Chapter II

Incidence and Prevalence of ESRD

Key Words:
ESRD incidence
ESRD prevalence
Dialysis patient counts
HCFA data
ESRD growth rates
Diabetic ESRD
ESRD Medical Evidence Form 2728
ESRD Medicare
Cause of ESRD
Race
Gender

This chapter contains basic information about the number of individuals with treated ESRD. In particular, the chapter addresses the total number of treated ESRD patients (prevalence), the number of new treated ESRD patients (incidence), and time-trends for these attributes. Prevalence data are of particular interest for understanding the medical and social resources needed to care for ESRD patients. Incidence data are important for understanding the epidemiology of kidney disease. Growth trends are relevant to both resource management and epidemiologic research. The chapter begins with a description of the ESRD registration process and the epidemiologic tools and concepts used to construct the incidence and prevalence data. We then address incidence, prevalence, and growth for the entire population and for selected subgroups.

Medical Coverage for ESRD

The majority of ESRD patients are covered by the Medicare program, which is also the source of most USRDS registry data. Medicare provides health insurance for individuals who have reached the age of 65 years, individuals with certain disabilities, and individuals with ESRD. The ESRD entitlement was added to the Medicare program in 1972 and implemented in 1973. ESRD entitlement is based on age and the number of fiscal quarters of Social Security contributions as determined by the Social Security Administration.

Medicare is composed of two programs, the Hospital Insurance Fund and the Supplemental Medical Insurance Fund. The Hospital Insurance Fund (HI or Part A) covers the cost of hospitalization through a trust fund that has accrued from employee and employer payroll deductions. The Supplemental Medical Insurance Fund (SMI or Medicare Part B) covers physician and outpatient services, including dialysis. SMI benefits are funded by governmental general funds and a monthly premium paid by beneficiaries ($42.50 in 1996). SMI benefits pay providers 80 percent of reasonable charges as determined by a fee schedule based on relative value scale (RVS) methodology. Most patients purchase a supplemental policy to cover the remaining 20 percent. Patients who are unable to afford a supplemental insurance policy may be eligible for Medicaid, which covers the portion of ESRD treatment not covered by Medicare. Under current law, if a patient is already covered by an employer-provided group health insurance plan at the time of ESRD, then that plan is obligated to provide primary insurance coverage for 18 to 24 months following Medicare eligibility. During this period of "coordination," Medicare serves as the secondary insurer for eligible charges not covered by the primary plan. Medicare becomes the primary insurer after 18 to 24 months. Increasingly, Medicare patients may receive coverage through an HMO or other managed care plan that provides a listed set of medical services for a prepaid fixed payment. With this option, individual Medicare

payment records may not be generated for each provided service. Due to varying insurance arrangements, HCFA records offer a potentially incomplete representation of the entire ESRD population to the extent that services are paid for by private insurance, Medicaid, Medicare "at-risk" HMOs, other insurance programs (e.g., VA) and provider charity. While some HCFA records attempt to track non-Medicare ESRD patients, year-to-year variability in this endeavor could lead to misleading interpretations of ESRD trends. These lapses are potentially relevant to determining ESRD incidence and prevalence (as well as other attributes of ESRD patients). The USRDS uses several sources of data to measure the incidence and prevalence of ESRD including the HCFA ESRD database (PMMIS), the Medical Evidence Form 2728, HCFA payment records, the ESRD Network Census, the UNOS Transplant database, the Annual ESRD Facility Survey, the ESRD Death Notification Form, and the Medicare Eligibility File. Chapter XIII provides a detailed description of these data sources and the conventions adopted by the USRDS.

Measuring Incidence and Prevalence of ESRD

ESRD is defined by treatment with any form of chronic dialysis or renal transplantation. Patients who die of renal failure without first receiving dialysis or a transplant are not considered ESRD patients. Dialysis for acute renal failure is not considered ESRD unless the renal function fails to recover. As a practical matter, the degree of renal failure or the reason for initiation of dialysis does not impact the ESRD classification.

A patient is considered incident at the time of first regular dialysis for chronic renal failure or transplantation. Center dialysis patients who were not receiving Medicare benefits at the start of dialysis must wait 60 to 90 days for Medicare eligibility to begin. For purposes of incidence and prevalence, the true ESRD start date is used.

A patient is considered prevalent if he/she is known to be receiving dialysis treatment or to have a working kidney transplant (regardless of when the transplant was performed). Point prevalence refers to the number (or population normalized fraction) of ESRD patients at a particular point in time (e.g., on 12/31/95). Period prevalence refers to the number of patients with ESRD (as defined above) during an interval of time, usually a year. Period prevalence is somewhat higher than point prevalence due to deaths during the period. Most prevalence statistics reported by the USRDS refer to a point prevalence. Prevalence is a direct function of incidence and survival. Prevalence rates are 3 to 4 times higher than incidence rates because the average survival time is 3 to 4 years. Changes in prevalence are attributable to changes in either incidence, average survival time, or both.

Patients who return to dialysis after a failed transplant are not counted as incident ESRD patients; this situation is technically viewed as a modality change. Similarly, patients who stop chronic dialysis and then restart are counted as prevalent, not incident patients. Patients are maintained in the ESRD database until death. Patients who lack any evidence of payment activity in the Medicare database for 1 year are classified as lost-to-followup and are no longer counted as prevalent since they may have recovered renal function. If such a patient reappears in the Medicare payment records, they are again counted as prevalent. It is important to note the dynamic quality of the USRDS registry as the status of some patients becomes clarified over time. This is why a prevalent or incident count for a prior period may change at a later date.

Incidence and prevalence are expressed in terms of absolute counts as well as rates (i.e., number per million population). Technically, incidence is expressed as a rate (number/million population/year) while prevalence is expressed as a proportion (number/million population). For simplicity, we will refer to both incidence and prevalence as rates.

