Chapter V

Patient Mortality and Survival

Key Words:
ESRD mortality
ESRD survival
Dialysis outcomes
Expected remaining lifetimes
Standardized mortality ratios
Hemodialysis
Long-term survival
U.S. death rates

This chapter focuses on patient mortality and survival among treated ESRD patients. Transplant recipients are included in some of the results, but the primary focus is on dialyzed patients. Chapter VII includes more detailed results for transplant recipients. The analyses in this chapter are based primarily on mortality data for 1986-1997.

Mortality among ESRD patients continued to decrease in 1997 compared to earlier years, for many age-race-sex-diabetes subgroups of patients and during the first and second years of ESRD treatment. It is possible that both changes in patient condition and in treatment patterns have contributed to this drop in mortality. Chapter IV indicates that since 1995, the starting serum creatinine levels have fallen among incident ESRD patients, which could result from earlier start of dialysis. Earlier start of ESRD treatment could be responsible for some of the drop in mortality reported here. Further, the average body mass index among incident patients has increased since 1995, which is also correlated with better survival. There have been many changes in treatment patterns during this time interval that might also have led to improved mortality.

Methods and definitions

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. Patients from Puerto Rico and the U.S. Territories are included in results that are based on data from the HCFA Annual Facility Survey (Table V-2), but are not included in the other results, which are based solely on the USRDS database.

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 factors such as changes in enrollment criteria for ESRD treatment or changes in treatment patterns over time.

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. Sudden changes in mortality among prevalent cohorts would primarily reflect factors, such as innovations in treatment, that tend to affect all patients being treated in a given year. More gradual changes in mortality could reflect changes in enrollment criteria or slowly changing treatment patterns.

Outline

This chapter has seven major sections:

1. <u>Adjusted first-year death rates among incident patients</u> for the years 1986-1996. 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 1986 and 1996. Similar mortality decreases have been seen during the second year of treatment, although these results are not shown.

2. *Long-term survival from first ESRD treatment.* The 5-year survival rates are 90.4 percent and 47.0 percent among 15-19-year-olds and 50-54-year-olds, respectively, based on the 1992 incident cohort of ESRD patients, and the 10-year survival rates are 78.5 and 23.0 percent for the same two age groups, respectively, based on the 1987 ESRD incident cohort. The unadjusted survival at 5 years is higher for the 1992 cohort than for the 1987 cohort for both age groups, despite the fact that the 1992 cohort has many more diabetic patients than did the earlier cohort. Adjusted death rates during the first, second, and third through fifth years after start of ESRD treatment have generally decreased since 1986, with especially large reductions during the first and second year of treatment.

3. *Adjusted death rates for prevalent patients* over the years 1990-1997. Mortality among prevalent dialysis patients decreased between 1990 and 1994, and has remained nearly constant since 1994. Mortality among all prevalent ESRD patients (including transplant patients) decreased over the entire time period.

4. *Mortality by year since first treatment in incident cohorts 1990-1997*. Standardized mortality ratios (SMRs) are used to compare mortality in annual incident cohorts over successive years of observation. The death rates are high during the first year of treatment, are lower during the second and third years, and then rise again after the fourth year.

5. *Standardized mortality ratios by state*. SMRs were calculated by state for dialysis patients prevalent between 1995 and 1997.

6. *Projected remaining years of life* for the United States population, ESRD patients, and dialysis patients by patient age (regardless of duration of ESRD), race, and sex. The expected remaining years of life for the entire U.S. population are between 2.3 and 5.4 times greater than those for corresponding all ESRD patient groups, and between 2.7 and 6.4 times greater than those for corresponding dialysis patient groups.

7. Methods for calculating *national death rates*. Several major changes in the analysis methods for calculating the death rates for prevalent patients were introduced in the 1997 report, and apply to this year's analysis as well (Reference Tables D.2 and D.3). In summary, deaths not plausibly related to dialysis were excluded, and a regression model was used to stabilize the year-to-year variation in the rates. In this chapter, these changes impact only Tables V-3 and V-4 and Figures V-8 and V-9.

Adjusted First-Year Death Rates Among Incident Patients

Methods

The death rates for patients during their first year of therapy are reported in this section. 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 91^{st} day of therapy occurred during each specific year, and calculated death rates in 1-year increments from day 90. To calculate adjusted survival probabilities, the probability of surviving 1 year was estimated using a proportional hazards (Cox) regression model with adjustment for age, race, sex, and diabetes as cause of ESRD. The survival curves for each incident cohort were adjusted to correspond to the average characteristics of the 1995 incident cohort of ESRD or dialysis patients, or all patients first transplanted in 1995, as appropriate (see Chapter XIII for further details).

From these estimated adjusted survival proportions, we then calculated the average first-year death rate using a standard actuarial relationship given in equation 5.1 below.

(5.1) *death rate = - ln(fraction alive at year 1)*

A similar equation was used to calculate death rates in later years, as well. The death rate per 100 patient years is calculated as the first-year death rate times 100.

This adjustment process yields estimates of the death rates that would have arisen in each year for the "average" patient from the reference population. Since the adjusted survival curves are all adjusted to the same type of patient in any given table, any remaining differences between them are due to factors other than age, race, sex, and cause of ESRD.

As shown in Table V-1, among incident patients both the average age and the percent with diabetes as cause of ESRD has been increasing (Young; Reference Tables, Section A). The adjusted rates reported here show the rates that would have been expected had the patient mix by age, race, sex, and diabetes been unchanged over the years. However, changes in other patient characteristics during the past decade may not be accounted for by these adjustments, and may explain the trends seen here. For example, the USRDS data cannot be adjusted for changes in specific disease comorbidity in the overall ESRD population because these measures have been recorded for all patients only since 1995. However, the adjustment for age and diabetes does account for the average levels of comorbidity associated with aging and diabetes.

Although the death rates reported in this chapter are comparable across the years 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 and because the adjustment methodology has changed this year. The mortality results in this report are generally adjusted to an older and more diabetic population than were results in prior reports, so the adjusted death rates are higher in this report than were reported in prior annual data reports. Differences in the reference population in different years may arise because of changes in the population composition or changes in the methods used to identify the ESRD population, as detailed in Chapter I. In addition, these results will differ from unadjusted death rates presented elsewhere in this ADR. Readers who are interested in the unadjusted 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 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 general patterns to be seen despite variations 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 national trends shown here.

The death rates during the first year for each incident cohort are presented. Death rates during the second year for those surviving the first year were very similar to those during the first year (USRDS, 1995) and are not presented here.

