Chapter V

Patient Mortality and Survival

Key Words:
ESRD mortality
ESRD survival
Dialysis outcomes
Expected remaining lifetimes
Unit-Specific Reports
Standardized mortality ratios
Dialysis-unrelated deaths
Long-term survival
U.S. death rates

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

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

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

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

The six sections are:

1. Trends in adjusted first-year death rates among *incident patients* for the years 1984-1994. These trends, in mortality during the first year of ESRD therapy, are shown for several patient subgroups. Adjusted mortality rates during the first year of ESRD therapy have decreased for nearly all successive cohorts of incident patients between 1984 and 1994.

2. *Long-term survival*. The 5-year survival rates are 88.2 percent and 46.1 percent among 15-19-year-olds and 50-54-year-olds, respectively, in the 1990 incident cohort of ESRD patients, and the 10-year survival rates are 74.7 and 21.6 percent for the same two age groups, respectively, for the 1985 ESRD incident cohort. One-, 2-, and 5-year survival rates are also compared for the various incident cohorts of dialysis patients. Long term survival (through 5 years) is better for the 1990 cohort than for the 1985 cohort, although most of the gains are seen in the early years of therapy.

3. Standardized mortality rates for *prevalent patients* over the years 1984-1996. Mortality among prevalent patients decreased between 1988 and 1994, and has remained nearly constant since 1994.

4. Projected *remaining years of life* for ESRD patients, by patient age (regardless of duration of ESRD). The expected remaining years of life or life expectancies for the entire U.S. population are between 2.1 and 5.5 times those for corresponding ESRD patient groups, while the ratio is between 2.7 and 6.3 compared to dialysis patients.

5. *Facility-specific* standardized mortality ratios for 1993-1995. The average patient age and percent of patients who are diabetic varies substantially among facilities, so the standardized mortality ratio is a more useful tool for facilities for evaluating mortality than the crude mortality rate. Standardized mortality ratios vary by ± 15 percent (standard deviation) among facilities, representing 1 in 6 extra or fewer deaths than would be expected based on the age, race, sex, and diabetes mix (but not the severity of concomitant disease) of the patients at a facility.

6. Methods for calculating *national death rates*. There were several major changes in the analysis methods used for this year: deaths not plausibly related to dialysis were excluded and a regression model was used to stabilize the year-to-year variation in the rates.

Trends in Death Rates Among Incident Patients

Methods

We calculated adjusted survival curves for the incident groups of patients starting ESRD therapy in each calendar year for the years 1984-1994 and report the corresponding death rates for patients during their first year of therapy. Since the Medicare system does not achieve complete reporting of patient data before day 90, we defined the incident cohort to consist of those patients whose 91st day of therapy occurred during each specific year.

Specifically, we calculated directly adjusted (Breslow) *Kaplan-Meier* (KM) survival curves (Kaplan) starting 91 days after first treatment for each such incident cohort. The resulting surviving proportions are weighted averages of Kaplan-Meier estimates for patient subgroups defined by age, race, sex, and diagnostic categories, for each incident cohort of patients. The weights correspond to the proportion of ESRD patients in each subgroup in the designated reference population, which is the 1993 incident cohort, as described in Chapter XIII.

The adjustment method was used to account for the fact that the age, race, sex, and diagnosis characteristics of the incident cohorts of ESRD patients have changed through the years. Unadjusted survival proportions (and the corresponding death rates) are likely to differ across cohorts merely because of such changes in patient characteristics. Readers who are interested in the outcomes for a particular year, rather than in comparisons across years, should refer to the tables of unadjusted survival probabilities in Section E of the Reference Tables.

The adjustment process yields estimates of the survival patterns that would have arisen for the cohorts, had they all had the same age, race, sex, and diagnosis composition as the reference population (incident in 1993). Since the adjusted survival curves are all adjusted to the same reference population, any remaining differences between them is due to factors other than age, race, sex, and diagnosis. Thus, direct comparison of adjusted survival proportions and/or mortality rates across various years yields more useful interpretations than would comparison of unadjusted survival proportions or mortality rates.

We then calculated the average death rate per 100 patient years during the first year from these estimated adjusted surviving proportions using equation 5.1 below.

(5.1) $\text{death rate} = -100 \cdot \ln(\text{fraction alive at year 1})$

Correspondingly, the fraction alive at 1 year can be calculated from the reported death rates as the exponential function of (-death rate). Thus the fraction dead can be calculated using equation 5.2.

(5.2) $\text{fraction dead at year one} = 1 - e^{-\text{death rate}}$

For example, a death rate of 25.2 per 100 patient years corresponds to 22.3 percent dead annually ($1 - e^{-0.252}$). These relationships follow from standard actuarial relationships between rates and surviving proportions (Allison).

Although the mortality rates reported in this chapter are comparable across the years specifically reported in this Annual Data Report (ADR), they are not comparable to results from other USRDS ADRs because the definition of the reference population differs for each ADR. The reference population for this ADR is the 1993 incident cohort.

The small number of patients seen by individual physicians or facilities makes it difficult for health care providers to observe trends because of statistical variation. The combined data from the USRDS allow aggregation so that general patterns can be seen despite the variations present in the outcomes for individual patients or facilities.

The trends shown here represent the aggregate national experience for the U.S. ESRD population as reported to the USRDS. Improvements in technology and practice patterns are initiated at different times from facility to facility, so changes at the facility level may not correspond to the trends shown here.

The trend in death rates among incident ESRD patients is presented as death rates during the first year for each incident cohort. For those surviving the first year, death rates during the second year were very similar (1995 ADR) and are not presented here.

Results

Table V-1 shows the importance of accounting for the mix of patient characteristics when evaluating mortality results. The average age and the percent of patients with diabetes as the cause of ESRD are shown in columns 2 and 3 of Table V-1 for successive cohorts of incident patients between 1987 and 1994. The percent diabetic and the average age have increased each year, with only minor exceptions. If there were no other changes, we would expect crude death rates to increase for these successive cohorts, due to the 2.8 year increase in average age and the 24 percent increase in percent diabetic patients. However, column 4 shows that the crude death rates during the first year of therapy for these incident cohorts did not increase, but instead declined by 10 percent during this same time period. This raises the question: By how much would the crude death rates have decreased if the average age and percent diabetic had not increased? One answer is given by the adjusted mortality rates, which are shown in the last column. The adjusted mortality rates are adjusted for race and sex, as well as for age and diabetes. The adjusted rates can be interpreted as the death rates that would have arisen if the patients in each successive year had the same age-race-sex-diabetes characteristics as did the 1994 incident cohort. The 19 percent reduction in the **adjusted** rates during this time period is substantially larger than the 10 percent reduction in the **unadjusted** death rates and can be interpreted as the reduction that would have occurred if the patient characteristics had not changed over the years.

The adjusted death rates during the first year of ESRD are shown in Figure V-1 for several treatment groups of ESRD patients, classified by year of incidence or transplantation. Results for "Dialysis patients" and "All ESRD patients" are categorized by year of first treatment for ESRD, measured from 90 days after the initiation of therapy (to account for Medicare enrollment). The mortality data for dialysis patients are censored at transplantation for those patients transplanted within 1 year of ESRD enrollment. First cadaveric transplant recipients are categorized by year of transplantation with followup measured from the time of first transplantation.

Death rates in the first year of therapy were 3 percent lower in the 1994 cohort than they were in the 1993 incident cohort of all ESRD patients. This continues the general trend that has been seen during the first year for most incident cohorts since 1983, (except for the 1985 and 1987 cohorts). The adjusted first-year death rates for all dialysis patients have decreased from 36 per 100 patient years at risk for the 1984 cohort to 25 per 100 patient years at risk for the 1994 cohort.

As shown above, there has been a trend during the past decade of treating older patients and more patients with diabetes (Young; Reference Tables, Section A). The adjusted rates reported here account for these changes, and show what would be expected

Changing Profile of Incident ESRD Patients by Year of Incidence

Year of Incidence	Average Age	Percent Diabetic	Unadjusted Death Rate*	Adjusted Death Rate*
1987	56.8	30.1	26	30
1988	57.1	30.8	26	29
1989	58.0	32.8	26	28
1990	58.5	34.2	25	27
1991	59.1	35.8	25	27
1992	59.5	36.4	25	26
1993	59.7	35.9	24	25
1994	59.6	37.3	24	24

* deaths per 100 patient years at risk
Source: Reference Tables A.1, A.14, E.14, and E.18

