Chapter II

Incidence and Prevalence of ESRD

This chapter addresses basic questions about the number and characteristics of individuals with end-stage renal disease (ESRD). The report is based on patients who are registered in the national USRDS database of patients receiving some form of renal replacement therapy (i.e. dialysis or transplantation). The description of new (incident) and existing (prevalent) ESRD patients have been combined in the ADR this year because of the close and natural relationship between these two attributes. Formal definitions of the terms as used in this chapter are given below. In a theoretical steady state situation (which does not technically exist yet for ESRD), disease prevalence is equal to the incidence rate multiplied by the average duration of the disease (i.e. survival). Incidence and prevalence are described in this chapter and survival is discussed separately in Chapter V. Changes in prevalence can occur secondary to changes in either the incidence or survival of ESRD. The chapter contains a general description of the Medicare ESRD program, definitions of the terms to describe the number of patients, an overall summary of ESRD incidence and prevalence, and a detailed characterization of the ESRD population.

The Medicare ESRD Program

This ADR documents improved success over the last decade with both dialysis and kidney transplantation (see Chapters V and VII). Despite these improvements, kidney failure is almost always associated with devastating medical, social and economic costs. The U.S. Government has implemented several programs designed to improve access to quality treatment for ESRD and to alleviate the financial impact of ESRD on patients and their families. The most immediate and timely help comes through the provision and regulation of medical care to the patient and through financing much of the cost of this care. As part of the 1972 Amendments to the Social Security Act, Congress extended coverage under Medicare, the public insurance program funded by the Federal Government, to people with end-stage kidney failure (Fox, Rettig, HCFA 1993). A database for all people receiving Medicare insurance, and for some without Medicare insurance, gives the basis for many of the statistics reported in this chapter (see Chapter XII for details).

Medicare coverage for the ESRD program was recently expanded to include immunosuppressive drugs administered to kidney transplant recipients for up to 3 years and for erythropoietin therapy in dialysis patients (Erslev, HCFA 1993). Both of these programs provide coverage for outpatient drugs, and are exceptions to the general rules governing Medicare insurance.

Measuring the Incidence and Prevalence of ESRD

A few important concepts are central to the material presented in this chapter. A brief definition of these terms as used throughout this ADR is provided below.

Incidence. The annual incidence count is the number of new patients who begin treatment for irreversible chronic renal failure during a year. Measurements of the incidence of ESRD are helpful in identifying patterns in the development of the disease. The incidence rate expresses the incidence count as a fraction of the U.S. general population per unit of time (e.g., new ESRD patients per million population per year). When group-specific incidence rates are given (e.g. for race or age groups), the appropriate segment of the general population is used in the denominator.

Prevalence. The prevalence count includes patients who are new or are continuing to receive treatment for ESRD, whether in the form of dialysis

or a functioning kidney transplant. Measurements of the prevalence of ESRD are helpful in identifying the scope of the disease and the associated social and economic costs. The prevalence of ESRD is influenced by patterns in both the incidence of the disease and the survival of ESRD patients. The prevalence rate per million population is the prevalence count divided by the population size in millions on either a particular date or during an interval of time.

Point prevalence is a specific measure of the prevalence of ESRD that reflects the number of patients receiving treatment for ESRD on a particular date, usually December 31 of the year. Point prevalence is the most common definition of prevalence used throughout the ADR. When used by itself, the term "prevalence" almost always refers specifically to "point prevalence," which is either a count of patients or a rate per million population.

Period prevalence is a different measure of the prevalence of ESRD that counts the number of patients receiving treatment for ESRD anytime during a particular interval of time, such as a calendar year. It can be calculated for a calendar year as the sum of the point prevalence on the first day of the year plus the incidence during the year. This term is used less often than point prevalence.

Reported incidence and reported prevalence of treated ESRD. Throughout this chapter and the rest of this ADR, we describe the "reported" incidence and "reported" prevalence of "treated" ESRD. This is because information about incidence and prevalence in this ADR reflects most but not all Americans who have ESRD. As described in further detail below, the USRDS primarily provides information for patients who are treated for ESRD and are covered by the Medicare program. The incidence of ESRD as reported in this chapter corresponds to the term "ESRD acceptance rate" used by the European Dialysis and Transplant Association Registry. These counts do not include people who died of kidney failure without receiving treatment.

Medicare Eligibility

USRDS estimates of the incidence and prevalence of ESRD include all patients who are reported to Medicare as receiving treatment for ESRD in the United States. Medicare insures the vast majority of Americans treated for ESRD, providing coverage to over 92 percent of dialysis patients and 90 percent of kidney transplant recipients in 1993 (see discussion later in this chapter). In addition, many new patients

Reported Medicare ESRD Period and Point Prevalence, Incidence, Death and Lost-to-Follow-up Counts, 1984-93

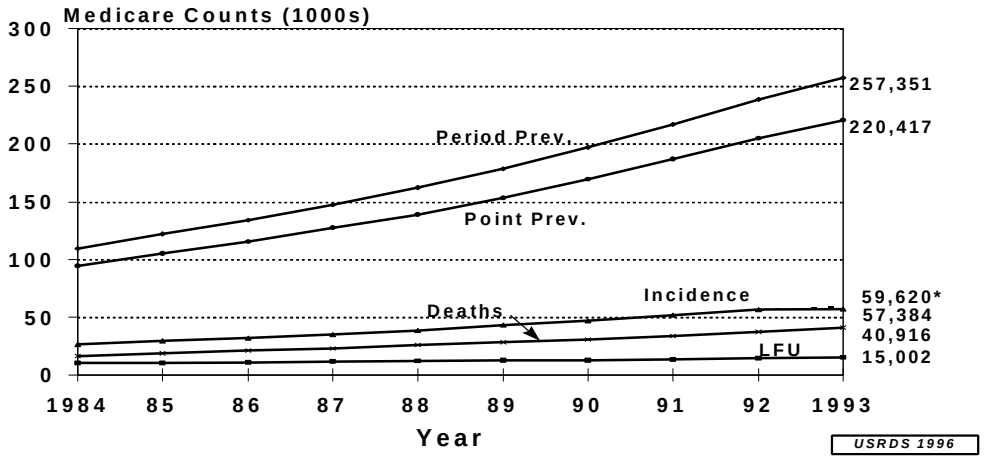

Figure II-1

*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 XII for details). Point prevalence counts exclude patients lost to followup (LFU). *Total incidence for 1993 is expected to be slightly higher (shown by the dashed line) than is currently reported (shown by the solid line). See text for further explanation. 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, D.1.*