Results

Table V-1 shows the importance of accounting for the mix of patient characteristics when evaluating

Changing Profile of Incident ESRD Patients by Calendar Year of Incidence

Year of Incidence	Average Age	Percent Diabetic	Unadjusted Death Rate*	Adjusted** Death Rate*
1989	58.1	32.9	25.4	22.8
1990	58.6	34.4	24.9	21.6
1991	59.1	36.1	25.4	21.7
1992	59.5	36.6	25.2	21.3
1993	59.9	36.4	24.5	20.5
1994	59.8	38.4	23.9	20.0
1995	59.6	40.5	23.7	20.4
1996	60.2	41.8	23.5	19.8

* Deaths per 100 patient years at risk for patients in the first year of ESRD therapy
** Adjusted to the characteristics of the average ESRD patient incident in 1995 (age, race, sex, and primary cause of ESRD). Adjusted rates do not match unadjusted rates even for 1995.
Source: Reference Tables A.1, A.14, E.14, and E.22

USRDS 1999

Table V-1

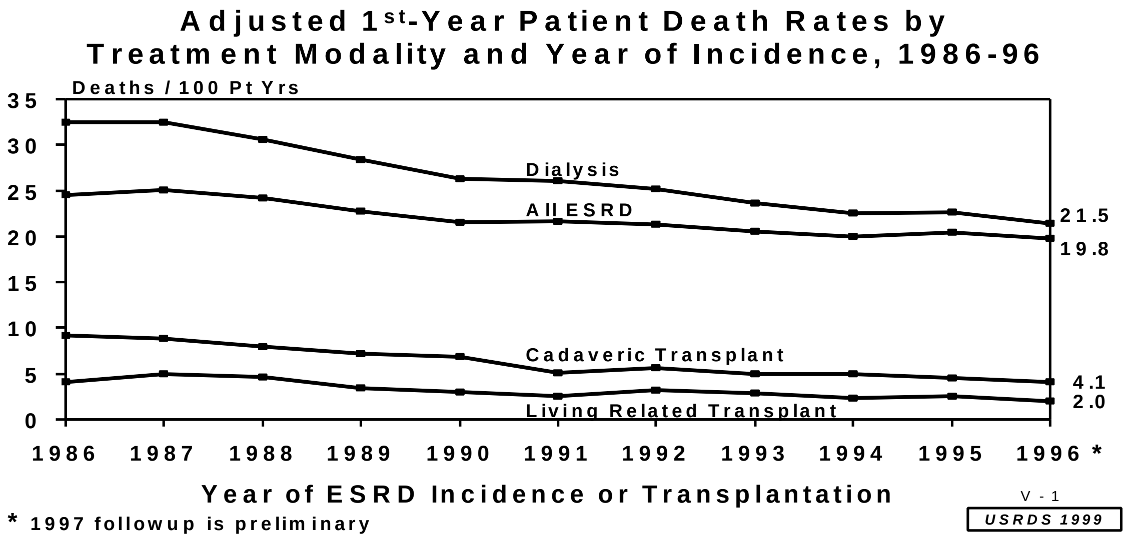

Figure V-1

Death rates based on estimates from proportional hazards regression models, by modality and year of ESRD incidence or of first transplantation. Patients followed for up to 1 year starting at day 91 following onset of ESRD (censored at first transplant) for both the ESRD and dialysis patient groups, and starting at day of first transplant for transplanted patients. For each category (Dialysis, All ESRD, Cad Tx, LR Tx), death rates are adjusted by age, race, sex, and diabetes to the average patient in the corresponding standard population. Source: Reference Tables E.22, E.54, E.70, and E.86 (with equation 5.1).

mortality results. For successive cohorts of incident patients between 1989 and 1996, Table V-1 gives the average age in column 2 and the percent of patients with diabetes as the cause of ESRD in column 3. The average age and percent diabetic have increased in almost every year. If there were no other changes, we would expect crude death rates to increase for these successive cohorts, due to the 2.1 year increase in average age and the increase in percent diabetic patients from 32.9 to 41.8. 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 7.5 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? This question is addressed 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 1995 incident cohort. Although the rates from the two different columns cannot be directly compared, the percent changes in each column are interpretable as showing the relative improvements in crude and adjusted death rates. The 13 percent reduction in the **adjusted** rates during this time period is larger than the 7.5 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 both dialysis and all ESRD patients, for the cohorts incident in 1986 (includes mortality through 1987) through 1996 (includes mortality through 1997). In addition, Figure V-1 presents adjusted death rates for the first year following transplantation for those receiving either cadaveric or living related transplants between 1986 and 1996. The mortality data for dialysis patients are censored at transplantation for those patients transplanted within 1 year of ESRD enrollment.

Adjusted death rates for all ESRD patients in the first year of therapy fell from 24.6 in the 1986 cohort to 19.8 per 100 patient years (19.4 percent lower) in the 1996 incident cohort. This general trend of declining death rates during the first year of ESRD treatment has been seen for most successive incident cohorts since 1986. The adjusted first-year death rates for all dialysis patients have decreased from

32.4 per 100 patient years at risk for the 1986 cohort to 21.5 per 100 patient years at risk for the 1996 cohort.

Figure V-1 shows that the cohort of patients receiving cadaveric transplants during 1996 experienced slightly lower 1-year death rates than the 1995 cohort, continuing a trend in improving survival over the entire time period, 1986-1996. First-year mortality for patients who received living related transplants has been generally decreasing since 1986, and continued to decrease between 1995 and 1996 (annual death rates of 2.5 and 2.0, respectively).

The dialysis and transplant modality groups have different reference populations in Figure V-1. These death rates are adjusted for the age, race, sex, and diabetes as cause of ESRD characteristics of the population of ESRD dialysis patients incident in 1995, or the population of patients transplanted during 1995, as appropriate. For example, age differences exist across these modality groups, so the dialysis group is adjusted to an older age than the transplant groups. Thus, the differences in adjusted death rates across years are due to factors other than age, race, sex, and diabetes, while the differences between dialysis and transplant modalities are partially due to the age, race, sex, and diabetes differences between modalities.

The adjusted first-year mortality shown in Figure V-1 for cadaveric or living related transplant recipients, measured from the day of transplant, is lower than for patients starting treatment on dialysis. Part of the markedly lower mortality seen among transplant recipients, relative to all dialysis patients, can be explained by the fact that these patients are younger on average than dialysis patients. Also, transplant patients are drawn from dialysis patients on a transplantation wait list, who have substantially lower mortality than do dialysis patients who are not wait-listed. Further, the mortality risk is high in the first year of ESRD, but many transplants occur later in a period of lower risk. Because of these differences, survival of transplant recipients is more appropriately compared to the survival of wait-listed dialysis patients rather than all dialysis patients (Port; Wolfe, 1997). In addition, part of the reduction in mortality seen among transplant recipients 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.

Age: Figure V-2 shows the first-year death rates for dialysis patients by age group and calendar year of first ESRD therapy. These death rates are adjusted

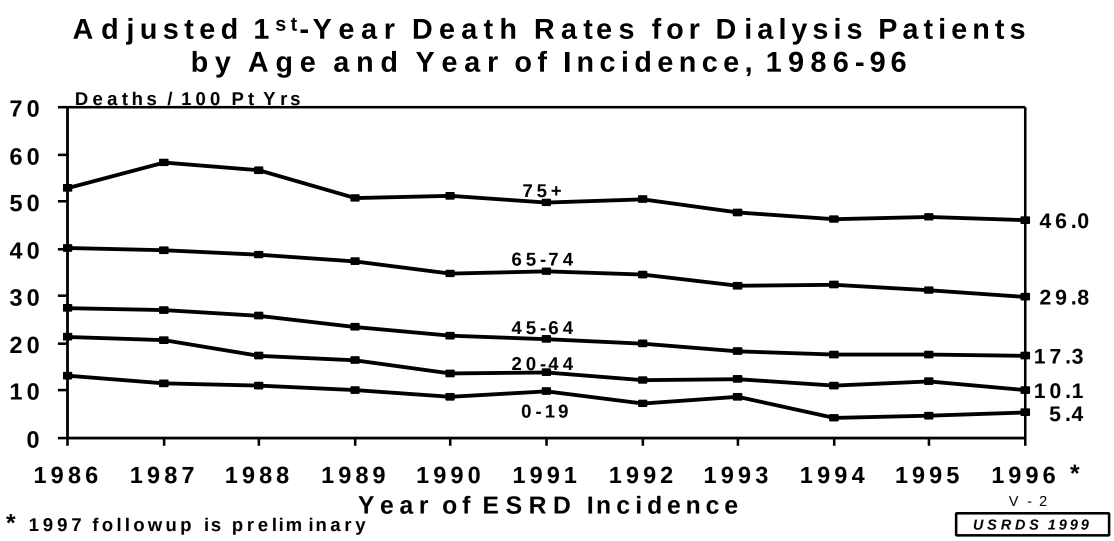

Figure V-2

Death rates for dialysis patients based on estimates from proportional hazards regression models, by age at onset of ESRD and year of incidence. Patients followed for up to 1 year starting at day 91 following onset of ESRD (censored at first transplant). Death rates are adjusted by race, sex, and diabetes to the average patient in the 1995 incident cohort of dialysis patients. Source: Reference Table E.54 (with equation 5.1).

