

Chapter IV

Incidence and Causes of Treated ESRD

The statistics in this chapter show a continued increase in the annual incidence rate of newly treated ESRD in the United States. The incidence rate in the general population stands at 198 per million in 1991. The incidence rate has doubled in the last 10 years and has grown 8.8 percent per year since 1982. The increase has been most substantial for the elderly (15 percent per year among those over age 75), Asian/Pacific Islanders (13.6 percent per year), and Native Americans (12.4 percent per year). The increase in incidence rates has been most dramatic for ESRD caused by diabetes and hypertension, although cystic kidney disease and glomerulonephritis incidence have also increased substantially in certain race groups. There is substantial geographic variability in age, race, and sex adjusted incidence rates, ranging between 169 and 238 per million among the 18 networks.

Methods

The USRDS ESRD database includes data for all patients registered as receiving treatment for irreversible chronic renal failure in the United States. Registration is complete for those patients who have Medicare insurance

coverage. Medicare patients are estimated to comprise approximately 93 percent of treated ESRD patients in the United States. In addition, new patients who started receiving ESRD treatment through the Veteran's Administration Facilities or who receive medical insurance coverage through the Department of Veteran's Affairs have been registered in the USRDS since 1990. Patients who are not registered in the USRDS include those with private medical insurance or with Medicaid insurance. Further, during the first 90 days after the start of ESRD therapy, there may be an undercount of patients who die within the first few weeks before they are registered. Chapter XIV has further details concerning the completeness of the USRDS.

Since the USRDS is a treatment-based registry, it does not include information for patients who die a uremic death without receiving treatment for the condition. Thus, the incidence count in this report is defined as the number of new patients per year starting ESRD therapy who are subsequently registered. This corresponds to the "ESRD acceptance rate" of the European Dialysis and Transplant Association Registry. Kjellstrand has estimated the

number of untreated patients dying of chronic renal failure in the United States in 1985 to be nearly as high as the treated ESRD incidence (Kjellstrand). The incidence rate of registered treated patients has been increasing annually since 1985 and has doubled during the last 10 years, so the fraction of untreated patients with chronic uremia has likely diminished since then.

This chapter describes both annual incidence counts and rates of ESRD treatment. Annual incidence counts are based upon all patients newly registered in the USRDS during a year. Annual incidence rates are computed as the incidence count during a year divided by the population count on July 1 of that year. The incidence rate for a particular group is based on the incidence count and the population count for that particular group. Since population counts are not consistently reported for specific age and race groups in Puerto Rico and United States territories, incidence rate calculations exclude patients from these regions as well as non-US citizens. This chapter also provides summaries of the demographic characteristics of newly treated ESRD patients, the primary causes of treated ESRD, and several interrelations among these parameters.

Causes of Treated ESRD

End-stage renal disease may be caused by progressive primary renal disease, kidney damage due to other diseases, or acute irreversible damage resulting in permanent renal failure.

The damage to the kidneys which leads to ESRD can occur for a number of reasons:

- primary renal diseases, comprising conditions in which direct renal injury results from poorly defined immunological mechanisms, such as in primary glomerulonephritis
- hypertension, causing nephrosclerosis
- systemic diseases causing renal injury, such as diabetes mellitus, systemic lupus erythematosus or AIDS
- inherited or congenital conditions, including polycystic kidney disease and renal dysgenesis
- neoplastic diseases, such as renal cell carcinoma requiring bilateral nephrectomy or multiple myeloma
- urologic diseases, such as obstructive uropathy
- drugs and toxins which cause glomerular or tubulo-interstitial injury acutely or chronically.

Acute renal injuries are usually reversible and rarely lead to ESRD, unless they are superimposed on a previous chronic focus.

For analytical purposes, most tables and graphs in this annual data report use up to eight primary disease categories causing ESRD as listed below:

- Diabetes
- Hypertension
- Glomerulonephritis
- Cystic Kidney Disease (primarily adult polycystic kidney disease)

