

# **Chapter IX**

## **Pediatric End Stage Renal Disease**

This chapter examines the incidence, prevalence, modalities of treatment, and survival outcomes specific to the national pediatric ESRD population. Children with advanced chronic renal failure require special attention since patterns of treatment and subsequent outcomes are unique to the pediatric population. Furthermore, issues of physical growth in all 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).

International differences exist in the definition of the pediatric cohort, with the upper age limit of the pediatric group ranging between 15 and 19 years. This 1994 Annual Data Report, like previous Annual Data Reports, 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: age is defined as age at onset of ESRD for analyses of treated incidence and the accompanying dialysis patient survival; age on December 31 is used for analyses of point prevalence; and 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 all analyses. Because of very small cell sizes, analyses of kidney transplant counts and rates exclude children receiving grafts from living non-related donors.

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### **Incidence of Reported Pediatric ESRD**

During 1991, 822 newly diagnosed cases of children beginning treatment for ESRD under the Medicare system were reported. This corresponds on average to a rate of more than one in one hundred thousand United States children. This is a rate of incidence that has remained generally constant for the past decade. An additional 23 children from Puerto Rico and United States Territories were reported to have initiated treatment for ESRD during 1991.

Among the pediatric and adult ESRD populations, rates of incidence increase substantially by age. ESRD treated incidence, adjusted for race and sex, indicates that ESRD is many times more common among adults than among children. During 1991 the adjusted ESRD incidence rate per million United States population (in each age group) was 11 for ages 0-19 years, 96 for ages 20-44 years, 392 for ages 45-64 years,

846 for ages 65-74 years, and 725 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.) Evidence of increasing ESRD incidence by age is also found across five-year age groups within the pediatric cohort when adjusting for differences in sex and race. Table IX-1 indicates that average incidence rates for the combined years 1989-91 are twice as high among children 15-19 years as they are for children 10-14 years, and almost four times higher than rates for children 0-4 and 5-9 years of age at onset of ESRD. Average annual counts of incident children, for the years 1989-1991, reported in Table IX-1, reveal that 422 out of 833 children beginning treatment for ESRD, or 51 percent, were between the ages of 15 and 19 at onset of ESRD.

Unlike the adult population, the overall incidence rate of pediatric ESRD is not increasing and has remained nearly constant over the past ten years. By contrast, the average overall compound rate of change for all ages has been 8.3 percent per year between the years 1982 and 1991 (Reference Table A.6).

Within the pediatric cohort, there are 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 1989-91 period is illustrated by race and age in Figure IX-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 predominantly due to the more than two-fold excess of ESRD among blacks

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### Pediatric ESRD Incidence and Prevalence Counts and Rates, 1989-91

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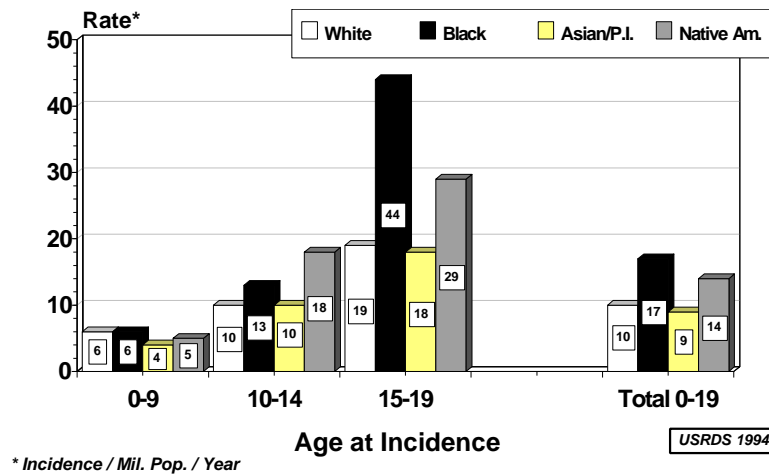
Age at Incidence	Incidence		Point Prevalence*	
	Average Counts Per Year	Adjusted Annual Rate**	Average Counts Per Year	Adjusted Annual Rate**
0-4	117	6	268	14
5-9	108	6	591	32
10-14	187	10	982	56
15-19	422	22	2047	111
Total (0-19)	833	11	3889	53

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**Table IX-1**

\* Point prevalence on December 31 of 1989-91. \*\* 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.7, A.8, A.34, A.35, B.9, B.10, B.26 and B.27.

**Pediatric ESRD Treated Incidence Rate  
by Age and Race, 1989-91**



**Figure IX-1**

*Reported pediatric ESRD incidence per million population by age and race, adjusted for sex. Average rate per year, 1989-91. 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.35 and additional special analysis.*

compared to whites in the 15-19 year old age group. Treated incidence rates in whites and blacks become more similar as age decreases. There is also evidence that incidence rates for Native Americans compared to whites increase with age. In the adult population (defined as 20 years or older at onset of ESRD), by contrast, there is overall a nearly four-fold greater incidence of ESRD among blacks compared to whites and a 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 generally coincide with differences in rates of diabetes and hypertension. This is not the case with the pediatric ESRD population, where only 5.1 percent of renal failure is associated with hypertension and 1.2 percent of renal failure is linked to diabetes. Figure IX-2

illustrates the incidence of reported pediatric ESRD by sex according to five-year pediatric age groups. Males have higher treated incidence rates among children in all four age groups, revealing the overall higher incidence of chronic renal failure among males in younger populations. While similar trends are observed for adults as for children, the increased incidence for boys is pronounced for children less than five years of age.

### Pediatric ESRD Treated Incidence Rate by Age and Sex, 1989-91

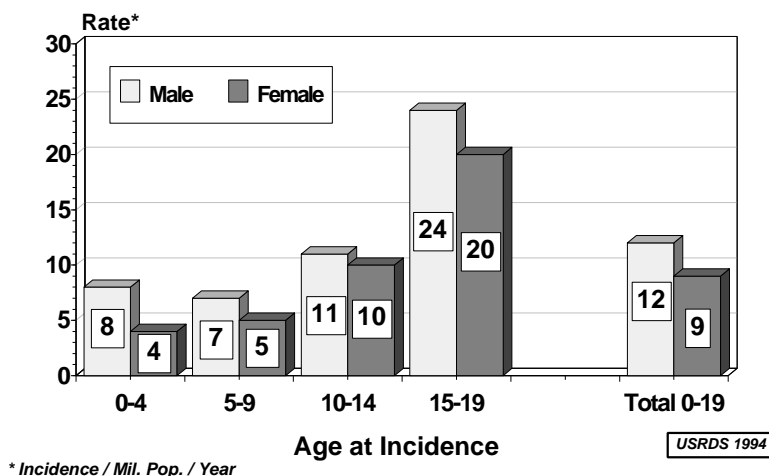


Figure IX-2

Reported pediatric ESRD incidence per million population by age and sex, adjusted for race. Average rate per year, 1989-91. 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.35.

