Chapter VIII

Pediatric End Stage Renal Disease

The patterns of treatment and the patient outcomes of the national pediatric ESRD population have unique characteristics. In addition, issues of physical growth in children with ESRD and the development of secondary sexual characteristics in older children apply only to the pediatric ESRD population (McEnry; Fine, Salusky, et al 1987; Fine 1987). For these reasons, the pediatric ESRD population requires special attention and this chapter will focus exclusively on the incidence, prevalence, modalities of treatment, and survival outcomes specific to the national pediatric ESRD population.

There are international differences in the definition of the pediatric patient, with the upper age limit of the pediatric group ranging between 15 and 19 years. As with previous Annual Data Reports, this 1995 Annual Data Report uses the broader definition that includes the 19th year. In many of the following analyses, pediatric patients are further divided into 5-year age groups: 0-4, 5-9, 10-14, and 15-19 years. Several definitions of age are used in this chapter: 1) age is defined as age at onset of ESRD for analyses of treated incidence and the accompanying dialysis patient survival; 2) age on December 31 is used for analyses of point prevalence; and 3) age at time of transplantation is used for analyses of kidney transplants. In all cases, only patients less than 20 years of age are considered. Only Medicare patients are included in the analyses. Since children on Medicaid (the State and Federal medical insurance program for the poor) are over represented in the general population as compared to adults, there may be a similar overrepresentation of children on Medicaid (and without Medicare) in the population of patients with ESRD. If so, the population of pediatric Medicare patients with ESRD may be a smaller proportion of the total pediatric ESRD population than is the proportion of the adult Medicare ESRD to the total adult ESRD population. Future work by the USRDS will investigate this possibility using the 1993 Census of dialysis patients. Because of very small cell sizes, analyses of kidney transplant counts and rates exclude children receiving grafts from living non-related donors.

Incidence of Reported Pediatric ESRD

The rate of incidence of pediatric ESRD has remained generally constant over the past decade with 832 newly diagnosed children beginning treatment for ESRD under the Medicare system reported in 1992. This corresponds on average to an annual rate of slightly more than one in one hundred thousand United States children.

In both the pediatric and adult ESRD populations, rates of ESRD incidence increase substantially with age. ESRD treated incidence, adjusted for race and sex, indicates that ESRD is many times more common among adults than among children. During 1992 the adjusted ESRD incidence rate per million United States population (in each age group) was 11 for ages 0-19 years, 100 for ages 20-44 years, 380 for ages 45-64 years, 833 for ages 65-74 years, and 717 for ages 75 and over. (Since these rates are per million in each age group, the rates for children are directly comparable to adult rates as reported in Chapters III and IV.) A higher ESRD incidence with older age is also found across five-year age groups within the pediatric cohort when adjusting for differences in sex and race. Table VIII-1 indicates that average incidence rates for the combined years 1990-92 were more than twice as high among children 15-19 years (23 per million) as they were for children 10-14 years (11 per million), and almost four times higher than rates for children 0-4 (6 per million) and 5-9 (6 per million) years of age at onset of ESRD. Average annual counts of incident children, for the years 1990-1992, reported in Table VIII-1, reveal that 418 out of 839 children beginning treatment for

Pediatric ESRD Incidence and Prevalence Counts and Rates, 1990-92

Age at Incidence	Incidence		Point Prevalence*	
	Average Counts Per Year	Adjusted Annual Rate**	Average Counts Per Year	Adjusted Annual Rate**
0-4	115	6	277	14
5-9	108	6	606	33
10-14	199	11	1,040	56
15-19	418	23	2,078	119
Total (0-19)	839	11	4,000	55
Adults (20-44)	9,575	96	55,343	550

Table VIII-1

** Point prevalence on December 31 of 1990-1992. ** Rate per million U.S. population (in each age group), adjusted for sex and race. Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded from estimates of incidence and prevalence. Counts are averaged over three year period. Medicare patients only.*

Source: Reference Tables A.6, A.7, A.35, B.6, B.8, and B.26.

ESRD, or 50 percent, were between the ages of 15 and 19 at onset of ESRD.

During the past ten years, both incidence rates and incidence counts have remained fairly stable for each of the four pediatric age groups. This is notably different from the adult population where the average overall compound rate of change for all ages was 7.6

Pediatric ESRD Treated Incidence Rate by Race and Age, 1990-92

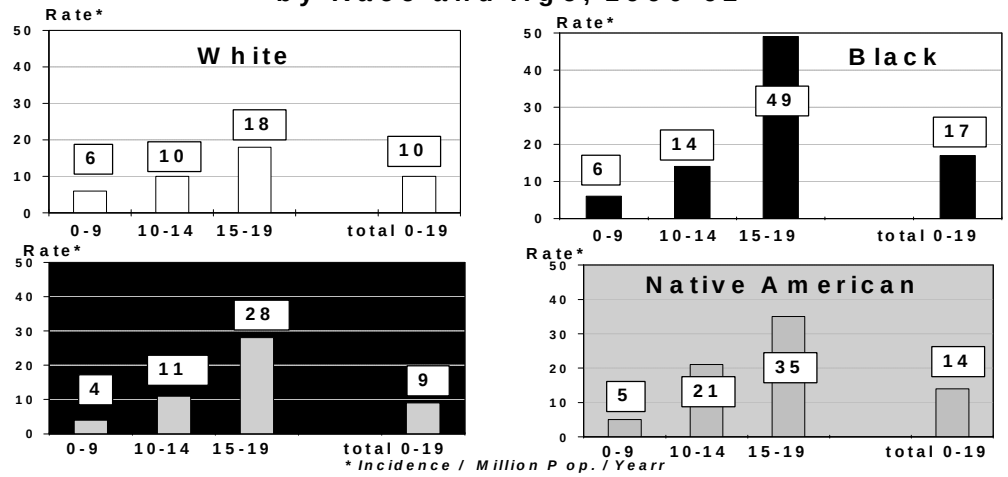

Figure VIII-1

Reported pediatric ESRD incidence per million population by age and race, adjusted for sex. Average rate per year, 1990-92. Incidence rates for all children (0-19) adjusted for sex . Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded. Medicare patients only. Source: Reference Tables A.8 and A.39.

percent per year between the years 1983 and 1992 (Reference Table A.6).

Within the pediatric ESRD population, there were variations in the incidence of ESRD by race as well as age. The treated pediatric ESRD incidence rate per million United States population per year for the 1990-92 period is illustrated by race and age in Figure VIII-1. Overall incidence rates per corresponding million population were 10 for Whites, 17 for Blacks, 9 for Asians/Pacific Islanders, and 14 for Native Americans. The higher reported incidence of ESRD for Black children was primarily the result of the almost three-fold excess of ESRD among Blacks compared to Whites in the 15-19 year old age group (49 per millions versus 18 per million). Treated incidence rates in Whites and Blacks differed less for younger age groups. The incidence rates for Native Americans compared to Whites show a similar pattern with a rate of 35 per million Native Americans between the ages of 15-19 which is twice that of Whites in the same age group.

The differences in incidence rates by race were even more striking in the adult population (defined as 20 years or older at onset of ESRD) where there was overall a four-fold greater incidence of ESRD among Blacks compared to Whites and a more than three-fold greater incidence of ESRD among Native Americans compared to Whites. In the adult population, these differences in incidence of ESRD among Whites, Blacks and Native Americans may have been partly due to the differences in rates of diabetes and hypertension among Whites, Blacks and Native Americans.

This association with chronic diseases was not the case within the pediatric ESRD cohort, where only 5.6 percent of renal failure was associated with hypertension and 1.3 percent of renal failure was linked to diabetes. Figure VIII-2 illustrates the incidence of reported pediatric ESRD by sex according to five-year pediatric age groups. Treated incidence rates of chronic renal failure were greater for males than females across all pediatric age groups. Similar trends are seen in the adult population where, for example, the treated incidence rate among patients 20-44 years of age, adjusted for race, was 119 per million for males and 74 per million for females. In children, this trend was especially noteworthy in patients less than five years old, where the rate of incidence for males was double that of females.

