

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 USRDS Special Study data are collected by or through the ESRD Networks.

The present USRDS 1999 Annual Data Report is the 11th 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 the eight USRDS special studies is provided in Chapter I, "The USRDS and Its Products."

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 as well as analyses 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 98 requests. Chapter I provides 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. In order to reduce the size of this report, certain tables, listed at the end of each section of the Table of Contents for the Reference Tables (beginning on page RT.iii), are available only through the USRDS World Wide Web (WWW) site or the USRDS 1999 Annual Data Report CD-ROM.

We have provided the complete version of the USRDS 1999 Annual Data Report (including all reference tables) at the USRDS WWW site (<http://www.med.umich.edu/usrds/>) and on CD-ROM. Please contact the USRDS CC for further information or if you would like to request a copy of the 1999 ADR on CD-ROM. Chapters on the USRDS Special studies from previous ADRs are also available in the Researcher's Guide on the WWW site.

Changes from Previous Reports and Continuing Notes of Importance

The USRDS has issued ten previous reports, the most recent of which was published in spring of 1998. The current report is based on an update of biomedical information from HCFA dated September 1998. The USRDS added nearly 80,000 new patients since the last update. In addition to the biomedical information, the Medicare billing data incorporated into the USRDS for 1989-97 for institutional claims,

consists of over 350 million paid Medicare claims. All of these claims records are currently on-line, occupying over 30 billion bytes of computer disk storage. Data records for almost 40,000 patients from the eight Special Studies are currently in the database as well.

The ESRD data in this report are current through 1997 for all patient-specific, biomedical, and Medicare payment data; through 1997 for ESRD providers; and into 1998 for the certain characteristics of patients incident in 1998 (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. 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."

Several innovations should be noted in this 1999 report:

Data Sources. Selected results from the HCFA ESRD Core Indicators study are included in Chapter III (Treatment Modalities) as a source of contemporary information about dialysis treatment practices in the United States. The Core Indicator data are based on a random sample of over 20,000 dialysis patients in the United States. Data from several other national registries are included in Chapter XII (International Comparisons). Chapter IV summarizes data from the revised Medical Evidence Form (HCFA-2728), in use since 1995, which offers much new information about the population of all incident ESRD patients (including non-Medicare patients) in the United States. The USRDS works with many data sources in order to provide a comprehensive resource for the renal community. Detailed tables based on the Medical Evidence Form are presented in Section L of the Reference Tables.

New Methodology for adjusting patient and graft survival. The USRDS database includes consistent data series that show how patient and graft survival has changed for patients starting ESRD therapy in successive years. Part of the differences in outcomes among years is due to changes in the types of patients being treated in different years. Adjusted statistics are computed in order to show what the yearly statistics would have been, had the patients in all years shared the same age, race, sex, and diabetes characteristics. The methodology for computing these standardized statistics was changed this year. This affects the results in Reference Tables E (patient survival) and G (graft survival). The old methodology used direct adjustment, while the new methodology uses proportional hazards (Cox) regression models for the adjustment calculations. This is discussed in more detail in Chapter 13.

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.

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.

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.

Two significant changes were made to the Annual Data Report this year. A new section (L) was added to the Reference Tables to present tabulations from the Medical Evidence Form (HCFA-2728). Chapter IV discusses the characteristics of new ESRD patients based on data from the 1995 revision of the Medical Evidence Form. In addition, the patient and graft survival tables in Section E and G of the Reference Tables are now adjusted using Cox proportional hazard models.