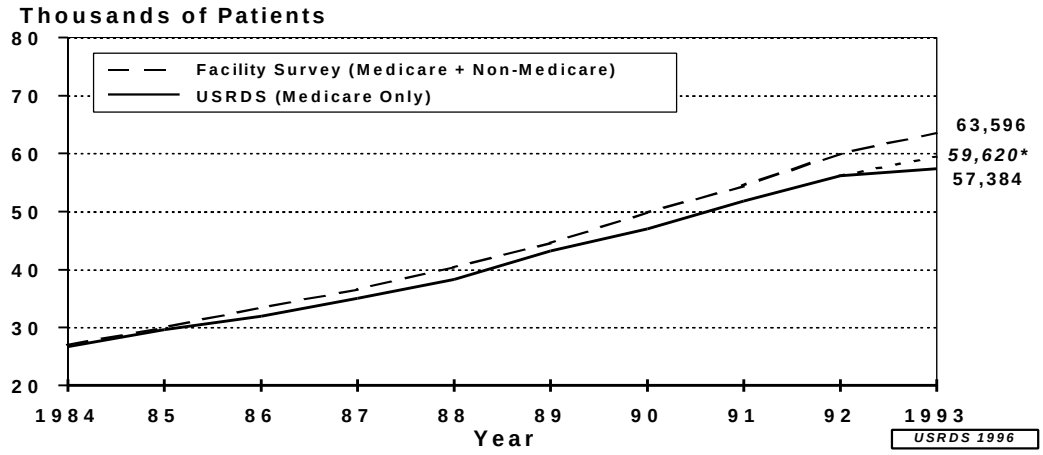

Figure II-2

*Treated ESRD incidence counts for Medicare patients only (from the USRDS database) and for all Medicare and non-Medicare patients combined (from the Annual Facility Survey). *Total Medicare incidence for 1993 is expected to be slightly higher (shown by the dashed line) than is currently reported (shown by the solid line). See text for further explanation. All incidence counts include patients in Puerto Rico and U.S. Territories. Source: Reference Tables A.1, I.15.*

who started receiving ESRD treatment through the Department of Veteran's Affairs have been registered in the USRDS since 1990.

The ESRD population represents a growing fraction of total Medicare beneficiaries, largely due to growth in the incidence of treated ESRD. Between 1976 and 1991, the ESRD portion of the total Medicare population increased five-fold, from 0.1 to 0.5 percent (Eggers 1994). During the same time period, Medicare expenditures for ESRD increased from 3.2 percent to 5.1 percent of the total Medicare budget (Eggers 1994).

The USRDS does not include many patients with medical insurance provided solely through a private source or solely through Medicaid. Also, we suspect an increasing number of ESRD patients are insured by health maintenance organizations (HMOs) or other managed care organizations. We expect that most of these patients are covered by Medicare. However, the USRDS is aware of the need to monitor the completeness of the USRDS database for patients enrolled in HMOs or similar plans, and hopes to provide such information in future ADR reports.

The USRDS does not include all patients who die before they are eligible for Medicare coverage, usually by 60 to 90 days after the start of ESRD therapy. Further, since the USRDS is a treatment-based registry, it does not include information for patients who die of kidney failure without receiving renal replacement treatment. Once estimated to be nearly as high as the treated ESRD incidence (Kjellstrand 1988), the number of untreated patients dying of chronic renal failure in the U.S. may have diminished over time in light of the steady growth observed in the rate of treated ESRD.

Limited information about ESRD patients not insured by Medicare is reported in this chapter. Estimates of the total incidence and prevalence of ESRD, regardless of Medicare eligibility, are available from the HCFA Annual Facility Survey. The Facility Survey also reports separately the number of non-Medicare dialysis patients in the U.S. This chapter also describes characteristics of non-Medicare dialysis patients based on Wave I of the USRDS Dialysis Morbidity and Mortality Study, which represents a national random sample of U.S. dialysis patients point prevalent on 12/31/93.

See Chapter XII for further discussion of the completeness of the USRDS database.

How Many Americans are Treated for ESRD?

Overview

During 1993 more than 257,000 people (period prevalence count) in the 50 states and the District of Columbia were treated for end-stage renal disease under the Medicare program (Figure II-1). A total of 217,479 ESRD patients (point prevalence count) were being treated under the Medicare program as of the end of 1993 (Table II-1). An additional 2,939 ESRD patients were treated in Puerto Rico or other U.S. territories as of 12/31/93. These figures represent a more than doubling in the prevalence of ESRD during the last decade, corresponding to an annual increase of 10.0 percent and 9.8 percent in the overall period prevalence and point prevalence counts, respectively.

The rising prevalence of treated ESRD can be attributed primarily to the rapid increase in the incidence of treated ESRD. In 1993 alone, more than 57,000 people initiated treatment for ESRD under the Medicare program (Figure II-1), receiving either dialysis or a kidney transplant.

A total of 40,916 Medicare ESRD patients died during 1993, while another 15,002 patients were considered lost-to-followup (LFU). The reported prevalence of ESRD does not include dialysis patients who are lost to followup, indicated by a period of one year without information that the patient is receiving dialysis, has received a kidney transplant or has died. As described further in Chapter XII, this represents a change since the 1995 ADR, in which patients were considered to be lost to followup at the beginning rather than the end of the one-year period in which the USRDS received no information about a patient. An exception to the lost to followup status is made during the first year of ESRD, since many patients who have private insurance are not yet eligible for Medicare or have other primary insurance coverage during the first year of ESRD (and up to 21 months from start of ESRD).

Undercount for 1993

As discussed in Chapter XII, there appears to be an undercount of treated ESRD patients reported to the USRDS for 1993. The reported number of patients newly treated for ESRD under the Medicare program during 1993 (57,384) in Figure II-1 is only 2.0 percent higher than the number of new patients reported for 1992 (56,243). In contrast, the number of new Medicare patients reported to the USRDS had risen more than 7.5 percent each year since 1984,

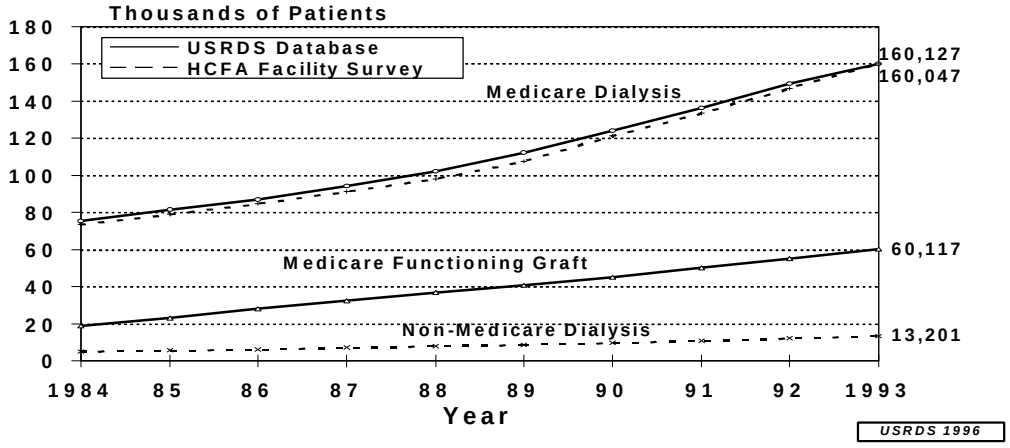

Figure II-3

Reported point prevalent counts on December 31 of each year from 1984-93 for: 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.