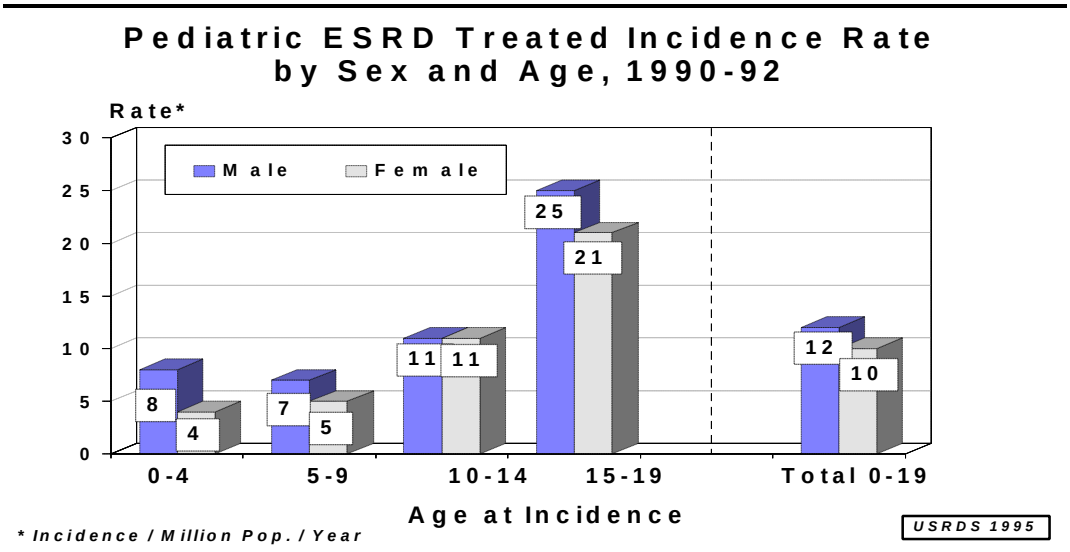

Figure VIII-2

Reported pediatric ESRD incidence per million population by age and sex, adjusted for race. Average rate per year, 1990-92. Incidence rates for children of all ages (0-19) are adjusted for race. Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded. Medicare patients only.

Source: Reference Tables A.8 and A.39.

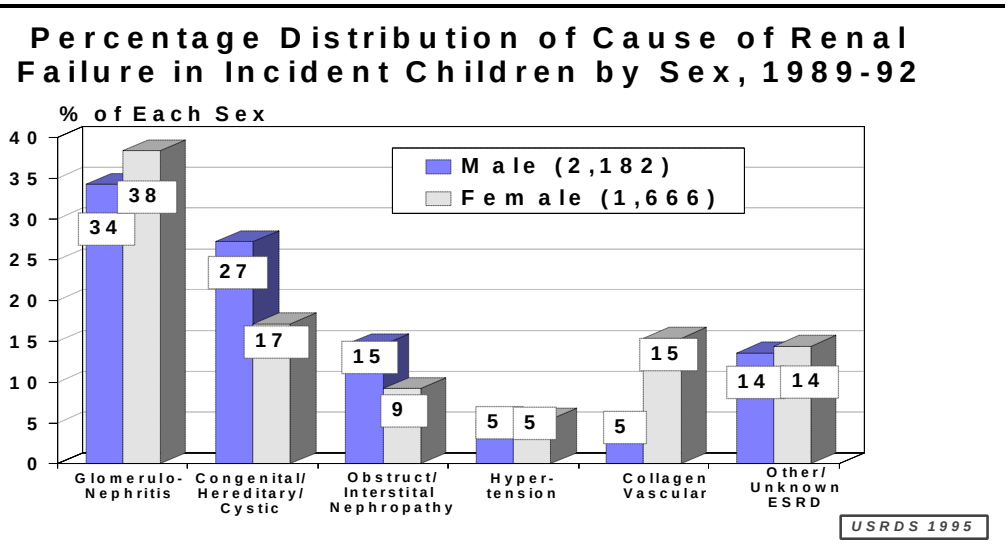

Figure VIII-3

Incident pediatric cases by disease group, by sex, as a percent of total pediatric ESRD within each sex. Boxed numbers represent the percent within each sex over a five year time period. For example, 5% of incident male (n=2,182) children between 1988-92 had collagen vascular disease as the primary cause of ESRD. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table A.29.

Causes of Pediatric ESRD

The distribution of causes of ESRD by sex among pediatric patients incident during the 1988-92 period is shown in Figure VIII-3. The largest single disease group causing ESRD in children was glomerulonephritis (35.8 percent of all reported causes), followed by congenital /other hereditary/cystic diseases (22.4 percent). Females were over represented (had a higher than average

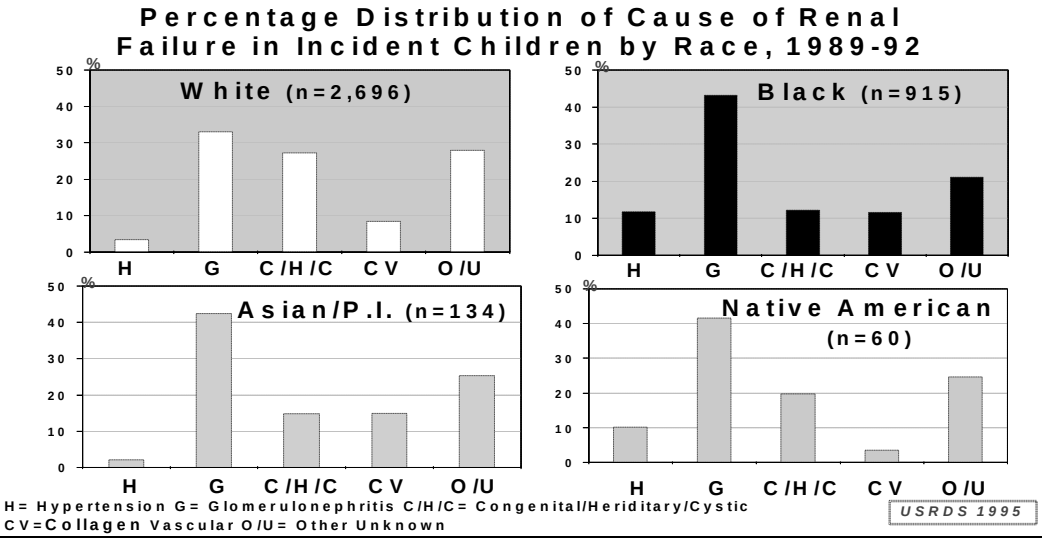

Figure VIII-4

Incident pediatric cases by disease group, by race, as a percent of total pediatric ESRD for that race. Percentages within each panel add to 100. Total excludes missing disease. Average percent over a five year period, 1988-92. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table A.29.

percentage of a given disease compared to their percentage of the total pediatric ESRD population) among patients with ESRD due to glomerulonephritis and collagen vascular disease and males were over represented among patients with congenital/ other hereditary/cystic disease and obstructive nephropathy/interstitial nephritis as the primary cause of ESRD.

Figure VIII-4 provides the distribution of causes of ESRD within each race among pediatric incident patients during 1988-92. Glomerulonephritis (35.8% of all pediatric ESRD), as a primary cause of ESRD was over represented among Blacks, Asians and Native Americans; hypertension (5.6% of all pediatric ESRD) was over represented among Blacks and Native Americans and congenital/other hereditary/ and cystic diseases (22.4% of all pediatric ESRD) was over represented among Whites.