USRDS 1997

Table V-1

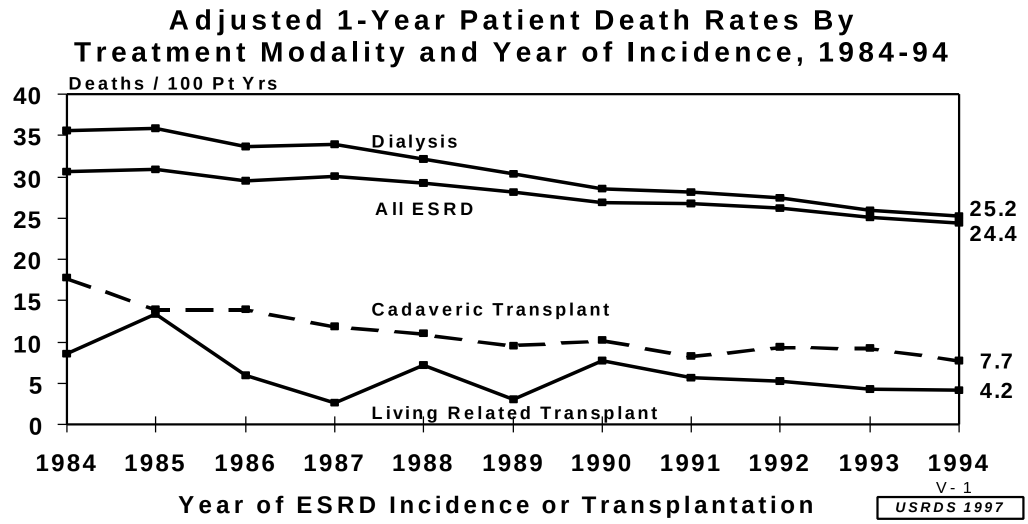

Figure V-1

Death rates based on adjusted Kaplan-Meier estimates, by modality and year of ESRD incidence or of transplantation. Calculation of death rates starts at day 91 following onset of ESRD for dialysis patients and continues through 1 year plus 90 days (censored at first transplant), and at day of transplant for transplanted patients. Adjusted for age, race, sex, and primary diagnosis (diabetes, hypertension, glomerulonephritis, other) characteristics of the 1993 incident cohort. Source: Reference Tables E.18, E.34, E.42 and E.50 (with equation 5.1).

had the patient mix by age, sex, race, and diabetes been unchanged over the years. Thus, the adjusted death rate reported for the 1984 cohort, for example, gives more weight to older diabetic patients than were present in that cohort, and is thus higher than the observed crude (unadjusted) rate for that group (Table V-1). However, there may be other changes in the patient characteristics during the past decade which are not accounted for by the adjustments for age, race, sex, and cause of ESRD, which may explain the trends seen here. For example, the USRDS data cannot be adjusted for specific comorbidity in the overall ESRD population because these measures are not recorded for all patients. However, the adjustment for age and diabetes accounts for the average levels of comorbidity associated with aging and diabetes.

Figure V-1 shows that the cohort of patients receiving cadaveric transplants during 1994 experienced lower 1-year death rates compared to the 1992 and 1993 cohorts. Survival for patients who received living related transplants has also been improving since 1990.

Figure V-1 shows that adjusted first-year mortality for cadaveric or living related transplant recipients, measured from the day of transplant, is lower than for patients starting treatment on dialysis. However, Figure V-2 shows that the death rates, as summarized by the adjusted mortality risk ratio, for dialysis patients after they were put on the transplantation wait-list, are less than half (48 percent) those of all dialysis patients. Thus, part of the large reduction in mortality seen among transplanted patients, relative to all dialysis patients, can be explained by the fact that transplant patients are drawn from wait-listed dialysis patients, who have substantially lower mortality than do dialysis patients who are not wait-listed. Because of these differences, survival of transplanted patients is more appropriately compared to the survival of wait-listed dialysis patients rather than all dialysis patients. Nonetheless, death rates among cadaveric and living related transplant patients are only 32 percent and 21 percent as high as those among all dialysis patients, respectively, and are even lower than among wait-listed dialysis patients. Thus, in addition to the effect of selection of healthier patients to be on the waiting list, part of the reduction in mortality seen among transplanted patients is likely to be related to the benefit of transplantation itself. The remainder of this section will be limited to mortality results for dialysis patients, with followup for mortality stopped (censored) on the day of first transplantation. More detailed results are reported for transplant patients in Chapter VII.

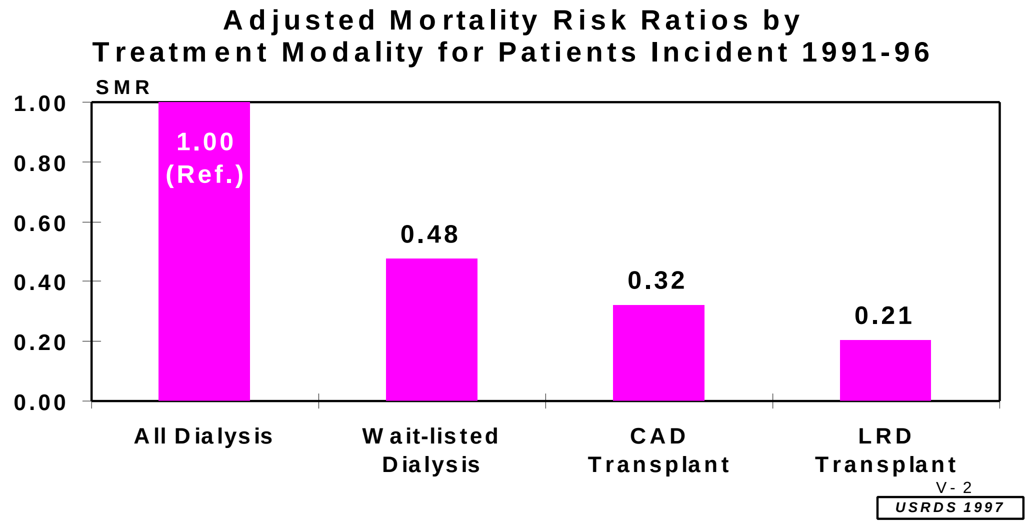

Figure V-2

Adjusted mortality risk ratios by treatment modality for patients incident 1991-96. Adjusted to the age, race, sex, and primary diagnosis (diabetes, other) characteristics of the 1995 prevalent dialysis population excluding DU deaths. Source: Special Analysis.

Age: Figure V-3 shows the first-year death rates for dialysis patients by year of first ESRD therapy and age group. These death rates for all but the youngest age group (0-19 years) are adjusted for race, cause of ESRD, and sex, while the death rates for the youngest age group (0-19 years) are adjusted only for the age characteristics of the 1993 incident cohort due to small sample sizes. There is some improvement in survival for the 1994 cohort relative to earlier cohorts for all age groups.

Death rates for pediatric patients (0-19 years)

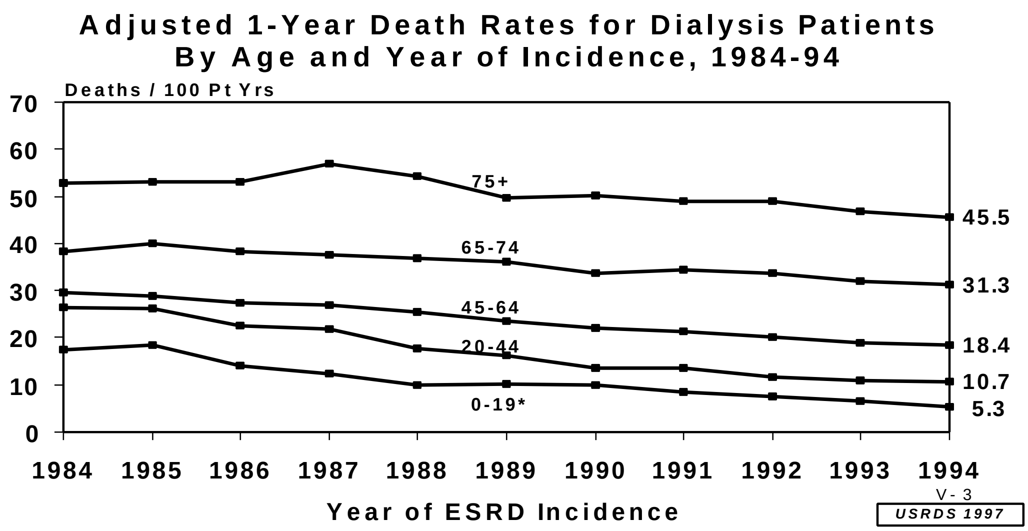

Figure V-3

Death rates based on adjusted Kaplan-Meier estimates by age at onset of ESRD and year of incidence. Starting at day 91 following onset of ESRD and continued through 1 year plus 90 days (censored at first transplant). Adjusted for the race, sex, and primary diagnosis characteristics (8 categories; see reference table) of the 1993 incident cohort for those 20 years and older. Death rates for the 0-19-age-group adjusted for only the age characteristics of the 1993 incident cohort. Source: Reference Tables E.30, E.34 and A.1 (with equation 5.1).

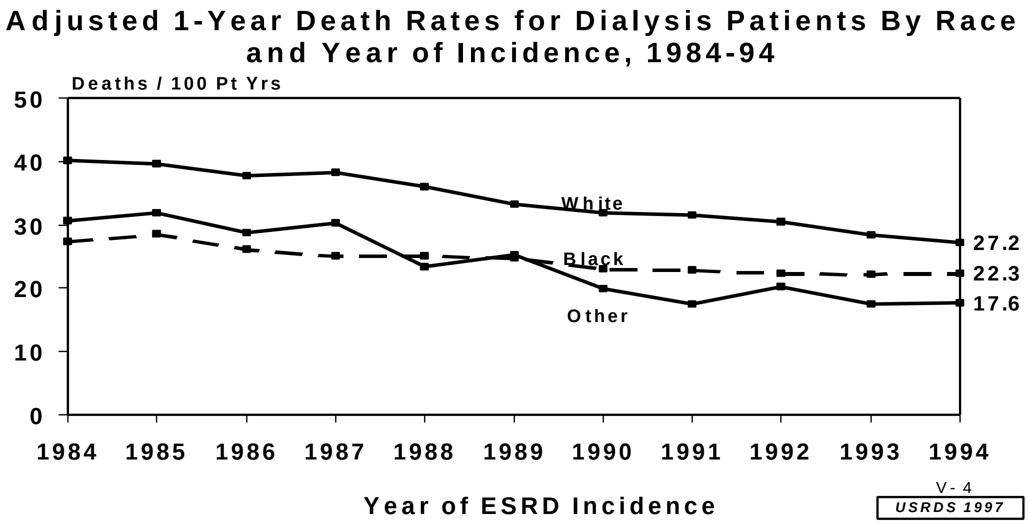

Figure V-4

Death rates based on adjusted Kaplan-Meier estimates by race and year of incidence. Starting at day 91 following the onset of ESRD and continued through 1 year plus 90 days (censored at first transplant). Adjusted for the age, sex, and primary diagnosis (diabetes, hypertension, glomerulonephritis, other) characteristics of the 1993 cohort. Source: Reference Table E.34 (with equation 5.1).

have decreased from 17 per 100 patient years at risk in 1984 to 5 per 100 patient years at risk in 1994. More detailed results for pediatric patients are reported in Chapter VIII.