increasing approximately 9.8 percent per year between 1984 and 1992. We suspect that the reported incidence counts for 1993 do not indicate a sharply reduced rate of growth of ESRD. Rather, the modest increase in the number of new Medicare ESRD patients between 1992 and 1993 may be the result of a temporary decline in the number of Medical Evidence forms filed with HCFA during the third quarter of 1993. The reduction in the number of Medical Evidence forms filed during 1993 has the following implications for this chapter:

- The reported Medicare ESRD incidence count for 1993 is approximately 4 percent lower than expected, based on trends in an independent count of ESRD patients (including both Medicare and non-Medicare patients) from the Annual Facility Survey (AFS). Similarly, the reported Medicare ESRD point prevalence counts for 1993 are approximately 1 percent lower than expected (see discussion below). Based on estimates from the AFS, the estimated rate of growth of new ESRD cases was 6.0 percent between 1992 and 1993. However, until these discrepancies are better resolved, the estimate of Medicare ESRD growth trends through 1993 cannot be considered reliable.
- In an effort to include the undercounted ESRD patients, the USRDS registration process was supplemented to a greater than usual extent by Medicare billing records. These records allow identification of patients who were receiving renal replacement therapy in the absence of a registered Medical Evidence Form (HCFA-2728). Billing records, unlike the Medical Evidence Form, lack a diagnosis for cause of ESRD. Therefore, the percentage of patients with a missing diagnosis increased in 1993. Patients with a missing primary diagnosis represent approximately 13 percent of incident patients and 9 percent of prevalent patients for 1993, compared to approximately 4 percent and 8 percent, respectively, during the previous five years.
- There is less emphasis in this chapter on evaluating trends in the incidence and prevalence of ESRD, since there is uncertainty about the precise growth in incidence during 1993.
- The decline in Medical Evidence forms appeared to occur equally across patient age, race, sex and geographic region. Therefore, information in this chapter regarding the patterns of incidence and prevalence according to these characteristics is likely to be valid.

A more detailed discussion of this issue is provided in Chapter XII.

Counts of Medicare and Non-Medicare Patients

Information about the incidence and prevalence of ESRD presented throughout this chapter focus on the approximately 92 percent of ESRD patients who have Medicare insurance and are thereby included in the USRDS patient database. Estimates of the number of ESRD patients without Medicare insurance are available from a separate source, the HCFA Annual Facility Survey (AFS). The number of newly treated ESRD patients reported from both sources is shown in Figure II-2. The AFS reports a total of 63,596 patients beginning treatment for ESRD during 1993. This figure includes all ESRD patients regardless of Medicare eligibility. The number of new Medicare ESRD patients reported in the USRDS database is shown for comparison. Between 1986 and 1992, Medicare patients represented from 94 to 96 percent of the total reported incidence count from the AFS.

As described above, the Medicare incidence count from the USRDS database is lower than expected for 1993 due to a decrease in the number of Medical Evidence forms filed with HCFA. However, we can estimate the expected Medicare incidence for 1993 based on the growth in incidence from the AFS from 1992-93. It is reasonable to assume that the growth in Medicare incidence will closely approximate the growth in overall incidence from the AFS, since the two sources have indicated very similar growth in incidence during the last decade. Growth in the AFS incidence count of 6.0 percent from 1992-93 yields an expected incidence of 59,620 new Medicare patients during 1993. The estimated Medicare incidence count for 1993 is shown by a separate dashed segment in Figure II-2 (also in Figure II-1).

The reported prevalence of ESRD is shown separately for dialysis patients with and without Medicare eligibility and for kidney transplant recipients in Figure II-3. The USRDS point prevalence count of dialysis patients who are (or will be) insured by Medicare was 160,127 after excluding patients lost to followup. This estimate is only slightly different from the count of Medicare dialysis patients from the AFS, varying by two percent or less of the AFS count for most of the 1984-93 period. These counts do not include dialysis patients who were not insured by Medicare (and are not included in the USRDS database), numbering 13,201 patients in 1993.

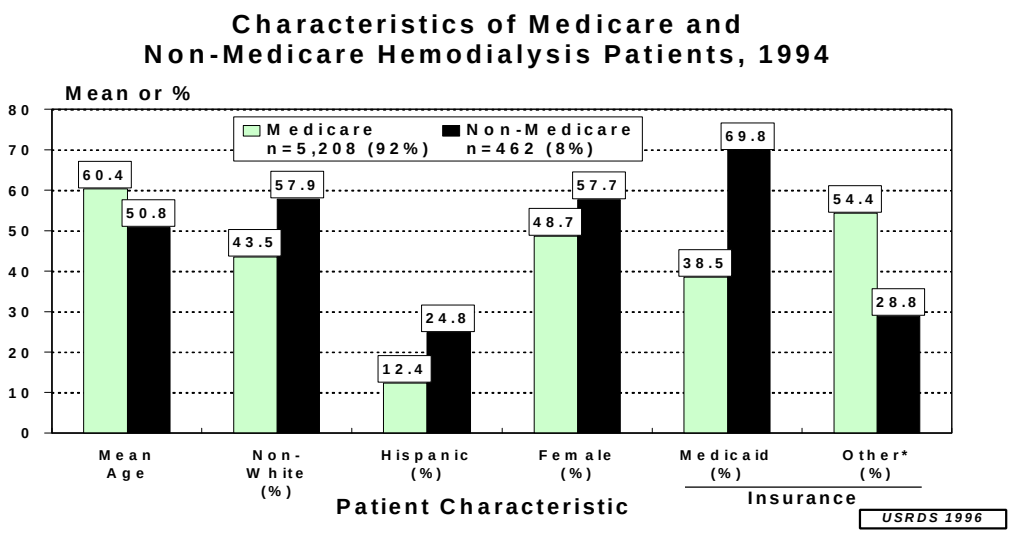

Figure II-4

*Average age and percent distribution by race, ethnicity, gender and type of health insurance for prevalent Medicare and non-Medicare hemodialysis patients in 1994. Data are from Wave I of the Dialysis Morbidity and Mortality Study (DMMS). Excludes missing data. *'Other insurance' includes private, Blue Cross/Blue Shield, VA or another unspecified type of insurance. Source: special analysis.*

An additional 60,117 people with a functioning kidney transplant were reported in the Medicare ESRD program for 1993. This estimate includes transplant recipients whose Medicare eligibility has been terminated. An analysis of patients who received a kidney transplant during 1983-86 and were Medicare eligible at time of transplant (USRDS 1993) shows that one third of recipients were no longer Medicare eligible at 3.5 years following transplant. Kidney transplant recipients who lose Medicare eligibility are included in all USRDS prevalence estimates throughout this report.

