Average incidence rates for the combined years 1994-96 were more than twice as high among children 15-19 years (30 per million) as they were for children 10-14 years (14 per million), and more than 3 times higher than rates for children 0-4 (9 per million) and 5-9 (8 per million).

Children with ESRD continue to have high transplantation rates. Thirty-seven percent of children starting ESRD therapy during the 1992-96 period received a transplant during the first year of renal replacement therapy, compared to 9 percent of patients 20-64 years of age at ESRD incidence. Only 28 percent of children (ages 0-19) were treated with some form of dialysis at 2 years following onset of ESRD compared to 56 percent of young adults (age 20-44). The differences in patterns of treatment between younger and older children are no longer as striking as reported for earlier years, although younger children are much more likely to receive peritoneal dialysis, predominantly CCPD than older children. Transplantation is clearly the most favored treatment modality in each pediatric age group.

Pediatric transplant patients had higher survival rates than pediatric dialysis patients overall, and the largest benefit of transplantation appeared to occur in the youngest patients age group. Evaluation of hospitalization rates as the first admission rate per 100 patient-years at risk in 1994-1996 revealed that there were more hospital admissions for younger children and for patients receiving hemodialysis than peritoneal dialysis.

The overall death rate was 1.7 per 100 patient years for all pediatric ages which is substantially higher than for young adult (ages 20-44) patients (5.6 per 100 patient years). The death rate for pediatric dialysis patients was substantially lower than for children with functioning transplants. However these comparisons do not adjust for the possible selection bias. Infection was the most common cause of death in children (22 percent), followed by cardiac arrest (16 percent). Cardiac arrest and other cardiac deaths combined accounted for 33 percent of patient deaths. Note that hyperkalemia (3 percent) is listed separately and not as a cardiac cause of death.

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## Chapter IX. Hospitalization

Hospitalization rates reflect a number of important aspects of ESRD therapy. Various factors often make it difficult to accurately measure and interpret data on hospitalization. The use of the HCFA Standard Analysis Files, introduced in the 1996 ADR, has improved, but not perfected, the ability of the USRDS to analyze such data. The screening process adopted for the 1997 ADR used to determine patient eligibility proved to include too many patients with incomplete hospitalization profiles. The majority of these patients had Medicare as secondary payer. New criteria have been adopted this year that are tied directly to available cost data and largely resolve these problems. As a result of more complete recording the hospitalization rates in this chapter tend to be higher than those reported in previous years. All of the analyses in this chapter are based on data obtained through 1996.

This chapter evaluates trends in admissions and hospital length-of-stay in a variety of ways. It also utilizes the standardized first hospitalization ratio, an improved comparison measure introduced in the 1996 ADR which employs "first hospital admission" rates in a given time period as way to compare the hospitalization experienced by patients at local levels (e.g., statewide) to national trends.

As in the 1997 ADR, distributions of hospital admissions and days are positively skewed with more patients having zero admissions and zero days in the hospital than any other number. There is some evidence that admission rates may be leveling off, perhaps indicative of an underlying "fixed cost" of treating ESRD. Furthermore, the number of hospital days per year is declining (11 percent between 1993 and 1996), consistent with national trends and likely reflective of efforts to reduce cost of treatment. Female diabetics are found to have the highest rates of hospitalization for all ages, followed by male diabetics, female nondiabetics, and finally male nondiabetics. Blacks are seen to have higher rates of hospitalization early and late in life, with this pattern being somewhat more pronounced for males than for females. As has been seen in every ADR chapter on hospitalization, Asians have uniformly lower rates of hospitalization in all age groups than do Blacks, Whites, and Native Americans.

We have used the SHR to make slightly different comparisons than those found in the 1997 ADR. Specifically, SHR's are now reported on a state-by-state basis using patient level data, with some grouping used in order to avoid sample size issues.

Facility-level data were used in the 1997 ADR. The regional variation in rates is similar to last years report, and reflects national trends. In particular, higher hospitalization rates are typically seen in the eastern and southern states. Similarly to last year, the Pacific, Mountain, and West North Central regions all have SMRs and SHRs which reflect mortality and hospitalization experience below national levels. Two states (Missouri and South Carolina) have hospitalization rates below the national average but mortality rates above the national average.

Finally, it was reported last year's ADR that there was a significant decrease in ESRD hospitalization over recent years. The modification in patient eligibility criteria has scaled back the magnitude of this trend; in particular, hospitalization rates in 1993 are seen to be only 4 percent above that for 1996. The new estimates are likely to be a more accurate reflection of the recent hospitalization trends in ESRD dialysis patients.

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## Chapter X. The Economic Cost of ESRD and Medicare Spending for Alternative Modalities of Treatment

This 1998 Annual Data Report (ADR) updates last year's analysis of the economic cost of End-Stage Renal Disease (ESRD) and Medicare spending for alternative treatment approaches. 1996 data are now included, as are Medicare inpatient "pass through" payments for costs such as medical education and capital investments. In addition to updating previously reported information, a detailed breakout of Part B physician/supplier spending by physician specialty and supplier type is reported for the first time.