The most consistent and greatest improvement in survival for dialysis patients has been seen in the younger adult age ranges (20-44 years). First-year death rates for this age group decreased from 26 per 100 patient years at risk in 1984 to 11 per 100 patient years at risk in 1994. The first-year death rate decreased from 30 per 100 patient years at risk to 18 per 100 patient years at risk in the 45-64-year-old age group and from 38 per 100 patient years at risk to 31 per 100 patient years at risk in the 65-74-year-old patients in the same time interval, 1984-1994.

Race: Figure V-4 shows first-year death rates for dialysis patients by year of first ESRD therapy and race, adjusted for age, cause of ESRD, and sex. There has been a consistent improvement in first-year mortality rates for White ESRD dialysis patients since 1984, except in 1987. There has also been an improving trend for Black patients since 1984, although the magnitude of the year-to-year improvement has not been as great as it has been for White patients.

There has also been a substantial improvement in survival for patients of other races since 1984, although the year-to-year trend has not been as consistent as it has been for White or Black patients, in part because of random fluctuations due to small counts of patients. In recent years, dialysis patients of other races had lower first-year mortality rates than did Black patients, while White patients consistently had the highest first-year mortality rates. The difference between Black and White patient 1-year death rates has decreased from 13 per 100 patient years at risk in the 1984 incident cohort to 5 per 100 patient years at risk in the 1994 incident cohort. These comparisons are adjusted for age, cause of ESRD, and sex, and are valid on average, but may not be true for each individual age-cause-sex subgroup.

Cause of ESRD: Figure V-5 shows the first-year mortality rates for dialysis patients by year of first ESRD therapy and primary cause of ESRD adjusted for age, race, and sex. The primary causes of ESRD for these results are diabetes, hypertension, glomerulonephritis, and “other”. Mortality during the first year was lower in 1994 than in 1992 and 1993, for patients with diabetes and “other causes”. In contrast, from 1993 to 1994, there was an increase in first-year mortality for patients with ESRD due to hypertension and to glomerulonephritis. This increase in first-year mortality is a change from the year-to-year decrease that has been seen since 1984.

There has been an overall improvement in survival for each incident cohort from 1984 to 1994

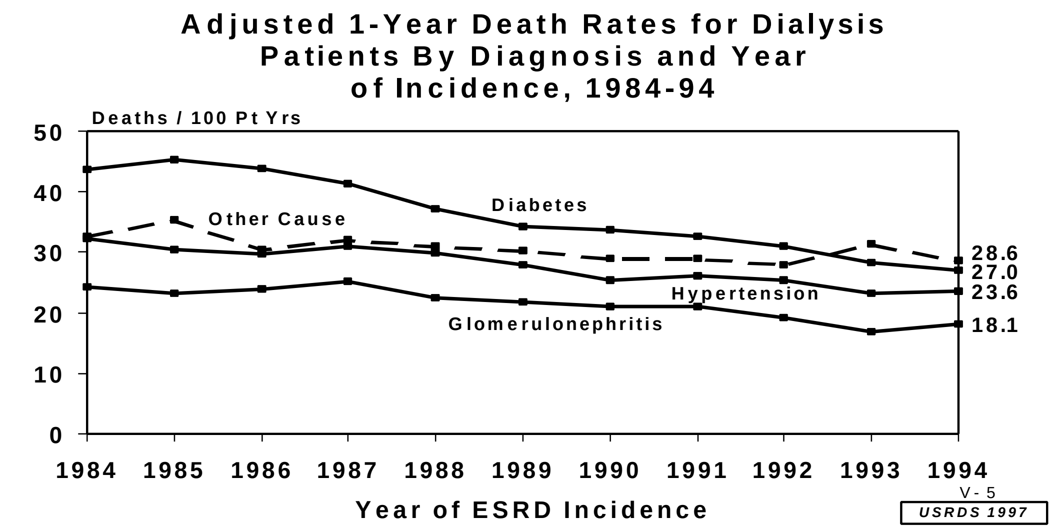

Figure V-5

Death rates based on adjusted Kaplan-Meier estimates by cause of ESRD and year of incidence. Starting at day 91 following the onset of ESRD and continued through 1 year plus 90 days (censored at first transplant). Adjusted for the age, race, and sex characteristics of the 1993 cohort. Source: Reference Table E.34 (with equation 5.1).

for each of the four major causes of ESRD. First year mortality decreased most dramatically and consistently for diabetic patients, from 44 per 100 patient years in 1984 to 27 per 100 patient years in 1994. Patients with glomerulonephritis have had the lowest first-year mortality in this 10-year time period. Through 1992, patients with diabetes had the highest first-year mortality. In 1993, patients with other causes of ESRD had the highest first-year death rate; this was again seen in 1994. Previous ADRs have reported that patients with diabetic ESRD had the highest first-year mortality but “other” causes of ESRD are now reported to have the highest mortality for 1993 and 1994. There have been some changes in the categorization of causes of ESRD, as described in more detail in Chapter II, which could be responsible for some of these changes in relative mortality rates. More details related to cause of ESRD are reported in Chapter VI.

Gender: Figures V-6 shows the first-year mortality rates for dialysis patients by year of first ESRD therapy and sex, after adjustment for age, race, and primary cause of ESRD.

There has generally been an improvement in survival for both males and females in each cohort since 1984. Until 1993, females had lower adjusted mortality at 1 year than males for each incident cohort. From 1983 through 1988 the difference was about 5 deaths per 100 patient years. This difference decreased to about 2 deaths per 100 patient years for the period 1989 through 1992. In the 1993 and 1994 cohorts the death rates have been similar for males and females (25.5 and 24.8 per 100 patient years, respectively, in the 1994 cohort).

Summary

There has been a progressive improvement in first-year survival for each successive year’s incident cohort since 1984. This improvement has been consistent across several classifications of patients and appears to have been largely sustained in the 1994 cohort. These findings were adjusted for age, race, sex, and cause of ESRD and thus are not likely to be due to changes in the patient mix of new ESRD patients with respect to these characteristics. It is possible that other patient characteristics not measured in these USRDS data have changed during this time period, and that these changes are responsible for the improved survival (McClellan, 1991; McClellan 1992; USRDS, 1992; Andersen; Collins; Held, 1994).

A possible explanation for the decline in mortality is that changes in dialysis therapy may be responsible for improved survival (Hakim; Owens; Parker; Held, 1996). During this time period the renal provider community has given increasing attention to the dose of dialysis that is delivered to hemodialysis patients (see Chapter III). In addition, there have been

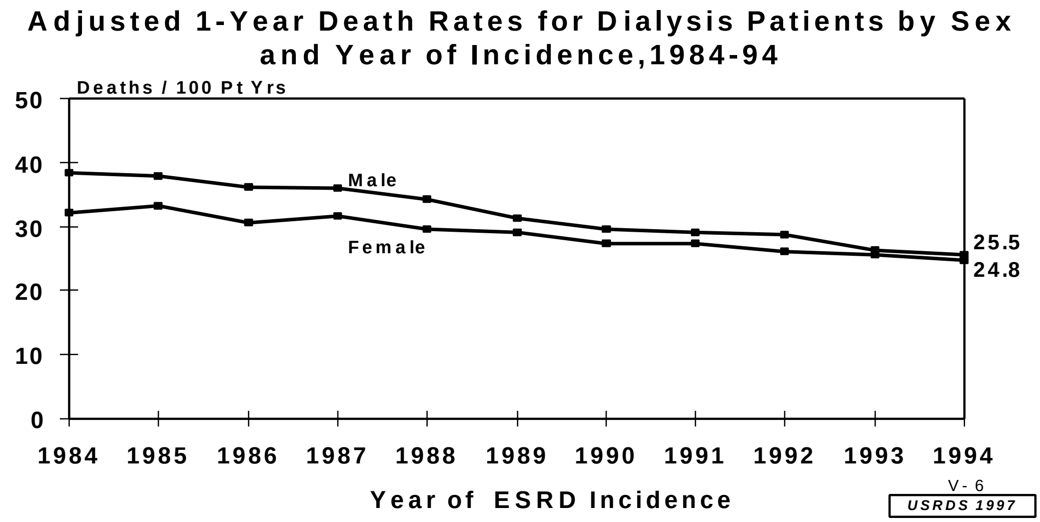

Figure V-6

Death rates based on adjusted Kaplan-Meier estimates by sex and year of incidence. Starting at day 91 following the onset of ESRD and continued through 1 year plus 90 days (censored at first transplant). Adjusted for the age, race, and primary diagnosis characteristics of the 1993 cohort. Source: Reference Table E.34. (with equation 5.1).

changes in dialysis equipment, including a shift from cellulosic to synthetic hemodialysis membranes and improved connection devices for peritoneal dialysis. As improvements in delivered care continue to spread through the community of renal providers, we may see continued improvements in survival across the nation.