The etiology of pediatric ESRD is substantially different from that of adult ESRD and therefore warrants closer examination. A more detailed description of the causes of renal failure among children (< 20 years) according to age, race, sex and one-year transplant and death status is provided in Table VIII-2. Except for the column labeled "% of Total" which is expressed as a percentage of the total for that column, percentages by sex, race, and transplant and death status in Table VIII-2 are expressed relative to the number of patients in each disease group, i.e., the total for that row. Only 6.9 percent of 1988-92 incident pediatric cases (n=4,352 minus the 504 cases in which a primary diagnosis was missing, or 3,848) were reported to have diabetes or hypertension as the primary cause of ESRD. This is in contrast to adults 20-64 years of age, where 64.7 percent of incident cases reported diabetes or hypertension as the primary cause of ESRD. The distribution of diagnoses among children varied by age. Compared to average values for pediatric patient characteristics in the top row of Table VIII-2, hemolytic uremic syndrome/TTP, malignancies, metabolic diseases, polyarteritis and renal dysgenesis/agenesis/dysplasia were associated with the lowest median age. Hypertension and diabetes were associated with the highest median ages of 17 and 18 respectively.

Blacks were over represented (have a higher than average percentage of a given disease compared to their % of the total pediatric ESRD population indicated in the top row of Table VIII-2) among children whose primary cause of ESRD was hypertension, glomerulonephritis, lupus erythematosus, and, as expected, sickle cell disease. Whites had higher than expected percentages of ESRD from cystic kidney disease, interstitial nephritis, obstructive nephropathy, malignancies, metabolic diseases and congenital/hereditary conditions. Asians were over represented for collagen vascular diseases. Native Americans were overrepresented for diabetes, hypertension, and cystic kidney diseases.

Table VIII-2 also reveals that males predominated among pediatric patients with ESRD due to obstructive conditions, malignancies and congenital and other hereditary diseases. Females predominated among patients with ESRD due to collagen vascular diseases, diabetes and metabolic diseases.

Frequency of kidney transplantation within one year of onset of ESRD also varied by primary disease, with evidence of higher than average rates of transplantation for diseases associated with a relatively low median age. The fraction of pediatric ESRD patients who died within one year following onset of ESRD was highest among those with hypertension, cystic kidney diseases, Wegener's granulomatosis, hemolytic uremic syndrome/TTP, and malignancies. Mortality was lowest among pediatric patients with interstitial nephritis and obstructive nephropathy. The reader should keep in mind that no adjustments have been made to the estimates shown in Table VIII-2 for differences in age, race, sex, and modality of care across these disease groups.

Prevalence of Reported Pediatric ESRD

ESRD treated point prevalence counts and rates per million United States population are shown in Table VIII-1 for the four pediatric age groups as well as for the overall pediatric cohort. A child incident (i.e., new to ESRD) at age 4 in 1984 would be prevalent (existing), if still alive, at age 12 in 1992. As this child and others grow older, they will be counted as prevalent in successively older age groups, which explains the higher prevalence rates among older age groups, i.e., patients 5-9 versus 0-4 years. Point prevalence rates per million population (adjusted for race and sex) reveal an approximate doubling of rates for each of the five-year age groups (Table VIII-1).

Incidence of Treated ESRD by Detailed Primary Disease, Age, Race, Sex and One-Year Transplant and Death Status for Pediatric Patients Age < 20 Yrs 1988-92

Primary Disease Groups	Total Incident Count 1988-92[1]	% of Total[2]	Median Age	Percent of Total					Percent[3]	
				Males	White	Black	Asian	Native Amer.	Tx'ed First Year	Died First Year
All Pediatric ESRD, (reference)	**4352**	**100**	**15**	**57**	**69.6**	**23.4**	**3.3**	**1.5**	**42.5**	**4.9**
Diabetes	**52**	**1.4**	**18**	**48.1**	**65.4**	**26.9**	**0**	**5.8**	**32.7**	**3.8**
Hypertension	**210**	**5.5**	**17**	**56.7**	**43.3**	**51.4**	**1.4**	**2.9**	**31.4**	**7.1**
Glomerulonephritis	**1387**	**36**	**16**	**53.9**	**64.2**	**28.5**	**4.1**	**1.8**	**41.4**	**4.1**
. Goodpasture's Syndrome	20	0.5	18	40	80	20	0	0	35	0
. Focal glomerulosclerosis, focal GN	350	9.1	15	58.3	51.4	45.7	2	0.9	44.3	3.7
. Membranous nephropathy	23	0.6	15	43.5	60.9	39.1	0	0	52.2	4.3
. Membranoproliferative GN	128	3.3	15	46.9	71.1	21.1	3.9	3.1	50	3.1
. All other glomerulonephritis	866	22.5	16	53.8	68.1	22.5	5.2	2.1	38.8	4.5
Cystic Kidney Diseases	**170**	**4.4**	**11**	**52.9**	**89.4**	**4.7**	**2.9**	**2.4**	**54.1**	**7.1**
Interstitial Nephritis	**169**	**4.4**	**16**	**53.8**	**79.3**	**14.8**	**4.1**	**0.6**	**47.3**	**3**
. Analgesic nephropathy	32	0.8	14	53.1	81.3	15.6	3.1	0	53.1	3.1
. All other interstitial nephritis	137	3.6	16	54	78.8	14.6	4.4	0.7	46	2.9
Obstructive Nephropathy	**304**	**7.9**	**12**	**75**	**78.6**	**16.1**	**3**	**1.3**	**47.4**	**3.3**
Collagen Vascular Diseases	**362**	**9.4**	**16**	**29**	**63**	**29.3**	**5.5**	**0.6**	**20.2**	**5**
. Lupus erythematosus	242	6.3	16	22.7	49.2	40.1	7.9	0.4	12.4	4.1
. Wegener's granulomatosis	14	0.4	16	50	100	0	0	0	35.7	14.3
. Hemolytic uremic syndrome / TTP	67	1.7	8	38.8	92.5	6	1.5	0	31.3	6
. Henoch-Schonlein Purpura	33	0.9	15	48.5	87.9	9.1	0	3	45.5	0
Malignancies	**12**	**0.3**	**4**	**66.7**	**83.3**	**16.7**	**0**	**0**	**16.7**	**16.7**
. Renal and urinary tract neoplasms	11	0.3	4	72.7	81.8	18.2	0	0	18.2	18.2
Metabolic Diseases	**51**	**1.3**	**10**	**49**	**90.2**	**9.8**	**0**	**0**	**82.4**	**5.9**
. Oxalate nephropathy	13	0.3	10	61.5	100	0	0	0	84.6	7.7
. Cystinosis	38	1	11	44.7	86.8	13.2	0	0	81.6	5.3
Congenital/Other Hereditary Diseases	**710**	**18.5**	**11**	**71**	**81.8**	**14.5**	**2.1**	**1.1**	**53.5**	**5.1**
. Congenital obstructive uropathy	156	4.1	12	79.5	87.2	9	1.9	1.9	55.8	4.5
. Renal dysgenesis, agenesis, dysplasia	173	4.5	9	64.2	78.6	17.9	2.9	0.6	59.5	8.1
. Alport's Syndrome	381	9.9	11	70.6	81.1	15.2	1.8	1	49.9	3.9
Sickle Cell Disease	**10**	**0.3**	**15**	**50**	**30**	**70**	**0**	**0**	**20**	**0**
Other ESRD	**43**	**1.1**	**8**	**53.5**	**83.7**	**11.6**	**0**	**2.3**	**20.9**	**11.6**
Cause Unknown	**366**	**9.5**	**16**	**56.8**	**68.3**	**23**	**4.9**	**1.6**	**43.2**	**3.8**
Missing Information	**504**		**14**	**59.3**	**66.1**	**20.6**	**2**	**1**	**42.1**	**6.3**

Table VIII-2

Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Bolded rows represent disease category headings. Except for the column labeled "percent of total", which is expressed as a total for that column, percentages by sex, race, and transplant and death status are expressed relative to the number of patients in each disease group, i.e., the total for that row. Source: A. 30 and A.31. [1]Divide total by 5 to determine the average annual count of children new to ESRD between 1988 and 1992. [2]Patients with missing information (12% of total) are excluded from the percent calculation [3]In these two columns, "1st Year" refers to the 1st year of ESRD therapy, Tx'ed=transplanted. The following are not reported due to counts less than 10: Scleroderma, Polyarteritis, Lymphonas, AIDS-related

Over 50 percent of the 1990-92 point prevalent pediatric ESRD cohort was in the 15-19 year age group. As such, aggregate descriptions and outcomes associated with the pediatric ESRD population are strongly influenced by the experience of children in the oldest five-year pediatric age group.