**Observed vs. Calculated* Treated Incidence Rates
1982-1991**

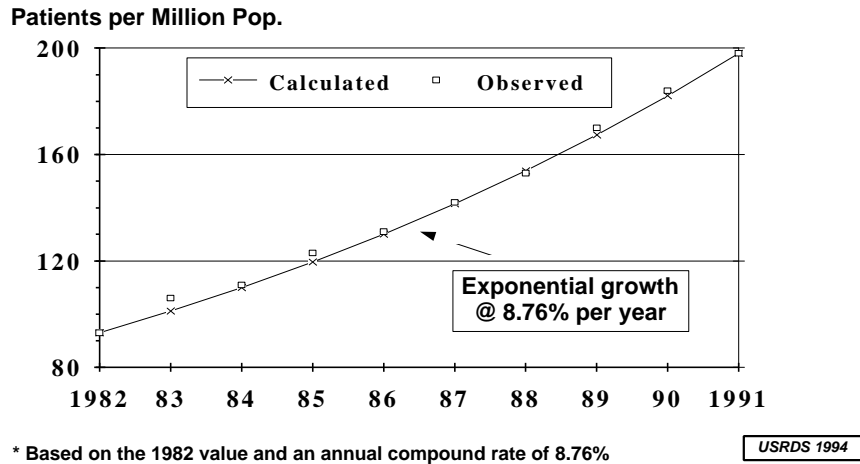


Figure IV-1

Observed vs. Calculated Incidence rates for 1982-1991. Calculated rates based on 1982 value and exponential growth of 8.76%. Medicare patients only, rates do not include patients from Puerto Rico or other U.S. Territories.

- Other Urologic Disease (primarily obstructive nephropathy)
- Other Identifiable Diseases
- Cause Unknown. It is not unusual for patients to seek medical attention only when their chronic renal failure is so far advanced that they have shrunken kidneys. At such a late stage, it is often impossible to define the cause of the renal disease. Among new ESRD patients, 5.4 percent (5.3 percent excluding Puerto Rico and other U.S. territories) were classified in this category in 1989-91.
- Missing Information. This occurs when the primary disease causing ESRD is not reported or the HCFA Medical Evidence form is missing.

Reporting of primary disease is subject to misclassification and incomplete reporting but has improved over time. Primary disease was coded as missing information for only 3.7 percent

and cause unknown for only 5.3 percent of incident patients in 1991. Data on primary disease for incident patients before 1982 are of questionable value because of the high proportion of missing information and are generally not reported here. Chapter XV, "Technical Notes," has further information about how these primary disease categories are defined.

The causes of ESRD reported in the USRDS database are for the most part based on clinical diagnoses provided by renal physicians or from support personnel reading medical records. The validity of the diagnoses has been addressed by the Data Validation, Case Mix Severity, and Renal Biopsy special studies. Agreement of reported cause of ESRD and the diagnosis found by medical record abstraction was best for diabetes (97 percent) and worst for glomerulonephritis (77 percent).

Results

A total of 49,909 patients were registered as starting ESRD therapy during the year 1991, accounting for a rate of 198 new cases per million population (unadjusted) as shown in Table IV-1. Figure IV-1 shows that the incidence rate of treated ESRD in the United States appears to have increased exponentially since 1982, increasing by nearly 8.8 percent annually.

Incidence rates vary widely by age group, from 11 cases per million population in the pediatric group (ages 0-19 years), to a high level of 760 cases per million population among patients aged 65-74 years, as shown in Table IV-1. Figure IV-2 shows that there has been an increase in incidence rates of treated ESRD for all age groups over the period 1982 to 1991. The increase is particularly dramatic in the age group over 75 years, which exhibited a 3.9 fold

Treated ESRD Incidence Counts and Rates by Age Group, 1991

Age	Count	Percent of Total	Incidence per Million ¹
0-19	822	1.6	11.0
20-44	9,635	19.3	95.0
45-64	16,925	33.9	362.0
65-74	13,901	27.9	760.0
75+	8,626	17.3	653.0
Total	49,909	100.0	198.0

¹Rates are per million pop. in each group, and unadjusted. Note: Incidence counts do not include patients from Puerto Rico or U.S. Territories. Medicare patients only.

Table IV-1

increase in treated ESRD incidence over the ten year period.