Long Term Survival

Methods

Using a Kaplan-Meier (KM) regression model as described in the previous section of this chapter, we report the cumulative surviving fraction at 1, 2, and 5

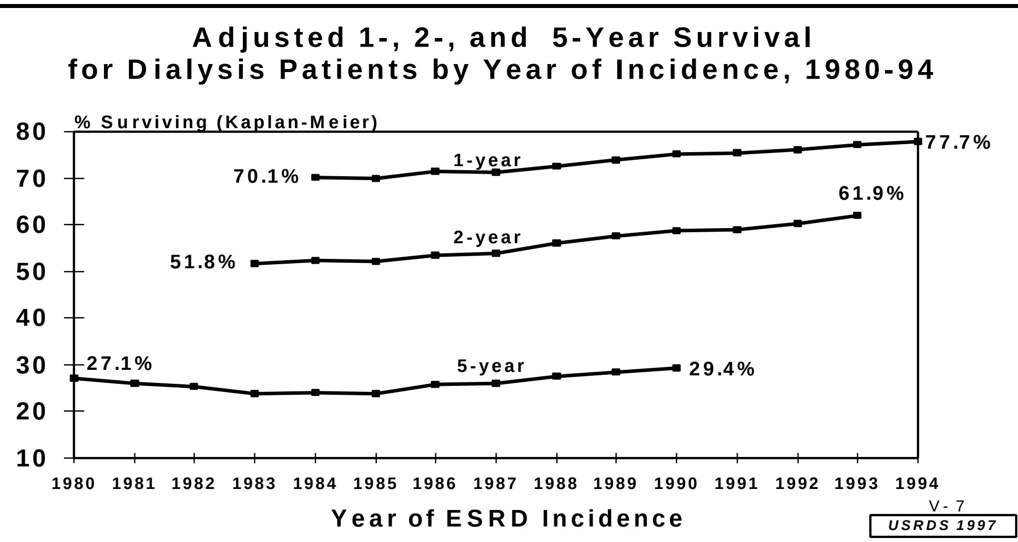

Figure V-7

Kaplan-Meier dialysis patient 1-, 2-, and 5-year survival estimates by year of incidence. Starting at day 91 following the onset of ESRD and continued through 1 year plus 90 days (censored at first transplant). Adjusted for the age, race, sex, and primary diagnosis (diabetes, hypertension, glomerulonephritis, other) characteristics of the 1993 incident cohort. Source: Reference Tables E.34, E.35 and E.36.

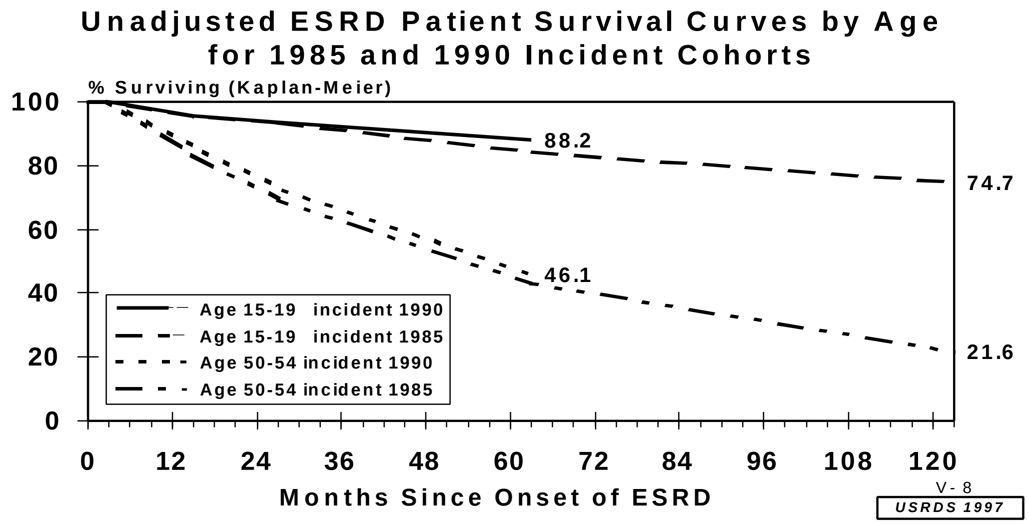

Figure V-8

Unadjusted Kaplan-Meier dialysis patient survival estimates (1985 and 1990 cohorts) for two age groups. Starting at day 91 following the onset of ESRD. Source: Reference Tables E.14, E.15, E.16, E.17 .

years after day 90 of ESRD for several incident cohorts of dialysis patients. These results are adjusted for age, race, sex, and cause of ESRD so that they can be compared across years.

In addition, we calculated 5- and 10-year survival curves for two age groups of the incident patients starting ESRD therapy in 1985 and 1990 and followed through 1994. These curves are not adjusted and include data for all ESRD patients, both dialysis and transplant. Since these results are not adjusted, the curves for the two cohorts reflect the actual experience and differences between the two cohorts, and should not be compared as though they are similar with regard to age, race, sex, and diabetes.

Results

The percent of dialysis patients surviving at 1, 2, and 5 years by year of first ESRD therapy and adjusted for age, sex, race, and cause of ESRD is shown in Figure V-7. Five-year survival is shown for the 1980 through 1990 incident cohorts, 2-year survival for the 1983 through 1993 incident cohorts, and 1-year survival for the 1984 through 1994 incident cohorts. There has been a consistent improvement in 1-, 2-, and 5-year survival since 1984. Five-year survival declined from 1980 to 1983, and has slowly improved since then. This decline may be due to a change in the way that the data were reported to HCFA. Thus the survival percentages before 1983 may not be directly comparable to those after 1983.

Figure V-8 shows the 5- and 10-year survival curves for 1985 and 1990 incident cohorts of all ESRD patients. Only the 15-19-year-old and 50-54-year-old strata are presented. The 1990 cohort has better survival than the 1985 cohort throughout the first 5 years of ESRD therapy. Most (74.7 percent) of the 15-19-year-old patients survived for more than 10 years and a large fraction (21.6 percent) of the 50-54-year-old patients survived for 10 years in the 1985 incident cohort. Based on the higher 5-year survival in the 1990 cohort we expect that more will also live to 10 years.

Mortality Rates for Prevalent Patients

Methods

Tables of national mortality rates for dialysis patients are given in Section D of the Reference Tables of this data report for dialysis patients being treated in 1995. These are based on prevalent dialysis patients (patients already being treated at the beginning of the year), incident dialysis patients (patients starting ESRD therapy with dialysis during the year), and previously transplanted patients who have returned to dialysis. These tables are based on

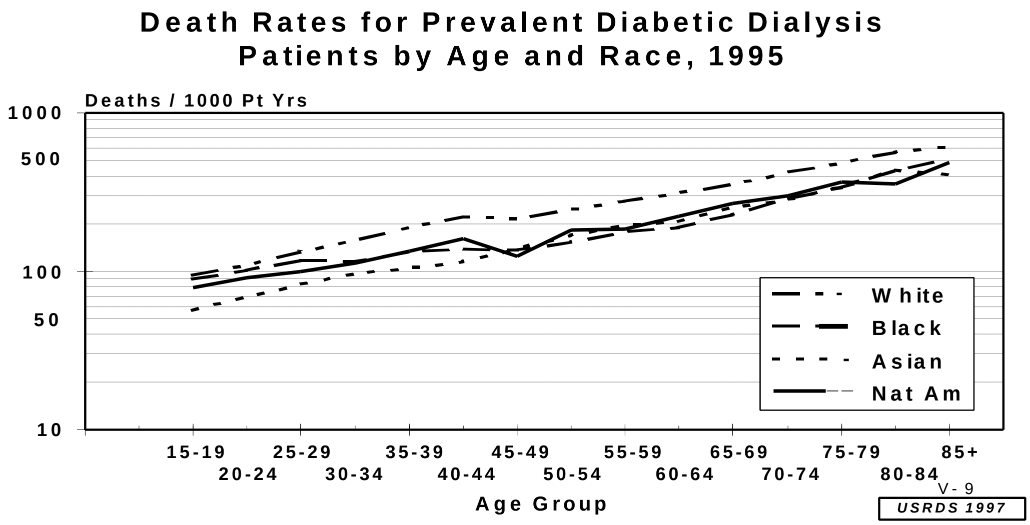

Figure V-9

Death rates for diabetic dialysis patients prevalent during 1995 by age and race, adjusted for sex. Starting at day 91 following the onset of ESRD (censored at first transplant). Patients with missing or unknown race, or missing primary diagnosis are excluded. DU deaths are excluded. Source: Reference Table D.2.

data for patients treated during 1993-95, but report death rate estimates for 1995 for 248 groups of patients classified by age, race, sex, and diabetes. These death rate tables exclude mortality due to AIDS, illegal drugs, and violent death, as described later in this chapter.

In order to show adjusted comparisons across a range of years, similar calculations were made based on data for patients treated during 1984-95. As described in section 6 of this chapter, a Poisson regression model was used to adjust for age, race, sex, and diabetes. The resulting adjusted rates are shown for each year.