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

Summary Statistics on Reported ESRD Therapy in the U.S., 1997 ^a									
Patient Characteristic	ESRD Incidence		December 31 ESRD Point Prevalence				Medicare Kidney Tx Performed by Donor Type ^e		ESRD Deaths ^f
	Count ^b	Adjusted Rate ^c	Count ^b	Adjusted Rate ^c	Counts By Modality ^d		CAD	LRD	
					Dialysis	Tx			
Age^g									
0-19	1,069	13	5,480	66	1,768	3,771	343	398	97
20-44	11,800	109	76,018	708	39,398	37,484	3,674	1,790	4,438
45-64	26,253	545	117,865	2,360	81,904	37,875	3,968	1,261	16,187
65-74	22,056	1,296	63,197	3,840	57,316	6,616	537	129	18,267
75 plus	17,924	1,292	41,523	3,027	41,210	625	29	*	18,796
Race									
White	51,171	218	186,341	803	123,269	65,463	5,709	2,790	38,689
Black	22,926	873	97,503	3,579	82,624	15,282	2,240	542	15,944
Asian/Pacific Islander	2,383	344	10,795	1,369	7,885	3,191	398	107	1,595
Native American	928	586	4,614	2,773	3,663	957	89	47	788
Other	1,558		3,941		4,155	1,478	91	88	698
Unknown	136		889		w/other	w/other	24	10	79
Sex									
Male	42,129	348	165,176	1,314	115,902	51,576	5,166	2,082	30,202
Female	36,973	242	138,907	931	105,694	34,795	3,382	1,502	27,591
Primary Disease									
Diabetes	33,096	120	100,892	366	84,076	18,350			23,881
Hypertension	20,066	73	72,961	266	61,673	11,971			16,572
Glomerulonephritis	7,390	27	52,229	190	29,433	23,661			5,158
Cystic Kidney Disease	1,772	6	13,992	51	6,985	7,157			1,172
Urologic Diseases	1,388	5	6,093	22	4,182	2,007			893
Other Known Cause	8,284	30	33,919	124	21,639	12,581			6,008
Unknown Cause	2,920	11	14,103	51	8,938	5,340			2,473
Missing Data	4,186	15	9,894	33	4,670	5,304			1,636
Total	79,102	289	304,083	1,113	221,596	86,371	8,551	3,584	57,793
Unadjusted Rate^h		287		1,105		Total Txⁱ :	12,445		

Total Spending for ESRD in 1997: All sources: \$15.64 Billion Medicare: \$11.76 Billion Non-Medicare \$3.88 Billion
 Change in Medicare Spending 1997 vs. 1996: Total +5.5%; Per patient year -0.4%; Adj. for Inflation -3.2 to -2.1%
 Medicare \$/patient year 1993-97 (in \$1,000s): ESRD \$43; HD \$52; PD \$45; Tx \$18^j

^a USRDS Patient Database Updated from HCFA PMMIS September 1998, 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.

^b Incidence = new patients starting ESRD therapy during 1997. 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.

^c Rates were adjusted for age, race, and/or sex using the July 1, 1996 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.

^d 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.

^e Kidney Tx Performed = number of transplants performed during 1997.

^f Deaths = number of ESRD patient deaths during 1997.

^g 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.

^h Unadjusted total rates include all ESRD patients in the 50 states and the District of Columbia.

ⁱ Source: 1997 HCFA Facility Survey.

^j Excludes cost of organ procurement.

Sources: Reference Tables A.1, A.6, B.1, B.8, C.2, C.3, D.1, F.2, I.15, K.1, K.5, K.7, US Dept of Labor, Special Analysis

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Table ES-1

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 1998 USRDS ADR were distributed, starting at the ASN meetings in early October 1998. 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 1999 ADR.

Usage of the USRDS Standard Analysis Files continued to grow. In 1998, 145 CDs were supplied to 24 researchers. In the first 3 months of 1999, 183 CDs were supplied to 12 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.

The USRDS has produced a fourth round of facility-specific mortality and hospitalization reports, which will be distributed to dialysis units through the ESRD Networks.

Shorter requests for data were filled in large numbers. During 1998, approximately 3.5 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 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 2,000 times each month, and more than 1 billion bytes of data are downloaded from the site each month.

Chapter II. Incidence and Prevalence of ESRD

This ADR reports incidence and prevalence statistics for ESRD through 1997, which are not yet completely reported. Recent experience has shown that the reported 1997 incidence counts are likely to increase by approximately 4 percent in the year 2000 ADR. Based on the current data, 304,083 patients were being treated for ESRD as of the end of 1997 and 79,102 new patients started ESRD treatment in 1997. Currently, the 1997 incidence rate is estimated at 287 per million and the prevalence rate at 1,105 per million. The era of sustained annual growth rates of 9 percent seen in incidence rates prior to 1992 appears to be over. After adjusting for the expected lag in reporting new ESRD cases, the estimated rate of growth of new ESRD is 6 percent per year for 1992-97. While the incidence counts and rates have grown each year during the last decade, the rate of growth is smaller in the most recent 5 years than it was in the previous 5 years. There is some uncertainty in the interpretation of these estimates in part because the reporting of non-Medicare patients has been included in the database in recent years.