The incidence and prevalence rates are adjusted to a reference population using the direct method (described in Chapter XIII). Use of an adjusted rate accounts for growth and aging of the general population and permits meaningful comparisons across years. In other words, the adjusted rate assumes a constant reference population. The reference population for the 1997 ADR, which covers detailed data through 1995, comes from the U.S. Census estimates for 1995. The adjusted rates change slightly with each ADR because the reference population is updated (in addition to the yearly count update described above). When rates are given for specific subgroups (e.g., by age, sex, or race), they are adjusted for remaining characteristics. Growth trends over time should be evaluated on the basis of adjusted rates. Trends in counts reflect growth and aging of the general population as well as ESRD trends.

Interpreting ESRD Incidence, Prevalence, and Growth Data

Although HCFA and the USRDS expend considerable effort to compile accurate and usable information about the incidence and prevalence of ESRD, the process is subject to both potential undercounting and overcounting. Moreover, this variation is not necessarily consistent from year-to-year, complicating the analysis and interpretation of trends. Some major issues in identifying ESRD incidence and prevalence are as follows:

- Undercount of 1993 and compensatory growth in 1994. As described in the 1996 ADR, the count of new ESRD patients for 1993 was lower than expected based on prior trends and the Annual Facility Survey. The 1993 undercount has persisted even with the usual updating done by the USRDS and HCFA. There appears to be a compensatory overcount of new patients for 1994. Presumably the 1994 overcount is composed of patients who were truly incident in 1993. These anomalies have not yet been fully explained.
- Increased registration of non-Medicare Patients. Approximately 8 percent of prevalent ESRD patients are treated without Medicare coverage, based on data from the Annual Facility Survey. Medical Evidence Forms received by HCFA for non-Medicare-eligible patients were separately registered until 1994 when such patients were included in the general ESRD database. Furthermore, with adoption of the new Medical Evidence Form in 1995, providers were asked to complete a form on all ESRD patients. As a result, database counts for 1994 and 1995 may be inflated from inclusion of larger-than-usual numbers of non-Medicare patients. The USRDS is working on methods to adjust for year-to-year changes in the number of non-Medicare registrants.

Treated Medicare ESRD Point Prevalence and Incidence Counts and Rates[1]
By Age, Sex, Race, and Primary Diagnosis, 1995

	Prevalence on 12/31/95			Incidence during 1995		
Characteristic[2]	Count (n)	Percent of Total	Rate per Million[3]	Count (n)	Percent of Total	Rate per Million[3]
Age 0-19	4,658	1.8	60	1,087	1.6	13
Age 20-44	68,327	26.6	648	11,666	16.9	109
Age 45-64	97,670	38.0	2,120	23,225	33.7	508
Age 65-74	54,163	21.1	3,273	19,217	27.9	1097
Age 75+	32,448	12.6	2,587	13,675	19.9	1035
Female	118,356	46.0	818	32,788	47.6	216
Male	138,910	54.0	1,148	36,082	52.4	301
Asian/Pacific Islander	8,303	3.2	1,248	2,224	3.2	375
Black	82,105	31.9	3,186	20,332	29.5	800
Native American	3,807	1.5	2,449	1,108	1.6	744
White	160,587	62.4	704	42,650	61.9	185
Other/Unknown	2,464	1.0	n.a.	2,556	3.7	n.a.
Diabetes	80,667	31.4	303	27,851	40.4	104
Hypertension	63,891	24.8	241	17,895	26.0	67
Glomerulonephritis	46,935	18.2	176	7,366	10.7	27
Cystic Kidney	12,635	4.9	48	1,797	2.6	7
Total	257,266	100.0	967	68,870	100.0	253

[1]Rates are adjusted for age, sex and race. Rates are computed relative to the corresponding population for age, sex, and race results.
[2]Patients with other or unknown race are excluded from rate analyses. Other urologic, other, unknown and missing cause of ESRD are included in the total but are not shown.
[3]Counts and rates do not include patients from Puerto Rico or U.S. Territories.
Source: B.1 and A.1 for the counts and B.8 and A.6 for the rates.

USRDS 1997

Table II- 1

Reported Medicare ESRD Period and Point Prevalence, Incidence, Death and Lost-to-Followup Counts, 1986-95

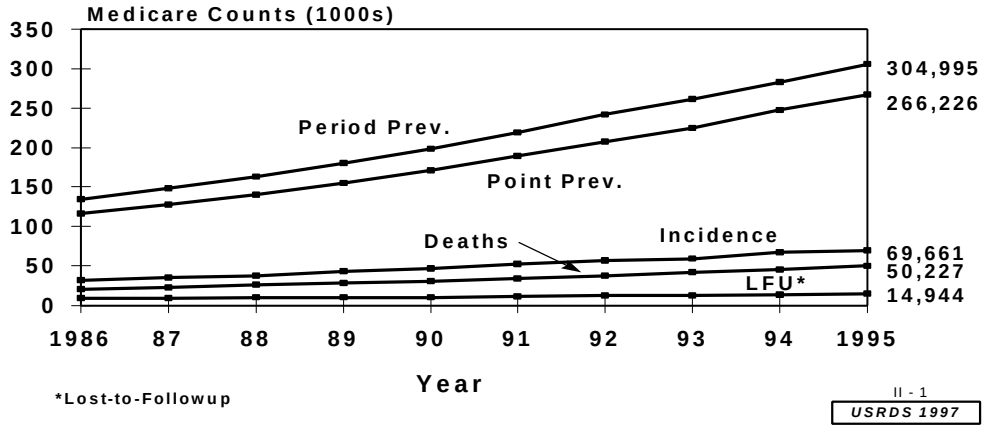

Figure II - 1

Reported ESRD period prevalence counts (patients alive at any time during the year), point prevalence counts (patients alive on 12/31 of the year), incidence counts, patient deaths, and patients lost to followup (see Chapter XIII for details). Point prevalence counts exclude patients lost to followup (LFU). Patients in Puerto Rico and U.S. Territories are included in all estimates. Medicare patients only. Source: Reference Tables B.1, B.3, A.1,A.2, D.1.