The reader should note that estimates of Medicare ESRD prevalence for the 1988-90 period, as reported in the *USRDS 1993 Annual Data Report* were 5% lower compared to rates reported in the *USRDS 1991 Annual Data Report* for the 1987-89 period. A change in the methodology now used to identify prevalent ESRD patients excludes patients who are lost to follow-up or untreated for one year or more, reducing overall Medicare ESRD prevalence estimates for the United States by approximately 10 to 13 percent during the 1980s. Chapter XIV of the present report, "Analytical Methods," provides further details on the classification of patients lost to follow-up and the effects on other estimates produced by the USRDS.

Pediatric prevalence counts for the 1990-92 period reveal an increase in overall prevalence of 3 percent compared to the 1989-91 period. Since pediatric ESRD rates of incidence have remained stable over these years, this increase can be largely attributed to improvements in the survival of pediatric ESRD patients.

Methods of Treating Pediatric ESRD

Pediatric ESRD patients have special needs and requirements that strongly influence preferences for treatment and patterns of treatment utilization (Held; USRDS 1991). There are substantial differences in treatment modality utilization between adult and pediatric patients (Alexander; Held). Various treatment options are available to children with ESRD, with different modalities intended to fulfill different physical, social, and emotional needs. Patterns of treatment reveal that children are more likely to utilize forms of peritoneal dialysis than are adults, and younger children are much more likely to receive a renal transplant than are older children and adult patients (Alexander; Held; Rizzoni). Several factors have contributed to differences between the adult and pediatric ESRD treatment modality use. These include the relatively greater availability of living related kidney donors (particularly parental) for pediatric transplantation, limitations on educational and social opportunities for patients treated with center hemodialysis, and problems associated with small vessels for vascular access. Evidence of reduced growth rates for children receiving dialysis compared to those receiving a transplant also contributes to a strong preference for kidney transplantation for children (Alexander; Webb).

The largest difference in methods of treatment for

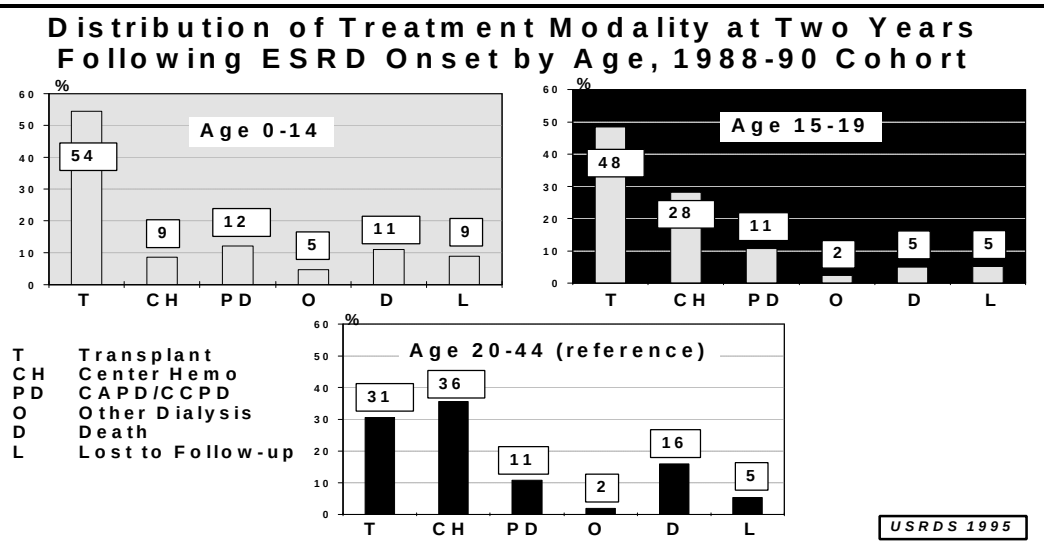

Figure VIII-5

Renal replacement therapy at two years past onset of ESRD by age at onset, 1988-90 cohort of treated incident patients. Percentages within each panel add to 100. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table C.22 and Special Analysis..

the pediatric versus the adult ESRD population was seen in transplantation. Forty-three percent of children starting ESRD therapy during the 1988-92 period received a transplant during the first year (Table VIII-2), compared to 11 percent of patients 20-64 years of age at ESRD incidence.

Figure VIII-5 profiles the methods of treatment used at two years following onset of ESRD for 2,636 pediatric patients incident in 1988-90 and compares this cohort to a cohort of incident patients 20-44 years old in the same time period. Fifty-four percent of children between the ages of 0-14 years and 48% of children 15-19 years of age had a functioning graft after two years of ESRD therapy, as children of all ages are aggressively transplanted. Children received dialysis less than adults with only 26% of children 0-14 years old and 41% of children 15-19 years having received some form of dialysis (the sum of all dialysis modalities in Figure VIII-5). In contrast, only 31 percent of adults in the 20-44 age group had a functioning graft after two years of ESRD therapy and 49% percent were receiving some form of dialysis. Eleven percent of children 0-14 years of age and 5% of children 15-19 years of age died within two years of onset of ESRD. By comparison, 16% percent of incident ESRD patients between 20-44 years had died within two years of onset of ESRD. In accordance with recent efforts by the USRDS to identify patients listed in the database who may not be receiving ESRD treatment, 7 percent of children between 0-14 years are considered lost to follow-up two years after onset of ESRD, a percentage that is higher than the comparable estimates for children 15-19 years and adult patients age 20-44 years of 5 percent.

Overall, differences in treatment utilization are more striking when comparing younger children, 0-14 years old, with adults 20-44 years old. The percentage of these same children who died (11%), is more similar to the adults (16%) (and substantially higher) than is the percentage of children 15-19 years old who died (5%).

The differences in patterns of treatment between older children and younger children can be summarized by noting that younger children are more likely to be treated with a transplant and older children are more likely to be treated with hemodialysis. Furthermore, younger children are more likely to die within the first two years of ESRD than are older children.

Number of Pediatric Renal Transplants

The number of Medicare pediatric renal transplants performed each year from 1982 through 1992 is plotted according to the transplant number (first or repeat) and type of donor (cadaveric or living related) in Figure VIII-6. Overall, the total number of Medicare pediatric transplants has been gradually decreasing since 1987 (781 pediatric transplants in 1987 compared to 628 pediatric transplants in 1992). The counts of cadaveric transplants (first and repeat) have been roughly similar to the counts of living related transplants (first and repeat) in the pediatric