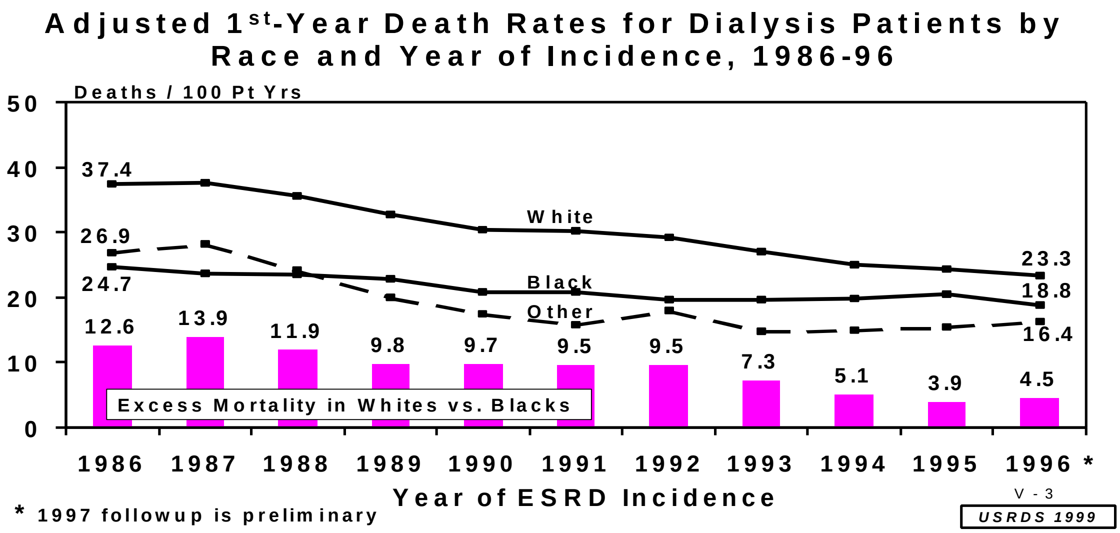

Figure V-3

Death rates for dialysis patients based on estimates from proportional hazards regression model, by race and year of incidence. Patients followed for up to 1 year starting at day 91 following onset of ESRD (censored at first transplant). Death rates are adjusted by age, sex, and diabetes to the average patient in the 1995 incident cohort of dialysis patients. Bars show the excess mortality in Whites compared to Blacks. Source: Reference Table E.54 (with equation 5.1).

for race, sex, and diabetes as cause of ESRD. There is some improvement in survival for the 1996 cohort relative to earlier cohorts for all age groups.

Dialysis death rates for pediatric patients (0-19 years) have decreased from 13.2 per 100 patient years at risk in 1986 to 5.4 per 100 patient years at risk in 1996, although there has been a slight increase

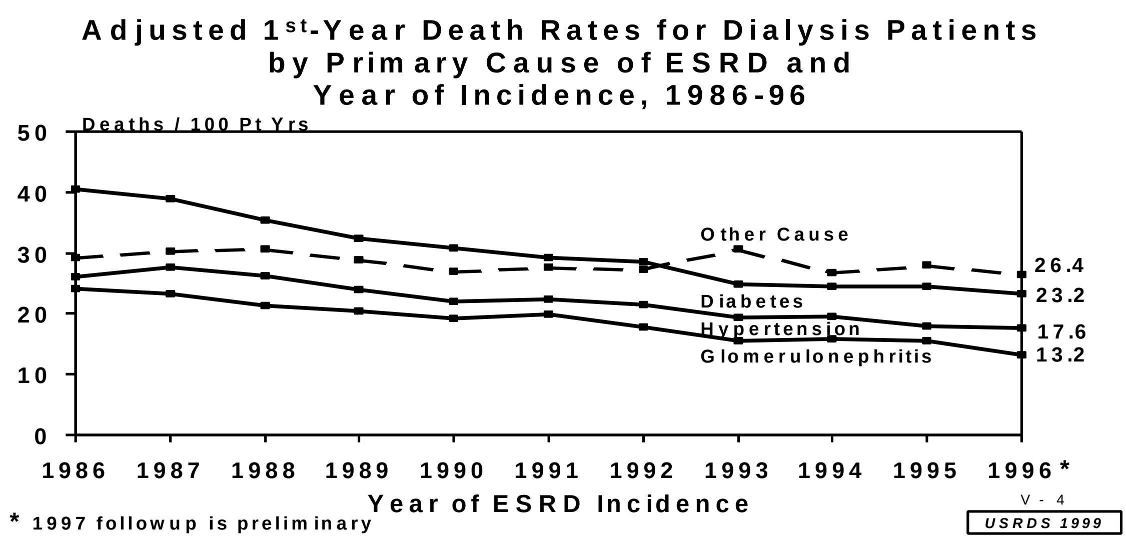

Figure V-4

Death rates for dialysis patients based on estimates from proportional hazards regression models, by primary cause of ESRD and year of incidence. Patients followed for up to 1 year starting at day 91 following onset of ESRD (censored at first transplant). Death rates are adjusted by age, race, and sex to the average patient in the 1995 incident cohort of dialysis patients. Source: Reference Table E.54 (with equation 5.1).

between 1994 and 1996. More detailed results for pediatric patients are reported in Chapter VIII.

The greatest improvement in survival for dialysis patients has been seen in the younger adult age ranges, with the improvement decreasing for each age group. First-year death rates for the age group 20-44 decreased from 21.4 per 100 patient years at risk in 1986 to 10.1 per 100 patient years at risk in 1996. The first-year death rate decreased from 27.5 to 17.3 per 100 patient years at risk in the 45-64-year age group; from 40.2 to 29.8 per 100 patient years at risk in the 65-74-year age group; and from 52.8 to 46.0 per 100 patient years at risk in the 75 and above age during the same time interval, 1986-1996.

Race: Figure V-3 shows first-year death rates for dialysis patients by race and year of first ESRD therapy, 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 1987. There has also been an improving trend for Black patients between 1986 and 1992 with an apparent leveling off or increase since 1993.

There has also been a substantial improvement in survival for patients of other races since 1986. Since 1989, dialysis patients of "other" races had lower first-year death rates than did Black patients, while White patients consistently had the highest first-year mortality rates. The bars at the bottom of Figure V-3 show that the difference between Black and White patient 1-year death rates has decreased from 12.6 to 4.5 per 100 patient years at risk between the 1986 and 1996 incident cohorts. These comparisons are adjusted for age, sex, and cause of ESRD, and are valid on average, but may not be true for each individual age-sex-cause subgroup.