Characteristics of Non-Medicare Patients

For the first time, the USRDS is able to describe the characteristics of non-Medicare dialysis patients (Figure II-4). Previously, the only source of information about non-Medicare dialysis patients was the Annual Facility Survey, which included only *counts* of patients not insured by Medicare. Information about non-Medicare patients is obtained from Wave I of the Dialysis Morbidity and Mortality Study (DMMS, described in Chapters I and IV). This study represents a national random sample of hemodialysis patients in the U.S regardless of Medicare eligibility. The average age of non-Medicare hemodialysis patients is 50.8 years, compared to 60.4 years for Medicare patients. Non-Medicare patients are also more likely to be non-White, and are twice as likely to be Hispanic. Females represent 57.7 percent of non-Medicare patients compared to 48.7 percent of Medicare patients.

The vast majority of non-Medicare patients (69.8 percent) have Medicaid insurance, a social insurance program primarily designated for the poor. In contrast, a much smaller percentage (38.5 percent) of Medicare patients are also covered by Medicaid. Private insurance, Blue Cross/Blue Shield and other insurance were far less common among non-Medicare patients. These patterns suggest that non-Medicare patients are more likely to be poor, female, non-White and of Hispanic origin.

Characteristics of ESRD Patients Registered in USRDS

The undercount of patients for 1993 makes it difficult to ascertain definite patterns and trends in ESRD over time. Similar caution must be used in interpreting variations in ESRD incidence and prevalence by demographic and diagnostic characteristics, although the apparent undercount seems to be random rather than systematic. Within these constraints, a description of the incident and prevalent ESRD population by patient attributes follows.

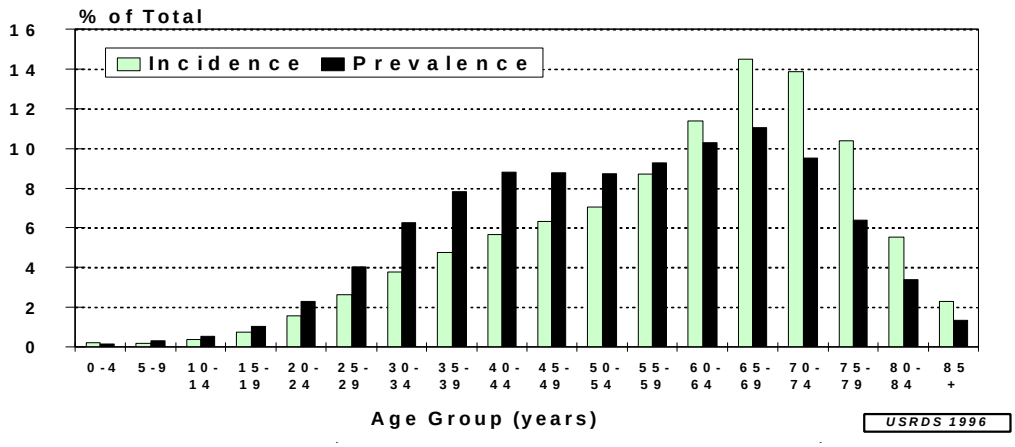

Figure II- 5

Distribution of treated incident and prevalent ESRD patients by age group, 1991-93. Patients in Puerto Rico or the U.S. Territories are not included. Medicare patients only. Source: Reference Tables A.7, B.9.

Diabetes	59,403	27.3	226	19,013	33.6	73
Hypertension	51,523	23.7	197	15,064	26.6	58
Glomerulonephritis	37,268	17.1	142	5,911	10.4	22
Cystic Kidney	10,512	4.7	38	1,397	2.5	5
Total	217,479	100.0	824	56,600	100.0	214

Table II- 1

[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 are 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.8 for the rates.

Age

Both the incidence rate and the prevalence of ESRD increase sharply with age until 65-74 years at which point the rates turn somewhat downward (Table II-1). The average age of new ESRD patients has been steadily rising. Incident ESRD patients are substantially older than the group of prevalent patients (Fig. II-5). For the period from 1991 to 1993, the average age of incident ESRD patients was 60.0 years and the average age of prevalent ESRD patients was 54.4 years. While ESRD develops preferentially in older individuals, the overall group of treated (prevalent) patients is relatively young due to the higher mortality among older age groups compared to younger aged patients (Chapter V).

Race

Distinct racial differences exist in the incidence and prevalence of treated ESRD. The lowest overall rate of ESRD is found in Whites (Table II-1, Figure II-6). For Blacks, the crude incidence and prevalence rates are over four-fold higher than for Whites. Blacks constitute 29.1 percent of the incident ESRD population as compared with 12.5 percent of the general population. Blacks make up an even higher 31.4 percent of the prevalent ESRD population, owing to their lower mortality rates (see Chapter V). The higher occurrence of ESRD among Blacks is not well explained at present although it has been associated with genetic, environmental, and socioeconomic factors . The ESRD incidence and prevalence rates for Asian/Pacific Islanders and native Americans are between those of Whites and Blacks with Native Americans having approximately twice the rates of Asian Americans.

Sex

ESRD is more common in men than women (Table II-1). Approximately 54 percent of the incident and prevalent ESRD population are men. The proclivity for ESRD among males is true for virtually all ages. However, the distribution of ESRD by sex varies by diagnosis as discussed below.

Diagnosis

The attributed cause of ESRD is derived from the Medicare Medical Evidence form (HCFA form 2728). This form is requested for all new ESRD

patients and compliance with filling out the form is reasonably high. However, there are several caveats about the ESRD diagnoses. No diagnosis is available when the Medical Evidence form is missing or incompletely filled out (see previous discussion of undercount by Medical Evidence Form registration).

While the Medical Evidence Form should be filled out for all new ESRD patients, it is possible that a form could be omitted for patients who are unlikely to qualify for Medicare, patients with excellent primary insurance at the time of ESRD onset, or patients who already qualify for Medicare such as the disabled and those over 65 years of age. In most years, the magnitude of this problem is relatively small and consistent. This year, however, diagnoses are lacking for the patients that were apparently undercounted in the registry in 1993. In that there is no evidence that specific diagnostic groups were undercounted, the distribution of registered renal diagnoses should be representative but this is not yet known with certainty. In addition to these database issues, it should be understood that the assignment of an ESRD diagnosis is made by the physician and is often based on clinical judgment. A kidney biopsy is usually not done, particularly for patients who present with clinical diagnoses of diabetes and hypertension, the two most common attributed causes of ESRD.

Unfortunately, the clinical criteria for making etiologic diagnoses are neither uniform, standardized, or completely validated. Undoubtedly, varying beliefs and attitudes among physicians about diagnostic criteria contributes to some of the uncertainty about etiologic renal diagnoses.