The rate of ESRD incidence varies dramatically among different age, race, and sex population subgroups. Incidence and prevalence rates tended to increase with age and then fall off for the oldest age group. The largest 5 year age group of patients falls in the 70-74-year age range among incident patients and in the 65-69 age range for prevalent patients. The treatment of ESRD is more common in men than women. The Black and Native American race populations continue to have much higher rates of ESRD than do the White and Asian race populations. Black patients constituted 32 percent of treated ESRD patients. 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. Diabetes is an especially common cause of ESRD in the Native American population.

Chapter III. Treatment Modalities for ESRD Patients

Growth has persisted in the number of patients being treated by both hemodialysis and by functioning transplants. However, 1996 and 1997 showed a leveling off and perhaps a small decrease in

the total number of patients being treated by peritoneal dialysis. Therefore, while remaining the third most common treatment modality, the proportion of ESRD patients managed on peritoneal dialysis had declined to approximately 8.7 percent of all prevalent ESRD patients, as of year-end 1997. Within the peritoneal dialysis population, the use of CAPD has continued to decline in favor of a continued sharp increase in the utilization of CCPD. The number of patients wait-listed for transplantation continues to expand disproportionately to the number of cadaveric transplants being performed annually, which has increased only slightly. While larger percentage increases have occurred in recent years in living unrelated and living related transplantation, these changes have not been sufficient to keep pace with a steadily growing demand. More organs are needed for transplantation.

The utilization of and/or access to the different treatment modalities continue to vary a great deal by census region and by patient characteristics, such as 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 and Asian patients than among older patients and other race groups. Over the decade from 1986-1996 hemodialysis dose steadily increased in both incident and prevalent patients treated by this modality. Delivered peritoneal dialysis doses also progressively increased over the years 1995 to 1998. A clear trend emerged from 1990 to 1997, showing increasing utilization of synthetic dialyzers (both high-flux and low-flux) in preference to the more traditional unmodified cellulosic membranes. However substantial variations are described for membrane utilization across census regions. Further, multiple data sources indicate a consistent trend in the increase of average hematocrit levels over time. These national trends and regional differences in both the overall distribution of treatment modality utilization and in dialytic prescriptions demand further comparative observational studies between treatment modalities to guide decision making within the renal community.

Chapter IV. Patient Characteristics at the start of ESRD: Data from the HCFA Medical Evidence Form

This new chapter of the annual data report describes the data collected on the revised Medical

Evidence Report Form, first introduced in 1995, which records detailed information on all new ESRD patients in the United States. It focuses on the distribution of characteristics of new ESRD patients in the time period 1995-1998. As such it provides a 'snapshot' of the health status of these incident patients by year of incidence and permits observation of trends in patients characteristics over these years.

As shown in Chapter III, dialysis remains the primary form of initial treatment among U.S. ESRD patients. For the period 1995-1997, almost 85 percent of patients are reported as using hemodialysis as their initial treatment modality, whereas CAPD, CCPD, and IPD together accounted for only 12 percent of new patients. Pre-emptive transplantation (without prior dialysis therapy) was available for 3.7 percent of new ESRD patients during this time period.

The demographic characteristics of the U.S. ESRD population as reported on the Medical Evidence Form are in agreement with other published USRDS reports, which were based on Special Studies of random samples of patients. In 1997, the mean age for new ESRD patients was 61 years, 53 percent were male, and 44 percent reported diabetes as a primary cause of ESRD. Over sixty-three percent of the incident ESRD population was White, 29 percent were Black, and Asian/Pacific Islander and Alaskan Native/Native American subgroups combined accounted for only 4 percent of the incident ESRD population. The Medical Evidence Form captures more detailed racial characterization of the ESRD population and allows for specific reporting of the proportion of ESRD patients that are of Pacific Islander, Middle East, and Indian Subcontinent race as well as Hispanic ethnicity.

The Medical Evidence Form allows for the reporting of 20 comorbid medical conditions among new ESRD patients. The most common comorbidities reported in 1997 were cardiovascular in nature, with congestive heart failure reported for 35 percent and coronary artery disease reported for 25 percent of the incident dialysis population. Ischemic heart disease was most prevalent among White dialysis patients with 31 percent of them having a history of ischemic heart disease and 12 percent with myocardial infarction. Non cardiovascular comorbidity was also prevalent; 7 percent of patients reportedly had a history of COPD, 5 percent a history of cancer and 5 percent were reported as being unable to ambulate. Analyses of laboratory data, height and weight, suggest there may be a trend towards earlier dialysis initiation. Pre-

dialysis erythropoietin use and employment status among new dialysis patients are also reported.