- Multiple sources of data on individual patients. The USRDS learns about potential ESRD patients through many sources including the Medical Evidence Form (PMMIS database), HCFA payment records, the ESRD Network Census, the UNOS Transplant database, the Annual ESRD Facility Survey, the ESRD Death Notification Form, and the Medicare Eligibility File. The level of confidence with which an individual can be considered a true ESRD patient depends on the number and source of these listings. Patients who are found in the HCFA payment records, PMMIS database, and Network Census report can confidently be classified as having ESRD. However, the evidence for other types of patients can be considerable weaker. Chapter XIII further discusses the sources of information about ESRD status. It is important to realize that ESRD counts can vary depending on the selected definition of ESRD based on the available records.
- Early reporting of 1995 data. This year, the 1997 ADR reports detailed data through 1995, whereas all previous ADRs had one additional year reporting lag (i.e., the 1996 ADR reported detailed data through 1993). This was achieved by performing an earlier and faster update of the database. However, patients reported late are continuously added to the HCFA database so earlier updating is expected to result in some degree of undercounting that is likely to be corrected in subsequent USRDS reports.

Overall Incidence and Prevalence

The ESRD point prevalence (on 12/31) and incidence counts and rates for 1995 are shown in Table II-1. During the year, 68,870 patients developed ESRD and, at the end of the year, 257,266 ESRD patients were alive in the continental United States. Distinct patterns in terms of age, sex, race and diagnosis are illustrated in Table II-1 and discussed further below.

Figure II-1 shows the time trends for period prevalence, point prevalence, incidence, death, and lost-to-followup (LFU) counts (this figure includes Puerto Rico and U.S. Territories). Incidence and prevalence have grown each year, including 1994 and 1995, the new years covered in this ADR.

Figure II-2 shows prevalence counts by Medicare eligibility. The Medicare dialysis counts obtained from HCFA (USRDS database) and the Facility Survey (described above and in Chapter XIII) are reasonably close. The count of Medicare patients with functioning transplants is derived from the HCFA database. The count of non-Medicare

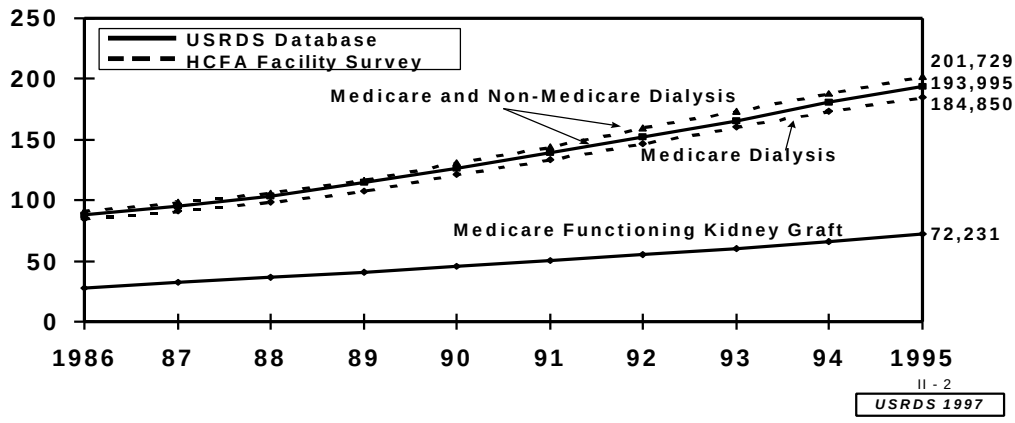

Figure II - 2

Reported point prevalent counts on December 31 of each year from 1986-95 for: Medicare and Non-Medicare dialysis patients, including patients whose Medicare eligibility is current or pending (from HCFA Annual Facility Survey, AFS, and the USRDS database (DB)); Medicare patients with a functioning kidney transplant (from USRDS DB); and dialysis patients not insured by Medicare (from AFS). Counts of Medicare dialysis patients from the USRDS DB do not include patients lost to followup. All prevalence counts include patients in Puerto Rico and U.S. Territories. Source: Reference Tables C.2, I.10.

dialysis patients is from the Facility Survey. Approximately 8.4 percent of dialysis patients are not covered by Medicare, as designated on the Facility Survey.

The uncertainty and instability in the ESRD counts over the past 3 years (as described in the previous section) necessarily mean there is uncertainty about growth rates. Nonetheless, provisional estimates are shown in Figure II-3

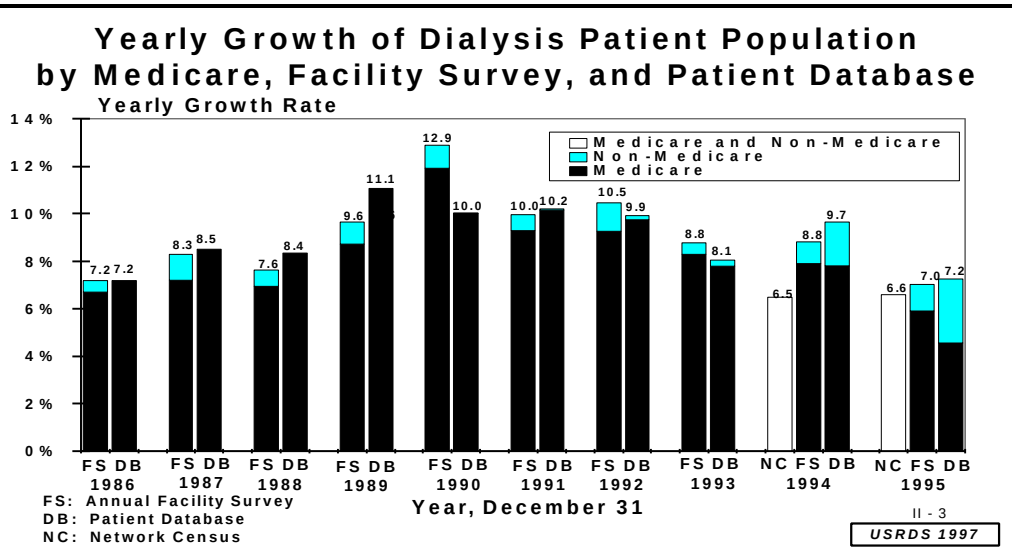

Figure II- 3

Yearly growth in point prevalence from December 31 of the previous year, 1986-1995, for dialysis patients by Medicare status. Data are from the Annual Facility Survey and Patient Database and for 1994-95, the Network Census. Source: Special Analysis.