Total ESRD spending by all payers in 1996 was estimated to be \$14.55 billion, up from \$13.06 billion in 1995. Medicare spending in 1996 was estimated to be \$10.96 billion, up from \$9.74 billion in 1995. Medicare spending per patient year at risk was estimated to be \$43,563 in 1996. This is a 4.5 percent increase compared to 1995 and represents the first time in several years that spending per patient year grew at a rate faster than both the general consumer price index and the medical component of the consumer price index. While the increase in the number of patients remains the driving force behind the overall growth in ESRD program expenditures, spending per patient also made a significant contribution to the overall spending increase. Increases in spending per patient year were found in all modalities. These increases may be due to a

variety of causes, such as changes in the actual care that is given to ESRD patients, changes in the types of patients who are being treated (older, more diabetic etc.), or changes in Medicare billing practices.

Medicare Part B spending totaled nearly \$10,000 per patient year at risk in 1996. The largest category was nephrology care, accounting for 22.6 percent of Part B spending. The primary care specialties accounted for 9.0 percent of Part B spending, but pediatric patients incurred primary care costs that were almost 3 times the population average. Other than nephrology and the primary care specialties, general surgery, radiology, cardiology, and anesthesiology were the most costly physician specialties. The growth of spending for vascular surgery and diagnostic and therapeutic radiology between 1992 and 1996 may reflect an increasing incidence of vascular access complications. Costs in the non-physician supplier categories were dominated by medical supply companies, laboratories, and ambulance services, which combined to account for 29.4 percent of Part B spending.

The reference tables (Section K) provides considerable detail on Medicare spending, including a major section on the distribution of spending by patient characteristic and type of provider. This latter set of statistics is designed to provide an indication of the financial risk facing a potential capitation plan. For example, the 99<sup>th</sup> percentile of Medicare spending per calendar year includes a cell with \$147,000 per patient.

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## Chapter XI. Annual Facility Survey of Providers of ESRD Therapy

The facility survey information remains fairly smooth. One additional year has been added in this report. The number of dialysis and transplant units increased by 37 percent over the last 5 years, with the greatest growth in NJ. There was substantial regional variation in changes in the number of patients treated over the last 5 years, with the greatest growth in NC, CO, and TX. PA had the least growth.

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## Chapter XII. International Comparisons of ESRD Therapy

The incidence rate of treated ESRD continues to grow worldwide. Data from most international registries demonstrate an increase in incidence rates through 1996 with the United States (incidence rate

of 276 per million population) leading other countries. Changes in acceptance and/or referral patterns, reduced cardiac mortality (competing risk) or an actual increase in the incidence of renal disease may be responsible for the observed trends.

There is a noticeable disparity in the prevalence of treated ESRD among international countries. Japan continues to have the greatest prevalence of treated ESRD with over 1,300 patients on renal replacement therapy while Romania records the lowest with only 57 on treatment per million population. The observation of a greater ESRD prevalence in Japan suggests better survival rates among Japanese as compared to US patients; however differences in acceptance patterns and comorbid conditions may in part be responsible for differences in mortality risk.

Hemodialysis remains the major dialytic modality in most countries. However there has been greater international acceptance of peritoneal dialysis over the last decade. In New Zealand this acceptance has made peritoneal dialysis the major type of dialytic therapy in 1996.

Although kidney transplantation remains the most successful form of renal replacement therapy for patients with ESRD, transplantation rates vary worldwide. Rates are highest in United States, Germany, and Poland. Lower rates are observed in Romania and Japan, which may be due to socioeconomic, cultural, and religious factors. It is encouraging that transplantation rates have increased in most countries over recent years.

Comparisons of ESRD programs among countries may be instructive despite differences in terms of treatment modalities, acceptance patterns, and patient demographics. International collaboration among registries with complete data or future prospective studies of representative samples of patients may serve to answer many unanswered questions from an international perspective.

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## Chapter XIII. Analytical Methods

Chapter XIII describes the technical details of analytical methods used in this ADR. It also points out areas in which data or methods have changed since the last ADR.

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## Errata to the USRDS 1997 Report

In the 1996 and 1997 ADRs an error was made in labeling physician/supplier dialysis payment categories as well as PD catheter payments affecting

Tables K-2, K-3, K-4 and K-7 in the Reference Tables. This error also affected corresponding values in Table X-1. The error led to overstating payment values for PD catheter and understating dialysis payments affecting also totals involving these categories. See Chapter X for details.

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## **Conclusion**

In summary, the USRDS 1998 Annual Data Report provides an ongoing and continuing status report on many dimensions of the incidence, prevalence, cost, treatment, and outcomes of ESRD in the United States. Incidence of ESRD continues to grow but growth may have slowed starting in 1993. (We will have to wait for future data to be sure of this news.) Mortality of dialysis patients remains high by any standard, although there are some continuing signs of improved survival. ESRD continues to be a disease that affects Blacks and Native Americans at a rate 3 to 5 times greater than the rate of White Americans. ESRD remains very expensive to treat both on a per patient basis and a program basis. The medical, social, and financial implications of this disease continue to make ESRD a major public health and public policy problem.