The data on comorbidity reported on the HCFA Medical Evidence Form were compared with data from the medical record abstraction in the USRDS, Dialysis Morbidity and Mortality Study Wave 2. In general, the prevalence of reported comorbid conditions was substantially lower for the HCFA Medical Evidence Form. The chapter includes a discussion related to these discrepancies and suggests that there are facilities wherein the section on comorbid conditions on the Medical Evidence Form is simply not completed. The chapter includes an appeal for improved reporting of comorbid conditions by ESRD providers, in order to recognize the full benefit of this data source for quality improvement activities and epidemiologic research of ESRD outcomes.

Chapter V. Patient Mortality and Survival

There has been a progressive improvement in first-year survival among dialysis patients for each successive year's incident cohort since 1985. This improvement is sustained in the 1996 cohort, and is consistent across many subgroups by age, race, sex, and diagnosis. The declines are more pronounced among diabetic, White, and male patients than among nondiabetic, Black, and female patients, respectively. Declining death rates for all prevalent patients between 1989 and 1997 reflect this trend. There have been many changes in dialysis therapy during the last ten years that could be associated with this drop in mortality. For example, as shown in Chapter III, data from both USRDS special studies and the HCFA ESRD Core Indicators data indicate that the average doses of both hemodialysis and of peritoneal dialysis have increased during this period.

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 ESRD therapy. Although second year death rates decreased by 33 percent between 1986 and 1996 (and by 22 percent between 1986 and 1992), the third through fifth year death rates for the period 1986-1992 only decreased by 10 percent. Furthermore, the expected lifetimes of dialysis ESRD patients are between 16 and 38 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.

Chapter VI. Causes of Death

Over 160,000 ESRD patients died during 1995-1997. This chapter focuses on the specific causes of their high mortality and may serve as a source to help decrease the death rates of ESRD patients through further in-depth epidemiological and clinical research. The cause specific death rates for various subgroups of prevalent dialysis and transplant patients are described. The reasons for withdrawal from dialysis therapy prior to death are also analyzed.

In past years, the USRDS files included a "missing" cause of death category for those patients who, by means of the Social Security Death Benefits files and hospital discharge records, are known to have died but for whom no Death Notification Form was received. Because of changes in REBUS, we are no longer able to distinguish between deaths where the physician indicated that the cause of death is unknown and cases where there is no Death Notification Form for the patient (i.e. unknown cause vs. missing form). Prior analyses of these separate data items for 1994-1996 (1998 Annual Data Report) revealed that the Death Notification Form was "missing/ incomplete" versus "cause unknown" in about 14 versus 6 percent of total reported ESRD deaths, 12 versus 6 percent of dialysis deaths, and 51 versus 4 percent of transplant deaths.

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 only slightly more common for males than for females and markedly more common in Whites than in 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.

In contrast to dialysis patients, cardiac causes accounted for a smaller proportion of deaths for transplanted patients with approximately 16 to 36 percent of all deaths for each age group. 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 1 out of 5 dialysis patients withdrew from dialysis before death. Rates for death preceded by withdrawal were two to three fold higher in Whites compared to Blacks for all adult age categories. Blacks and Whites have similar proportions of reasons for withdrawal in the 20-44 group. In the older age groups, however, Blacks have higher proportions of withdrawal due to medical complications and lower proportions of withdrawal due to failure to thrive than do Whites. Females withdrew at a slightly higher rate than males and the excess tended to be related to higher rates of withdrawal due to medical complications.

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 non-Medicare patients, collectively the data sources cover 98 percent of all adult and pediatric kidney transplants performed in the United States.

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 (10.6 percent) of living donor transplants and of CAD renal transplants (3.9 percent), although the rate of CAD and living donor (LD) transplantation was 2 and 3.5 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 1.5 and 4.4/100 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 2.5 times as many LD organs than the small pediatric group and almost two times more CAD organs than the two younger age groups combined (ages 0-34 years). The five-year trend in primary CAD transplantation rates shows the rates for all age groups are diminishing over time. In contrast, the rates in repeat CAD transplantation have only changed slightly over the same time period.