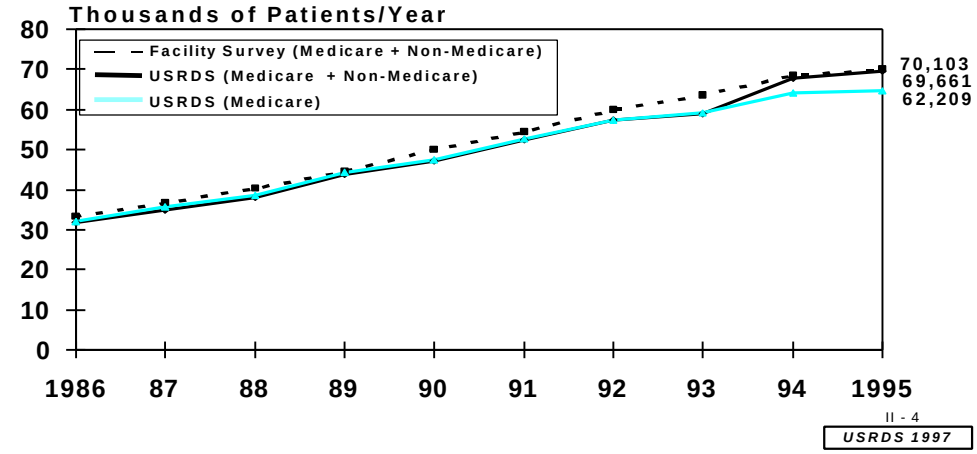

Figure II- 4

Treated ESRD incidence counts for Medicare and non-Medicare patients from the USRDS database and the Annual Facility Survey. All incidence counts include patients in Puerto Rico and U.S. Territories. Source: Reference Tables A.1, I.15.

for prevalence counts. As reported from two independent sources (USRDS database and Facility Survey), the prevalence counts showed a smaller rate of growth in 1995 as compared to prior years. A third source of data, the Network Census, displayed a growth rate comparable to the other two sources. The available data suggests that the prevalence count increased to a smaller extent in 1995 than in previous years (Figure II-3). This trend may mark the long-expected gradual stabilization of ESRD growth. However, additional years of data accrual are needed to validate these provisional findings.

Incident counts from the USRDS database and the Facility Survey are shown in Figure II-4. The Facility Survey count showed steady growth through 1994 and mild deceleration in 1995. The USRDS database count of Medicare

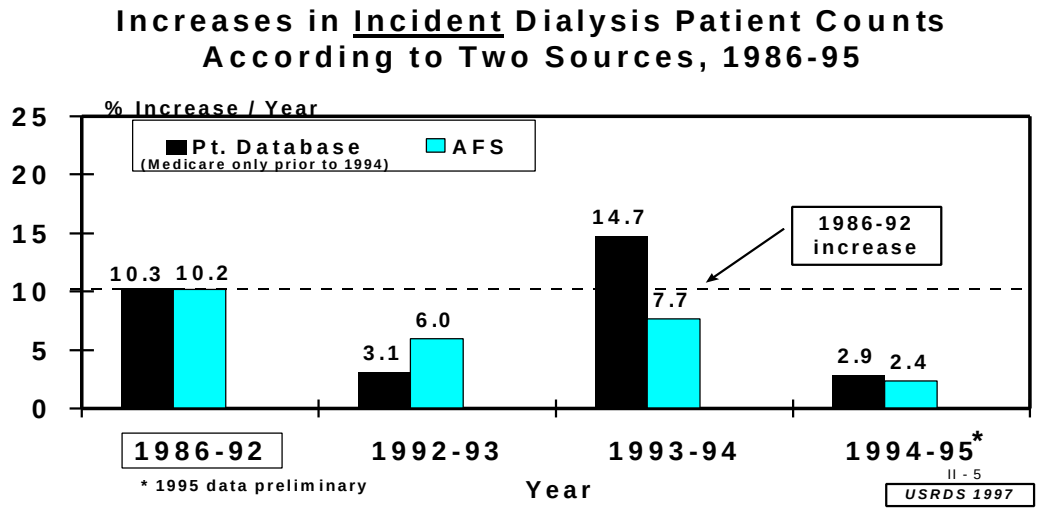

Figure II- 5

Increases in incident dialysis patient counts according to the USRDS patient database and the Annual Facility Survey, 1986-95. 1995 data is preliminary. Source: Special Analysis.

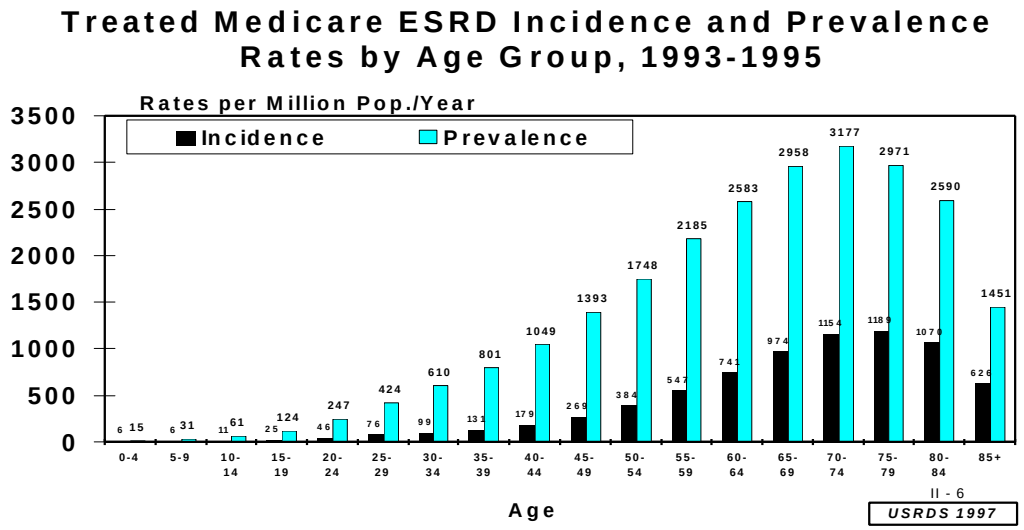

Figure II- 6

Total treated ESRD incidence and prevalence by age, 1993-95. Rates by age adjusted for sex and race. Rates do not include patients from Puerto Rico or the U.S. Territories. Medicare patients only. Source: Reference Tables A.8, B.8.

patients showed steady growth through 1992 as described in previous ADRs.