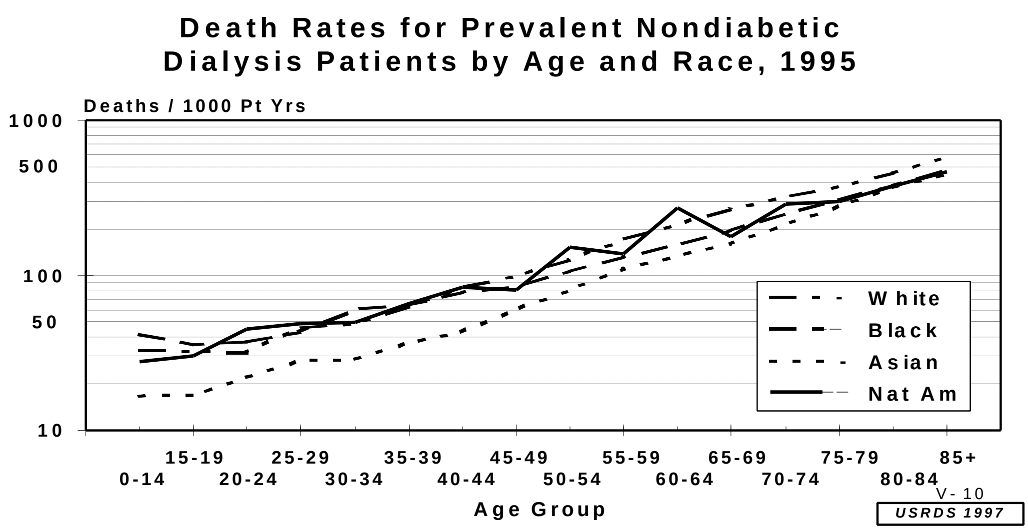

Figure V-10

Death rates for nondiabetic dialysis patients prevalent during 1995 by age and race, adjusted for sex. Starting at day 91 following the onset of ESRD (censored at first transplant). Patients with missing or unknown race, or missing primary diagnosis are excluded. DU deaths are excluded. Source: Reference Table D.2.

Results

Figures V-9 and V-10 show the U.S. death rates for diabetic and nondiabetic dialysis patients, respectively. Both are adjusted for sex, and stratified by age and race. The curves for the diabetics show a small decline in mortality from the 40-45 age group to the 45-49 age group for Whites, Blacks, and Native Americans. It is possible that this decline represents an age related change in the relative prevalence of type 1 and type 2 diabetes, since the younger ages would be predominantly type 1, and the older ages would be predominantly type 2. The single mortality curve shown is thus a combination of two mortality curves, one for each type of diabetes.

Among nondiabetics, Blacks have a higher mortality in the younger ages, and then a mortality rate below that of Whites after age 39. Asians have the lowest death rate in all age categories. The curve for Native Americans is somewhat unstable because of small numbers of patients. Previous ADR mortality results included deaths due to AIDS, illegal drugs, and violence, so differences in the reported mortality among various age-race-sex groups could have been due to differences in these causes of death. These causes of death have been excluded from the death rates reported this year in order to focus attention upon those deaths that can be managed by medical care after the start of treatment for end-stage renal disease.

The unadjusted death rates for an incident cohort of patients tend to drop substantially (23 percent, in the example shown below) across successive years, as it is followed through time. However, the adjusted death rates do not change as much (5 percent, in the example shown below), and this relatively minor variation has been ignored in the death rates reported in this ADR. For example, Table V-2 presents the demographic characteristics and mortality rates, over successive years of followup, for the 1987 incident cohort. The table gives results for those patients from the 1987 incident cohort receiving dialysis treatment in successive years. Between 1987 and 1995, the average age decreased by 1 year and there was a 36 percent decline in the proportion of diabetics. The decline in the prevalence of diabetes resulted from higher death rates among diabetics, leaving a greater fraction of nondiabetic patients among the survivors. The average age among surviving dialysis patients stayed nearly constant, despite substantially higher death rates among older patients, because of the counter-balancing effect of high rates of removal of younger patients due to transplantation. Not surprisingly, there were corresponding declines of 23 percent and 5 percent, respectively, in the unadjusted death rate and the standardized mortality ratio (using all dialysis patients in 1995 as a reference group). The magnitude of the reduction in the SMR is not as great as that in the crude death rate, because the SMR adjusts for the changes in age and diabetes (along with the race and sex) of the patients surviving in each year. Other changes, that were not accounted for by the adjustment calculations, could explain the remaining drop in the SMR values. Figure V-11 shows adjusted death rates per 100 patient years at risk (± 2 standard errors) for prevalent patients by

Changing Demographic Profile among Patients in the 1987 Incident Cohort on Dialysis during Successive Years of Treatment

Year of Treatment	Average Age	Percent Diabetic	Unadjusted Death Rate*	SMR**
1987	55.5	31.6	0.26	1.21
1988	56.8	32.0	0.25	1.15
1989	57.8	30.8	0.24	1.10
1990	58.1	29.5	0.25	1.15
1991	57.9	28.1	0.24	1.13
1992	57.6	25.7	0.24	1.17
1993	56.8	23.6	0.23	1.18
1994	55.7	21.4	0.21	1.15
1995	54.8	20.2	0.20	1.15

* deaths per 100 patient years at risk
**SMRs based on 1995 national death rates for all dialysis patients adjusted for age, race, sex, and diabetes and excluding DU deaths.
Source: Special Analysis USRDS 1997

Table V-2

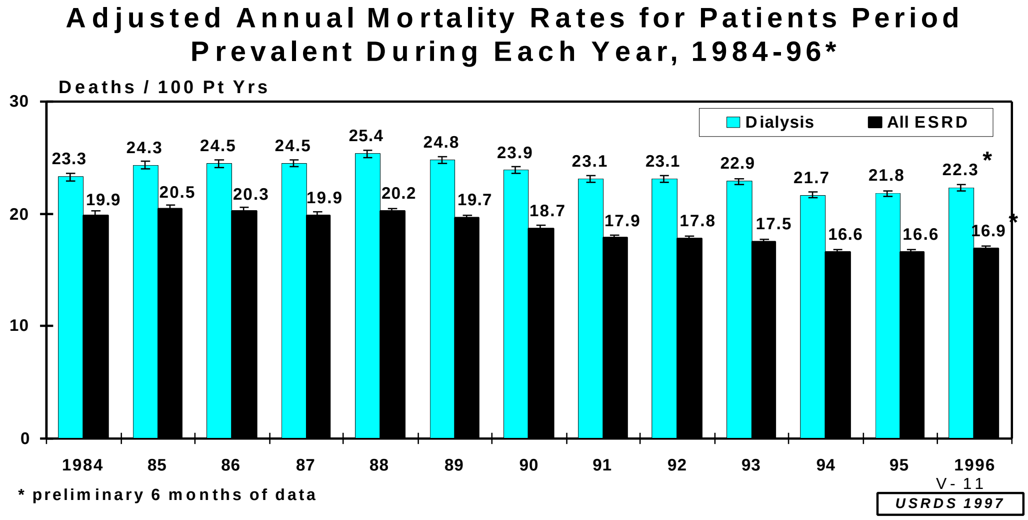

Figure V-11

Mortality rate (deaths/100 patient years at risk) for all dialysis patients and for all ESRD patients prevalent at any time during each year, this includes point prevalent patients at the beginning of each year and patients starting during each year (1984-96). Rates are adjusted for age, race (black, white, Asian, Native American), sex, and diagnosis (diabetic, other) and the bars show ± 2 standard errors for each rate. Patients with missing or unknown race, or missing primary diagnosis are excluded. (DU deaths included.) Source: Special Analysis.

year of treatment from 1984 to 1996, including all deaths. This figure presents both the results for dialysis patients only and for all ESRD patients (includes transplant patients). The 1996 rates are preliminary and are based on only the first six months of data in 1996.

The adjusted death rates for prevalent dialysis patients tended to increase between 1984 and 1988. Throughout this time period, and continuing to the present, patients not previously considered dialysis candidates, such as the elderly and diabetics, are now receiving renal replacement therapy (Young; Reference Tables, Section A). Thus, the level of unmeasured comorbidity could also have increased during this time period and could be responsible for part of the rise in adjusted death rates. The adjusted death rates for prevalent dialysis patients fell between 1988 and 1994. Since the trend to accept older and more diabetic patients for renal replacement therapy continued during this period, it seems unlikely that the level of unmeasured comorbidity fell. We are not aware of other changes in the criteria for starting renal replacement therapy (such as a pattern of starting therapy earlier in the progression of ESRD) that would lead to a reduction in death rates. However, there were many changes in treatment patterns during this time interval that might have led to improved mortality. The death rates were essentially unchanged between 1994 and 1995. There appears to be a small increase in the death rate for dialysis patients in 1996 when compared to 1995 (from 21.8 to 22.3 deaths per 100 patients years), but these results should be considered to be preliminary at this time since the data for 1996 may not be complete.

The adjusted death rates for all prevalent ESRD patients was fairly constant through 1988, followed by nearly a 20 percent decrease from 1988 to 1994. The lower death rates for all ESRD patients compared to dialysis patients is due to the effect of including healthier transplant patients in the “all ESRD” group.