Cause of ESRD: Figure V-4 shows the first-year death rates for dialysis patients by primary cause of ESRD and year of first ESRD therapy, adjusted for age, race, and sex. The primary causes of ESRD presented here are diabetes, hypertension, glomerulonephritis, and "other". Mortality during the first year was lower in 1996 than in 1995 for all four categories of patients.

In fact, for each of the four major causes of ESRD there has been an overall improvement in survival for each incident cohort from 1986 to 1996. First-year mortality decreased most dramatically and consistently for diabetic patients, from 40.4 per 100 patient years in 1986 to 23.2 per 100 patient years in 1996. Patients with glomerulonephritis have had the lowest first-year death rates during the entire 11-year time period. Through 1992, patients with diabetes had the highest first-year death rates. In 1993 through 1996, patients with other causes of ESRD had the highest first-year death rate. Some changes in

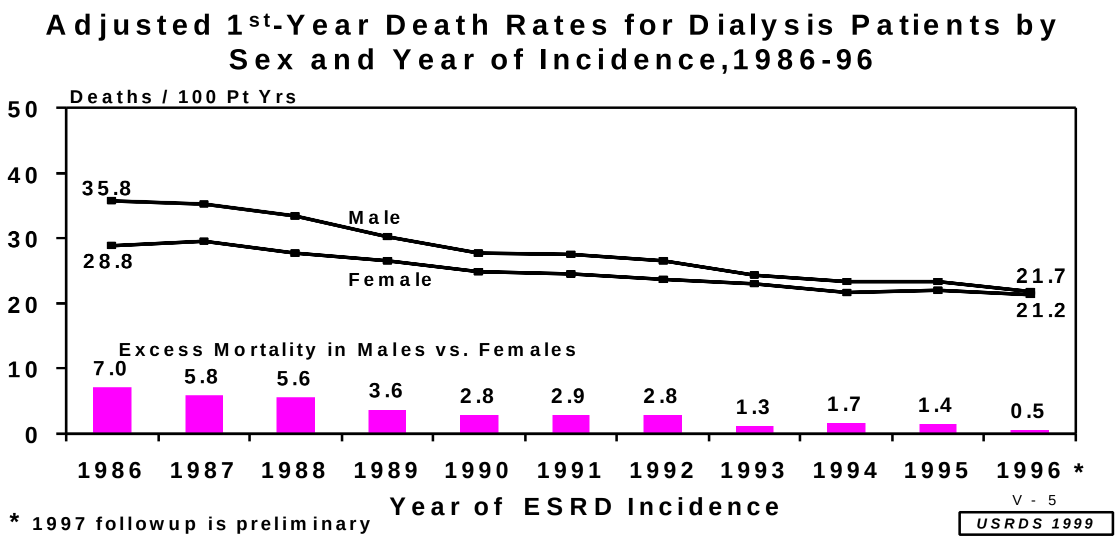

Figure V-5

Death rates for dialysis patients based on estimates from proportional hazards regression models, by sex and year of incidence. Patients followed for up to 1 year starting at day 91 following onset of ESRD (censored at first transplant). Death rates are adjusted by age, race, and diabetes to the average patient in the 1995 cohort of dialysis patients. Bars show the excess mortality in males compared to females. Source: Reference Table E.54 (with equation 5.1).

the categorization of causes of ESRD starting in 1995, as described in Chapter II of the 1997 ADR, could be responsible for some of these changes in relative mortality rates. For example, ESRD attributed to renal artery occlusion had been classified as Other, but is now included in the hypertension category. More details related to cause of ESRD are reported in Chapter VI.

Gender: Figure V-5 shows the 1-year death rates for dialysis patients by sex and year of first ESRD therapy, adjusted 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 1986. Females had lower adjusted mortality at 1 year than males for each incident cohort with the difference (shown by the bars at the bottom of Figure V-5) decreasing throughout the time period. In 1986 there were 7.0 more deaths per 100 patient years in males than females, while in 1996 the death rates for the two groups were very similar (21.2 and 21.7 per 100 patient years, for females and males respectively).

Summary

There has been a progressive improvement in first-year survival for each successive year's incident cohort since 1986. This improvement has been consistent across several classifications of patients and appears to have been largely sustained and continued in the 1996 cohort. These findings were adjusted for age, race, sex, and primary 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). Chapter 4 documents several changes in the characteristics of incident patients since 1995.

A possible explanation for the decline in mortality is that changes in dialysis therapy may be responsible for improved survival (Hakim; Owen; Parker; Held, 1996; USRDS, 1997). During this time period the renal provider community has given increasing attention to the dose of dialysis that is delivered to hemodialysis patients (USRDS, 1997, Chapter III; HCFA, 1998). In addition, there have been changes in dialysis equipment, including a shift from cellulosic to synthetic hemodialysis membranes and improved connection devices for peritoneal dialysis (Chapter III). The management of anemia through the use of rhEPO and parenteral iron has also

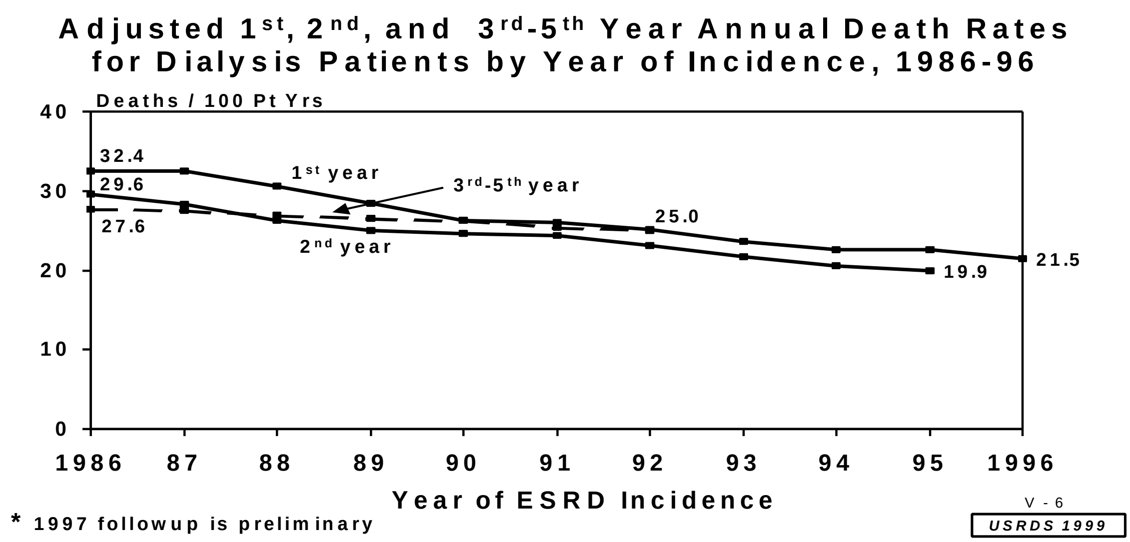

Figure V-6

Adjusted 1st, 2nd, and 3rd-5th year survival estimates for dialysis patients by year of incidence. Calculation of death rates starts at day 91 following the onset of ESRD. Death rates are adjusted by age, race, sex and diabetes to the average patient in the 1995 incident cohort of dialysis patients. Source: Reference Tables E.54, E.56, and E.58.

improved to increase during this time period (USRDS, 1997; HCFA, 1998). 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 from First ESRD Treatment

Methods

Adjusted death rates were calculated based on survival probability estimates from Cox proportional hazards models, as described in the previous Methods section of this chapter. We report the adjusted death rates for the first, second, and third through fifth years after day 90 of ESRD for successive incident cohorts of dialysis patients based on these survival probabilities using equation 5.1. These results are adjusted for age, race, sex, and cause of ESRD so that they can be compared across years.