However, the count plateaued inexplicably in 1993, surged in 1994, and leveled off in 1995. Figure II-5 summarizes the annual growth in incidence counts from the USRDS database and the Facility Survey. A number of factors, as described above and in Chapter XIII, apparently underlie these erratic growth patterns. The lower-than-expected number of incident ESRD cases in HCFA records for 1993 has not been adequately explained and is probably erroneous. It is likely that the number of new cases reported to HCFA in 1994 was exaggerated and partly reflects unreported cases that were truly incident in 1993. However, the USRDS database and the Annual Facility Survey both show a lower rate of growth for 1995 as compared to previous years (particularly the years of stable growth

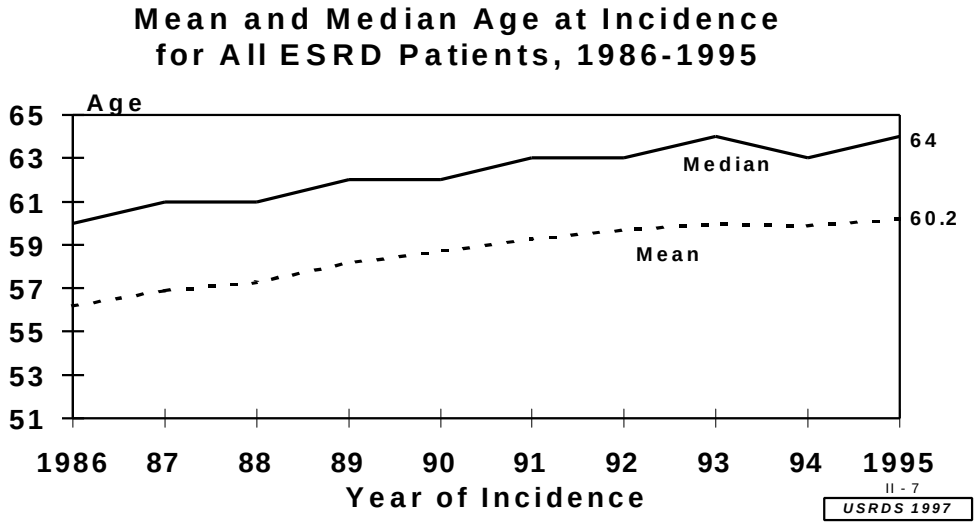

Figure II- 7

Mean and median age at incidence of ESRD by year, 1986-1995. Includes patients from Puerto Rico and U.S. Territories. Medicare patients only. Source: Reference Table A.13., A.14

from 1986-1992). For understanding the epidemiology of ESRD, it is more important to consider changes in the adjusted incidence rate which grew by only 0.8 percent in 1995. Thus, the trends in prevalence counts (Figure II-3) and incidence counts (Figure II-5) both suggest that ESRD growth may be slowing. However, the growth trends for 1995 must be considered tentative because of the uncertainties in the database as described above and in Chapter XIII.

Figure II-4 is also noteworthy for showing that the USRDS total incident count matched the Facility Survey count for the first time in 1994. One possible explanation is increased reporting of non-Medicare patients to HCFA and entry of such patients into the HCFA database.

Characteristics of ESRD Patients

ESRD incidence, prevalence, and growth vary markedly by reported patient characteristics. This section provides a subgroup description of ESRD.

Age

ESRD incidence and prevalence increase dramatically with age as shown in Table II-1 and Figure II-6. Incidence and prevalence rates peak in the eighth decade and then fall off modestly (Figure II-6). The age of ESRD patients had been rising each year but appears to have stabilized in 1993 (Figure II-7). In 1995, the mean age at ESRD incidence was 60 years and the median age was approximately 64 years.

Sex

ESRD is more common in males than females as shown in Table II-1. Among incident patients, 52.5 percent are male. Similarly, males predominate among prevalent ESRD patients.

Race

The adjusted incidence and prevalence of ESRD vary markedly by race as shown in Table II-1 for 1995 and in Figure II-8 for 1993-95. Incidence and prevalence are highest for Blacks followed in order by Native Americans, Asian/Pacific Islanders, and Whites.

Treated Medicare ESRD Incidence and Prevalence Rates by Race, 1993-95

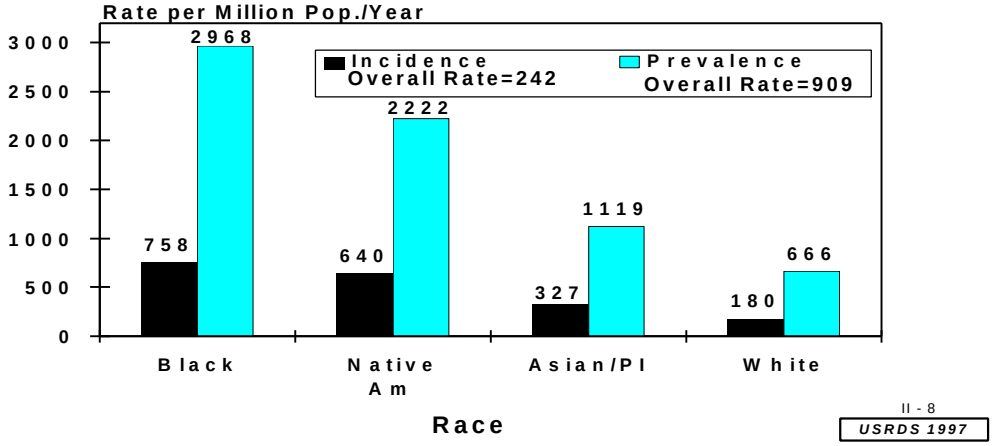

Figure II- 8

Total treated ESRD incidence and prevalence by race, 1993-95. Rates by race adjusted for sex and age. Overall rates adjusted by age, race, and sex. Rates do not include patients from Puerto Rico or the U.S. Territories. Medicare patients only. Source: Reference Tables A.8, B.8.