As shown in Table II-1 and Figure II-7, over 60 percent of new ESRD cases are attributed to either diabetes (35.2 percent) or hypertension (28.4 percent). Primary glomerulonephritis constitutes 10.8 percent of incident ESRD cases. Glomerulonephritis is more common and diabetes and hypertension are less common among prevalent compared to incident ESRD patients

The remaining 30 percent of new ESRD cases are attributed to causes other than diabetes, hypertension, and primary glomerulonephritis. Tables II-2 and II-3 present detailed diagnostic information for incident ESRD cases. Tables II-2 and 3 differ from Table II-1 in that they summarize the period from 1989 to 1993 (as compared to 1993 alone), cases with missing diagnoses (6.4 percent of total new cases) have been excluded (resulting in higher percentages for the non-missing diseases), and more detailed renal diagnoses are shown. Table II-2 presents the column-wise percentages of ESRD incidence by age, sex, and race whereas Table II-3 shows row-wise percentages.

Column Percents for Incidence of Treated ESRD by Detailed Primary Disease, Age, Sex and Race for all Patients, 1989-1993 [1,2]

			Age Group[3] (%)			Sex[3] (%)		Race[3] (%)			
Primary Disease	**Total 1989-93**	**% of Total[2]**	**<20**	**20 - 64**	**>64**	**Male**	**Female**	**White**	**Black**	**Asian**	**Nat. Amer**
All ESRD, (reference)	255573	**100.0**	4427	135953	115193	137754	117819	169126	73596	6030	3331
Diabetes	88,936	**37.2**	1.4	42.6	32.3	32.6	42.5	37.1	35.8	38.5	63.3
Hypertension	72,483	**30.3**	5.9	22.4	40.1	32.4	27.8	26.9	39.9	23.9	13.9
Glomerulonephritis	29,439	**12.3**	36.1	14.4	9.2	14.1	10.2	13.2	9.8	19.8	9.7
Goodpasture's Syndrome	688	**0.3**	0.5	0.2	0.3	0.3	0.3	0.4	0.1	0.2	0.2
Focal glom-sclerosis, focal GN	3,783	**1.6**	9.5	2.2	0.6	1.9	1.2	1.3	2.2	1.5	0.9
Membranous nephropathy	1,171	**0.5**	0.6	0.6	0.4	0.6	0.3	0.6	0.4	0.3	0.2
Membranoproliferative GN	922	**0.4**	3.2	0.5	0.2	0.4	0.3	0.5	0.2	0.7	0.5
All other glomerulonephritis	22,875	**9.6**	22.3	10.8	7.7	10.8	8.1	10.4	6.9	17.1	7.9
Cystic Kidney Diseases	7,188	**3.0**	4.4	4.2	1.6	2.9	3.1	3.8	1.2	2.3	1.7
Interstitial Nephritis	7,173	**3.0**	4.4	2.9	3.1	2.6	3.5	3.7	1.5	2.8	1.8
Analgesic nephropathy	1,957	**0.8**	0.9	0.8	0.9	0.7	0.9	1.0	0.4	0.7	0.4
All other interstitial nephritis	5,216	**2.2**	3.5	2.1	2.2	1.9	2.5	2.7	1.1	2.1	1.4
Obstructive Nephropathy	4,869	**2.0**	8.8	1.4	2.5	2.8	1.2	2.4	1.2	1.4	1.2
Collagen Vascular Diseases	5,261	**2.2**	9.6	3.1	0.9	1.1	3.4	2.1	2.3	2.8	1.4
Lupus erythematosus	3,301	**1.4**	5.9	2.2	0.3	0.5	2.4	1.1	2.0	2.5	1.0
Scleroderma	567	**0.2**	0.1	0.3	0.2	0.1	0.4	0.3	0.1	0.1	0.2
Wegener's granulomatosis	623	**0.3**	0.6	0.2	0.3	0.3	0.3	0.4	0	0.1	0.2
Hemolytic uremic synd/TTP	509	**0.2**	2.0	0.2	0.1	0.1	0.3	0.3	0.1	0.1	0
Polyarteritis	125	**0.1**	0.1	0.1	0	0.1	0	0.1	0	0	0
Henoch-Schonlein Purpura	102	**0**	1.0	0	0	0	0	0.1	0	0.1	0
Rheumatoid arthritis	34	**0**	n.a.	0	0	0	0	0	0	0	0
Malignancies	3,132	**1.3**	0.4	0.9	1.8	1.5	1.1	1.6	0.8	0.6	0.6
Multiple myeloma, chain dis.	2,095	**0.9**	n.a.	0.6	1.3	1.0	0.8	1.0	0.6	0.5	0.5
Renal,urinary tract neoplasms	983	**0.4**	0.3	0.3	0.5	0.5	0.3	0.5	0.2	0.1	0.2
Lymphomas	46	**0**	0.1	0	0	0	0	0	0	0	0
Metabolic Diseases	1,159	**0.5**	1.3	0.5	0.5	0.5	0.4	0.6	0.2	0.3	0.2
Amyloidosis	820	**0.3**	n.a.	0.3	0.4	0.4	0.3	0.4	0.1	0.2	0.2
Gouty/Uric acid nephropathy	121	**0.1**	n.a.	0	0.1	0.1	0	0.1	0.1	0.1	0
Oxalate nephropathy	92	**0**	0.3	0	0	0	0	0.1	0	0	0
Cystinosis	50	**0**	1.0	0	0	0	0	0	0	0	0
Fabry's disease	58	**0**	n.a.	0	0	0	0	0	0	0	0
Macroglobulinemia	18	**0**	n.a.	0	0	0	0	0	0	0	0
Congenital/Oth Hereditary Dis.	1,541	**0.6**	17.0	0.6	0.1	0.8	0.4	0.8	0.3	0.5	0.6
Congen. obstructive uropathy	355	**0.1**	3.4	0.1	0	0.2	0.1	0.2	0.1	0.1	0.2
Renal dysgenesis, dysplasia	361	**0.2**	4.3	0.1	0	0.2	0.1	0.2	0.1	0.1	0.2
Alport's Syndrome	825	**0.3**	9.3	0.3	0	0.4	0.2	0.4	0.1	0.3	0.2
Sickle Cell Disease	235	**0.1**	0.3	0.2	0	0.1	0.1	0.0	0.3	0.0	0
AIDS-Related	1,358	**0.6**	0.1	1.1	0	0.9	0.2	0.1	1.8	0.1	0
Other ESRD	3,530	**1.5**	1.3	1.0	2.0	1.7	1.2	1.9	0.6	0.7	0.9
Cause Labeled Unknown	12,961	**5.4**	9.1	4.8	6.0	5.9	4.8	5.8	4.4	6.2	4.5
Missing Information	16,312	.	.	.	.	.	.	.	.	.	.

Table II- 2

[1] Medicare patients only. [2] Column percentages in any category should be compared with the overall percent of total (Column 2) as well as with neighboring categories. [3] Patients with a missing diagnosis have been excluded in calculating percentages.