In addition, for the age groups 15-19 and 50-54 we calculated unadjusted KM survival estimates for patients who started ESRD therapy in 1987 and 1992, followed through 1997. We report 5- and 10-year survival probabilities for these two age groups, including data for both dialysis and transplant patients. Since these results are not adjusted, the curves for the two cohorts should only be compared recognizing the fact that the groups differ with regard to race, sex, and diabetes.

Results

The death rates for dialysis patients during their first, second, and third through fifth year after ESRD diagnosis, by year of first ESRD therapy and adjusted for age, race, sex, and cause of ESRD, are shown in Figure V-6. Death rates in the third through fifth years of therapy are shown for the 1986 through 1992 incident cohorts, death rates in the second year of therapy for the 1986 through 1995 incident cohorts, and first-year death rates for the 1986 through 1996 incident cohorts. There has been a consistent improvement in first, second, and third through fifth year survival since 1986. However, there has been a much smaller improvement in third through fifth year survival than in first and second year survival.

Figure V-7 shows the 5- and 10-year survival curves for the 1987 and 1992 incident cohort of all ESRD patients. The 15-19 and 50-54-year age strata are presented as examples. The 1992 cohort has better survival than the 1987 cohort throughout the first 5 years of ESRD therapy. Most (78.5 percent) of the 15-19-year-old patients survived for more than 10 years and a large fraction (23.0 percent) of the 50-54-year-old patients survived for 10 years in the 1987

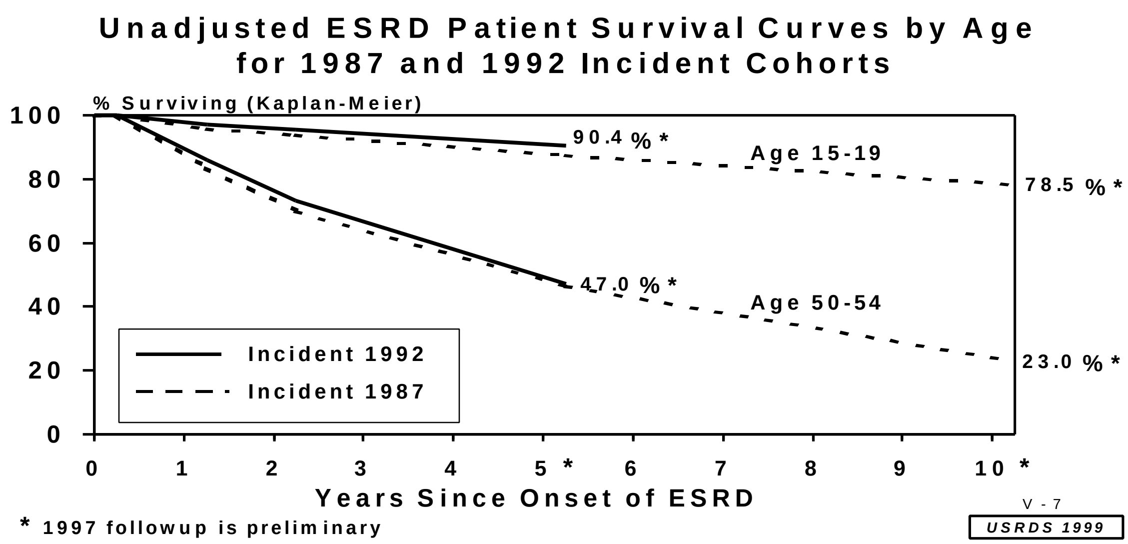

Figure V-7

Unadjusted Kaplan-Meier survival estimates for ESRD patients (1987 and 1992 cohorts) for two age groups. Calculation of death rates starts at day 91 following the onset of ESRD. Differences would be larger if the survival estimates were adjusted. Source: Reference Tables E.14, E.16, E.18, and E.20.

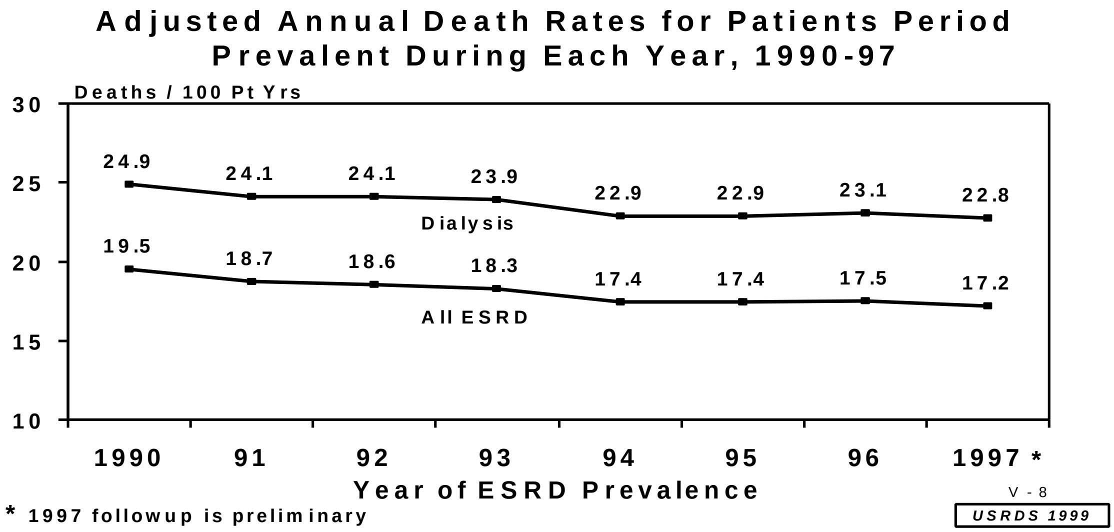

Figure V-8

Adjusted annual death rates (deaths/100 patient years at risk) for all dialysis patients and for all ESRD patients prevalent at any time during each year. The calculation for each year includes point prevalent patients at the beginning of that year as well as patients incident during the same year (1990-97). Death rates are adjusted by age, race (Black, White, Asian, Native American), sex, and diabetes to the 1996 prevalent dialysis or ESRD population. Patients with missing or unknown race, or missing primary diagnosis are excluded. (Dialysis unrelated deaths are included.) Source: Special Analysis.

incident cohort. Based on the higher 5-year survival in the 1992 cohort we expect that more will also live to 10 years. This improvement in survival occurred despite a substantially higher percent of patients with diabetes in the more recent cohort.

Adjusted Death Rates for Prevalent Patients

Methods

Adjusted death rates were calculated for prevalent patients treated during 1990-1997. A Poisson regression model was used to calculate the mortality rate for each year adjusted for age, race, sex, and diabetes as a cause of ESRD, relative to 1996. This model is similar to the model described in Chapter XIII, Analytical Methods. In order to standardize the rates to the reference year of 1996, the adjusted mortality rates were calculated by multiplying the crude 1996 mortality rate by the relative rate for each year (Selvin). Deaths from all causes were included in these calculations.