An analysis of the annually compounded change in ESRD incidence by sex and age groups for the years 1986-88 versus 1989-91 is shown in Figure IV-3. Overall, the increase in

Treated Medicare ESRD Incidence by Age Group, 1982-1991

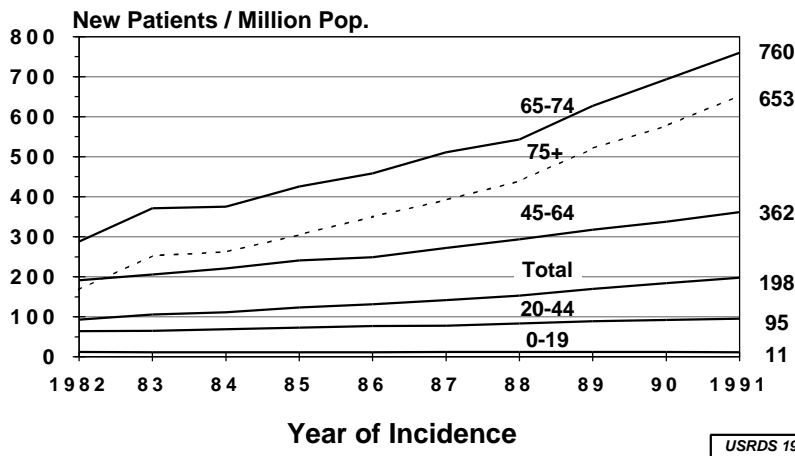


Figure IV-2

Incidence rates of treated ESRD per million population, by age group, 1982-1991. Rates are unadjusted. Rates do not include patients from Puerto Rico or U.S. Territories. Medicare patients only. Source: Reference Table A.3.

Annualized Change in Treated Medicare ESRD Incidence Rate by Age Group, from 1986-1988 to 1989-1991

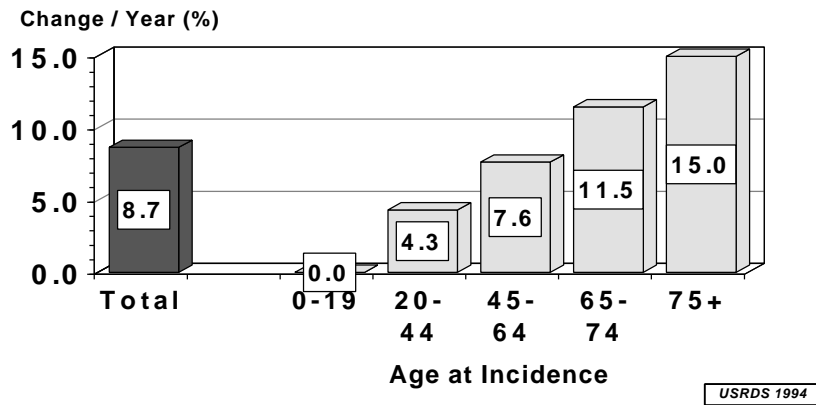


Figure IV-3

Change in treated ESRD incidence rates for the years 1986-88 versus 1989-91, by age group. Percent change per year is defined as the percent annual compound rate of change. Total rate adjusted for age, race, and sex. 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 Table A.35.

incidence averaged 8.7 percent per year. While there was no growth for pediatric patients, the annual increase among adults ranged from 4.3 percent for ages less than 45 years to 15.0 percent for ages over 75 years when adjustments are made for race and sex.

Similar annualized changes by race are shown in Figure IV-4 adjusted for age and sex. The largest increase in treated ESRD incidence has been for Asian/Pacific Islanders and Native Americans who experienced an annualized increase of 13.6 and 12.4 percent per year, respectively, during the second half of the 1980s.

Large differences in age and sex adjusted incidence of treated ESRD exist by race: rates among Native American and black patients are typically three to four times higher than rates among white patients. Figure IV-5 shows rates by race and age groups. In all age ranges, the

incidence rate is highest for the black population and next highest for the Native American populations. In all but the age range 20-44, the rate is lower for whites than for Asian/Pacific Islanders. The differences by race are generally consistent among the age groups, although somewhat smaller for ages over 74 years and for pediatric patients (see Chapter IX).

Further information by race and diagnosis is shown in Table IV-2. In 1989-91 the median age at onset of ESRD of 62 years overall is exceeded by whites (64 years), while other groups have lower median ages. There is a slight predominance of males among incident ESRD patients (54 percent), which is especially pronounced among whites.