Row Percents for Incidence of Treated ESRD by Detailed Primary Disease, Age, Sex and Race for all Patients, 1989-1993 [1,2]

Primary Disease	Total 1989-93	Age Group [3] (% Age) <20	20 - 64	>64	Sex [3] (%) Male	Race [3] (%) White	Black	Asian	Nat. Amer.
All ESRD, (reference)	255573	4427	135953	115193	137754	169126	73596	6030	3331
% of Total ESRD	**100.0**	**1.7**	**53.2**	**45.1**	**53.9**	**66.2**	**28.8**	**2.4**	**1.3**
Diabetes	88,936	0.1	59.7	40.3	47.3	66.7	27.6	2.5	2.3
Hypertension	72,483	0.3	38.5	61.2	57.7	59.3	37.7	1.9	0.6
Glomerulonephritis	29,439	4.7	60.8	34.5	61.7	71.5	22.8	3.9	1.1
Goodpasture's Syndrome	688	2.9	41.9	55.2	48.8	89.1	8.0	1.5	*
Focal glom-sclerosis, focal GN	3,783	9.6	73.3	17.0	64.4	56.3	40.0	2.4	0.7
Membranous nephropathy	1,171	2.0	63.5	34.6	70.4	75.1	22.3	1.3	*
Membranoproliferative GN	922	13.1	66.9	20.0	61.4	78.4	14.6	4.4	1.7
All other glomerulonephritis	22,875	3.7	59.0	37.3	61.1	73.0	20.8	4.4	1.1
Cystic Kidney Diseases	7,188	2.3	73.4	24.2	52.5	85.6	11.4	1.9	0.8
Interstitial Nephritis	7,173	2.3	50.6	47.1	46.4	82.3	14.3	2.3	0.8
Analgesic nephropathy	1,957	1.7	48.5	49.8	46.7	81.5	15.6	2.1	0.7
All other interstitial nephritis	5,216	2.5	51.4	46.1	46.3	82.6	13.8	2.4	0.9
Obstructive Nephropathy	4,869	6.9	35.7	57.4	73.8	80.5	16.4	1.7	0.8
Collagen Vascular Diseases	5,261	7.0	74.6	18.3	27.8	64.9	30.2	3.1	0.9
Lupus erythematosus	3,301	6.9	84.5	8.6	19.2	51.5	41.9	4.5	1.0
Scleroderma	567	*	69.5	30.2	26.6	81.8	15.9	*	*
Wegener's granulomatosis	623	3.5	48.8	47.7	55.4	93.6	4.5	*	*
Hemolytic uremic synd/TTP	509	14.9	58.7	26.3	36.0	84.3	13.9	*	0
Polyarteritis	125	*	56.0	40.8	59.2	91.2	*	*	*
Henoch-Schonlein Purpura	102	37.3	53.9	*	59.8	90.2	*	*	*
Rheumatoid arthritis	34	n.a.	47.1	52.9	44.1	94.1	*	*	0
Malignancies	3,132	0.4	36.1	63.4	62.6	80.1	17.6	1.2	0.7
Multiple myeloma, chain dis.	2,095	n.a.	33.8	66.2	59.9	78.2	19.3	1.4	0.7
Renal,urinary tract neoplasms	983	1.2	40.6	58.2	68.4	83.8	14.2	*	*
Lymphomas	46	*	47.8	47.8	67.4	91.3	*	0	0
Metabolic Diseases	1,159	4.2	50.1	45.6	59.7	85.4	12.5	1.3	*
Amyloidosis	820	n.a.	47.7	52.3	56.3	86.1	11.6	1.2	*
Gouty/Uric acid nephropathy	121	n.a.	48.8	51.2	73.6	68.6	28.9	*	0
Oxalate nephropathy	92	12.0	60.9	27.2	55.4	96.7	*	0	0
Cystinosis	50	76.0	*	*	46.0	86.0	*	0	0
Fabry's disease	58	n.a.	98.3	*	93.1	94.8	*	0	0
Macroglobulinemia	18	n.a.	*	*	72.2	77.8	*	*	0
Congenital/Oth Hereditary Dis.	1,541	42.3	48.6	9.1	68.9	84.4	11.7	1.9	1.4
Congen. obstructive uropathy	355	37.2	47.9	14.9	75.2	84.2	11.8	*	*
Renal dysgenesis, dysplasia	361	45.7	39.9	14.4	60.4	82.0	13.6	*	*
Alport's Syndrome	825	43.0	52.7	4.2	69.9	85.5	10.8	1.9	*
Sickle Cell Disease	235	4.7	88.1	7.2	49.8	5.1	94.5	0	*
AIDS-Related	1,358	*	98.4	1.4	82.9	8.2	90.8	*	*
Other ESRD	3,530	1.4	36.2	62.5	62.9	86.4	11.4	1.1	0.8
Cause Labeled Unknown	12,961	2.7	46.3	51.0	59.0	71.7	23.4	2.8	1.1
Missing Information	16,312	3.7	68.7	27.6	53.2	.	.	.	.

Table II- 3

[1] Medicare patients only. [2] Row percentages for any diagnosis should be compared with the overall percent of total ESRD (Row 3). [3] Patients with a missing diagnosis have been excluded in calculating percentages.

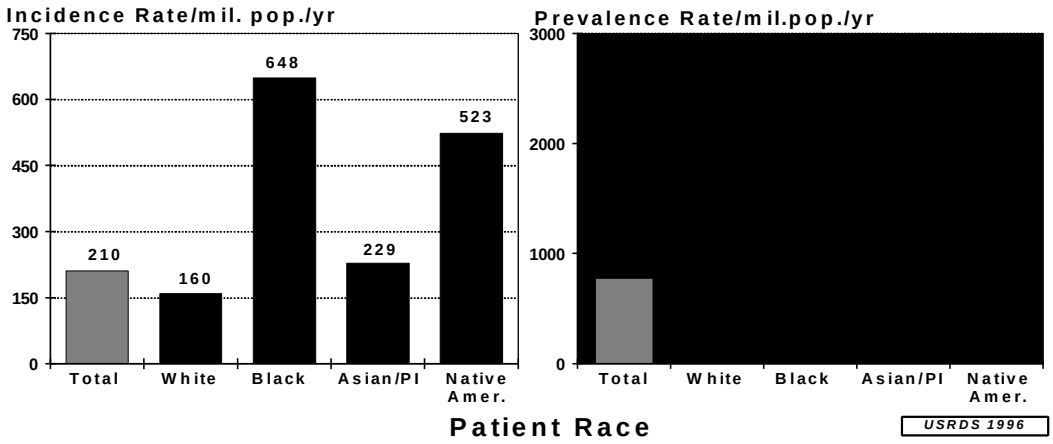

Figure II- 6

Medicare treated ESRD incidence and point prevalence rates by race, 1991-93. Rates adjusted for age and sex. Rates do not include patients in Puerto Rico or the U.S. Territories. Medicare patients only. Source: Reference Tables A.8, B.10.

Table II-2 reveals that the remaining attributed causes of ESRD include cystic kidney disease (3 percent),interstitial nephritis (3 percent), obstructive nephropathy (2 percent), collagen vascular diseases (2.2 percent), malignancies, metabolic diseases, congenital and hereditary diseases, sickle-cell disease, AIDS, and a small number of other minor entities. The cause was considered to be unknown by the physician in 5.4 percent of cases.