Table V-3 reports crude (unadjusted) death counts and crude death percents for successive cohorts of prevalent dialysis patients from 1986 to 1995 and compares results from two different data sources. These crude rates do not adjust for the increasing age and frequency of diabetes as a cause of ESRD in the successive cohorts of prevalent ESRD patients. Consequently, the crude death rates do not show clearly the reduction in death rates that has occurred among prevalent patients since 1988, as is shown in the adjusted rates of Figure V-11. The first set of columns is based upon the HCFA Annual Facility Survey (AFS), as reported by individual facilities, which includes Medicare and non-Medicare patients,

Crude Mortality Percent for All Dialysis Patients, 1986-95

Survey Year[1]	HCFA Annual Facility Survey[2]			USRDS Patient Data Base		
	Patients	Deaths	% Dead	Patients	Deaths	% Dead
1986	87,885	19,987	22.7	84,751	17,091	20.2
1987	94,687	22,186	23.4	91,419	18,598	20.3
1988	102,070	24,860	24.4	99,127	21,151	21.3
1989	111,090	26,342	23.7	108,817	23,167	21.3
1990	124,394	28,741	23.1	120,273	25,024	20.8
1991	137,786	31,663	23.0	132,448	27,625	20.9
1992	151,998	35,985	23.7	145,773	31,138	21.4
1993	166,291	39,554	23.8	158,812	34,145	21.5
1994	180,884	42,115	23.3	172,927	36,449	21.1
1995	195,008	45,394	23.3	187,444	39,909	21.3

[1] Calendar year
[2] Facility reported deaths excluding transplant only facilities and those with missing data. (includes Medicare and non-Medicare dialysis patients)
Source: Special Analysis

USRDS 1997

Table V-3

while the second set of columns is based upon the USRDS database which can connect deaths with other patient and treatment specific characteristics. The USRDS database starts patient followup on day 91 after first ESRD treatment because of data reporting patterns associated with Medicare coverage. Thus, the USRDS excludes the mortality seen during the first 90 days, which could largely explain the fact that numbers in the USRDS columns are lower than those from the AFS.

Remaining Years of Life

Methods

The average remaining years of life was calculated for each of several age-race-sex groups of dialysis patients, using actuarial methods (Gross). The actuarial method calculates the mortality that would result in a hypothetical population, if it were subject to the current age-specific death rates among ESRD patients. The 1995 prevalent patient death rates for Black and White males and females of various ages (Reference Table D.2) were used in this calculation. These death rates exclude deaths due to AIDS, accidents ("accidents unrelated to treatment" on the ESRD Death Notification), and illegal drugs ("drug overdose (street drugs)" on the Death Notification), so the lifetimes reported here correspond to hypothetical populations in which these causes of death do not occur. The expected remaining lifetimes for the total U.S. population, shown for comparison do include these causes of deaths.

Results

Table V-4 shows projections of the expected remaining years of life for prevalent ESRD patients by current age group. The results are shown by race and sex for all ESRD patients (includes transplant patients), and for dialysis patients only. In addition, the expected remaining lifetime for the entire U.S. population is presented for comparison. The values in Table V-4 represent averages, and the lifetimes of individual patients will vary considerably from these averages.

The expected lifetimes of the ESRD population exceeds that projected for the dialysis population by 2 to 12 years through age 29. This is because the inclusion of healthier transplanted patients in the all ESRD calculations yields longer lifetimes compared to the dialysis only calculations, especially for the younger ages which have higher rates of transplantation. Over age 65, the expected remaining lifetime for all ESRD is about the same as that for dialysis, since transplants are much less frequent in these older age groups.

In the U.S. population, the life expectancy among females is higher than for males at each age, and in both the Black and White populations. In the ESRD population, the male and female lifetimes are more similar, although at most ages male lifetimes exceed those of females, especially at younger ages. In the Black dialysis population, the difference between male and female lifetimes tends to be smaller than in the all ESRD Black population. In the White dialysis population, males have a longer life expectancy than do females through age 39, while females have a longer life expectancy over age 40.

Expected Remaining Lifetimes for U.S. Population (1990), All ESRD Patients[1] (1995) and Dialysis Patients (1995) by Age, Race and Sex

	U.S. Population, 1990[2]				ESRD population, 1995[4]				Dialysis population[3,4], 1995			
	Black		White		Black		White		Black		White	
Age	M	F	M	F	M	F	M	F	M	F	M	F
0-14	61.5	67.0	71.1	78.0	27.5	25.3	33.4	32.0	22.6	20.9	21.6	22.4
15-19	51.3	57.4	58.5	65.0	20.0	19.6	24.0	22.6	16.7	17.1	16.4	15.0
20-24	46.8	52.9	53.8	60.1	17.7	17.4	21.0	19.3	15.1	15.2	14.2	12.5
25-29	42.5	48.7	49.2	55.3	15.3	15.3	17.5	16.5	13.1	13.2	11.4	10.3
30-34	38.2	44.6	44.6	50.4	13.4	13.2	14.8	14.0	11.6	11.5	9.5	8.8
35-39	34.1	40.6	40.0	45.6	11.8	11.7	12.4	11.9	10.4	10.4	8.0	7.6
40-44	30.1	36.8	35.4	40.8	10.3	10.2	10.2	10.1	9.2	9.2	6.7	6.8
45-49	26.2	32.4	30.9	36.1	8.9	8.8	8.4	8.3	8.1	8.1	5.9	6.1
50-54	22.5	28.2	26.5	31.5	7.5	7.3	6.8	6.6	6.9	6.8	5.1	5.1
55-59	19.1	24.3	22.4	27.0	6.3	6.1	5.4	5.3	5.9	5.8	4.2	4.3
60-64	16.0	20.6	18.6	22.8	5.3	5.3	4.3	4.3	5.1	5.1	3.6	3.7
65-69	13.3	17.2	15.2	18.9	4.3	4.4	3.4	3.4	4.2	4.3	3.1	3.2
70-74	10.8	14.2	12.0	15.2	3.5	3.5	2.8	2.9	3.5	3.5	2.7	2.8
75-79	8.8	11.3	9.3	11.8	3.0	2.9	2.4	2.5	3.0	2.9	2.4	2.5
80-84	6.9	8.7	7.0	8.8	2.4	2.4	2.0	2.0	2.4	2.4	2.0	2.0
85+	5.4	6.5	5.1	6.1	1.9	2.1	1.6	1.8	1.9	2.1	1.6	1.7

[1]Includes patients treated with either dialysis or transplantation.
[2] Vital Statistics of the US, Vol 2,1990: Mortality, Part A, Table I-9.
[3] Mortality followup is censored at transplant.
[4]Death rates used for these calculations exclude DU deaths.
Source: Special Analysis

USRDS 1997

Table V-4

In the U.S. population, the life expectancy among Whites is higher than for Blacks at each age for both the males and females through age 85. In the all ESRD population, lifetimes of Whites exceed those of Blacks through age 39, while the opposite is true over age 40. In the dialysis ESRD population, lifetimes of Blacks exceed those of Whites at almost every age (Figure V-10 shows that this consistency may not hold among nondiabetic dialysis patients).

Black males in the all ESRD population over age 25 have an expected remaining lifetime that is between 32 and 36 percent that of the age matched U.S. Black males. Black females with ESRD over age 25 fare worse, with an expected remaining lifetime between 25 and 31 percent that of age-matched U.S. Black females. Relative lifetimes of White ESRD patients are even shorter, ranging between 23 and 35 percent for males and between 18 and 30 percent among females over age 25, compared to the U.S. population.

Overall, the expected lifetimes of dialysis ESRD patients are between 16 and 37 percent those of the age-sex-race matched U.S. population, while lifetimes of all ESRD patients are between 18 and 47 percent of the corresponding U.S population. The relative lifetimes of ESRD patients (as a percent of average U.S. remaining lifetime) are smallest in the middle age range of 25 to 65.

In summary, there are several inferences that can be made from this table. First, the expected remaining lifetimes of ESRD patients are between 16 to 50 percent of the expected lifetimes of the general U.S. population. Second, Black dialysis patients in general have greater expected remaining lifetimes for all ages when compared to Whites. Finally, the inclusion of healthier transplanted patients in the all ESRD calculations yields longer lifetimes compared to the dialysis only calculations, especially in the younger age groups which have higher rates of transplantation. Over age 70, the expected remaining lifetime for all ESRD is about the same as that for dialysis only, since transplants are much less frequent in these older age groups.

Standardized Mortality Ratios

1996 Facility-specific Reports

The USRDS distributed reports to each of the 2,379 dialysis facilities in the United States for which sufficient data were available concerning hospitalization and mortality. These reports were distributed through the 18 regional ESRD Network

Demographics and Mortality Among 2,379 Facilities with more than 5 Dialysis Deaths Expected[1] between 1993 and 1995, by Percentile

Percentile (Column 1)	Demographics[2] Black (%) (2)	White (%) (3)	Nat Am (%) (4)	Asian (%) (5)	Female (%) (6)	Diab (%) (7)	Mean Age (years) (8)	Mortality Crude Rate/100 Patients (9)	Crude Rate/100 PY[3] (10)	Expected Rate/100 PY[3] (11)	SMR[4] (12)
Minimum	0	0	0	0	17	0	35	2	3	11	0.16
1	0	3	0	0	27	14	47	6	9	14	0.40
10	1	18	0	0	39	23	55	12	15	18	0.68
25	8	37	0	0	44	28	58	14	19	20	0.84
50	**25**	**66**	**0**	**1**	**48**	**34**	**61**	**17**	**23**	**23**	**1.00**
75	57	85	1	3	53	40	63	21	28	26	1.19
90	77	93	3	7	58	47	65	23	33	29	1.37
99	95	100	47	30	68	66	70	30	45	34	1.87
Maximum	100	100	95	97	100	90	76	49	83	40	3.37
Mean	**33**	**60**	**2**	**3**	**48**	**35**	**60**	**18**	**24**	**23**	**1.03**
Std Dev	28	28	8	8	8	10	4	3	5	4	0.15

[1] Expected count based on 1995 national death rates for dialysis patients excluding DU deaths by age, race, sex, and diabetes.
[2] Demographics are reported as the percent of patients in the corresponding category, except for age, which is reported as a mean.
[3] PY = person years
[4] Adjusted by age, race, sex, and diabetes rates in 1995 dialysis population excluding DU deaths.
At the top of each column is a number which is used to refer to it in the text.
Source: Special Analysis

USRDS 1997

Table V-5

Offices for the continuing quality improvement initiative. The reports were based on patient data between 1993 and mid 1996.