Annualized Change in Treated Medicare ESRD Incidence Rate by Patient Race, from 1986-1988 to 1989-1991

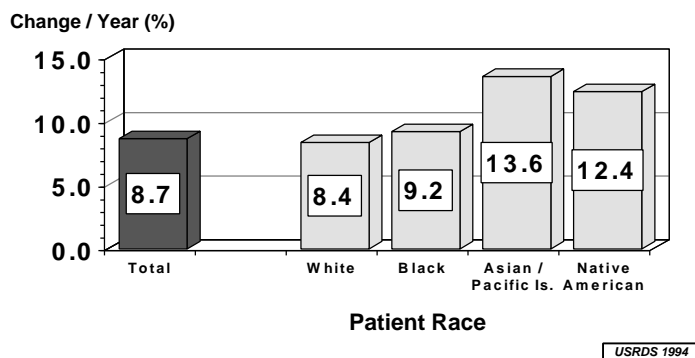


Figure IV-4

Change in treated ESRD incidence rates for the years 1986-88 versus 1989-91, by patient race. Percent change per year is defined as percent annual compound rate of change. Total rate adjusted for age, race, and sex. Rates by race adjusted for age and sex. Rates do not include patients from Puerto Rico or U.S. Territories. Medicare patients only. Source: Reference Table A.35.

Also shown in Table IV-2 are the percentage of patients, by race, for selected primary diseases causing ESRD. Diabetes has become the most common cause of renal failure among Native Americans, at a percentage nearly twice the average (64 versus 34.7 percent).

Black patients have a predominance of hypertension as their primary disease

(38.2 percent). Asian / Pacific Islanders, who have a treated ESRD incidence rate that is almost equal to the overall rate, report a lower percentage for hypertension (23.4 vs. 29.1), with somewhat higher percentages for diabetes (37.2 vs. 34.7) and glomerulonephritis (19.9 vs. 12.4 percent).

**New ESRD Patients in 1989-1991
Incidence Counts, Median Age, Distributions for Sex and Three Major Diagnoses, and Adjusted Incidence Rate, by Race for the Period 1989-1991**

Patient Race	Average Count/Year	Percent of Total	Median Age	Percent				Adjusted Incidence Rate ¹
				Male	Diabetes	Hyperten.	Glomer.	
Total	45,279	100.0	62.1	54.2	34.7	29.1	12.4	181
White	30,739	67.9	63.7	56.2	34.6	25.7	13.3	140
Black	13,043	28.8	57.7	50.1	33.3	38.2	9.9	550
Asian/Pacific Islander	924	2.0	60.4	50.2	37.2	23.4	19.9	186
Native American	573	1.3	58.3	48.3	64.0	12.9	9.4	437

¹Incidence rates are adjusted for age and sex. Total rate also adjusts for race. Medicare patients only.

Table IV-2

Incidence of treated ESRD by Detailed Primary Disease, Age, Sex, Race and One-Year Transplant and Death Status for all Patients, 1988-1991