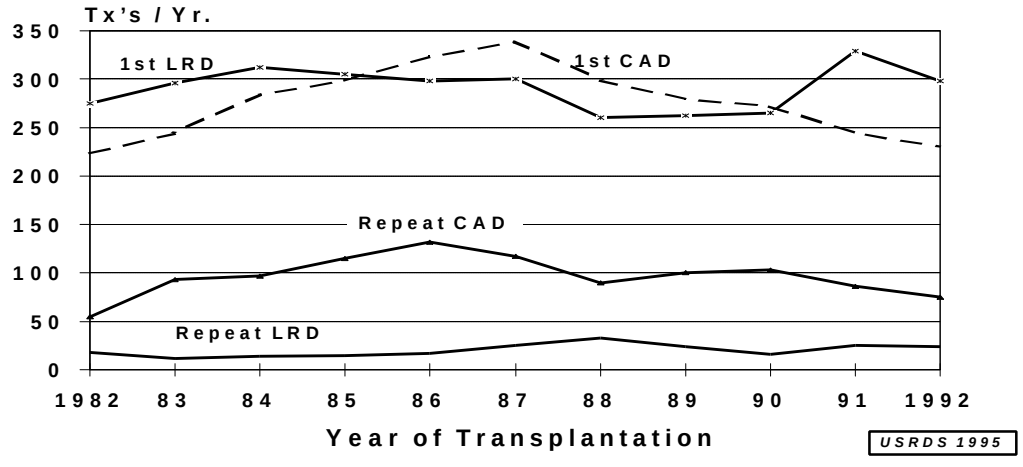

Figure VIII-6

Counts of pediatric renal transplants by donor type (cadaveric or living related) and transplant number (first or repeat) performed per year, 1982-92. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Tables F.11, F.12 and Spec. Analysis.

population. This is in marked contrast to the adult population for whom three to four times more transplants originate from cadaveric donors than from living related donors (see Chapter VIII of this report, Renal Transplantation: Access and Outcome). Although repeat cadaveric transplants have been more numerous than repeat living related transplants for both pediatric and adult patients, the relative difference is substantially greater among adult recipients (See Reference Tables F.11 and F.12).

The trends over time shown in Figure VIII-6 suggest that the steady increase in first cadaveric transplants among pediatric patients during the early 1980s has leveled off and, since 1987, has been declining. A similar decrease in the count of first living related kidney transplants performed since 1987 was observed until counts increased in 1991 and 1992.

Access to Kidney Transplantation: Transplant Rates

The previous section presented the total counts of pediatric renal transplants performed through 1992. This section further characterizes the patients who received kidney transplants, according to the type of donor (cadaveric or living related) as well as the age, sex, and race of transplant recipients. Shown in Figure VIII-7 are pediatric transplant rates by donor type and recipient age at time of transplantation, for transplants occurring in 1992. The transplant rate is calculated as the number of total transplants for a given cohort of patients (first and repeat) per 100 dialysis patient years. The same cohort of patients is used to measure the dialysis years (used in the denominator) and the number of transplants (used in the numerator). Dialysis patient years at risk represent the duration (in years) that children in the same age, sex, and race group received dialysis therapy during calendar year 1992. For children of all ages, there were 22.1 cadaveric transplants per 100 dialysis patient years and 24.1 living related transplants per 100 dialysis patient years. Rates of transplantation were highest among patients 5-9 years of age and in general decreased with pediatric age. It should be noted that calculations of transplant rates utilize the change in methodology since the 1993 Annual Data Report in which prevalence counts do not include patients lost to follow-up. For additional details, see Chapter 15: Analytical Methods.

Figure VIII-7 indicates that living related transplants dominated in every pediatric age group except 15-19 years. Both rates and counts of living related versus cadaveric transplantation revealed an emphasis on living related donors for pediatric transplantation, perhaps in response to a limited supply of cadaveric donors.

Pediatric Transplant Rates by Recipient Age and Donor Type, 1992

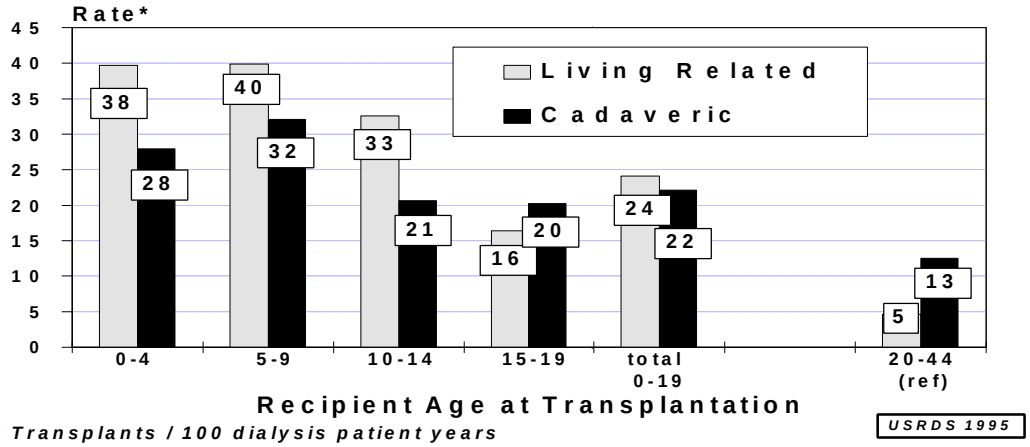

Figure VIII-7

Pediatric renal transplants per 100 dialysis patient years by recipient age (on 12/31 of transplant year) and donor type, 1992. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table F.44.

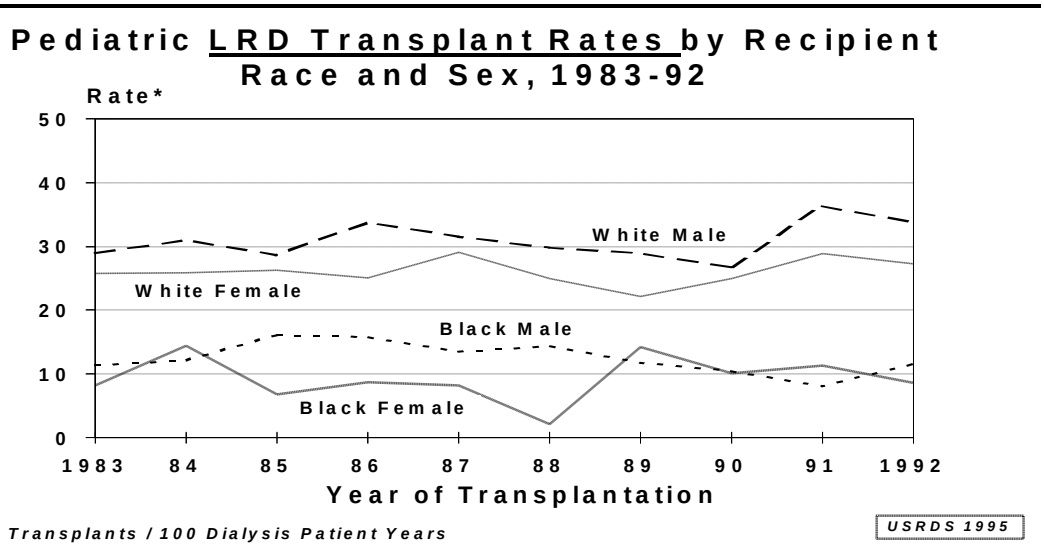

Figure VIII-8

Pediatric living related kidney transplants per 100 dialysis patient years, by recipient race and sex, by year, 1983-92. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

All pediatric patients ever transplanted as a percentage of all prevalent pediatric patients by recipient age is shown in Figure VIII-8. (This includes failed transplants.) This figure demonstrates the propensity of the pediatric nephrology community to choose transplantation as the preferred modality of treatment for children with ESRD. In 1992, 81.7 percent of prevalent ESRD patients 5-9 years had received at least one transplant compared to 30.3 percent of all ESRD patients. The percentage of patients ever transplanted decreased with each age group, once again revealing the preference for transplantation in younger age groups.