One of the main features of these reports was a standardized mortality ratio (SMR), that compares the mortality at a facility to the death rates for virtually all U.S. dialysis patients in the USRDS database. The SMR accounts for the age, race, sex, and diabetes status of the prevalent patients at a facility. The observed mortality rate at the facility is compared to the rate that would be expected based on national death rates for patients with similar characteristics.

Table V-5 summarizes the differences across facilities of several demographic and mortality measures, using 1993 through 1995 data. The table is limited to the 2,379 facilities with at least 5 dialysis patient deaths expected between 1993 and 1995. The rows of the table correspond to percentile values; for example the rows labeled 25 and 50 give the 25th percentile and median values for facilities, respectively, for each measure. The facilities in a percentile range for one measure are typically different facilities from those in the same percentile range for another measure. For example, the facilities with the 10 percent lowest crude (unadjusted) death rates are *not* the same facilities as those with the 10 percent lowest SMR values, although there is some overlap between these two groups of facilities. The last two rows of the table give the average (mean) and standard deviation of each measure among facilities.

Columns 9 and 10 of the table summarize crude mortality rates as the percent of patients who died. Column 9 of the table summarizes the crude mortality rates per 100 patients on January 1 of a year. Of the patients prevalent on January 1, 17 percent died during the year at the median (18 percent at the average) facility, while 12 percent or fewer died for 10 percent of the facilities and 23 percent or more died for 10 percent of facilities, as indicated in the 10th and 90th percentile rows respectively. The crude mortality rate per 100 patients does not account for the fact that patients are at risk for only part of a year, if transplanted during that year. Thus, some of the variation seen in these death rates among dialysis patients could be due to differences in transplantation rates among facilities.

Column 10 of the table summarizes rates of deaths per 100 dialysis **patient years**, which counts only part of a year for a patient if the patient is transplanted or dies during the year. This accounts for the fact that dialysis patients who were transplanted during the year were not at risk for death for the entire year. Rates of death per 100 patient years vary substantially among these facilities. Of patients prevalent on January 1 or starting dialysis during a year, the median death rate was 23 per 100 patient years (mean is 24), while the death rate was less than 15 per 100 patient years for 10 percent of these facilities (10th percentile) and was greater than 33 for 10 percent of facilities (90th percentile).

These unadjusted death rates are expected to vary among facilities because the measured characteristics (age, race, sex, diabetes) and the unmeasured characteristics (comorbid conditions, disease severity) of patients also vary among facilities. Columns 2 through 8 give the distribution among facilities of some of these patient characteristics.

The variation among facilities in percent of patients with diabetes as cause of ESRD and in average age is shown in columns 7 and 8 of the table. The 10th percentile row of column 7 shows that at 10 percent of facilities, fewer than 23 percent of the patients have ESRD due to diabetes, while in 10 percent of facilities more than 47 percent of the patients have ESRD due to diabetes (90th percentile). The percent diabetic is 34 percent at the average facility. Column 8 shows substantial variation in the average patient age among facilities. The average patient age at the average facility is 61 (standard deviation of 4) years. The race and sex characteristics also vary substantially among facilities.

Since there is substantial variation among facilities with regard to the age, race, sex, and diabetes characteristics of their patients, the crude mortality rates would also be expected to vary among facilities, even if the death rates at each facility were the same as the national death rates for similar patients. The expected number of deaths at a facility was calculated based on the number and duration of followup (until death or transplant) for the patients in each age, race, sex, diabetes subgroup at each facility, and on the national death rates for those subgroups. This total expected number of deaths was divided by the number of patient years of followup at each facility to yield an expected death rate for that facility. The "expected rate" is the death rate that would be expected at that facility if the death rates among its patients were the same as the national death rates among similar patients,. Thus, variation in the expected death rates reflects the variation in death rates that would be expected due to differences among facilities in patient age, race, sex, and diabetes.

Column 11 of Table V-5 reports the differences in expected death rates among facilities. For the lowest 10 percent of facilities, the death rate is expected to be 18 per 100 patient years or less, based on the age, race, sex, and diabetes characteristics of the patients at those facilities (10th percentile). Similarly, the death rate is expected to be 29 per 100 patient years or greater for 10 percent of these facilities (90th percentile). This variation in expected death rates explains some of the variation in the observed crude death rates.

The SMR (column 12) compares the crude (observed) death rate to the expected death rate as a ratio. The SMR gives a way to interpret the crude death rate relative to the expected death rate. Column 12 of the table shows that the crude death rate is only 68 percent (SMR=0.68) of the expected rate for 10 percent of facilities. That is, at 10 percent of facilities, the observed crude rate is at least 32 percent lower than the rate that would be expected based on the patient characteristics at that facility. Similarly, the crude mortality rate is at least 37 percent higher (SMR=1.37) than the expected death

Correlations Between SMRs Calculated for the Same Facilities for Different Calendar Years*

Comparison	Correlation
(1) 1993 SMR *vs* 1994 SMR	0.36
(2) 1993 SMR *vs* 1995 SMR	0.42
(3) 1994 SMR *vs* 1995 SMR	0.41
SMR and Comorbid Conditions:	
(4) 1993-95 SMRs *vs* average count of comorbid conditions** in incident patients 4/95-4/96	0.01

* restricted to n=395 facilities with ≥ 20 expected deaths in each of the years, 1993-95
** Count of comorbid conditions comes from the new 2728 Medical Evidence Form
Facility SMRs based on national death rates for dialysis patients excluding DU deaths.
Source: Special Analysis USRDS 1997

Table V-6

rate for the highest 10 percent of facilities (90^{th} percentile). Thus, while the differences in the expected death rates explain some of the variation in crude death rates, the variability in the SMR indicates that the crude rates vary even more than would be expected on the basis of the different age, race, sex, and diabetes characteristics of the patients at the facilities.

Some of this variability in both the crude death rates and the SMR values is due to random variation, and is therefore unimportant. The random variability in the SMR values was accounted for by calculation of the statistical significance (p-value) and confidence intervals in the individual facility reports. In this table we report the estimated standard deviation of the SMR values (in the row below the mean) that would arise if there were no variation due to random fluctuations, but only variation due to true differences among facilities. This standard deviation was estimated using a random effects model as described in the stabilized death rates section below. The estimated standard deviation is 15 percent indicating that the death rates are often as much as 15 percent higher or 15 percent lower than would be expected on the basis of the measured characteristics of the patients at a facility. This remaining variation of 15 percent in the SMR is not due to random fluctuations; or to age-race-sex-diabetes differences; or to differences in AIDS, violence, or illegal drug use deaths. Instead, this remaining variation is due to unmeasured patient characteristics or to differences in treatment of patients.

Table V-6 presents correlations between SMRs calculated for the same facilities at different time periods. Correlations of the SMR in a facility over the three years 1993, 1994, and 1995 (rows 1-3) are not high (ρ=0.36 to 0.42), even when the calculation is restricted to large facilities (those with at least 20 expected deaths in each year). Since the SMR varies substantially from year to year due to random fluctuations, its value in a single year should not be used in isolation as a measure of patient outcomes.

There is no correlation between the SMR for all prevalent patients in a facility and the average number of comorbid conditions in incident patients. The count of comorbid conditions was obtained from the information provided for incident patients between April of 1995 and April of 1996 on the new Medical Evidence Form. We found that the average number of comorbid conditions reported on the new Medical Evidence Form is much lower than that from Wave 1 of the Dialysis Morbidity and Mortality Study (mean 1.7 comorbid conditions from the Medical Evidence Form, versus 2.9 from DMMS) so the lack of relationship between the SMR and this count of comorbidities may be due to underreporting on the new Medical Evidence Form. Since the SMR is adjusted for age, race, sex, and diabetes, it is already adjusted for average comorbidity levels because increased comorbidity is associated with age and diabetes. Future analyses will address this in more detail.