Primary Disease	Total 1988-91 ¹	% of Total	Median Age	% Male	Percent by Race				Percent	
					White	Black	Asian	Native Amer.	Tx'ed in 1st year ^{2,3}	Died in 1st year ²
All ESRD, (reference)	177,660	100.0	62	54.2	100.0	100.0	100.0	100.0	11.6	22.3
Diabetes	60,052	33.8	61	47.4	34.0	32.5	36.8	63.9	9.2	22.8
Hypertension	50,347	28.3	68	58.0	25.2	37.9	23.0	11.9	6.1	26.4
Glomerulonephritis	22,517	12.6	54	61.9	13.6	10.2	20.0	9.7	19.7	14.2
Goodpasture's Syndrome	589	0.3	64	47.3	0.4	<0.1	0.1	0.2	7.9	22.2
Focal glomerulosclerosis, focal GN	2,637	1.4	40	66.5	1.2	2.1	1.1	0.6	19.8	9.3
Membranous nephropathy	846	0.4	55	70.8	0.5	0.3	0.1	0.1	20.7	12.0
Membranoproliferative GN	692	0.3	41	60.6	0.4	0.1	0.5	0.5	32.1	8.3
All other glomerulonephritis	17,753	9.9	56	61.3	10.9	7.3	18.0	8.0	19.4	15.0
Cystic Kidney Diseases	5,394	3.0	54	53.4	3.9	1.1	2.3	1.8	24.7	6.9
Interstitial Nephritis	5,464	3.0	63	46.3	3.7	1.5	3.0	1.9	16.6	18.7
Analgesic nephropathy	1,449	0.8	64	47.3	0.9	0.4	0.6	0.5	14.5	20.4
All other interstitial nephritis	4,015	2.2	62	45.9	2.7	1.1	2.4	1.3	17.3	18.1
Obstructive Nephropathy	3,716	2.0	68	72.5	2.5	1.1	1.4	1.3	11.3	26.7
Collagen Vascular Diseases	3,779	2.1	41	26.7	2.0	2.2	3.0	1.4	10.0	17.1
Lupus erythematosus	2,406	1.3	35	18.6	1.0	1.9	2.7	1.0	11.0	10.9
Scleroderma	413	0.2	58	26.2	0.2	0.1	0.1	<0.1	3.5	39.4
Wegener's granulomatosis	407	0.2	62	52.8	0.3	<0.1	<0.1	0.2	11.8	22.3
Hemolytic uremic syndrome / TTP	367	0.2	48	34.7	0.2	<0.1	<0.1	0.0	5.5	25.3
Polyarteritis	97	<0.1	58	62.9	<0.1	<0.1	<0.1	<0.1	11.6	30.9
Henoch-Schonlein Purpura	68	<0.1	29	60.3	<0.1	<0.1	<0.1	<0.1	22.2	4.4
Rheumatoid arthritis	21	<0.1	63	42.9	<0.1	<0.1	<0.1	0.0	8.3	19.0
Malignancies	2,248	1.2	68	61.8	1.5	0.7	0.5	0.4	1.1	45.9
Multiple myeloma, chain disease	1,502	0.8	68	58.6	0.9	0.5	0.4	0.3	0.1	49.6
Renal and urinary tract neoplasms	706	0.3	66	68.4	0.4	0.2	0.1	<0.1	2.3	38.1
Lymphomas	40	<0.1	66	65.0	<0.1	<0.1	0.0	0.0	11.1	47.5
Metabolic Diseases	884	0.4	62	59.2	0.6	0.2	0.1	0.1	9.9	33.2
Amyloidosis	630	0.3	64	56.2	0.4	0.1	0.1	0.1	5.2	40.9
Gouty / Uric acid nephropathy	87	<0.1	63	71.4	<0.1	<0.1	0.0	0.0	12.7	19.5
Oxalate nephropathy	63	<0.1	53	54.0	<0.1	<0.1	0.0	0.0	12.5	14.2
Cystinosis	37	<0.1	12	45.9	<0.1	<0.1	0.0	0.0	50.0	5.4
Fabry's disease	36	<0.1	41	97.2	<0.1	<0.1	0.0	0.0	42.8	5.5
Macroglobulinemia	9	<0.1	65	77.8	<0.1	<0.1	<0.1	0.0	0.0	22.2
Congenital/Other Hereditary Dis.	1,331	0.7	22	70.4	0.9	0.3	0.4	0.8	34.2	6.4
Congenital obstructive uropathy	348	0.1	26	77.4	0.2	<0.1	<0.1	0.2	26.6	8.0
Renal dysgenesis, agenesis, dysplasia	338	0.1	23	63.7	0.2	<0.1	0.1	0.1	34.0	9.1
Alport's Syndrome	645	0.3	20	75.6	0.4	0.1	0.1	0.4	38.0	4.1
Sickle Cell Disease	154	<0.1	36	55.2	<0.1	0.2	0.0	0.0	2.9	15.5
AIDS-Related	586	0.3	36	83.8	<0.1	1.0	<0.1	<0.1	0.3	48.8
Other ESRD	1,879	1.0	66	61.9	1.3	0.5	0.3	0.5	6.2	34.6
Cause Labeled Unknown	10,145	5.7	65	58.8	6.0	4.9	6.7	4.7	13.1	25.2
Missing Information	9,175	5.1	51	55.2	4.2	4.9	1.8	1.0	15.4	15.1

¹Divide total by 4 to determine average annual counts. Note these figures include patients in Puerto Rico and U.S. Territories.

See introduction to Section A of the Reference Tables for an explanation.

²Comparisons of death and transplant rates across primary disease should be done with caution since rates do not adjust for age, sex, or race.

³Only patients ages 20-64.

Medicare Patients Only.

Table IV-3

Much greater detail on the reported primary causes of ESRD for all ages is provided in Table IV-3. This table names the main diagnostic categories and their subgroups of specific diagnoses. The “percent of total” column may be multiplied by the overall incidence rate (184 per million population in 1988-91) to give an approximate incidence rate by category or specific diagnosis.