Crude death percents are also given for all dialysis patients treated between 1991 and 1997. Results are compared for the HCFA Annual Facility Survey (AFS) and the USRDS database.

Results

Figure V-8 shows that the adjusted death rates for all prevalent ESRD patients fell by 12 percent from 1990 to 1997. 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. 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.

Table V-2 reports crude (unadjusted) death counts and crude death percents for successive cohorts of prevalent dialysis patients from 1991 to 1997 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 1990, as is shown in the adjusted rates of Figure V-8. The first set of columns gives results from the HCFA Annual Facility Survey (AFS), which includes both

Crude Death Percent for All Dialysis Patients, 1991-97

Survey	HCFA Annual Facility Survey[2]			USRDS Patient Data Base[3]		
Year[1]	Patients	Deaths	% Dead	Patients	Deaths	% Dead
1991	137,786	31,663	23.0	131,294	27,621	21.0
1992	151,998	35,985	23.7	144,655	31,078	21.5
1993	166,291	39,554	23.8	157,590	34,053	21.6
1994	180,884	42,115	23.3	171,757	36,406	21.2
1995	195,008	45,394	23.3	188,190	39,947	21.2
1996	208,498	48,715	23.4	202,595	43,346	21.4
1997[4]	223,680	52,154	23.3	206,051	46,099	22.4

[1] Calendar year

[2] Facility reported deaths excluding patients treated in transplant only facilities and those with missing data. (Includes Medicare and non-Medicare dialysis patients.)

[3] USRDS data excludes most non-Medicare patients whose therapy started before 1995. In addition, calculation of death rates starts at day 91 following onset of ESRD, i.e. patients who die within the first 90 days are excluded.

[4] 1997 USRDS patients database data preliminary

Source: Special Analysis

USRDS 1999

Table V-2

Medicare and non-Medicare patients, and is reported in facility-level summaries. The second set of columns gives results from the USRDS database, which currently includes both Medicare and non-Medicare patients, and is reported as patient-level data. However, non-Medicare patients whose therapy started before 1995 are largely excluded from the USRDS database. In addition, the USRDS database excludes the first 90 days of ESRD therapy, and starts patient followup on day 91 after first ESRD treatment because of data reporting patterns associated with Medicare coverage. The exclusion of non-Medicare patients incident prior to 1995 and the exclusion of deaths during the first 90 days could largely explain the smaller total numbers of patients in the USRDS database compared with the AFS. The smaller percent of deaths in the USRDS data are probably due to the exclusion of deaths in the first 90 days, where the death rate is known to be higher than in the remainder of the first year. (Compare Reference Tables Section E unadjusted 1-year survival rates for patient age groups over 65 starting at day 91 versus day 1.)

Mortality by Year Since Diagnosis in Incident Cohorts

Methods

Standardized mortality ratios (SMRs) were calculated (Wolfe, 1992) to compare dialysis patient mortality by year since diagnosis for successive incident cohorts of ESRD patients. These SMR values measure mortality rates for a subgroup of patients relative to a set of reference rates, with adjustment for age, race, sex, and diabetes as a cause of ESRD. The mortality rates for the 1997 prevalent cohort (Reference Table D.2) have been selected as the reference, and the mortality for other prevalent cohorts is reported relative to them. Higher SMR values represent higher mortality. An SMR of 1.05 (0.95) represents adjusted mortality that is 5 percent higher (lower) than the reference rates, on average. On January 1st of each year, patients on dialysis are classified by year of incidence and followed for the remainder of that year. New dialysis patients are included after 90 days of ESRD treatment. Patients are censored at transplantation in each year, but are allowed to reenter the incident cohort if they return to dialysis.

SMRs for All Dialysis Patients by Year of First Treatment (Incidence) and by Year of Treatment (Prevalence)

	Calendar Year of Treatment							
Year of Incidence	1990 SMR	1991 SMR	1992 SMR	1993 SMR	1994 SMR	1995 SMR	1996 SMR	1997 SMR
<1990	1.10	1.08	1.11	1.12	1.10	1.14	1.16	1.24
1990	1.16	1.03	1.03	1.15	1.10	1.14	1.21	1.21
1991	.	1.16	1.04	1.05	1.06	1.13	1.12	1.14
1992	.	.	1.14	1.01	1.00	1.08	1.13	1.12
1993	.	.	.	1.02	0.92	0.94	1.05	1.07
1994	.	.	.	.	1.05	0.93	0.95	1.05
1995	.	.	.	.	.	1.03	0.95	0.92
1996	.	.	.	.	.	.	1.06	0.93
1997	.	.	.	.	.	.	.	1.06

SMRs are standardized to 1997 national dialysis patient death rates by age,race, sex, and diabetes as the primary cause of ESRD. Dialysis unrelated deaths are excluded.
For each incident cohort, the SMRs during the first year of treatment are shaded, and SMRs during the second year of treatment are outlined.
Source: Special Analysis

USRDS 1999

Table V-3

Results

Table V-3 shows the SMRs for all patients categorized by both the year of first therapy (incidence) and year of treatment (prevalence). The first row of the table combines all prevalent dialysis patients in each year who were diagnosed (incident) prior to 1990.

The relative mortality during successive calendar years of treatment for a single incident cohort can be seen by moving to the right in a single row of the table. Typically, mortality is high during the first year, then lower during the second and third years, and then rises after the third year. The drop in mortality rates after the first year is likely due to losses among those patients who are at immediate high risk of death when they start ESRD therapy, with only the healthier patients surviving to the second and third year of therapy. The cause of the gradual increase after the third year is unknown, but may be partly due to removal of healthier transplant recipients from the dialysis population or to progressive deterioration of health associated with ESRD.

The SMRs for successive incident cohorts during their first calendar year of therapy are shown by the shaded entries on the lower diagonal of the table. The upper left shaded SMR is for patients incident in 1990 during their first year of therapy, while the lower right hand SMR is for the 1997 incident cohort during its first year of therapy. Moving down the shaded diagonal in Table V-3, a general decline in SMR values can be seen. This pattern is consistent with the decline in first-year mortality rates reported earlier in this chapter. Since patients are classified by calendar year of treatment in this table, the first calendar year mortality rates on the shaded diagonal are <u>not</u> the same as first-year (365 days past day 90) mortality rates reported earlier in this chapter. This is because a patient who starts treatment in the middle of the year is considered to be in the first calendar year of treatment only until December 31st of the year. This means that patients on the shaded diagonal are followed for between 0 and 12 months with an average of 6 months of followup.

The SMRs for successive incident cohorts during their second calendar year of therapy, shown by the entries on the second lowest diagonal of the table (see outlined cells in Table V-3), also show a general decline between 1990 and 1996. Similarly, the higher successive diagonals in the table report SMR values for the third and fourth calendar years of therapy, which show less consistent trends over the years, with both increases and decreases between successive years.

Prevalent cohorts of patients are given in successive columns of Table V-3. Detailed tabulations of annual death rates for prevalent patients are reported in Section D of the Reference Tables by a cross-classification of age, race, and diabetes. These death rates are based on all period-prevalent ESRD patients treated during 1995 through 1997 and correspond to the summary death rates for the last 3 columns from Table V-3. They can be used to calculate expected mortality for many study groups of ESRD patients using the methodology described by Wolfe, 1992.