### Causes of Pediatric ESRD

The distribution of causes of ESRD

by sex among pediatric patients incident during the 1988-91 period is shown in Figure IX-3. The largest single disease

### Percentage Distribution of Cause of Renal Failure in Incident Children by Sex, 1988-91

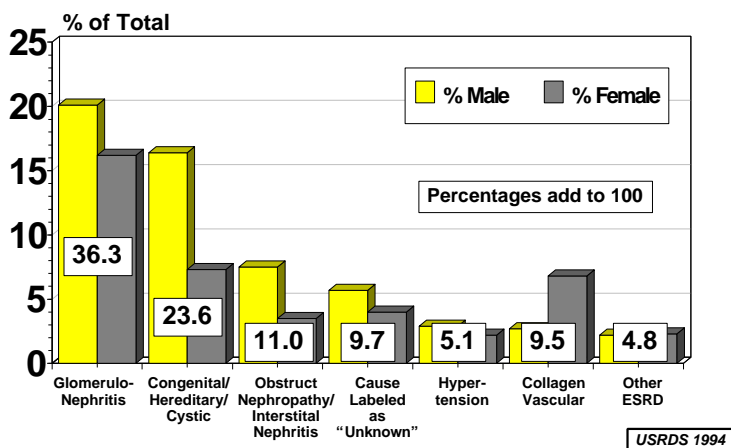


Figure IX-3

Incident pediatric cases by disease group, by sex, as a percent of total pediatric ESRD. Total excludes missing disease. Average percent over four-year period, 1988-91. Boxed numbers represent the sum of both sexes. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table A.30.

group for children new to ESRD is glomerulonephritis (36.3 percent of all reported causes), followed by congenital /other hereditary/cystic diseases (23.6 percent). Figure IX-4 provides the distribution of causes of ESRD by race among pediatric incident patients during 1988-91. Glomerulonephritis, as a primary cause of ESRD appears to be overrepresented among blacks, Asians and Native Americans; hypertension appears overrepresented among blacks; and congenital/other hereditary/cystic diseases appear overrepresented among whites and Native Americans.

A more detailed description of the causes of renal failure among children according to age, race, sex and one-year transplant and death status is provided in Table IX-2. Unlike the columns labeled “% of Total” and “Percent of Race,” which are expressed as a percentage of

the total for that column, percentages by sex and transplant and death status in Table IX-2 are expressed relative to the number of patients in each disease group, i.e., the total for that row. Only 6.3 percent of 1988-91 incident pediatric cases (n=3,021) were reported with diabetes and hypertension as the primary diagnosis. This is in marked contrast to the adult population where 63.4 percent of incident cases report diabetes and hypertension. The distribution of diagnoses among children varies by age. Compared to average values for pediatric patient characteristics in the top row, hemolytic uremic syndrome/TTP, malignancies, metabolic diseases, polyarteritis and renal dysgenesis/agenesis/dysplasia are associated with the lowest median age. Hypertension and diabetes are associated with the highest median ages.

### Percentage Distribution of Cause of Renal Failure in Incident Children by Race, 1988-91

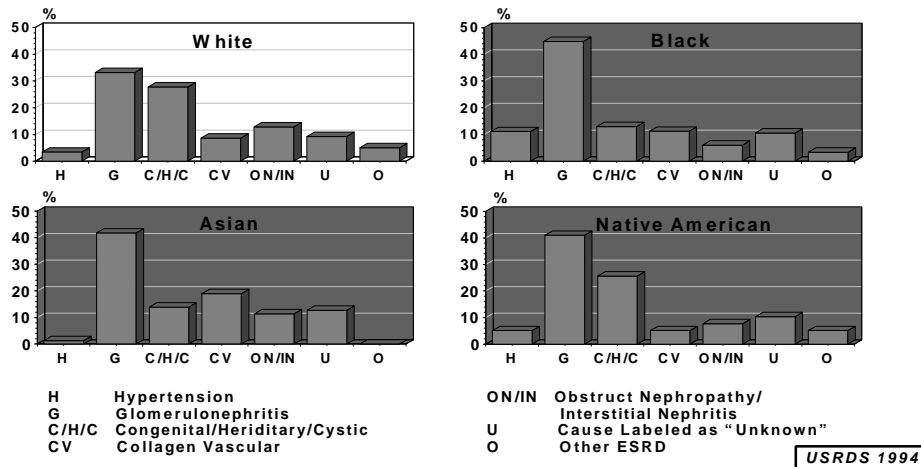


Figure IX-4

Incident pediatric cases by disease group, by race, as a percent of total pediatric ESRD. Total excludes missing disease. Average percent over four-year period, 1988-91. Percentages within each panel add to 100. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table A.30.

**Incidence of Treated ESRD by Detailed Primary Disease, Age, Race, Sex  
and One-Year Transplant and Death Status for Pediatric Patients Age < 20,  
1988-1991**