Diabetes mellitus is the most common cause of ESRD (33.8 percent). Additionally, it is one of the few conditions with a predominance of females (52.6 percent female). However, Cowie et al. (Cowie) have shown that there is no female predominance among type I (IDDM) patients. Unfortunately, classification of diabetes into type I (IDDM) and type II (NIDDM) is still flawed by incorrect reporting of some type II patients as IDDM because insulin therapy is being used (CDC).

Other diagnoses with higher female than male ESRD incidence include Goodpasture’s syndrome, interstitial nephritis, lupus erythematosus, scleroderma, hemolytic uremic syndrome/TTP, and rheumatoid arthritis. Relative to the overall median age of 62 years, patients with most glomerulonephritis, cystic kidney disease, collagen vascular diseases, congenital and hereditary diseases, (discussed further in Chapter IX) as well as those with AIDS-related nephropathy, sickle cell disease, and cystinosis are younger. These statistics complement previous reports which have also described rare causes of ESRD (Nissenson, 1989 and Port, 1990).

After examining incidence rates by detailed diagnosis it is clear that there exist striking differences between race groups. Sickle cell disease causes ESRD almost exclusively among blacks (91.5 percent), yet it accounts for only 0.2

Treated Medicare ESRD Incidence Rates by Age, and Race, Adjusted for Patient Sex, 1989-1991

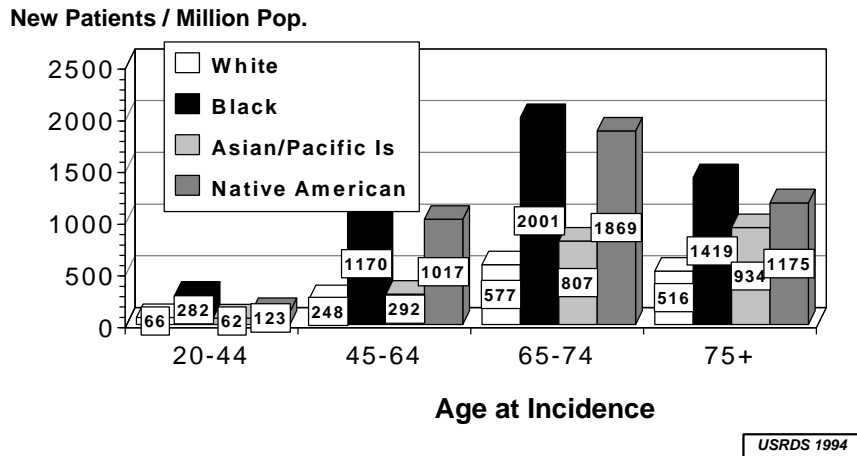


Figure IV-5

Incidence rates of treated ESRD per million population, by age and race, 1989-91, adjusted for sex. Total incidence rates adjusted for age and sex. Rates do not include patients from Puerto Rico or U.S. Territories. Medicare patients only. Source: Reference Table A.35.

Treated Medicare ESRD Incidence Rates for Selected Diagnoses, 1982-1991

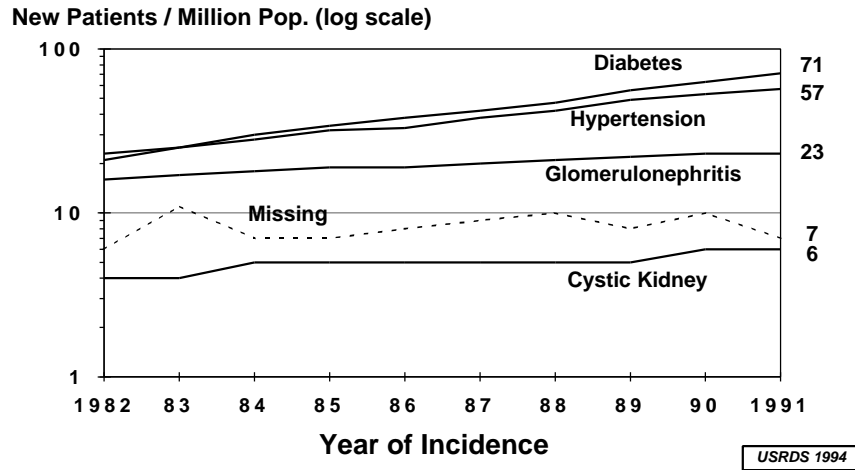


Figure IV-6

Incidence rates of treated ESRD per million population, by selected primary disease groups, 1982-91. Rates are unadjusted. Semi-log scale used to show smaller rates. Rates do not include patients from Puerto Rico or U.S. Territories. Medicare patients only. Source: Reference Table A3

percent of the primary causes of ESRD among blacks. Incidence percentages among blacks are relatively high for hypertensive ESRD (37.9 percent vs. 28.3 percent overall) and ESRD due to lupus erythematosus (1.9 percent vs. 1.3

percent overall and 1.0 percent white).