Transplant rates by recipient race, sex, and transplant year are shown in Figure VIII-9 and VIII-10 for cadaveric and living related donors,

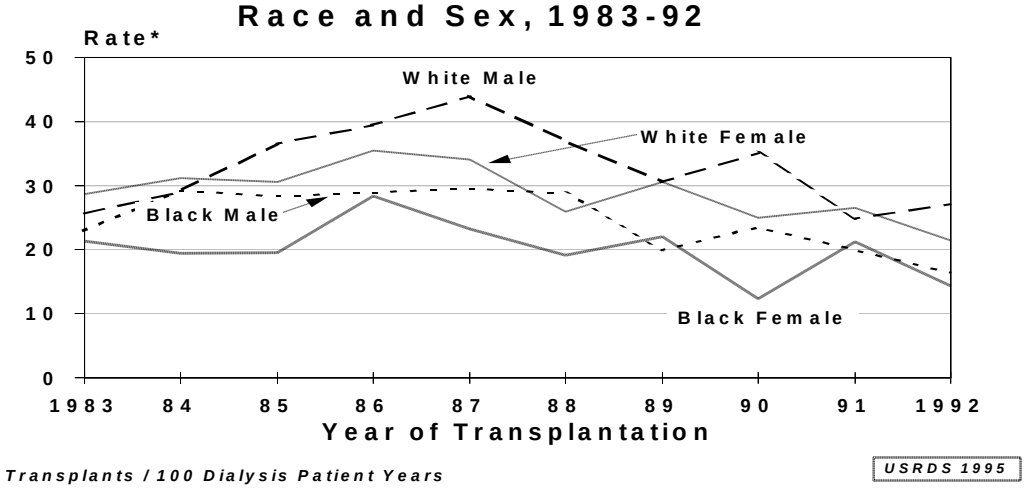

Figure VIII-9

Pediatric cadaveric kidney transplants per 100 dialysis patient years, by recipient race and sex, by year, 1983-92. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

respectively. As with adult ESRD patients, there was greater concordance of rates by sex than by race, with generally lower rates of cadaveric and living related transplants for both White and Black females compared to White and Black males. Overall, there were greater differences in transplantation observed by race for both cadaveric and living related transplants. The magnitude of differences in rates by race, however, was greater for living related than for cadaveric transplants. Rates of living related transplantation (Figure VIII-10) were twice as high for White males and White females compared to both Black males and Black females. With relatively small numbers of patients in each of these groups, considerable year-to-year variation was observed in rates by sex and race for each type of transplant (Figures VIII-9 and VIII-10).

Overall, rates of transplantation for children receiving grafts from cadaveric donors (Figure VIII-9) declined since the mid to late 1980s for both Black and White children of both sexes. Prior to the late 1980's, the United Network for Organ Sharing's (UNOS) policy was that kidneys from young donors would first be offered to pediatric ESRD patients. This policy was eliminated and replaced by one in which children were to receive "extra points" to increase their priority on the waiting list for a kidney transplant (Ettenger).

Rates of living related transplants (Figure VIII-10) in children of both sexes and race increased since the mid-1980's, with the exception of rates for Black males which remained constant.

Following the trends in pediatric transplantation during the 1990s will reveal how a limited supply of cadaver donors impacts rates of pediatric living related transplantation as well as the overall rates of pediatric transplantation.

Figures VIII-9 and VIII-10 summarize the trends in transplantation rates in children showing substantial variance by year, with larger differences by race than by sex.

Figure VIII-11 demonstrates that pediatric cadaveric kidney transplants, both in younger and older children, as a percentage of all cadaveric transplants, declined over the years 1983-1992. (The corresponding figure in the 1994 ADR was incorrect.) Figure VIII-12 shows rates of cadaveric transplants on a semi-logarithmic scale. Since the slopes of the lines for 0-14 year olds, 15-19 year olds and 20-29 year olds are all roughly similar, this can be taken as evidence that the number of transplants per 100 dialysis patient years, for the three age groups was decreasing at approximately the same rate between the years 1988 and 1992. While allocation of the actual number of cadaver kidneys to adult ESRD patients may have increased relative to the allocation of the actual number of cadaver kidneys to the pediatric ESRD population, transplants per 100 dialysis patient years for both pediatric patients and adult patients were decreasing at the same rate. This is likely due to the substantial increases over the past five years in prevalent adult patients relative to prevalent pediatric patients.

Pediatric Cadaveric Transplants as a Percentage of Total (Adult + Pediatric) Cadaveric Transplants by Age Group, 1983-92

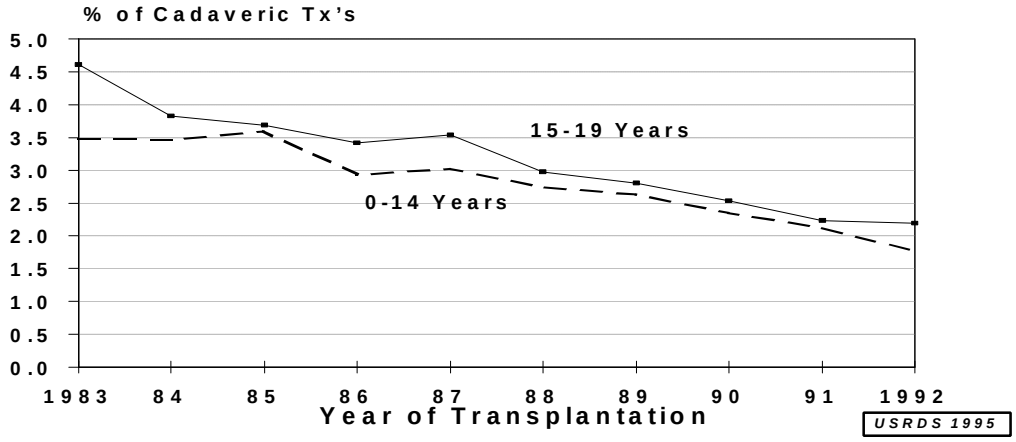

Figure VIII-11

Pediatric cadaveric transplants as a percentage of total (adult and pediatric) cadaveric transplants by age group, 1983-92. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special Analysis.

Table VIII-3 provides estimates of the number of pediatric transplants performed in relation to the number of adult kidney transplants in the same transplant center. These estimates indicate that 58% of pediatric transplants, during the years 1989-1992, occurred at transplant centers where less than a total of 10 pediatric transplants were performed in the same 4 year time period. While 36% of these same pediatric transplants occurred at transplant centers where more than 100 total transplants were performed during the same four years; 22% were performed at transplant centers where less than 100 total transplants were performed in a four year period *and* less than 10 pediatric transplants were performed. These data provide evidence that the majority of pediatric transplants occurred where experience with

Cadaveric Transplantation Rates by Age Group and Year, 1982-92

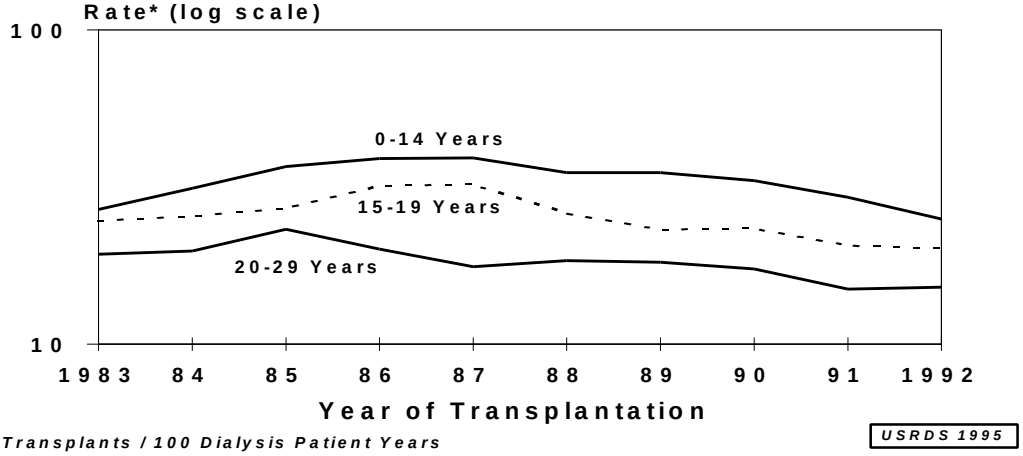

Figure VIII-12

Cadaveric transplant rate per 100 dialysis patient years at risk by year and age, 1982-92. Rates are calculated on a semi-logarithmic scale. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

Percentage of Pediatric Transplants Performed by Size of Facility (Total tx's, Number of Pediatric tx's), 1989-92

		Total Transplants Over 4 years		
		< 100	≥ 100	Total
Pediatric Transplants	< 10	22	36	58
	≥10	14	29	42
	Total	35	65	100

Table VIII-3

Percent of Medicare pediatric transplants performed by size of transplant center (as measured by the number of kidney transplants performed), for the four year period 1989-92. Patients Puerto Rico and U.S. Territories included. Source: Special Analysis.

pediatric transplant surgery may be limited, even though many more adult transplants were performed in these same centers. Further analysis should focus on whether outcomes are different in these various groupings of transplant centers.