Primary Disease	Total Incident Count 1988-91*	% of Total**	Median Age	% Male	Percent of Race				Percent***	
					White	Black	Asian	Native Amer.	Tx'ed in 1st year	Died in 1st year
<b>All ESRD, (reference)</b>	<b>3475</b>	<b>100</b>	<b>15</b>	<b>57.6</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>100</b>	<b>43.3</b>	<b>4.2</b>
<b>Diabetes</b>	<b>39</b>	<b>1.2</b>	<b>18</b>	<b>51.2</b>	<b>1.3</b>	<b>1.1</b>	<b>0.0</b>	<b>2.5</b>	<b>33.3</b>	<b>2.5</b>
<b>Hypertension</b>	<b>156</b>	<b>5.1</b>	<b>17</b>	<b>57.0</b>	<b>3.4</b>	<b>11.0</b>	<b>1.2</b>	<b>5.1</b>	<b>31.4</b>	<b>7.0</b>
<b>Glomerulonephritis</b>	<b>1097</b>	<b>36.3</b>	<b>16</b>	<b>55.4</b>	<b>33.1</b>	<b>44.8</b>	<b>41.7</b>	<b>41.0</b>	<b>42.7</b>	<b>3.5</b>
. Goodpasture's Syndrome	17	0.5	18	47.0	0.5	0.5	0.0	0.0	29.4	0.0
. Focal glomerulosclerosis, focal GN	286	9.4	15	60.8	6.7	18.7	5.0	5.1	45.8	3.8
. Membranous nephropathy	18	0.5	15	50.0	0.5	0.9	0.0	0.0	61.1	0.0
. Membranoproliferative GN	98	3.2	16	47.9	3.4	2.7	5.0	2.5	50.0	2.0
. All other glomerulonephritis	678	22.4	16	54.5	21.8	21.7	31.6	33.3	40.2	3.8
<b>Cystic Kidney Diseases</b>	<b>138</b>	<b>4.5</b>	<b>11</b>	<b>54.3</b>	<b>5.8</b>	<b>0.7</b>	<b>2.5</b>	<b>7.6</b>	<b>54.3</b>	<b>7.2</b>
<b>Interstitial Nephritis</b>	<b>127</b>	<b>4.2</b>	<b>16</b>	<b>55.9</b>	<b>4.8</b>	<b>2.1</b>	<b>5.0</b>	<b>2.5</b>	<b>48.0</b>	<b>0.7</b>
. Analgesic nephropathy	23	0.7	14	60.8	0.8	0.5	0.0	0.0	56.5	0.0
. All other interstitial nephritis	104	3.4	16	54.8	4.0	1.5	5.0	2.5	46.1	0.9
<b>Obstructive Nephropathy</b>	<b>208</b>	<b>6.8</b>	<b>13</b>	<b>75.4</b>	<b>7.9</b>	<b>3.8</b>	<b>6.3</b>	<b>5.1</b>	<b>48.5</b>	<b>3.8</b>
<b>Collagen Vascular Diseases</b>	<b>287</b>	<b>9.5</b>	<b>16</b>	<b>28.5</b>	<b>8.5</b>	<b>11.2</b>	<b>18.9</b>	<b>5.1</b>	<b>20.2</b>	<b>3.8</b>
. Lupus erythematosus	196	6.4	16	22.4	4.7	10.2	18.9	2.5	12.7	3.0
. Scleroderma	2	<0.1	16	0.0	<0.1	0.1	0.0	0.0	0.0	50.0
. Wegener's granulomatosis	10	0.3	16	50.0	0.4	0.0	0.0	0.0	50.0	10.0
. Hemolytic uremic syndrome / TTP	55	1.8	8	38.1	2.3	0.5	0.0	0.0	30.9	5.4
. Polyarteritis	3	<0.1	8	33.3	0.1	0.0	0.0	0.0	33.3	0.0
. Henoch-Schonlein Purpura	21	0.6	16	52.3	0.8	0.2	0.0	2.5	47.6	0.0
<b>Malignancies</b>	<b>12</b>	<b>0.3</b>	<b>4</b>	<b>66.6</b>	<b>0.4</b>	<b>0.2</b>	<b>0.0</b>	<b>0.0</b>	<b>16.6</b>	<b>16.6</b>
. Renal and urinary tract neoplasms	11	0.3	4	72.7	0.4	0.2	0.0	0.0	18.1	18.1
. Lymphomas	1	<0.1	5	0.0	<0.1	0.0	0.0	0.0	0.0	0.0
<b>Metabolic Diseases</b>	<b>41</b>	<b>1.3</b>	<b>10</b>	<b>46.3</b>	<b>1.6</b>	<b>0.7</b>	<b>0.0</b>	<b>0.0</b>	<b>82.9</b>	<b>2.4</b>
. Oxalate nephropathy	13	0.4	10	61.5	0.5	0.0	0.0	0.0	84.6	7.6
. Cystinosis	28	0.9	11	39.2	1.0	0.7	0.0	0.0	82.1	0.0
<b>Congenital/Other Hereditary Diseases</b>	<b>578</b>	<b>19.1</b>	<b>11</b>	<b>72.8</b>	<b>21.8</b>	<b>12.2</b>	<b>11.3</b>	<b>17.9</b>	<b>55.1</b>	<b>4.3</b>
. Congenital obstructive uropathy	134	4.4	12	81.3	5.6	1.4	0.0	5.1	54.4	2.2
. Renal dysgenesis, agenesis, dysplasia	144	4.7	8	65.2	5.1	3.6	6.3	2.5	62.5	7.6
. Alport's Syndrome	300	9.9	11	72.6	11.1	7.1	5.0	10.2	52.0	3.6
<b>Sickle Cell Disease</b>	<b>8</b>	<b>0.2</b>	<b>16</b>	<b>50.0</b>	<b>0.1</b>	<b>0.7</b>	<b>0.0</b>	<b>0.0</b>	<b>25.0</b>	<b>0.0</b>
<b>AIDS-Related</b>	<b>1</b>	<b>&lt;0.1</b>	<b>13</b>	<b>100.0</b>	<b>0.0</b>	<b>0.1</b>	<b>0.0</b>	<b>0.0</b>	<b>0.0</b>	<b>100.0</b>
<b>Other ESRD</b>	<b>35</b>	<b>1.1</b>	<b>8</b>	<b>42.8</b>	<b>1.3</b>	<b>0.4</b>	<b>0.0</b>	<b>2.5</b>	<b>22.8</b>	<b>11.4</b>
<b>Cause Labeled as "Unknown"</b>	<b>294</b>	<b>9.7</b>	<b>16</b>	<b>58.8</b>	<b>9.2</b>	<b>10.5</b>	<b>12.6</b>	<b>10.2</b>	<b>42.8</b>	<b>3.0</b>
<b>Missing Information</b>	<b>454</b>	<b>.</b>	<b>14</b>	<b>57.7</b>	<b>.</b>	<b>.</b>	<b>.</b>	<b>.</b>	<b>41.4</b>	<b>5.2</b>

Table IX-2

Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Shaded rows sum to All ESRD (reference) row for total incident count, percent of total and percent of race categories. Source: Reference Tables A.30 and A.31. \* Divide total by 4 to determine the average annual count of children new to ESRD between 1988 and 1991. \*\* Patients with missing information (13% of total) are excluded from this column. \*\*\* In these two columns, "1st year" refers to 1st year of ESRD therapy.

Blacks are overrepresented (have higher than expected average percentages as compared to the “% of total” column) among children whose primary cause of ESRD is hypertension, glomerulonephritis, lupus erythematosus, and, as expected, sickle cell disease. Whites have slightly higher than average percentages of ESRD from cystic kidney disease, interstitial nephritis and congenital/hereditary conditions. Asians are overrepresented for interstitial nephritis and collagen vascular diseases. Native Americans are overrepresented for diabetes, glomerulonephritis, cystic kidney diseases and congenital/other hereditary diseases.

Males predominate among pediatric patients with obstructive conditions as well as congenital and other hereditary diseases. Females predominate among patients with collagen vascular diseases and metabolic diseases.

Frequency of kidney transplantation within one year of onset of ESRD also varies by 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 dead at one year following onset of ESRD is highest among those with hypertension, cystic kidney diseases, hemolytic uremic syndrome/TTP, and malignancies. Mortality is lowest among pediatric patients with interstitial nephritis and diabetes. The reader should keep in mind that no adjustments have been made for differences in age, race, sex, and modality of care across these disease groups.