Asians/Pacific Islanders are over represented in lupus ESRD and in the primary glomerulonephritis group. Among Native Americans, there is a

Treated Medicare ESRD Incidence Rates by Diagnosis and Race, Adjusted for Sex and Age, 1989-1991

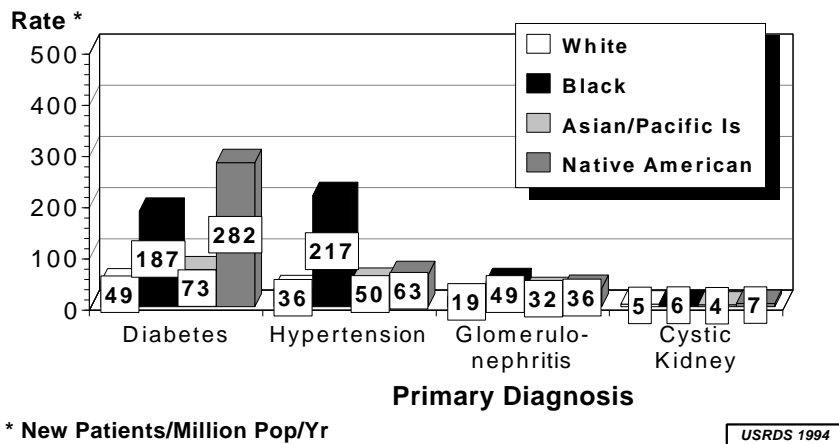


Figure IV-7

Incidence rates of treated ESRD per million population, by race and four major primary disease groups, 1982-91. Adjusted for age and sex. Rates do not include patients from Puerto Rico or U.S. Territories. Medicare patients only. Source: Reference Tables A.46 and A.47.

Annualized Change in Treated Medicare ESRD Incidence Rate by Primary Diagnosis and Race, from 1986-1988 to 1989-1991

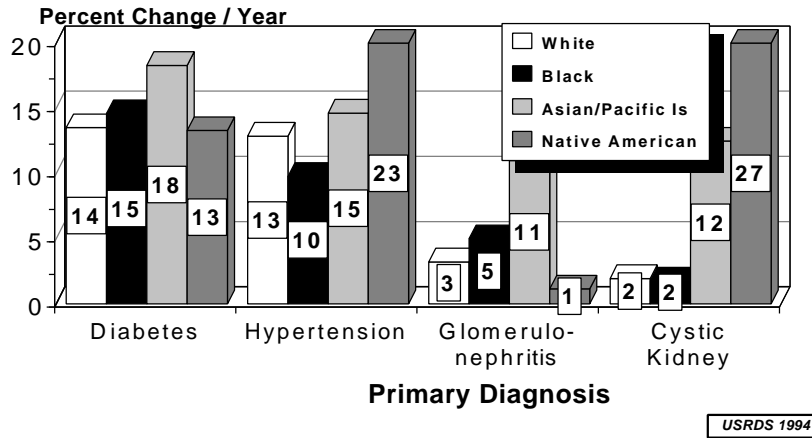


Figure IV-8

Change in treated ESRD incidence rates for the years 1986-88 versus 1989-91, by diagnosis and patient race. Percent change per year is defined as the percent annual compound rate of change. Rates by race adjusted for age and sex. Rates do not include patients from Puerto Rico or U.S. Territories. Medicare patients only. Source: Reference Tables A.43, A.44, A.46, A.47.

striking predominance of diabetic ESRD—accounting for 63.9 percent of their ESRD as compared to 34.0 percent among whites and 32.5 percent among blacks (since these percentages are only of patients with reported cause over a four-year period and include some non-U.S. residents, these numbers are slightly different from those in Table IV-2). Most of the diabetes in Native Americans is NIDDM occurring at relatively young ages (Nelson).