Standardized Mortality Ratios by State

Standardized mortality ratios (SMRs) were calculated to compare the death rates for all prevalent dialysis patients in a state to the death rates for virtually all U.S. dialysis patients in the USRDS database for the years 1995 through 1997. The SMR accounts for the age, race, sex, and diabetes status of the prevalent dialysis patients in a state. The observed death rate in a state is compared to the rate that would be expected based on national death rates for patients with similar characteristics. The mortality rates for the 1997 prevalent cohort (Reference Table D.2) have been selected as the reference, and the mortality for 1995-1997 for each state is reported relative to them.

The resulting SMRs are graphically presented in Figure V-9. Although it appears that the eastern half of the United States has generally higher standardized mortality than the western half, further investigation would be required to better explain any observed patterns.

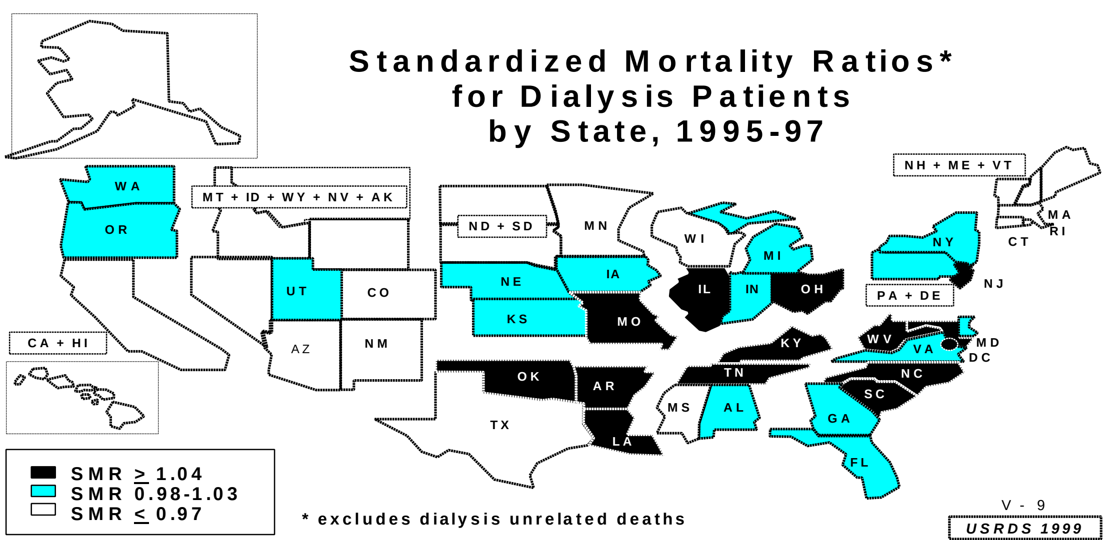

Figure V-9

Standardized Mortality Ratios for dialysis patients by state, 1995-97. Small states are grouped together as indicated in the reference table. Death rates are adjusted by age, race (Black, White, Asian, Native American), sex, and diabetes to the 1997 prevalent dialysis population . Patients with missing or unknown race, or missing primary diagnosis are excluded. Dialysis unrelated deaths are excluded. Source: Reference Table D.3.

Expected Remaining Lifetimes for U.S. Population (1995), All ESRD Patients[1] (1997) and Dialysis Patients (1997) by Age, Race and Sex

	U.S. Population, 1995[2]				ESRD population, 1997[4]				Dialysis population[3,4], 1997			
	Black		White		Black		White		Black		White	
Age	M	F	M	F	M	F	M	F	M	F	M	F
0-14	61.1	69.7	68.7	74.8	26.7	24.3	32.6	30.0	18.0	16.2	16.9	15.4
15-19	51.7	60.2	59.2	65.2	22.2	19.6	24.6	23.3	18.6	16.6	16.2	15.2
20-24	47.2	55.4	54.5	60.4	19.3	17.0	21.3	20.0	16.4	14.4	14.0	12.9
25-29	42.9	50.6	49.9	55.5	16.5	15.3	17.9	16.8	14.1	13.0	11.4	10.4
30-34	38.6	46.0	45.2	50.6	14.2	13.5	15.1	14.3	12.2	11.6	9.4	8.7
35-39	34.5	41.4	40.7	45.8	12.4	11.8	12.7	12.3	10.8	10.5	8.0	7.5
40-44	30.5	36.9	36.1	41.0	10.7	10.1	10.6	10.3	9.5	9.0	6.9	6.8
45-49	26.7	32.6	31.7	36.3	9.0	8.6	8.8	8.4	8.1	7.8	6.1	5.9
50-54	23.0	28.4	27.3	31.7	7.7	7.2	7.1	6.7	7.0	6.7	5.2	5.0
55-59	19.6	24.4	23.2	27.3	6.6	6.0	5.7	5.4	6.1	5.7	4.4	4.3
60-64	16.4	20.6	19.3	23.0	5.4	5.3	4.5	4.4	5.1	5.0	3.7	3.8
65-69	13.6	17.1	15.7	19.1	4.3	4.5	3.6	3.5	4.1	4.4	3.2	3.2
70-74	11.0	13.9	12.5	15.4	3.6	3.6	2.9	2.9	3.5	3.6	2.8	2.8
75-79	8.8	11.1	9.7	12.0	2.9	3.0	2.5	2.5	2.9	3.0	2.4	2.4
80-84	6.8	8.4	7.2	8.9	2.5	2.5	2.0	2.1	2.5	2.5	2.0	2.1
85+	5.1	6.2	5.2	6.3	1.9	2.1	1.7	1.7	1.9	2.1	1.6	1.7

[1]Includes patients treated with either dialysis or transplantation.

[2] Ventura SJ, Peters KD, Martin JA, Maurer JD. Births and Deaths: United States 1996. Monthly vital statistics report, Vol 46 No. 1, supp 2. Hyattsville, MD; National Center for Health Statistics, 1997: Table 16

[3] Mortality followup is censored at transplant.

[4]Death rates used for these calculations exclude dialysis unrelated deaths.

Source: Reference Table D.2 and Special Analysis

USRDS 1999

Table V-4

Projected Remaining Years of Life

Methods

The average remaining years of life was calculated using actuarial methods (Gross) for the ESRD population (including transplant patients) and the dialysis population, for each of several age-race-sex subgroups. The actuarial method calculates the life expectancy that would result in a standard population subject to a table of age-race-sex-specific death rates. The 1997 prevalent patient death rates for Black and White males and females of various ages (Reference Table D.2) were used in this calculation for dialysis and all ESRD patients. These death rates are calculated after excluding deaths due to AIDS, accidents ("accidents unrelated to treatment" on the ESRD Death Notification), and illegal drugs ("drug overdose (street drugs)" on the HCFA Death Notification Form), 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 (Ventura), shown for comparison, do include these causes of deaths. The difference between ESRD and total U.S. life expectancy is thus underestimated.

Results

Table V-4 shows the expected remaining years of life for the U.S. population, the total ESRD population, and the dialysis population. The results are shown by age, race, and sex subgroups. The values in Table V-4 are average remaining lifetimes, and the lifetimes of individual patients will vary considerably from these averages.