Short- and long-term patient and allograft survival has improved steadily in the last decade. Prior racial differences between Blacks and Whites in one-year patient and graft survival have disappeared. Rates of

primary CAD and LD graft loss have declined by more than 50 percent during this period. Five-year LD graft survival improved from 69.0 percent in the 1986-87 cohort to 75.2 percent for transplants performed in 1992. Among CAD recipients, five-year graft survival also increased from 51.3 percent in 1986-87 to 59.8 percent in 1990-91. Because these increases have been observed during the post-cyclosporin years, it is most likely the result of multiple factors including, but not limited to, the availability of newer immunosuppressive and anti-rejection drugs.

The number of cadaver kidneys transplanted annually ranged from 8,526 in 1996 to 8,523 in 1997. This represents virtually no change. In 1997 there were 12,445 renal transplants performed in the United States. Among these 3,217 (25.8 percent) were from living relatives and 705 (5.7 percent) from spousal and other biologically unrelated donors. During 1993-97, kidney donation from biologically unrelated donors increased annually by 37.5 percent, whereas living-related kidney donation increased annually by 5.1 percent, and cadaveric donation showed a minimal increase of 1.2 percent per year. The growth of kidney donation among biologically related and unrelated donors is promising, yet the lack of growth in cadaveric donation remains discouraging.

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 1995-97 were more than twice as high among children 15-19 years (28 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 (7 per million).

Children with ESRD continue to have high transplantation rates. A little over 44 percent of children starting ESRD therapy during the 1993-97 period received a transplant during the first year of renal therapy, compared to 10 percent of patients 20-64 years of age at ESRD incidence. Only 31 percent of children 0-9 years and 29 percent of children 10-19 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 than are 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 patient age group. Evaluation of hospitalization rates as the first admission rate per 100 patient-years at risk in 1997 revealed that there were more hospital admissions for younger children and for patients receiving hemodialysis than peritoneal dialysis.

The overall death rate was approximately 19 per 1,000 patient years for all pediatric ages which is substantially higher than for young adult patients, ages 20-44 (57 per 1,000 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 known cause of death in children (21 percent), followed by cardiac arrest (16 percent). Cardiac arrest and other cardiac deaths combined accounted for almost 25 percent of patient deaths. Note that hyperkalemia (4 percent) is listed separately and not as a cardiac cause of death.

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 were adopted last year that tie in directly to available cost data and largely resolved 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 1997. 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 that employs "first hospital admission" rates in a given

time period as a way to compare the hospitalization experienced by patients at local levels (e.g., statewide) to national trends. As in the 1998 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 (12 percent between 1993 and 1997), 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 similar comparisons to those found in the 1998 ADR. Specifically, SHR's are 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 reports over the last two years, 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 that reflect mortality and hospitalization experience below national levels. Finally, it was reported in 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 and 1996 are seen to be only 5 and 3 percent, respectively, above that for 1997. The new estimates are likely to be a more accurate reflection of the recent hospitalization trends in ESRD dialysis patients.

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

This 1999 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 1997 data are now

included. In addition, this report updates calculations of Medicare spending per patient year at risk by renal replacement modality and other patient characteristics as well as the detailed breakout of Part B physician/supplier spending by physician specialty and supplier type first reported last year. New in this year's report is information on interstate spending on ESRD care per patient year at risk.

Total ESRD spending by all payers in 1997 was estimated to be \$15.64 billion, up from \$14.55 billion in 1996. Medicare spending in 1997 was estimated to be \$11.76 billion, up from \$10.96 billion in 1996. Medicare spending per patient year at risk was estimated to be \$44,764 in 1997. This represents a 1.3 percent increase compared to 1996, following cost growth of 4.9 percent in 1994-95 and 5.4 percent in 1995-96 (revised estimates). Thus, the increase in the number of patients remains the driving force behind the overall growth in ESRD program expenditures. Changes in Medicare expenditures per patient year can arise from 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 prices paid by Medicare for specific services, and changes in Medicare billing practices.

Medicare Part B spending totaled just over \$10,000 per patient year at risk in 1997. The largest category was nephrology care, accounting for 21.5 percent of Part B spending. The primary care specialties accounted for 8.9 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 above average growth of spending for vascular surgery and diagnostic and therapeutic radiology between 1993 and 1997 may reflect an increasing incidence of vascular access complications. Some of the highest growth rates were observed among the specialties of hematology/oncology, infectious disease, therapeutic services, and podiatry. Costs in the non-physician supplier categories were dominated by medical supply companies, laboratories, and ambulance services, which combined to account for 30.2 percent of Part B spending.