The age of the patient at the onset of ESRD is strongly associated with the attributed diagnosis. In the pediatric and adolescent age group, the major causes of ESRD are glomerulonephritis (36.1 percent of incident cases), congenital/hereditary diseases (17 percent), collagen vascular diseases (9.6 percent), and obstruction (8.8 percent) whereas these diagnoses

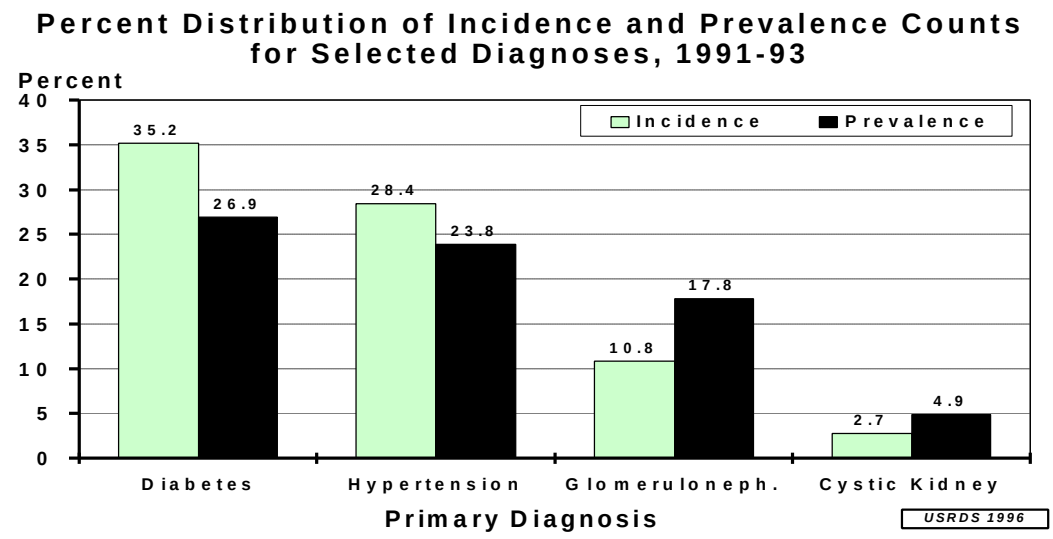

Figure II- 7

Distribution of treated incident and prevalent ESRD patients for the most common primary diagnoses, 1991-93. Patients in Puerto Rico or the U.S. Territories are not included. Medicare patients only. Source: Reference Tables A.1, B.1.

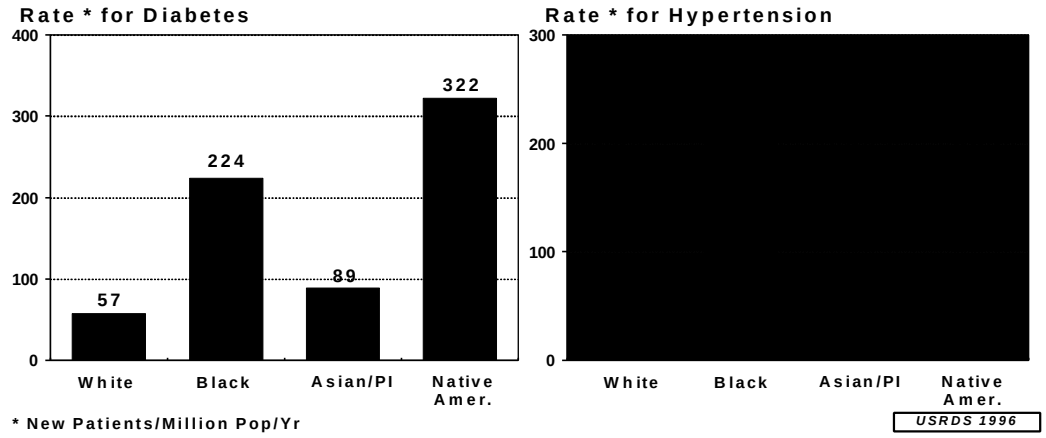

Figure II- 8

Medicare treated ESRD incidence rates by primary diagnosis (diabetes, hypertension) and race, 1991-93. Rates adjusted for age and sex. Rates do not include patients in Puerto Rico or the U.S. Territories. Medicare patients only. Source: Reference Table A.35.

become progressively less common in older age groups (Table II-2).

In contrast, hypertension and diabetes are far less common causes of ESRD in the <20 year age groups than in adults. Table II-3 illustrates through the use of row percentages that the pediatric/adolescent ages compose a small fraction of ESRD overall (1.7 percent) but they are relatively over-represented in the congenital/hereditary category and underrepresented in diabetes and hypertension.

There are also important interactions between diagnosis and race. Table II-2 shows that Blacks exceed Whites in the percentage with ESRD attributed to hypertension, sickle-cell disease, and AIDS whereas Blacks have a smaller than expected percentage of most other attributed diagnoses (as

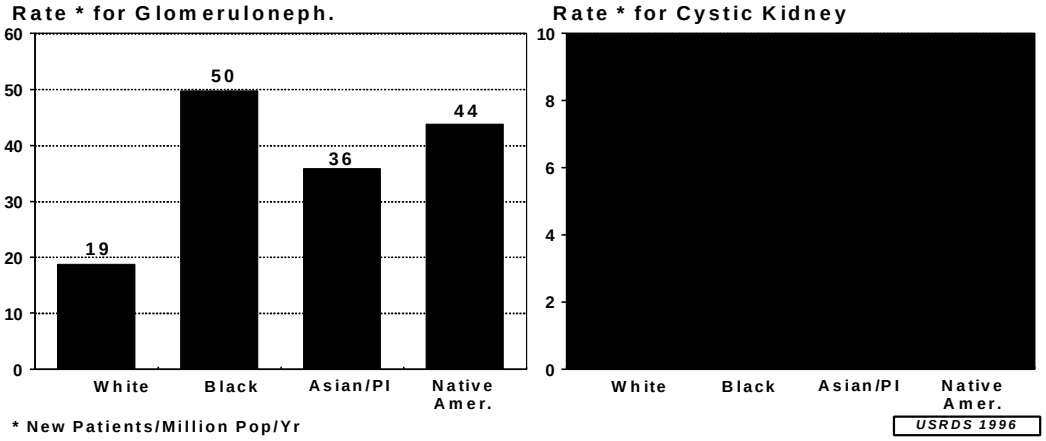

Figure II- 9

Medicare treated ESRD incidence rates by primary diagnosis (glomerulonephritis, cystic kidney disease) and race, 1991-93. Rates adjusted for age and sex. Rates do not include patients in Puerto Rico or the U.S. Territories. Medicare patients only. Source: Reference Table A.35.