Patient Survival for All Renal Replacement Therapies

Figure VIII-13 depicts two and ten year patient survival by five-year pediatric age groups. Both two-year and ten-year survival is estimated using unadjusted Kaplan-Meier survival estimates derived from the average of two one-year incident cohorts. Ten year survival for the 0-4 year age group has been suppressed due to the small size of the sample but can be found in Reference Table E.20. The reader should keep in mind that these incident cohorts overlap only for the 1982-83 incident cohort, where a true comparison of survival can be made.

The youngest age group (0-4 years) experienced the lowest two-year survival. A comparison of two and ten year survival of the 1982-83 incident pediatric cohort reveals that survival decreased on average 1-2 percent each year between two and ten years. Survival of patients in the 5-9 age group was 94 percent at two years and 81 percent at ten years; survival of patients 10-14 years was 97 percent at two years and 81 percent at ten years; survival of patients

Pediatric ESRD 2-Year and 10-Year Patient Survival by Age and Year of Incidence, Unadjusted

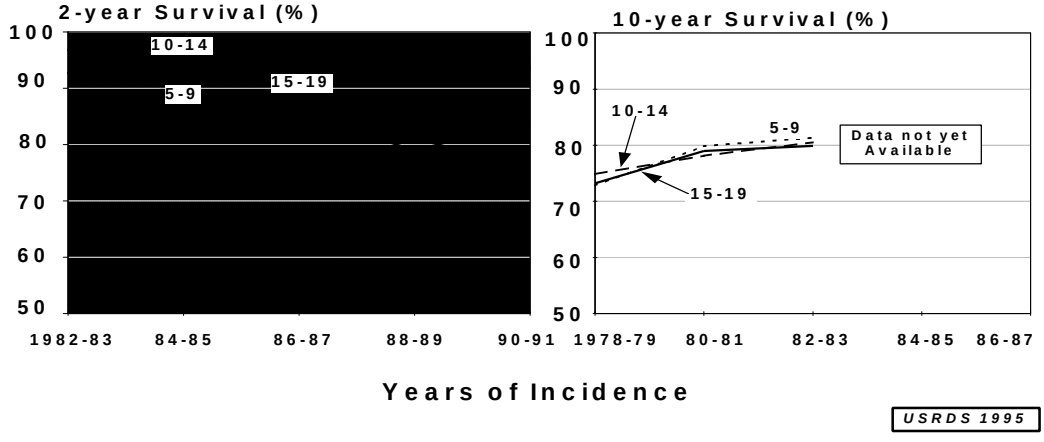

Figure VIII-13

Pediatric two-year and ten-year Kaplan-Meier patient survival (percent), starting at day 91 following onset of ESRD, derived from one-year cohorts, and averaged over two years. Ten year survival for patients 0-4 not reported. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare patients only. Source: Reference Tables E.16 and E.20..

15-19 years was 93 percent at two years and 80 percent at ten years. By comparison, the two and ten year survival for corresponding patients in the 30-34 age group was 82% and 51%, respectively.

Patient Survival by Modality

Pediatric patient death rates after two years of therapy for a 1991 incident patient cohort are shown in Figure VIII-14 according to five-year age groups and modality of care. Within each age group, the percentage of deaths was compared for those receiving dialysis or receiving a kidney transplant from a cadaveric or living related donor in 1991.

In every age group, transplant patients had overall lower death rates than dialysis patients, particularly among younger children. Pediatric patients with a living related graft had, on average, lower death rates than patients with a cadaveric graft. Since there was no control for race, sex, primary diagnosis, or case severity in these estimates, it would be inappropriate to assign any causal relationship to a particular modality of care. A comparison of the same death rate data in Table E.80 of this report reveals that living related transplant death rates in pediatric patients increased between 5 percent and 12 percent in each age group between 1989 and 1990. This trend appears to have reversed itself in 1991, with death rates decreasing over 1990 death rates from between 4% and 12% in each age group. Several more years of data will be needed to demonstrate whether or not the increase in death rates between 1989 and 1990 in living related transplant was evidence of an adverse trend or was simply a chance occurrence.

This analysis of patient deaths by modality does not consider other important patient outcomes such as rates of growth and sexual development and other indicators of quality of life, which may also vary by modality. The relative success of a particular modality of care in addressing the needs of children with ESRD can be determined only by considering differences in these measures of patient outcomes, in addition to survival.

Pediatric Growth

Preliminary analyses of pediatric growth have been conducted by the USRDS Coordinating Center using data from the Special Study of Pediatric Growth and Development.

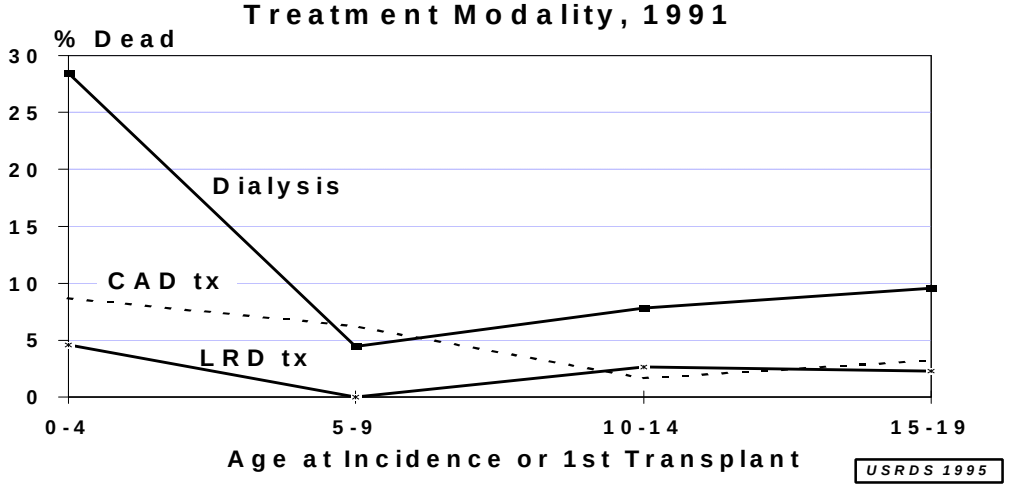

Figure VIII-14

Pediatric patient two-year Kaplan-Meier death rates (percent) by five year pediatric age groups and treatment modality for incident patients, 1991. Survival follow-up starting from day 91 following ESRD for dialysis patients incident in 1991 and from date of transplant for patients transplanted in 1991. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare patients only. Source: Reference Tables E.48, E.64 and E.80.