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## Prevalence of Reported Pediatric ESRD

ESRD treated point prevalence counts and rates per million United States population are shown in Table IX-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 11 in 1991. As this child and others grow older, they will be considered prevalent in continually older age groups, which provides a partial explanation for higher prevalence rates among older age groups, i.e., patients 5-9 versus 0-4 years, despite incidence rates that have remained similar for these age groups throughout the 1980s. 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 IX-1). Over 50 percent of the 1989-91 point prevalent pediatric ESRD cohort is in the 15-19 year age group. Aggregate descriptions and outcomes associated with the pediatric ESRD population are therefore dominated 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 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 15, of the present report "Analytical Methods," or Chapter XI in the 1992 Annual Data Report 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 1989-91 period reveal an increase in overall prevalence of 4 percent compared to the 1988-90 period. This increase in prevalence reflects the relatively good survival in pediatric patients.

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### **Methods of Treating Pediatric ESRD**

Various treatment options are available to children with ESRD, with different modalities intended to fulfill different physical, social, and emotional needs. There are significant differences in treatment modality utilization between pediatric and adult patients (Alexander; Held). Children are more likely to utilize forms of peritoneal dialysis than are adults; younger children are much more likely to receive a renal transplant than are older children and adult patients (Alexander; Held; Rizzoni). These differences reveal the special needs of children with ESRD (Held; United States Renal Data System 1991). Several factors and preferences have contributed to differences between the adult and pediatric ESRD populations, including the greater availability of living related kidney donors, limitations on educational and social opportunities for patients treated with center hemodialysis, and problems associated with vascular access. Evidence of reduced growth rates for children receiving dialysis compared to those

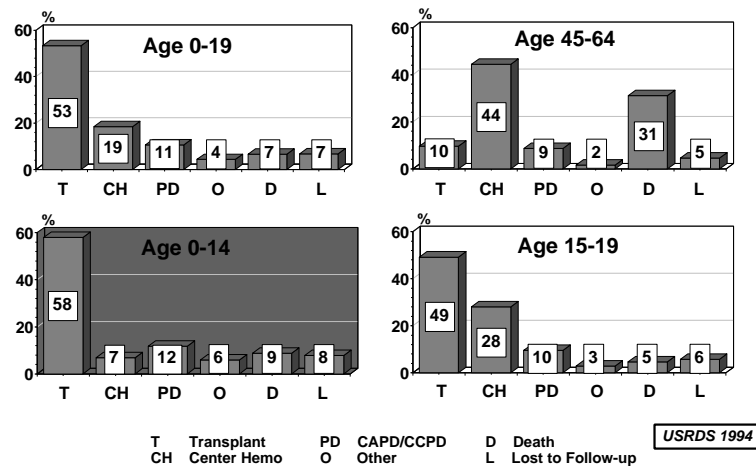
receiving a transplant contribute to a strong preference for kidney transplantation among children (Alexander; Webb).

The largest difference in methods of treatment for the adult versus the pediatric ESRD population is seen in transplantation. Forty-three percent of children starting ESRD therapy during the 1988-91 period received a transplant during the first year (Table IX-2), compared to approximately 12 percent of patients 20-64 years of age at ESRD incidence.

Figure IX-5 profiles the methods of treatment used at two years following onset of ESRD for 2,619 pediatric patients incident in 1987-89 and compares this cohort to a cohort of incident patients 45-64 years old in the same time period. Fifty-three percent of children have a functioning graft after two years of ESRD therapy, as children of all ages are aggressively transplanted, while only 34 percent of children are receiving dialysis of any form. By comparison, only 10 percent of adults in the 45-64 age group have a functioning graft after two years of ESRD therapy while 55 percent are receiving some form of dialysis. Nearly seven percent of children died within two years of onset of ESRD, a rate significantly lower than the adult population. By contrast, 31 percent of incident ESRD patients between 45-64 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 are considered lost to follow-up two years after onset of ESRD, a percentage that is higher than the comparable estimate for



**Distribution of Treatment Modality at Two Years Following ESRD Onset by Age, 1987-89 Cohort**



**Figure IX-5**

*Renal replacement therapy at two years past onset of ESRD by age at onset, 1987-89 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.29 and C.32.*

adult patients age 45-64 years of 5 percent.

Overall, hemodialysis is utilized more frequently than peritoneal dialysis among children; 19 percent of children receive hemodialysis after two years of ESRD, while 11 percent of children receive peritoneal dialysis after two years of ESRD. Figure IX-5 also depicts the differences in modality of treatment between younger children (0-14 years) and older children (15-19 years). Younger children are more likely to be treated with a transplant or peritoneal dialysis than older children, while older children are more likely to be treated with hemodialysis than younger children(Held).

**Number of Pediatric Renal Transplants**

The total number of Medicare pediatric renal transplants performed each year from 1982 through 1991 is

plotted according to the transplant number (first or repeat) and type of donor in Figure IX-6. Overall, the number of Medicare pediatric transplants remained constant between 1990 and 1991. There was, however, a significant increase in the number of first living related transplants and a significant decrease in the number of first cadaveric transplants between 1990 and 1991, with almost 100 more first living related transplants than first cadaveric transplants. This is in marked contrast to the adult population for whom three to four times more first transplants originate from cadaveric donors than from living related donors (see Reference Tables F.11, F.12). Repeat cadaveric transplants are more numerous than are repeat living related transplants for both pediatric and adult patients, though the difference is greater among adult recipients.

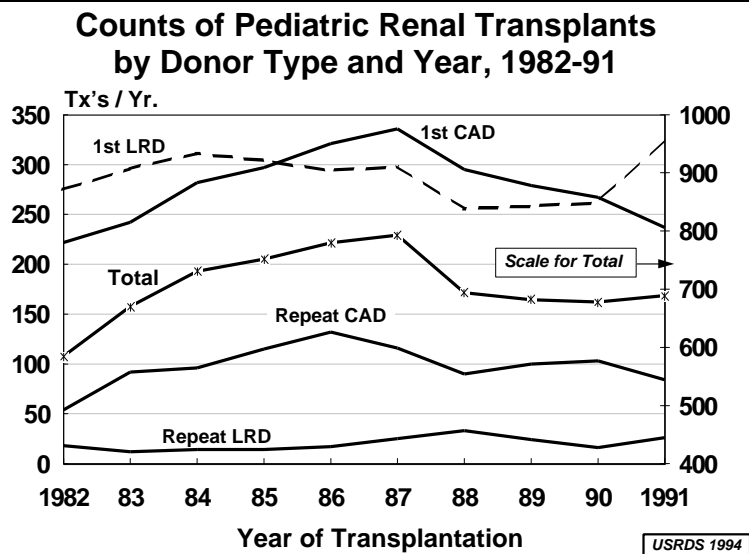


Figure IX-6

Counts of pediatric renal transplants by donor type (cadaveric or living related) and transplant number (first or repeat) performed per year, 1982-91. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Tables F.11 and F.12.

The trends over time shown in Figure IX-6 suggest that the steady increase in first cadaveric transplants among pediatric patients during the early 1980s has leveled off and, since 1987, is declining. A similar downturn in the number of first living related kidney transplants performed since 1987 was observed until 1990, with an increase in 1991. If the number of pediatric cadaveric transplants continues to decrease, it will be desirable for living related pediatric transplants to increase since kidney transplantation is the overall preferred modality of treatment for children with ESRD.