Diagnosis

The process of recording the primary cause of ESRD changed with the new Medical Evidence Form introduced in 1995. For the previous version of the Medical Evidence Form, the primary cause of ESRD was written onto the form and then translated by HCFA into one of 130 possible causes, including many redundant or antiquated diagnoses. The detailed diagnoses were then aggregated by the USRDS into eight primary categories (diabetes, glomerulonephritis, hypertension, cystic kidney, other urologic, other causes, unknown, and missing) and four major groups (diabetes, hypertension,

glomerulonephritis, and other). For the new version of the Medical Evidence Form, providers enter a primary cause of ESRD from a relatively complete and contemporary coded list of 72 diagnoses. The new list is organized into 10 primary disease categories (diabetes, primary glomerulonephritis, secondary glomerulonephritis /vasculitis, interstitial nephritis/pyelonephritis, hypertensive large vessel disease, cystic/hereditary/ congenital disease, neoplasms/tumor, miscellaneous conditions, unknown, and missing) that can be easily recoded into the same four major diagnosis groups (diabetes, hypertension, glomerulonephritis, and other). For this ADR, the old list of possible ESRD diagnoses from years prior to 1995 were recoded to the new detailed diagnoses listed on the new form. The cause of ESRD is expressed in several ways throughout the text and reference tables: new detailed diagnoses, old primary categories, new primary categories, and major diagnosis groups. The new list of primary diagnosis categories will be adopted to a greater extent in future ADRs.

It should be noted that the category of hypertension (both a primary and major disease category) includes several diseases that affect the renal arteries. Specifically, ESRD attributed to renal vascular disease (renal artery stenosis and occlusion) and cholesterol emboli are included in this category. For the previous version of the Medical Evidence Form, ESRD attributed to renal artery stenosis was classified under "hypertension" and ESRD attributed to renal artery occlusion was classified under "other". Cholesterol emboli or atherosclerotic disease were not included in the previous list of detailed renal diagnoses. The inclusion of cholesterol emboli in the hypertension/large vessel disease category is obviously arbitrary and debatable. However, renal artery disease and cholesterol emboli are very rarely invoked as the primary cause of ESRD. The category of hypertension is predominately composed of ESRD attributed to hypertensive nephrosclerosis.

Figure II-9 shows the adjusted incidence and prevalence rates by primary diagnosis category (using the old set of primary diagnosis categories). Diabetes, hypertension, and primary glomerulonephritis are the three most common attributed causes of ESRD. The relative difference between the diagnosis-specific prevalence and incidence rates

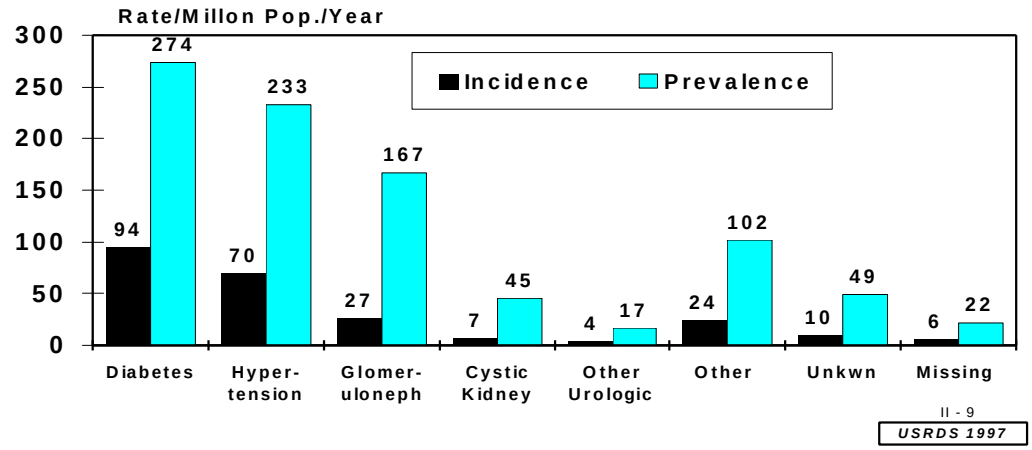

Figure II- 9

Total treated ESRD incidence and prevalence by primary diagnoses, 1993-95. Rates by diagnoses adjusted for age, sex and race. Rates do not include patients from Puerto Rico or the U.S. Territories. Medicare patients only. Source: Reference Tables A8, A.34, B.10, B.26.

indicates variations in average survival with smaller differences suggesting higher mortality rates.

Primary Disease, Age, Sex and Race for all Patients, 1991-1995 [1,2]