Treated Medicare ESRD Incidence and Prevalence by ESRD Network, 1996

Net-work	Location of Network Office[1]	States and Territories	Network Name	Point Prevalence Rate, 1993 [2]	Incidence Rate, 1993 [2]
1	CT	CT, MA, ME, NH, RI, VT	ESRD Network of New England	733.9	207.4
2	NY	NY	ESRD Network of New York, Inc.	861.5	210.0
3	NJ	NJ, PR3, VI3	TransAtlantic Renal Council	923.6	250.3
4	PA	DE, PA	ESRD Network Organization No. 4	897.7	219.3
5	VA	DC, MD, VA, WV	Mid-Atlantic Renal Coalition	968.5	218.8
6	NC	GA, NC, SC	Southeastern Kidney Council, Inc.	1,036.9	218.3
7	FL	FL	ESRD Network of Florida, Inc.	893.3	219.8
8	MS	AL, MS, TN	Network 8, Inc.	993.1	209.7
9	IN	IN, KY, OH	Tri State Renal Network, Inc.	810.3	235.5
10	IL	IL	Renal Network of Illinois	883.7	237.3
11	MN	MI, MN, ND, SD, WI	Renal Network of the Upper Mid-West, Inc.	797.7	220.0
12	MO	IA, KS, MO, NE	ESRD Network Organization No. 12	776.8	227.3
13	OK	AR, LA, OK	ESRD Network Organization No. 13	898.7	228.4
14	TX	TX	ESRD Network of Texas, Inc.	874.0	254.9
15	CO	AZ, CO, NM, NV, UT, WY	Intermountain ESRD Network, Inc.	687.9	212.7
16	WA	AK, ID, MT, OR, WA	Northwest Renal Network	592.8	198.1
17	N-CA	AS3, CA (N), CM3, HI, GU3	TransPacific ESRD Network	790.1	211.7
18	S-CA	CA (S)	ESRD Network Organization No. 18	704.2	208.3

Table II- 4

[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. [3] PR=Puerto Rico, VI=Virgin Islands, AS=American Samoa, CM=Marianna Islands, GU=Guam. Source: B.20, A.28.

compared to the column labeled '% of Total'). Table III-3 further illustrates that the percentage of Blacks with ESRD attributed to hypertension, focal glomerular sclerosis, collagen vascular disease (predominately lupus), sickle-cell disease, and AIDS is higher than the expected from the overall percentage of Blacks with ESRD (28.8 percent).

Figures II-8 and II-9 show the incidence rates for several major diagnoses by race group for 1991-93.. Viewed in this way (as an adjusted rate), it is clearly seen that the incidence rate of ESRD attributed to diabetes, hypertension, and glomerulonephritis is much higher for Blacks than for Whites. The incidence of these three ESRD diagnoses is modestly higher for Asian/Pacific Islanders than for Whites. Native Americans have the highest incidence rate of ESRD due to diabetes and the second highest rate for glomerulonephritis. ESRD attributed to hypertension is twice as likely in Native Americans than Whites but substantially less common than for Blacks. ESRD attributed to cystic kidney disease is primarily composed of autosomal dominant polycystic kidney disease. It is interesting to note the relative absence of large racial differences in the incidence of ESRD related to this largely genetically determined renal disease.

The interaction between diagnosis and sex is seen best in Table II-3. The overall predilection of males for ESRD is especially marked for hypertension, glomerulonephritis, obstructive nephropathy, malignancy, congenital/hereditary diseases, and

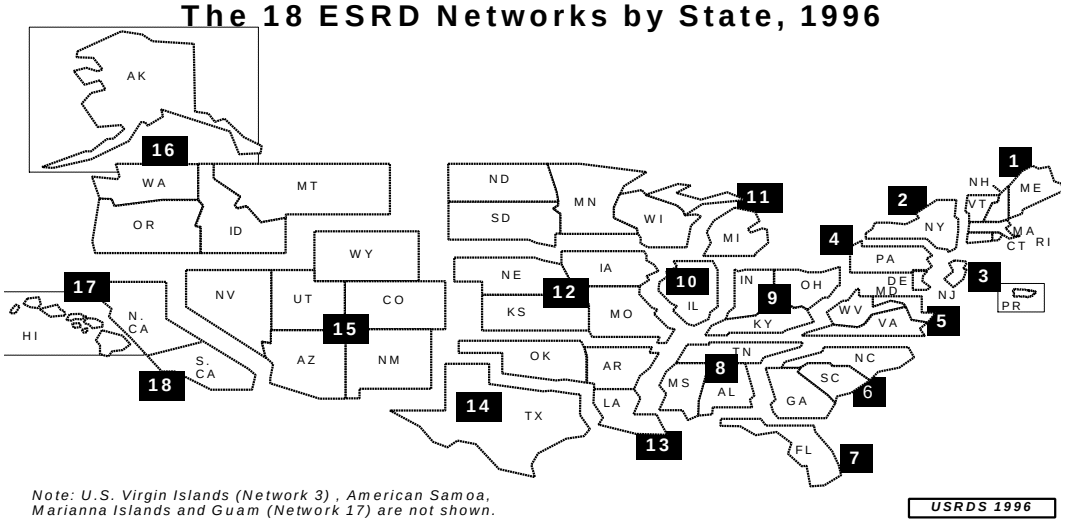

Figure II -10

Geographic location of the 18 ESRD Networks under contract with the Health Care Financing Administration of the U.S. Department of Health and Human Services. The Networks are frequently identified throughout this report by the location of each Network Office, as shown in Table II-4.

AIDS-related ESRD. In contrast, women predominate (i.e. < 50 percent male) in diabetes, interstitial nephritis, and most collagen vascular diseases. In part, the overall and disease specific differences in ESRD incidence by sex are related to differences by sex in the prevalence of the underlying diseases. For example, collagen vascular disease, analgesic abuse, and diabetes are more common in women whereas hypertension and urinary obstruction are more common in men. It is interesting to note that cystic kidney disease is approximately equal among men and women. There is no difference by sex in the penetrance of this category, consisting primarily of autosomal dominant polycystic kidney disease.

Network Patterns

There are regional differences in the incidence and prevalence of treated ESRD as illustrated by the variation across the 18 ESRD networks (Figure II-10), even after adjustment for differences in the age, sex, and race composition of the general population in each region (Table II-4). For example, the adjusted incidence of ESRD in 1993 ranged from a high of 255 patients per million population for the Network of Texas (TX) to a low of 198 new patients per million in the Northwest Renal Network (WA). As with other USRDS data, the rates in this ADR report for any given year may differ slightly from previous ADR reports due to continuous updating of the database and random fluctuations.

Longitudinal data on incidence patients by geographic region allow comparisons of trends over time. Thus, the incidence counts and adjusted rates from 1984 to 1993 have been calculated by state and ESRD networks (reference tables A.23 - A.29). The variability between locations could arise from differences in access to ESRD care, medical practice, environmental factors, or random variation. Variations between years at the same location may be due to the improvement of the data sources over the last few years.

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