### Access to Kidney Transplantation: Transplant Rates

The previous section presented the total counts of pediatric renal transplants performed through 1991. This section further profiles 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 IX-7 are pediatric transplant rates by donor type and recipient age at time of transplantation, for transplants occurring in 1991. 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 (dialysis years are drawn from the same cohort of patients for the denominator as the number of transplants for the numerator). Dialysis patient years at risk represent the duration (in years) that children in the same age, sex, and race group are receiving dialysis therapy during calendar year 1991. For children of all ages, there were 21.5 cadaveric transplants per 100 dialysis patient years and 19.7 living related transplants per 100 dialysis patient years. Transplant rates are generally lower among older children compared to younger children. It should be noted that calculations of

### Pediatric Transplant Rate by Recipient Age and Donor Type, 1991

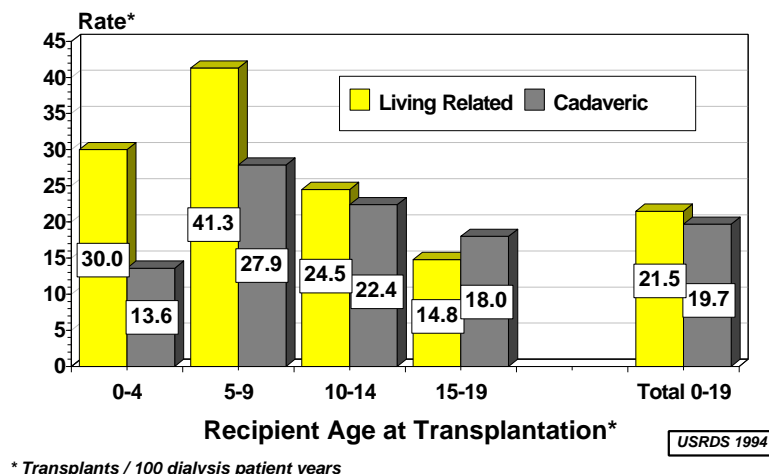


Figure IX-7

Pediatric renal transplants per 100 dialysis patient years by recipient age (\*on 12/31 of transplant year) and donor type, 1991. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table F.44.

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 further discussion of this detail, see Chapter 15: Analytical Methods.

It is noteworthy that in comparing pediatric transplant rates reported in the 1993 Annual Data Report to pediatric transplant rates reported in the present report, as depicted in Figure IX-7, living related transplants now dominate in every pediatric age group except 15-19 years. The 1993 Annual Data Report reported transplant rates in which cadaveric transplant rates dominated in every pediatric age group. (The reader should note that the 1993 Annual Data Report erroneously stated that these rates were based on the years 1988-90 when in fact they were based on the year 1990 only). This phenomenon probably reveals an emphasis on living related donors for pediatric transplantation in

response to a limited supply of cadaveric donors.

All pediatric patients ever transplanted as a percentage of all prevalent patients by recipient age are shown in Figure IX-8. This figure demonstrates how resolutely the pediatric nephrology community has pursued transplantation as the preferred modality of treatment for children with ESRD. In 1991, 82.5 percent of prevalent ESRD patients 5-9 years had received at least one transplant compared to 32.4 percent of all ESRD patients. The percentage of patients ever transplanted generally decreases with each age group, demonstrating a preference for transplantation in younger age groups.

### Percent of Patients Ever Transplanted by Recipient Age, 1991

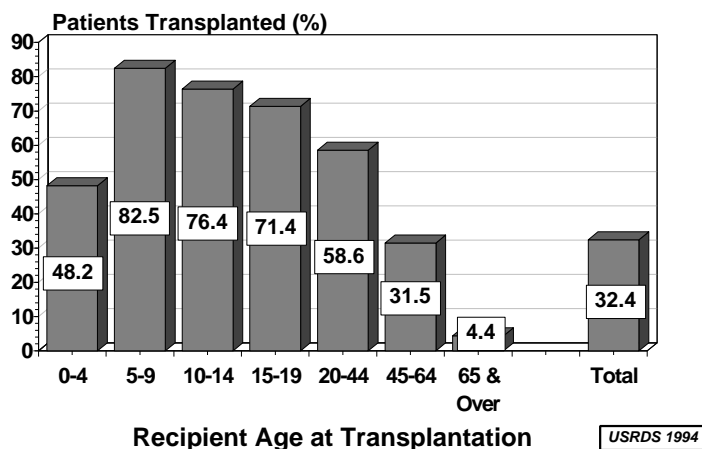


Figure IX-8

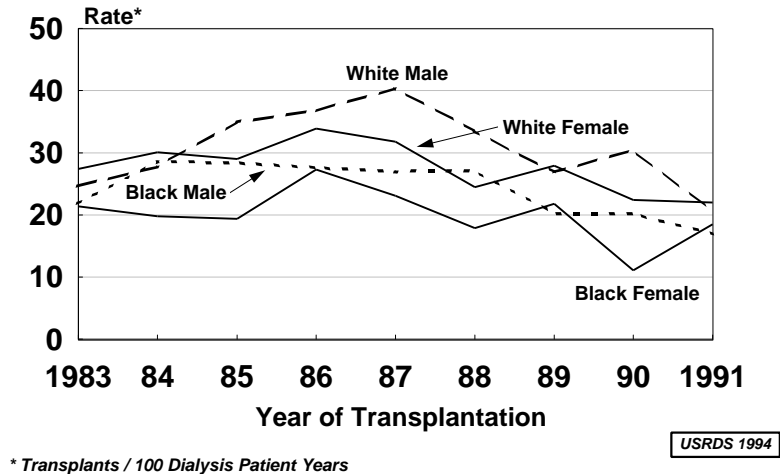
Patients ever transplanted as a percent of all prevalent patients alive on December 31, 1991. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Reference Table F.19.

Transplant rates by recipient race, sex, and transplant year are shown in Figure IX-9 and Figure IX-10 for cadaveric and living related donors, respectively. As with adult ESRD patients, there is greater correspondence of rates by sex than by race, with greater differences in rates observed by race. There is considerable year-to-year variation in rates of living related and cadaveric transplants for girls and boys, as well as whites and blacks, due to the small number of patients in each of these groups.

Figure IX-9 demonstrates that nationally, in 1990 the number of cadaveric kidney transplants per 100 dialysis patient years ranged from 30 for white boys to 23 for white girls, 19 for black boys, and 11 for black girls. Between 1990 and 1991, there is a convergence of rates of transplantation

created by a sharp decrease in the rate of transplantation for white boys and a sharp increase in the rate of transplantation for black girls. In 1991, kidney transplants per 100 dialysis patient years range from 22 for white girls, 20 for white boys, 18 for black girls and 17 for black boys. Overall, rates of transplantation for children receiving grafts from cadaveric donors (Figure IX-9) have declined since the mid-1980s for both black and white children. Cadaveric transplant rates for white boys had been generally higher than rates for white girls throughout the 1980's, but in 1991 they are almost equal. The overall downward trend in rates for girls of both races since the mid 1980s took an upward swing in 1991, with transplant rates increasing substantially for black girls and remaining unchanged for white girls.