Interstate variation in Medicare expenditures (per patient year at risk) was substantial. Spending varied almost twofold from a low of \$27,594 in North Dakota to \$52,308 in the District of Columbia. The mean (per patient year at risk) expenditure across

states (not weighted by the states' ESRD populations) was \$40,380 (median \$40,237) with a standard deviation of \$5847. Many of the highest spending states were concentrated in the New England and Middle Atlantic regions. Other high expenditure states included Florida, Louisiana, Texas, and California. With the exception of Oregon, the lowest spending states were found exclusively in the Mountain and West North Central regions.

Several factors contribute to this variation in spending, including differences in prices paid by Medicare for various services, case mix, distribution of patients across modalities, and regional practice patterns with respect to the types and intensities of services provided. Data for individual states were examined to provide insights into the relative importance of these several sources of variation.

Chapter XI. Annual Facility Survey of Providers of ESRD Therapy

The growth in the number of dialysis facilities continued at a linear pace with more than 200 new facilities added to the total number of dialysis facilities. The number of transplant facilities remained stable. Growth in the number of dialysis facilities is not correlated within networks with growth in number of patients in the networks. The 6 networks with the largest growth in number of facilities all had a patient growth rate less than the national average. The network with the second lowest growth in facilities had the fourth highest growth in patients.

Chapter XII. International Comparisons of ESRD Therapy

The incidence rate of treated ESRD continues to grow worldwide. Data from most national registries demonstrate an increase in incidence rates through 1997 with the United States (incidence rate of 296 per million population) leading other countries. The increase in the incidence of treated ESRD was particularly great in some countries, which may indicate improved health resources and greater acceptance of new ESRD patients. 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 these observed trends.

There is a noticeable disparity in the prevalence of treated ESRD between countries. Japan continues to record the greatest prevalence of treated ESRD per

million population with 1,397 on renal replacement therapy compared to 1,131 in the United States. The observation of a greater ESRD prevalence in Japan suggests better survival rates among Japanese as compared to U.S. patients; however differences in acceptance patterns and comorbid conditions need to be also considered.

Hemodialysis remains the major dialytic modality in most countries. In New Zealand and Australia, a relatively high number of patients utilize home hemodialysis compared to the other countries that report utilizing this mode of therapy. There is also much geographic variation in the international use of peritoneal dialysis. In Hong Kong and New Zealand, this use continues to make peritoneal dialysis the major type of dialytic therapy in 1996 and 1997. Most other countries utilize peritoneal dialysis to a lesser extent.

Although kidney transplantation remains the most successful form of renal replacement therapy for patients with ESRD, transplantation rates vary to a large degree worldwide. Rates are highest in Spain, United States, and New Zealand. Lower rates are observed in Brazil, Uruguay 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, using standardized data collection instruments, or future prospective studies of representative samples of patients, may serve to answer many unanswered questions from an international perspective.

Chapter XIII. Analytical Methods

Chapter XIII serves a number of functions. First, it points out the principal changes in the ADR for readers who get the ADR every year. Second, it provides a summary of where the data come from for readers who want more than the very brief summary in Chapter I. Third, it is the primary reference for all technical aspects of the ADR methodologies. This year it includes a detailed discussion of the new methodology for computing adjusted survival rates. Finally, it discusses many characteristics and limitations of the data for those readers who need those details. This year additional figures and discussion were added about how we determine that these patients have ESRD and about how we classify

patients as lost-to-followup. For data issues, Chapter XIII is supplemented by the *Researcher's Guide to the USRDS Database*.

Errata to the USRDS 1998 Report

Extensive examination of the cost tables in Section K of the Reference Tables uncovered a number of errors in the classification of Medicare physician/supplier claims. The effect of these errors were minimal except for one. A significant portion of the physician/supplier claims for physicians performing transplants was not included in the transplant rows of tables K.2, K.3, and K.7. These changes are discussed in more detail in Chapters X and XIII.

Updates

Updates and corrections to the current data report will be posted on the Internet at the USRDS World Wide Web site at <http://www.med.umich.edu/usrds>, which will have the most accurate and up-to-date information available.

Conclusion

In summary, the USRDS 1999 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. Mortality of dialysis patients remains high, 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.