Figure V-12 presents SMRs by state for 1995. There appears to be variation in the SMR among

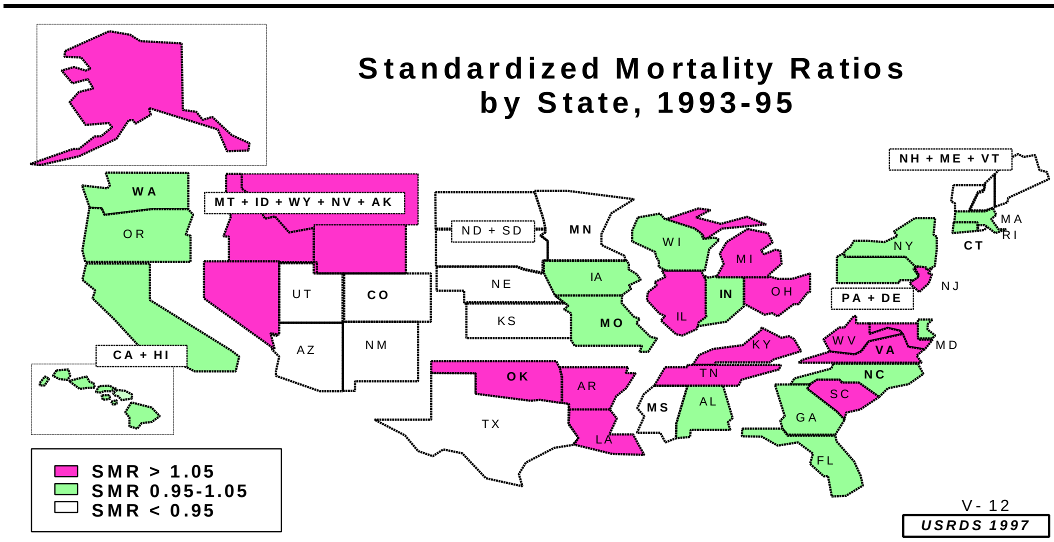

Figure V-12

Standardized Mortality Ratios by state, 1993-95. Small states are grouped together as indicated in the reference table. DU deaths are excluded. Source: Reference Tables D.3.

small clusters of states but investigation of the characteristics of low and high SMR regions is needed to understand why the variation occurs.

National Death Rates

Methods

Several major changes were made to the methods for calculating national death rates this year.

1. Dialysis-unrelated deaths were excluded from the calculations (includes deaths due to AIDS, accidents unrelated to treatment such as violence, and street drug overdoses).

2. The 1995 death rates for patient subgroups published in this report are estimated using a Poisson regression model. This new method yields more stable and interpretable estimates than does the previously used method of estimating the death rates separately for each subgroup.

3. The adjustment for disease remains in the simplified form that accounts only for diabetes versus nondiabetes, rather than the four groups used previously (glomerulonephritis, hypertension, diabetes, other).

These changes are discussed below. Further details were reported in abstracts presented at the 1996 American Society of Nephrology meeting (Turenne, Wolfe 1996).

Dialysis-unrelated deaths

Based on the cause of death information available from the ESRD death notification form, deaths due to AIDS, accidents unrelated to treatment, and street drug overdoses were classified as dialysis-unrelated deaths (DU deaths) and were not included in the death count when we computed the national ESRD and dialysis death rates (Reference Tables, Section D). The DU deaths continue to be counted as deaths in the survival curve calculations (Reference Tables, Section E). Our intent in excluding the DU deaths is to make the death rate tables more useful as a norm for evaluating the care given to ESRD patients. Since the deaths due to AIDS, accidents unrelated to treatment (e.g. violence), and street (illegal) drug overdoses are largely beyond the control of the ESRD caregivers, we have excluded them from the death rate calculations. The survival curves reported in Section E of the Reference Tables report all deaths, so that the survival curves reflect the overall mortality among ESRD patients. Studies that make comparisons to these new USRDS published death rates should exclude deaths due to AIDS, accidents unrelated to treatment, and street drug overdoses from their calculations. Both the deaths and person years of survival for patients who died of AIDS were excluded from the calculations of death rates. For other DU deaths, the death was not counted, but the person years of survival were counted. These two methods of accounting are different because a patient with AIDS and ESRD is very likely to die soon of AIDS-related causes while patients who eventually die from accidents or drug-related causes were at risk for an ESRD-related death throughout their ESRD treatment. Table V-7 reports the number of DU deaths during 1993. Although the DU deaths account for only a small fraction of the total deaths among ESRD patients, they can account for a larger fraction of deaths at some facilities.

Figure V-13 shows how excluding DU deaths affects facility SMRs. For most facilities there is very little change in the SMR as seen by the large number

Distribution of Medicare Dialysis Patient Deaths, 1993

Cause of Death*	Count	Percent
All Causes	30,182	100.0
Dialysis Unrelated Deaths		
AIDS	420	1.4
Accidents**	107	0.3
Street Drug Overdoses	63	0.2
Total	590	1.9

* As recorded in any position (1-5) on the HCFA ESRD Death Notification Form.
** Unrelated to treatment
Source: Special Analysis

USRDS 1997

Table V-7

Comparison of Facility SMRs Before and After Excluding DU Deaths, 1991-93

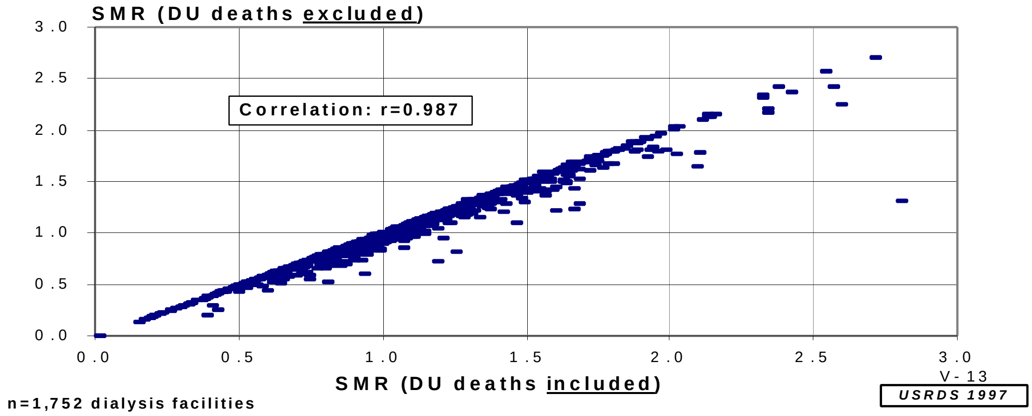

Figure V-13

Facility SMRs before and after excluding dialysis unrelated deaths (DU deaths), 1991-93. DU deaths are defined as deaths due to AIDS, accidents unrelated to treatment, or street drug overdoses (as recorded in any position on the HCFA ESRD Death Notification Form). Source: Special Analysis.

of data points near the 45 degree line. This is because the number of deaths excluded is small in comparison to the total number of deaths. However, the SMRs for some facilities decrease quite a bit because a large number of their patients have AIDS or die from violence or drugs.

Stabilized death rates

Death rates are reported for the 248 patient subgroups defined by age (16 groups), diabetes (2 groups), sex (2 groups), and race (4 groups), where all patients less than 15 years of age were classified as having a nondiabetic cause of ESRD. In previous reports, these rates were calculated based on the observed mortality among patients in each subgroup during a 3-year period. This year, a regression model was used to estimate more stable death rates for these patient subgroups, based on data from 1993-1995. Several years were used to improve the stability of the rates, but only recent years were used to give current results. We used a log-linear Poisson regression model with 2-way interactions between diabetes, sex, and race and between age (linear) and each of sex, race, and diabetes. In addition, the model included adjustments to estimate the overall percentage differences in death rates among the 3 years. The reported death rates in a category are a weighted average of the observed death rates and the death rates predicted by the regression model for that

Comparing Instability of Death Rates Estimates: Modeled versus Observed

Groups of Patients by Age-Race-Sex-Diabetes		Instability: Mean Change in Rate Estimates between 1989-91 and 1991-93	
Size(1989-91)	# Groups	Observed	Estimated
0 patients	5	- *	± 18%
0-5 deaths	52	± 84%	± 13%
6+ deaths	191	± 18%	± 8%
ALL	248	± 32%	± 9%**

* cannot be calculated
** variability for modeled rates significantly less than for observed (p<0.0001)
Source: Special Analysis
USRDS 1997

Table V-8

category. More weight is given to the observed data for categories with many patients and more weight is given to the regression model for categories with few patients. The model is called a "random effects model" and the resulting estimates are called "best linear unbiased predictors" in the statistical literature (Robinson). The results reported this year are based on the estimates for 1995 death rates.

Table V-8 shows that among the 248 patient categories, there were 5 with no patients, and 52 with 5 or fewer deaths, based on the 1989-1991 data. Such small death counts lead to unstable estimates of death rates. In order to evaluate the stability of the new method compared to the old method, we calculated four sets of death rates: for both the 1991-1993 and the 1989-1991 period using both the new method of stabilizing the rates and the old method of reporting observed death rates. We then compared the rates for 1991-1993 to those for the 1989-1991. On average, using the old method, the observed death rates in 1991-1993 differed from the observed rates in 1989-1991 by 32 percent while the rates calculated with the new method differed by only 9 percent. For the 52 categories with 5 or fewer deaths between 1989-1991, the observed death rates (the old method) fluctuated by 84 percent on average between these two time periods. In contrast, the regression model for these 52 categories yields a fluctuation of only 13 percent. The poor stability of the observed death rates over the years is due to random fluctuations, which are not particularly relevant for understanding or evaluating mortality patterns. The new method yields death rate values that are much more stable over time and allow more consistent and interpretable results.

Cause of ESRD

We calculated death rates separately for patients with diabetes and nondiabetes as a cause of ESRD. In several previous ADRs, the USRDS has reported such death rates separately for diabetes, glomerulonephritis, hypertension, and other causes. This simplification was made to reduce the likelihood of miss-classification of patients. Identification of diabetes as a cause of ESRD is relatively unambiguous, while the classification of other causes of ESRD is more difficult and is prone to differences among geographical regions or physicians. Further, the differences in mortality by disease category are most pronounced for the diabetes versus nondiabetes categories, while the differences among glomerulonephritis, hypertension, and other causes were less pronounced. Those who are interested in cause specific death rates should consult Chapter VI, which gives results for a detailed classification of diseases.

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