**Pediatric CAD Transplant Rates by Recipient Race and Sex, 1983-91**



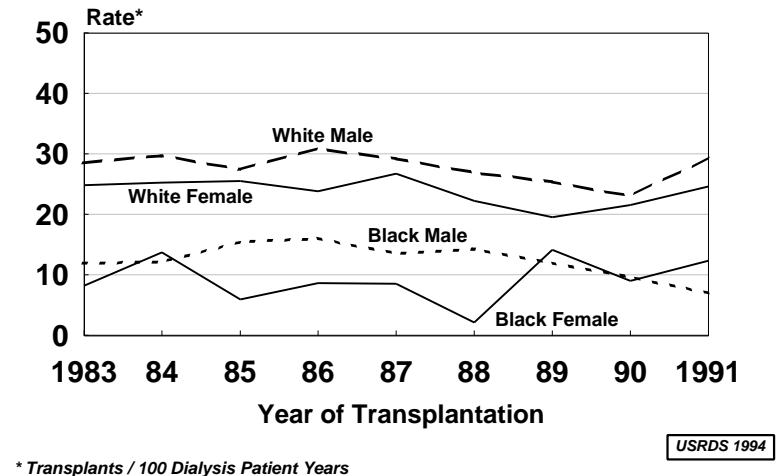
**Figure IX-9**

Pediatric cadaveric kidney transplants per 100 dialysis patient years, by recipient race and sex, by year, 1983-91. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

Transplant rates for children receiving grafts from living related donors (Figure IX-10) reveal similar patterns by race

and by sex as transplant rates for children receiving grafts from cadaver donors. The magnitude of differences in

**Pediatric LRD Transplant Rates by Recipient Race and Sex, 1983-91**



**Figure IX-10**

Pediatric living related kidney transplants per 100 dialysis patient years, by recipient race and sex, by year, 1983-91. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

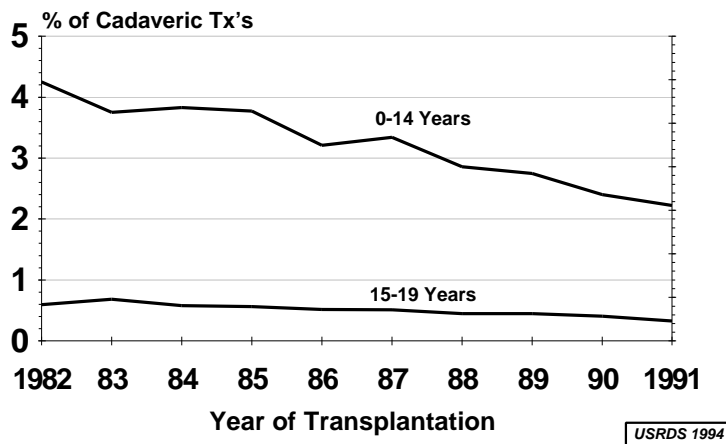
rates by race, however, is greater for living related than for cadaveric transplants. Children who are white received living related grafts more than twice as frequently in 1991 (25 to 29 transplants per 100 dialysis patient years) as children who are black (7 to 12 transplants per 100 dialysis patient years), with differences by sex similar to those observed for cadaveric transplant rates. For children of both races, living related transplant rates are generally greater for males than for females. Unlike rates of cadaveric transplantation, there was an overall upward trend in living related transplant rates between 1990 and 1991. Following the trends in pediatric transplantation during the 1990s will reveal the effects of limited cadaver donors on living related transplantation rates and transplantation rates in general.

reveal trends in which cadaveric transplantation rates in children show substantial variance by year, with differences by sex disappearing and differences by race persisting. Differences in living related transplantation rates in children by sex and race have generally continued.

Figure IX-11 demonstrates that the percentage of cadaveric kidney transplants that are pediatric has been declining over the years 1982-1991, particularly among 0-14 year olds. Figure IX-12 further describes this trend by demonstrating that pediatric cadaveric transplant rates have declined substantially between the years 1987 and 1991, from over 36 per 100 dialysis patient years to less than 25 per 100 dialysis years in 0-14 year olds. Total transplants among all ESRD patients have increased 9 percent since 1986, and total cadaveric transplants have

In summary, Figures IX-9 and IX-10

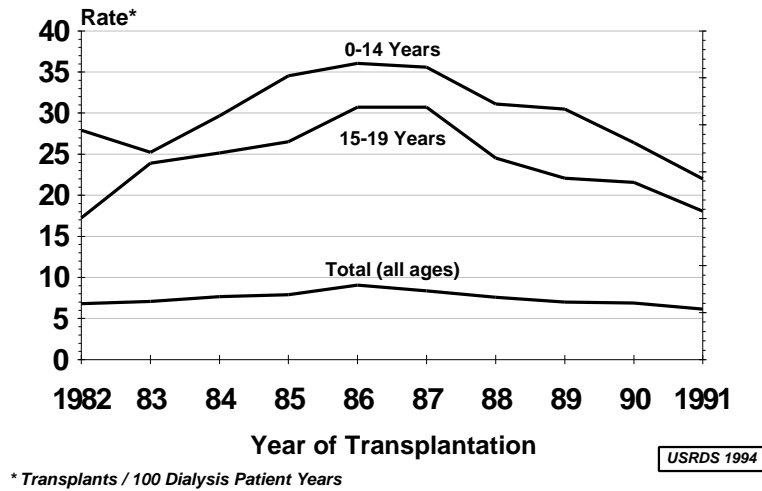
**Percent of Cadaveric Transplants Received by Pediatric Patients by Age Group, 1982-91**



**Figure IX-11**

Percent of all cadaveric kidney transplants received by pediatric patients by year and age group, 1982-91. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

**Cadaveric Transplant Rate by Year and Age, 1982-91**



**Figure IX-12**

*Cadaveric transplant rate per 100 dialysis patient years at risk by year and age, 1982-91. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.*

increased 7 percent since 1986. Pediatric transplants, however, have decreased 11.6 percent between 1986 and 1991. While living related pediatric transplants have increased slightly in the same time period, this increase has not been substantial enough to make up for the sizable decrease in pediatric cadaveric transplants. These data provide evidence for a trend in which cadaver kidneys are being allocated disproportionately to the adult ESRD population.