Primary Disease	Total 1991-95 Total	% of Total [3]	Age Group (% Age) <20	20-64	>64	Sex (%) Male	Female	Race (%) White	Black	Asian	Nat Am
All ESRD (reference)	305876	100.0	4787	156372	144537	162426	143450	197741	89261	8626	4337
% of Total ESRD	115938	37.4	1.6	51.2	47.3	53.1	46.9	64.6	28.0	2.8	1.4
Diabetes	115938	100.0	1.6	51.2	47.3	53.1	46.9	64.6	29.2	2.8	1.4
. Type I, juvenile type, ketosis prone	47839	41.3	0.1	57.6	42.3	47.0	53.0	65.4	28.5	3.0	2.4
. Type II, juvenile type, ketosis prone	68099	58.7	0.1	51.3	48.6	58.8	41.2	64.1	29.2	2.7	3.9
. Type II, adult onset or unspec. type	47839	41.3	0.7	66.6	33.3	47.0	53.0	65.4	28.5	3.0	2.4
Glomerulonephritis	68099	22.3	0.1	51.3	48.6	58.8	41.2	64.1	29.2	2.7	3.9
. Focal glomerulosclerosis, focal GN	33958	11.1	3.4	13.3	83.3	12.7	87.3	64.6	29.2	2.7	3.9
. Membranous nephropathy	5353	15.8	4.5	61.2	34.3	60.7	39.3	69.2	24.0	4.6	2.3
. Membranoproliferative GN types 1&2	1392	4.1	0.5	76.4	23.1	62.1	37.9	67.5	28.1	2.5	1.9
. Membranoproliferative GN, types 1&2	1095	3.2	2.8	62.9	35.3	67.5	32.5	73.3	23.1	1.8	1.8
. IgA nephropathy, Berger's disease	515	1.5	1.6	69.2	29.5	60.4	39.6	74.2	17.2	5.8	2.7
. IgM nephropathy	69	0.2	5.6	82.5	11.8	67.7	32.3	75.0	9.3	11.1	4.6
. Rapidly progressive GN	1128	3.3	2.8	82.6	14.6	64.0	36.0	72.5	7.2	13.5	4.4
. Goodpasture's Syndrome	896	2.6	0.8	49.2	50.0	52.0	48.0	79.9	13.5	3.7	3.6
. Post infectious GN, SBE	157	0.5	4.0	45.5	50.4	47.0	53.0	89.0	7.1	2.0	1.3
. Glomerulonephritis (GN)	22660	65.3	5.1	58.6	36.3	60.7	39.3	78.3	18.5	1.9	0.6
. Other proliferative GN	693	2.0	3.2	58.9	37.9	60.9	39.1	69.7	22.8	5.2	2.1
Secondary GN/vasculitis	7375	2.4	9.3	63.3	27.4	58.6	41.4	76.0	17.3	2.5	2.8
. Lupus erythematosus, (SLE nephritis)	3866	52.4	6.0	71.0	23.0	32.7	67.3	64.6	30.0	3.3	1.1
. Polyarteritis	157	2.1	6.3	85.0	8.6	19.6	80.4	49.9	43.1	4.5	0.1
. Wegener's granulomatosis	824	11.2	4.5	63.2	32.3	51.3	48.7	84.7	11.5	2.5	1.3
. Henoch-Schonlein syndrome	135	1.8	8.9	69.6	21.5	58.7	41.3	92.4	5.3	1.0	1.7
. Vasculitis and its derivatives	247	3.3	32.6	57.8	9.6	55.7	44.3	85.2	5.9	5.2	1.2
. Scleroderma	656	8.9	1.2	63.7	35.1	46.1	53.9	87.9	7.7	2.0	1.2
. Hemolytic uremic syndrome	642	8.7	1.9	68.2	29.9	23.3	76.7	82.3	15.5	0.9	1.1
. Nephropathy from heroin/related abuse	769	10.4	0.4	59.3	40.3	37.1	62.9	83.2	14.6	1.3	0.3
. Secondary GN, other	79	1.1	2.7	59.2	38.0	60.9	39.1	63.7	30.3	3.6	1.8
Interstitial Nephritis/Pyelonephritis	13837	4.5	12.3	67.1	20.6	56.1	43.9	60.8	34.2	1.9	3.8
. Chronic pyelonephritis, reflux neph.	1563	11.3	5.6	59.2	35.2	36.5	63.5	84.5	10.0	3.9	0.9
. Analgesic abuse	263	1.9	0.4	64.6	35.0	48.7	51.3	76.4	20.2	2.8	0.8
. Nephropathy caused by other agents	1891	13.7	1.8	50.6	47.6	59.9	40.1	78.7	18.2	1.9	0.5
. Nephrolithiasis, Obstruction, Gouty	3612	26.1	5.3	39.9	54.8	74.5	25.5	79.0	16.7	2.8	0.6
. Nephrocalcinosis	58	0.4	1.7	39.3	59.0	72.5	27.5	84.0	12.5	2.1	1.4
. Chronic interstitial nephritis	6208	44.9	2.7	49.1	48.2	54.8	45.2	82.4	12.8	1.5	3.3
. Acute interstitial nephritis	242	1.8	2.1	50.3	47.7	49.4	50.6	79.2	16.5	2.5	1.7
Hypertensive/Large Vessel Disease	8903	2.9	5.5	21.6	72.9	50.8	49.2	80.6	15.5	4.7	0.0
. Hypertension (no primary renal dis.)	8341	93.7	5.0	21.0	74.0	50.8	49.2	80.6	15.5	4.7	0.0
. Renal artery stenosis or occlusion	506	5.7	0.5	26.4	73.1	50.8	49.2	80.6	15.5	4.7	0.0
. Cholesterol emboli, renal emboli	56	0.6	0.0	14.4	85.7	50.8	49.2	80.6	15.5	4.7	0.0
Cystic/Hereditary/Congenital Dis	10759	3.5	23.0	46.6	30.4	66.3	33.7	93.7	4.5	1.5	2.5
. Polycystic kidneys, adult (dominant)	8360	77.7	0.2	39.3	60.5	55.6	44.4	83.3	12.8	2.0	1.8
. Other cystic	72	0.7	1.9	72.6	25.4	52.2	47.8	84.0	12.5	2.1	1.4
. Alports, other hereditary/familial dis	597	5.5	4.7	43.1	52.3	47.2	52.8	79.2	16.7	1.4	2.4
. Other congenital hereditary	1730	16.1	19.8	73.9	6.4	74.3	25.7	85.3	9.4	2.0	3.5
Neoplasms/Tumors	4846	1.6	4.5	46.1	49.4	65.4	34.6	79.4	15.1	1.9	1.2
. Renal or urological neoplasms	1266	26.1	0.5	37.7	61.8	62.0	38.0	80.1	17.2	1.6	0.8
. Multiple myeloma	2556	52.7	1.9	37.3	60.8	70.5	29.5	82.2	15.3	1.4	1.0
. Light chain nephropathy	69	1.4	0.0	34.1	65.9	60.3	39.7	77.5	19.8	1.6	0.9
. Amyloidosis	955	19.7	0.0	36.2	63.8	60.6	39.4	71.0	23.2	2.0	0.8
Miscellaneous Conditions	6648	2.2	2.1	48.2	49.7	55.3	44.7	84.7	12.5	1.5	1.1
. Complications of transplants/other txp	47	0.7	1.5	68.1	30.4	67.1	32.9	50.0	47.1	1.1	0.7
. Complication post bone marrow txp	291	4.4	2.1	78.7	19.1	68.0	32.0	85.1	10.6	2.1	2.1
. Sickle cell disease/anemia or trait	2646	39.8	4.1	91.1	4.8	53.4	46.6	5.8	92.1	0.1	0.2
. AIDS nephropathy	67	1.0	0.0	98.1	1.4	78.4	21.6	9.2	88.4	0.0	0.4
. Traumatic/surgical loss of kidney(s)	256	3.8	0.0	49.3	50.7	63.4	36.6	79.1	10.4	3.0	3.0
. Hepatorenal syndrome	2651	39.9	1.0	77.1	21.8	68.8	31.2	85.9	11.0	2.4	0.5
. Tubular necrosis (no recovery)	1	0.0	0.0	100.0	0.0	100.0	0.0	100.0	0.0	0.0	0.0