The expected lifetimes of the ESRD population exceed that projected for the dialysis population by 2 to 16 years through age 34. This is because the ESRD population includes the healthier transplant recipients that are not included in the dialysis group; this effect is stronger for the younger age groups that have higher rates of transplantation. Over age 65, the expected remaining lifetime for all ESRD patients is about the same as that for dialysis patients, 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 dialysis population, the difference between male and female lifetimes tends to be smaller than in the "all ESRD" population, particularly in the younger age groups. As in the "all ESRD" population, male lifetimes exceed those of females among dialysis patients in the younger age groups (through age 64 for Blacks and age 59 for Whites), while in the older age groups, females tend to have slightly longer lifetimes than males.

In the U.S. population, the life expectancy among Whites is higher than for Blacks at each age for both the males and females. In the "all ESRD" population, lifetimes of Whites exceed those of Blacks through age 39 for males (through age 44 for females), while the opposite is true for older ages. In the dialysis population, lifetimes of Blacks exceed those of Whites of the same sex, at every age.

Black males in the "all ESRD" population over age 25 have an expected remaining lifetime that is between 32 and 38 percent that of the age matched U.S. Black males. Black females over age 25 with ESRD fare worse, with an expected remaining lifetime between 25 and 34 percent that of age-matched U.S. Black females. Relative lifetimes of White ESRD patients are even shorter, ranging between 23 and 36 percent for males and between 19 and 30 percent among females over age 25, compared to the U.S. population.

Overall, the expected lifetimes of dialysis patients are between 16 and 38 percent those of the age-sex-race matched U.S. population, while lifetimes of all ESRD patients are between 19 and 47 percent of the corresponding U.S. population. Black dialysis patients in general have greater expected remaining lifetimes for all ages when compared to Whites. Finally, the inclusion of healthier transplant recipients in the all ESRD calculations yields longer lifetimes compared to the dialysis only calculations, especially in the younger age groups that 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.

Methods for Calculating National Death Rates

The methods for calculating these death rates are discussed in Chapter XIII, Analytical Methods. In particular, two major features of the calculations are:

1. Patients with any of three specific dialysis-unrelated causes of deaths (DU deaths) were excluded from the calculations (deaths due to AIDS, accidents unrelated to treatment such as violence, and street drug overdoses) (Turenne, Wolfe, 1996).

2. The 1997 death rates for patient subgroups published in this report are estimated using a Poisson regression model.

References

Allison PD. Survival analysis using the SAS system: A practical guide. Cary, NC: SAS Institute Inc., 1995.

Anderson JE, Kraus J, Sturgeon D. Incidence, prevalence, and outcomes of end-stage renal disease patients placed in nursing homes. Am J Kidney Dis 1993; 21: 619-627.

Breslow NE, Day NE. Statistical methods in cancer research (Volume II), IARC, Lyon, 1987.

Collins AJ, Hanson G, Umen A, Kjellstrand CM, Keshaviah P. Changing risk factor demographics in end-stage renal disease patients entering hemodialysis and the impact on long-term mortality. Am J Kidney Dis 1990; 15: 422-432.

Cox DR. Regression Models and life tables (with discussion). J R Stat Soc 1972; 34: 197-220.

Gross AJ, Clark VA. Survival Distributions: Reliability Applications in the Biomedical Sciences. Wiley, 1975, p. 47.

Hakim RM, Breyer J, Ismail N, Schulman, G. Effects of dose of dialysis on morbidity and mortality. Am J Kidney Dis 1994, 23 :661-669.

Health Care Financing Administration. 1998 Annual Report, End-Stage Renal Disease Core Indicators Project. Department of Health and Human Services, Health Care Financing Administration, Office of Clinical Standards and Quality, Baltimore, MD, December, 1998.

Held PJ, Port FK, Turenne MN, Gaylin DS, Hamburger RJ, Wolfe RA. Continuous ambulatory peritoneal dialysis and hemodialysis: a comparison of patient mortality with adjustment for comorbid conditions. Kidney Int 1994; 45:1163-1169.

Held PJ, Port FK, Wolfe RA, Stannard DC, Carroll CE, Daugirdas JT, Bloembergen WE, Greer JW, Hakim RM. The dose of hemodialysis and patient mortality. Kidney Int 1996; 50:550-556.

Kaplan EL, Meier P. Nonparametric estimation from incomplete observations. J. Am. Stat. Assoc. 1972; 53:457-481.

McClellan WM, Anson C, Birkeli K, Tuttle E. Functional status and quality of life: Predictors of early mortality among patients entering treatment for end-stage renal disease. J Clin Epidemiol 1991; 44:83-89.

McClellan WM, Flanders WD, Gutman RA. Variable mortality rates among dialysis treatment centers. Ann Int Med 1992; 117:332-336.

McPherson K, Wennberg JE, Hovind OB, Clifford, P. Small-area variations in the use of common surgical procedures: an international comparison of New England, England, and Norway. N Engl J Med 1982; 307:1310-1314.

Owen WF, Lew NL, Yan Liu SM, Lowrie EG, Lazarus JM. The urea reduction ratio and serum albumin concentration as predictors of mortality in patients undergoing hemodialysis. N Engl J Med 1993; 329: 1101-1106.

Parker TF, Husni L, Huang W, Lew N, Lowrie EG. Survival of hemodialysis patients in the United States is improved with a greater quantity of dialysis. Am J Kidney Dis 1994, 23: 670-680.

Port FK, Wolfe RA, Mauger EA, Berling DP, Jiang K. Comparison of survival probabilities for dialysis patients versus cadaveric renal transplant recipients. JAMA 1993; 270:1339-1343.

Robinson G. K. That BLUP is a good thing: the estimation of random effects. Statistical Science 6, 15-32, 1991.

Selvin S. Practical biostatistical methods. Wadsworth, 1995.

Turenne MN, Loos ME, Port FK, Emmert G, Hulbert-Shearon TE, Wolfe RA, Levine GN, Daugirdas JT, Agodoa LYC, Held PJ. The impact of deaths due to AIDS, accidents and street drugs on standardized mortality ratios (SMRs) by facility. J Am Soc Nephrol 1996; 7:1469 (Abst).

United States Renal Data System. Comorbid conditions and correlations with mortality risk among 3,399 incident hemodialysis patients. Am J Kidney Dis 1992; 20 (Suppl 2):32-38.

United States Renal Data System. USRDS 1995 Annual Data Report. The National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, April 1995.

United States Renal Data System. USRDS 1997 Annual Data Report. The National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, April 1997.

Ventura SJ, Peters KD, Martin JA, Maurer JD. Births and Deaths: United States 1996. Monthly vital statistics report, Vol 46 No. 1, supp 2. National Center for Health Statistics, Hyattsville, MD. 1997.

Wolfe RA, Gaylin DS, Port FK, Held PJ, Wood CL. Using USRDS generated mortality tables to compare local ESRD mortality rates to national rates. Kidney Int 1992; 42:991-996.

Wolfe RA, Hulbert-Shearon TE, Levine GN, Agodoa LYC, Port FK. Mortality tables: interpretability and stability. J Am Soc Nephrol 1996; 7: 1469 (Abst).

Wolfe RA, Ashby VB, Milford EL, Ojo AO, Ettenger RE, Agodoa LYC, Held PJ, Port FK: Patient survival for wait-listed (WL) dialysis versus cadaveric renal transplant (tx) patients in the U.S. J Am Soc Nephrol 1997; 8: 708A (Abst).

Young EW, Carroll CE, Wolfe RA, Port FK, Held PJ. Trends in comorbidity and residual renal function in patients starting treatment for end-stage renal disease. J Am Soc Nephrol 1995; 6: 569.