Another notable trend in pediatric kidney transplantation is depicted in Figure IX-13, which displays the distribution of centers performing pediatric transplants for ages 0-14 years in the years 1984-1991. The percentage of pediatric transplants occurring at centers where 10 or more pediatric transplants were performed in a three year time period has decreased substantially from 42 percent in 1984-

1987 to 27 percent in 1988-1991. This decrease is accompanied by increases in the number of transplants occurring at centers where between 4 and 9 transplants are performed in a three year period. This trend provides evidence that more pediatric transplants are performed at smaller transplant centers. It may also support the notion that patients are traveling shorter distances for transplant care.

**Patient Survival for All Renal Replacement Therapies**

Figure IX-14 depicts two and ten year patient survival by five-year pediatric age groups. Two year survival is estimated using unadjusted Kaplan-Meier survival percentages derived from the average of two one-year incident cohorts. Ten year survival is estimated using unadjusted Kaplan-Meier survival percentages for the average of two one-year cohorts. Ten year survival for the

### Distribution of Centers Performing Pediatric Transplants, Ages 0-14, 1984-91

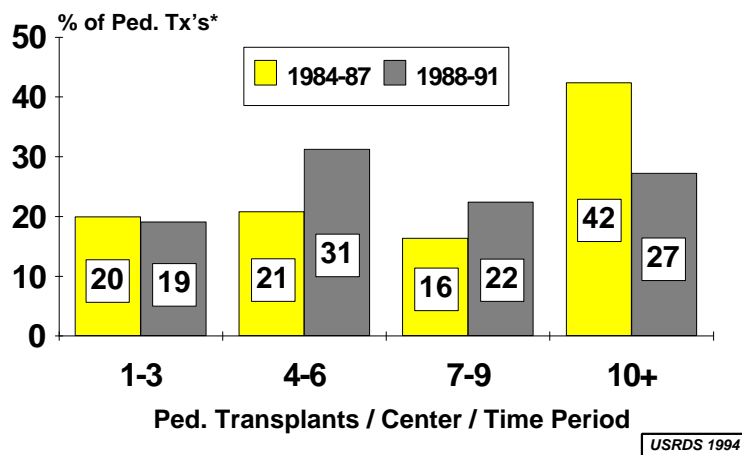


Figure IX-13

Distribution of centers performing pediatric transplants, ages 0-14, 1984-91. Percentages within each time period add to 100. Patients in Puerto Rico and U.S. Territories are included. Medicare patients only. Source: Special analysis.

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 1981-82 incident cohort, where a true comparison of survival can be made.

The youngest age group (0-4 years) demonstrates the lowest two-year

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

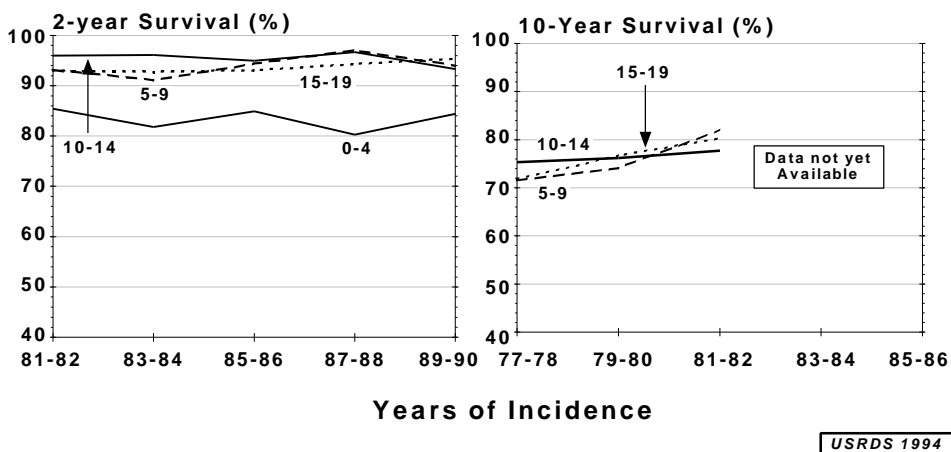


Figure IX-14

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 Table E.16 and E.20.



survival. A comparison of two and ten year survival of the 1981-82 cohort reveals that survival decreases on average 1-2 percent each year between two and ten years. Survival of patients 5-9 years is 93 percent at two years and 82 percent at ten years; survival of patients 10-14 years is 96 percent at two years and 78 percent at ten years; survival of patients 15-19 years is 93 percent at two years and 80 percent at ten years.

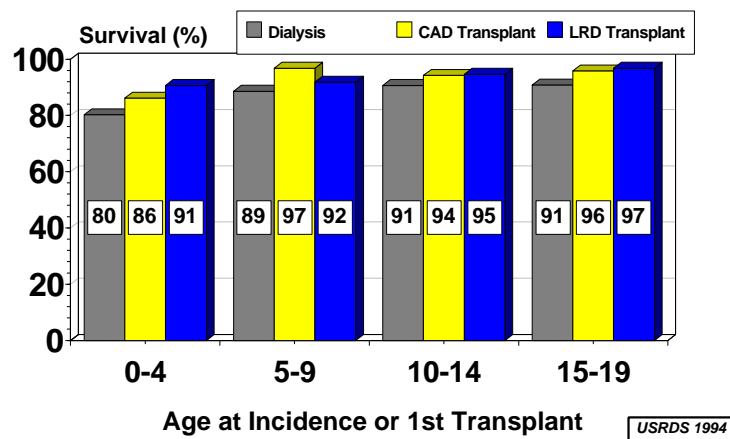
**Patient Survival by Modality**

Pediatric patient survival outcomes after two years of therapy are shown in Figure IX-15 according to five-year age groups and modality of care. Within each age group, patient survival is compared for those receiving dialysis or receiving a kidney transplant from a cadaveric or living related donor in 1990. In every age group, transplant

patients have overall better survival than dialysis patients, particularly among younger children. Pediatric patients with a living related graft have, on average, better outcomes than patients with a cadaveric graft. Since there is no control for race, sex, primary diagnosis, or case mix severity in these estimates, it would be inappropriate to assign any causal relationship to a particular modality of care. A comparison of the same survival data from the *USRDS 1993 Annual Data Report* reveals that living related transplant patient survival decreased between 2 percent and 8 percent in each age group between 1989 and 1990. Several more years of data will be needed to demonstrate whether or not this variation is an adverse trend in living related transplant patient survival and is real or random.

Patient outcomes not considered by

**Pediatric 2-Year Patient Survival by Age and Treatment Modality, 1990**



**Figure IX-15**

Two-year Kaplan-Meier patient survival (percent) by five-year pediatric age groups and treatment modality for incident patients, 1990. Survival starting from day 91 following ESRD for dialysis patients incident in 1990 and from date of transplant for patients transplanted in 1990. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare patients only. Figures are accurate to one decimal place. Source: Reference Tables E.32, E.40 and E.48.

the current analysis, such as rates of growth and sexual development and other indicators of quality of life, 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.

black children, a pattern by race that is also observed among adult patients. Graft survival estimates for patients not black or white are less precise due to smaller cell sizes.