[1] Primary Disease, Age, Sex, and Race for all Patients, 1991-1995

[2] Incidence & Prevalence of ESRD

Tables II-2 and II-3 display the new detailed diagnosis (collapsed for some rare diseases) and primary diagnosis categories, aggregated for the years 1991-1995. Table II-2 shows the column percentages and is useful for illustrating varying diagnosis patterns by age group, sex, and race. The column percents are best compared to the "% of total" column to evaluate deviations from the expected pattern. Primary glomerulonephritis and cystic/hereditary/congenital diseases are the most common causes of ESRD among patients less than 20 years of age (see Chapter VIII). Diabetes predominates in the 20-64-year age-group, whereas hypertension is the largest attributed cause of ESRD in the over 65-year age-group. Primary glomerulonephritis and hypertension are more common in males than females whereas diabetes and secondary glomerulonephritis are more common in females than males. For the race comparisons, Blacks have a strikingly high incidence of hypertension, Asians have a higher than average incidence of primary glomerulonephritis, and Native Americans have an extremely high incidence of diabetic ESRD and a relatively low incidence of ESRD attributed to hypertension.

Table II-3 is formatted similarly to Table II-2 but shows row percentages. This presentation is useful for showing demographic patterns for specific ESRD diagnoses as illustrated by several examples. Compared to the expected pattern described in the top row labeled "% of total ESRD", diabetes is rare in patients younger than 20 years and is more frequent in the 20-64 age-group and less frequent in the over 64 group. Only 47 percent of diabetic ESRD occurs in men even though they constitute 53.1 percent of all ESRD patients (top row). Almost 61 percent of all primary glomerulonephritis occurs in males whereas only 33 percent of all secondary glomerulonephritis/vasculitis occurs in males. Interstitial nephritis is disproportionately reported in Whites (79 percent vs. 64.2 percent of the ESRD population) and less in Blacks (16 percent vs. 29 percent of the ESRD population). Similar racial patterns are seen for congenital/hereditary/congenital diseases and for neoplasms/tumors. The opposite racial pattern is seen for hypertensive ESRD. The etiology of ESRD was more often listed as unknown for Whites than Blacks, relative to the representation of these groups in the ESRD population. The missing

Treated Medicare ESRD Incidence and Prevalence by ESRD Network, 1995

Net-work	Location of Network Office[1]	States and Territories	Network Name	Point Prevalence Rates[2] 1995	Incidence Rates[2] 1995
1	CT	CT, MA, ME, NH, RI, VT	ESRD Network of New England	843	225
2	NY	NY	ESRD Network of New York, Inc.	1018	224
3	NJ	NJ, PR[3], VI[3]	TransAtlantic Renal Council	1062	269
4	PA	DE, PA	ESRD Network Organization No. 4	1069	252
5	VA	DC, MD, VA, WV	Mid-Atlantic Renal Coalition	1111	236
6	NC	GA, NC, SC	Southeastern Kidney Council, Inc.	1209	279
7	FL	FL	ESRD Network of Florida, Inc.	988	222
8	MS	AL, MS, TN	Network 8, Inc.	1170	247
9	IN	IN, KY, OH	Tri State Renal Network, Inc.	925	242
10	IL	IL	Renal Network of Illinois	1035	262
11	MN	MI, MN, ND, SD, WI	Renal Network of the Upper Mid-West, Inc.	924	232
12	MO	IA, KS, MO, NE	ESRD Network Organization No. 12	885	237
13	OK	AR, LA, OK	ESRD Network Organization No. 13	1079	255
14	TX	TX	ESRD Network of Texas, Inc.	1008	269
15	CO	AZ, CO, NM, NV, UT, WY	Intermountain ESRD Network, Inc.	767	217
16	WA	AK, ID, MT, OR, WA	Northwest Renal Network	730	189
17 & 18	CA	AS[3], CA, CM[3], HI, GU[3]	TransPacific ESRD Network and ESRD Network Organization No. 18	875	231

[1] The state location of the Network Office is frequently used to identify ESRD Networks in figures throughout this report.

[2] Adjusted for age, race and sex. Per million population per year. Source: B.20, A.28.

[3] PR=Puerto Rico, VI=Virgin Islands, AS=American Samoa, CM=Marianna Islands, GU=Guam.

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Table II- 4

diagnosis category lacks information about race in one-third of cases, indicating that the entire Medical Evidence Form was missing.

Geographic Patterns

Geographic patterns are presented at the level of the Networks in Table II-4. There are multiple reasons for geographic variations in incidence including differences in referral and acceptance practices, competing risks, and frequency of renal disease. However, the role of each of these is presently unclear. Some of the geographic variations seen this year may be artifactual. This is probably due to differences in reporting time and/or in the fraction of non-Medicare patients. The USRDS is currently working to validate and investigate the regional rates.

Summary

The number of patients starting ESRD therapy continues to increase, although this report shows evidence that the incidence rates are growing at a slower pace than they did in earlier years. The number of patients undergoing ESRD therapy also continues to increase, but the rate of increase is down to 7 percent from 9-10 percent. There is some uncertainty in these estimates in part because the reporting of non-Medicare patients has changed.