The figures presented for the percent of patients receiving a transplant within the first year of ESRD are of interest but must be considered in light of the median age, since patients over age 65 are rarely transplant candidates. Similarly, the percent dead within the first year has to be viewed with caution since it would be expected to be relatively high for those diagnoses that have a relatively high median age.

Incidence rates for five major causes of ESRD are shown in Figure IV-5 for the years 1982-1991. Data quality on cause of ESRD has improved coincidentally with, and likely due to, the efforts of the ESRD Networks as documented by the reduction in the category of missing information on diagnosis from more than 30 per million population in the early years (32 percent of incident cases in 1980) to 7 per million population in 1991. For all diagnoses there has been a definite increase in the incidence rates over time. Use of a semi-log scale allows interpretation of the slopes of increase, which are steepest for ESRD due to diabetes and hypertension.

Figure IV-6 describes the 1989-91 average annual incidence rates for the major diagnostic groups by race with adjustment for differences in the age and sex composition. Figure IV-7 shows that the excess of diabetic ESRD among Native Americans is 5.7-fold that among

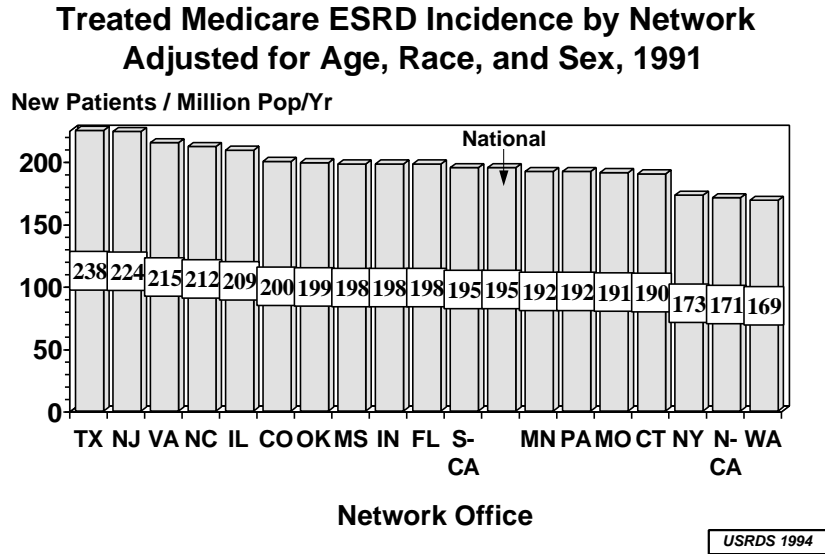


Figure IV-9

1991 treated ESRD incidence rates per million population, by Network. Rates by Network are indirectly standardized by age, sex, race, and primary diagnosis (See chapter XII for details). National rate is unadjusted. Rate for NJ network does not include patients from Puerto Rico or U.S. territories. Medicare patients only. Source: Reference Tables A.6, A.33.

whites. For hypertensive ESRD, blacks have a 6.0-fold higher adjusted incidence than whites (FitzSimmons). Cystic disease has similar adjusted ESRD incidence rates for all races.

The change in ESRD incidence compounded per year for the averages of 1986-88 versus 1989-91 is shown by diagnostic group and race in Figure IV-8. The incidence of diabetic ESRD is increasing at a high rate among all races, and hypertension is increasing greatly for all races but black. The changes in rates for Asians/Pacific Islanders and Native Americans are based on small numbers and may not be reliable.

The ESRD incidence rates by ESRD Network are shown in Figure IV-9. Rates adjusted for age, sex, race and diagnosis shown here vary less than the unadjusted crude rates. Some of the observed differences in incidence rates by Network may be due to differences in

1) true ESRD incidence, 2) acceptance policy and availability of treatment facilities and stations, 3) the fraction of patients covered by Medicare, 4) distance to treatment facilities, and 5) differences in populations served. The distance factor was recently evaluated in a USRDS study (USRDS). Two USRDS studies have evaluated incidence rates by county and race: one for ages less than 60 years so as to reflect more closely differences in the true incidence (Foxman), and one for geriatric ages to reflect differences in acceptance to therapy (Moulton). A third study has shown that ESRD incidence tends to be higher in counties with lower income (Young).

More research is needed to determine the reasons for observed differences in incidence by age, sex, race and geographic area as part of the effort to prevent or delay the development of ESRD (Levin).

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