### Renal Graft Survival

Kaplan-Meier two-year kidney graft survival estimates are shown in Figure IX-16 by race, age, and donor type for all children transplanted between 1987 and 1990. The count of transplants for each cell appears below the chart. On average, and not surprisingly, grafts transplanted from living related donors are associated with higher survival than grafts originating from cadaveric donors. For both age groups and donor types, white children keep their grafts longer than

### 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, alive at the start of 1989, 1990, or 1991, and followed until death or until the end of the year (see Reference Tables D.11 and D.17). The overall death rate was 23.1 deaths per 1,000 patient years for patients 0-19 years, substantially lower than comparable rates for patients 20-44 (63.2 deaths per 1000 patient years), patients 45-64 (156.5 deaths per 1000 patient years) and patients over 65 (358.9 deaths per 1000 patient years). Within the pediatric ESRD population, there is also substantial variation in death rates with younger patients, 0-14

**Pediatric 2-Year First Graft Survival by Donor Type and Recipient Age and Race, 1987-90**

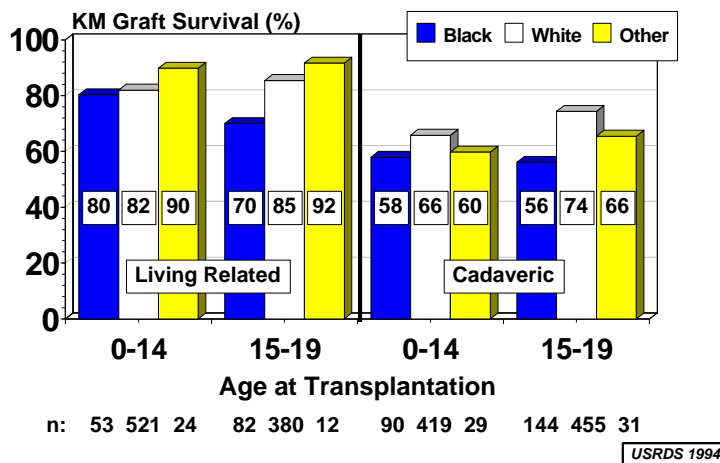


Figure IX-16

Two year Kaplan-Meier kidney graft survival (percent) by donor type, recipient age groups and recipient race for first transplants, 1987-90. Patients in Puerto Rico and the U.S. Territories are included in estimates. Medicare patients only. Source: Special analysis.

years having higher death rates (26.8 per 1000 patient years) than older patients, 15-19 years (20.0 deaths per 1000 patient years).

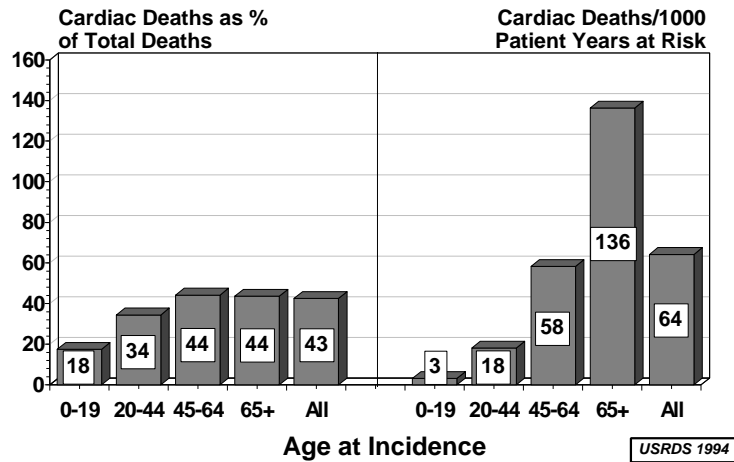
The leading cause of death was cardiac, accounting for 17.5 percent of all deaths among pediatric patients and a death rate of 3.1 per 1,000 patient years. Figure IX-17 provides a comparison of cardiac deaths in pediatric patients, both in terms of percentage of all deaths and death rates per 1000 patient years, to cardiac deaths in adult and all ESRD patients. This figure demonstrates that while rates of cardiac deaths are on average 20 times greater for adults than for children, cardiac deaths still comprise a large percentage of deaths in children (17.5 percent). The comparable percentages for adults (34-44 percent) are approximately two and a half times the percentage for children.

Cause of death in pediatric patients is

shown in Figure IX-18, which provides distribution of causes of death for patients 0-19 years old. After cardiac deaths, septicemia is the next most common cause of death in children (15.3 percent), followed by cerebrovascular accidents (8.5 percent) and withdrawal from dialysis (7.9 percent). The reader should note that these percentages include only reported deaths since in 23 percent of pediatric deaths, cause specific data are missing. Information pertaining to cause specific death rates would be significantly improved with the availability of these data.

Comparisons of survival probabilities for pediatric dialysis and transplant patients also yield interesting results (see reference tables E.63, E.67 and E.71). The two year survival probability for 1990 incident dialysis patients, age 0-19 years, was 79.4. Pediatric transplant patients have a higher probability of

**Cardiac Deaths as a % of Total Deaths and per 1000 Patient Years at Risk by Age Group, 1989-91**



**Figure IX-17**

Cardiac deaths as a percentage of total deaths and per 1000 patient years at risk by age group, 1989-91. Cardiac deaths include pericarditis, myocardial infarction and other cardiac deaths. Patients in Puerto Rico and the U.S. Territories are included. Medicare patients only. Source: Reference Table D.27.

### Distribution of Causes of Death, Ages 0-19, 1989-91

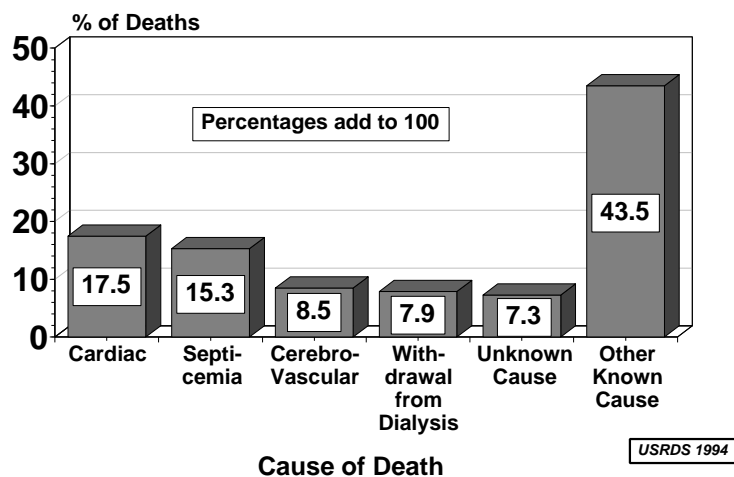


Figure IX-18

*Distribution of causes of death, ages 0-19, 1989-91. 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.27.*

survival with comparable rates of 94.6 and 97.7 for cadaveric and living related transplant patients, respectively.

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