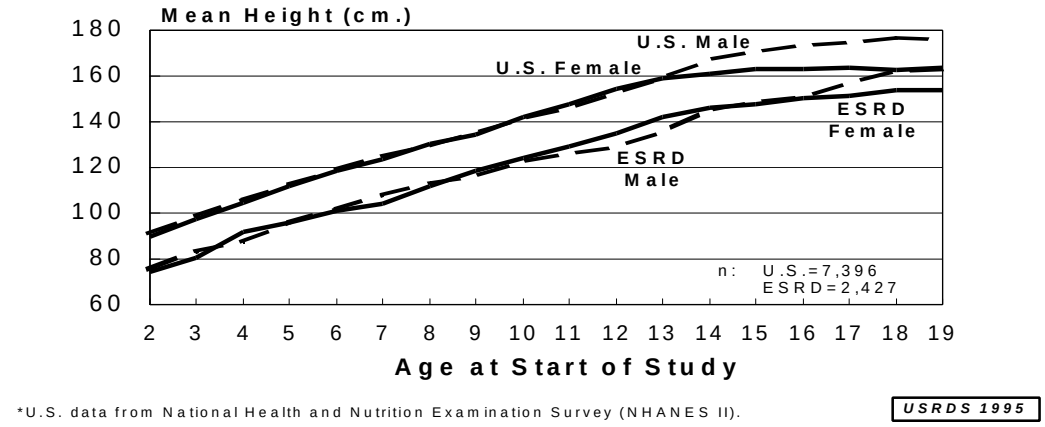

Figure VIII-15

Mean pediatric height in centimeters for 1990 prevalent ESRD patients, ages 2-19 compared to mean height in centimeters of children, 2-19, in the general U.S. population. Sources: pediatric data are from the USRDS Special Study of Pediatric Growth; U.S. data are from the National Health and Nutrition Examination Survey (NHANES II), from the years 1976-80.

Substantial height differences between pediatric ESRD patients and children in the general population existed at all ages, as seen in Figure VIII-15. In general, there was a difference of 10-20 centimeters of height between children with ESRD and children in the general population, with only small differences by sex. The relative benefits of a particular modality, in terms of pediatric growth, is a subject worthy of further analysis since pediatric growth provides an important measure of both physical well-being and quality of life.

Renal Graft Survival

Kaplan-Meier two-year kidney graft survival estimates are shown in Figure VIII-16 by race, age,

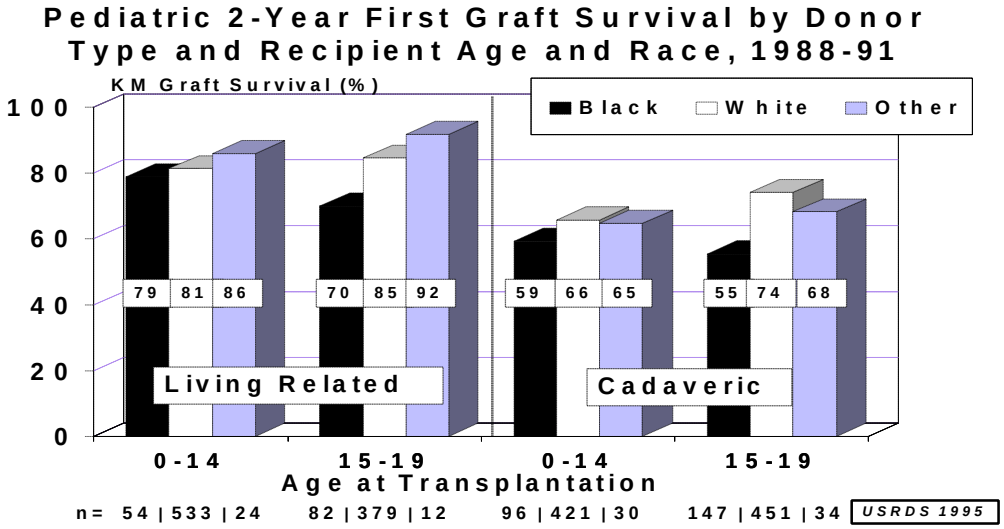

Figure VIII-16

Two year Kaplan-Meier kidney graft survival (percent) by donor type, recipient age groups and recipient race for first transplants, 1988-91. Patients in Puerto Rico and the U.S. Territories are included in estimates. Medicare patients only. Source: Special analysis.

and donor type for all children transplanted between 1988 and 1991. The count of transplants for each cohort appears below the chart. As is well known, grafts transplanted from living related donors are associated with higher survival rates than grafts originating from cadaveric donors. For both age groups and donor types, White children had longer graft survival than Black children, a pattern by race that is also observed among adult recipients. Graft survival estimates for recipients of other races are less precise due to small sample sizes.

Causes of Death

Deaths per 1,000 patient years at risk were analyzed by cause of death for all prevalent ESRD patients aged 0 to 19 years, who were alive at the start of 1990, 1991, or 1992, and followed until death or until the end of the year (see Reference Tables D.14 and D.21). The overall death rate was 23.7 per 1,000 patient years for patients 0-19 years, substantially lower than the rates for patients 20-44 (62.1 per 1000 patient years), patients 45-64 (152.3 per 1000 patient years) and patients over 65 (363.2 per 1000 patient years).

Within the pediatric ESRD population, there was also substantial variation in death rates, with younger patients, 0-14 years having higher death rates (27.4 per 1000 patient years) than older patients, 15-19 years (20.3 per 1000 patient years).

Causes of death in pediatric patients are shown in Figure VIII-17, which provides the distribution of causes of death during 1991-1992 for patients 0-19 years old. Cardiac arrest and other cardiac deaths accounted each for 15% with a combined percentage of 30.3% of patient deaths. Similarly, 36.4% of deaths among adults 20-44 years of age were attributed to cardiac deaths. After cardiac deaths, infection was the next most common cause of death in children (24.6 percent), followed by cerebrovascular accidents (5.1 percent). Data are available that secondarily label deaths according to whether or not withdrawal from dialysis occurred. (In other words a given death can be caused by infection and also result from withdrawal from dialysis). These data indicate that 10.5% of pediatric deaths in 1991-92 had followed withdrawal from dialysis. The reader should note that these percentages for cause of death include only reported deaths; specific-data are missing for 17% of pediatric deaths. Information pertaining to cause specific death rates would be significantly improved with more complete reporting of cause of death by pediatric nephrologists.

Comparisons of death rates for pediatric dialysis and transplant patients also yield interesting results (see Reference Tables D.17, D.20). The death rate for pediatric dialysis patients, (0-19 years), during 1990-92 was 46.9 per 1000 patient years. Pediatric patients with functioning transplants, during the same

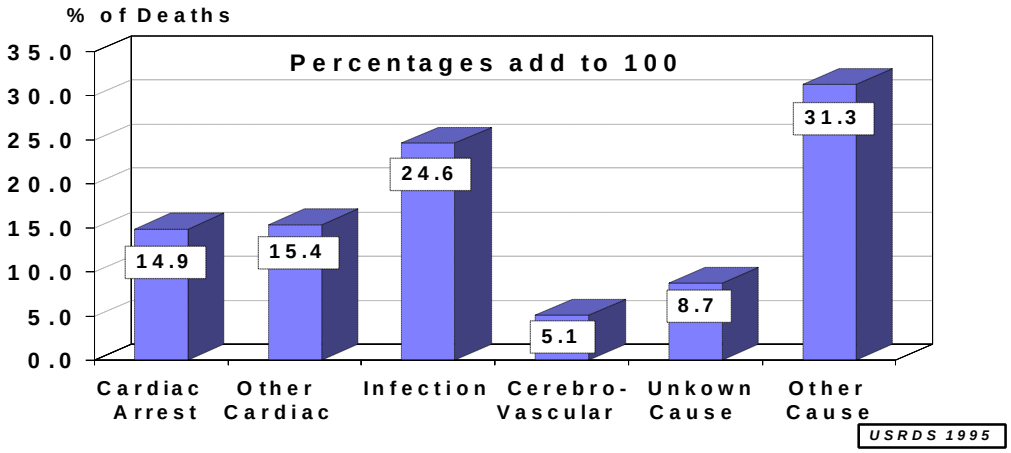

Figure VIII-17

Distribution of causes of death, ages 0-19, 1991-92. These percentages are calculated excluding those patients with missing data. Patients in Puerto Rico and the U.S. Territories are included. Medicare patients only. Source: Reference Table D.22

time period, had a substantially lower rate of 6.4 deaths per 1000 patient years. However, these data do not adjust for the possible selection of sicker patients who remain on dialysis.

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