Chapter VIII

Pediatric End-Stage Renal Disease

Key Words:
Pediatric ESRD
ESRD incidence in children
ESRD patient survival in children
Pediatric dialysis
Causes of pediatric ESRD
Renal transplants in children
CAPD in children

Children and adolescents with ESRD have unique characteristics, including different major causes of renal failure, issues of physical growth, cognitive delay, and, in adolescents, the development of secondary sexual characteristics (McEnry; Fine, Salusky, et al 1987; Fine 1987; Ettenger). For these reasons, the pediatric ESRD population requires special attention, and this chapter will focus on the incidence, prevalence, modalities of treatment, and survival outcomes specific to the national pediatric ESRD population.

The reported upper age limit for pediatric patients among ESRD registries worldwide ranges between 15 and 19 years. As in earlier Annual Data Reports, the 1997 Annual Data Report uses the broader definition that includes the 19th year. In many of the analyses in this chapter, 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 incidence and 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 here.

Incidence of Reported Pediatric ESRD

Pediatric incidence counts for the 1993-95 period reveal a small increase compared to the 1990-92 period. Since prior reports have shown virtually no change in incidence for treated pediatric patients covered by Medicare, this increase is likely due to the inclusion of non-Medicare patients in the 1994-95 incident patient counts. See Chapter II for more details.

In both the pediatric and adult ESRD populations, rates of ESRD incidence increase substantially with increase in age. Incidence of treated ESRD, adjusted for race and sex, is many times more common among adults than among children. During 1995 the adjusted ESRD incidence rate per million United States population (in each age group) was 13 for ages 0-19 years, 109 for ages 20-44 years, 508 for ages 45-64 years, 1097 for ages 65-74 years, and 1035 for ages 75 and over (Reference Table A.6). A higher ESRD incidence rate with older age is also found across the 5-year age groups within the pediatric cohort, when adjusting for differences in sex and race. Table VIII-1 indicates that average adjusted incidence rates over the combined years 1993-95 were more than twice as high among children 15-19 years (25 per million) compared to children 10-14 years (12 per million), and more than three times higher than rates for children 0-4 (7 per million) and 5-9 (6 per million) years of age at onset of ESRD. Average annual counts of incident ESRD among children for the years 1993-1995 show that 468 out of the 963 children beginning treatment for ESRD, or 48 percent, were between the ages of 15 and 19 at onset of ESRD (Table VIII-1).

Pediatric ESRD Incidence and Prevalence Counts and Rates, 1993-95

Age at Incidence	Incidence			Point Prevalence*		
	Average Counts Per Year	Unadjusted Annual Rate	Adjusted Annual Rate**	Average Counts Per Year	Unadjusted Annual Rate	Adjusted Annual Rate**
0-4	142	8	7	313	16	16
5-9	126	7	6	611	33	32
10-14	227	13	12	1,179	64	62
15-19	468	28	25	2,258	130	124
All Pediatric (0-19)	963	13	13	4,360	59	58
Adults (20-44)	10,928	110	111	64,767	641	626

*Alive on December 31 of 1993-95.
**Per million 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 adjusted incidence and prevalence rates. Counts are averaged over a three year period. Includes Medicare and Non-Medicare patients.

Source: Reference Tables A.3, A.4, A.6, A.31, B.5, B.6, B.8, and B.23

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Table VIII - 1

Within the pediatric ESRD population, there are large variations in the incidence of ESRD by race, as well as by age. The treated pediatric ESRD incidence rates per million United States population per year for the 1993-95 period were 10 for Whites, 19 for Blacks, 12 for Asians/Pacific Islanders, and 19 for Native Americans (Figure VIII-1). The higher reported overall incidence of ESRD for Black children was primarily the result of an almost three-fold excess of ESRD among Blacks compared to Whites in the 15-19 year old age group (51 per million versus 18 per million). Treated ESRD incidence rates in Whites and Blacks differed less in the younger age groups. The incidence rates for

Pediatric Treated ESRD Incidence Rate* by Race and Age, 1993-95

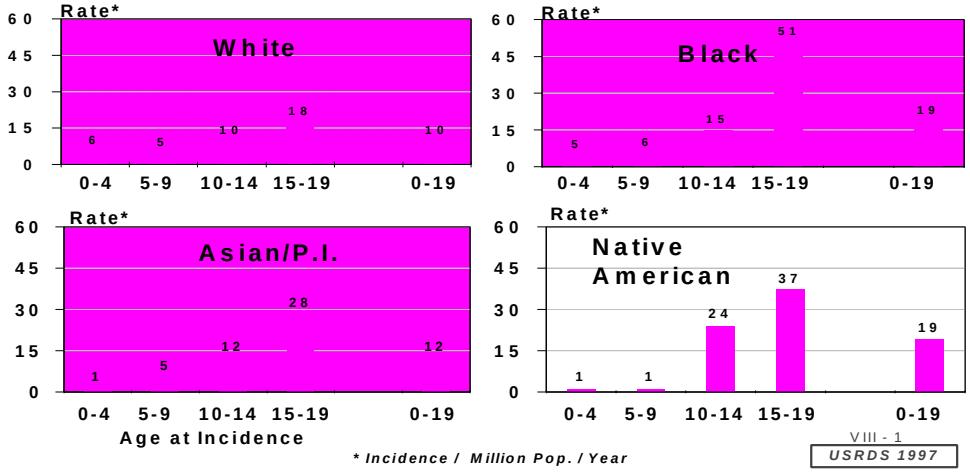

Figure VIII - 1

Reported pediatric ESRD incidence per million population by age group and race, adjusted for sex. Average rate per year, 1993-95. Incidence rates for all children (ages 0-19 years) adjusted for sex . Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded. Medicare and Non-Medicare patients are included. Source: Reference Tables A.8 and A.31.

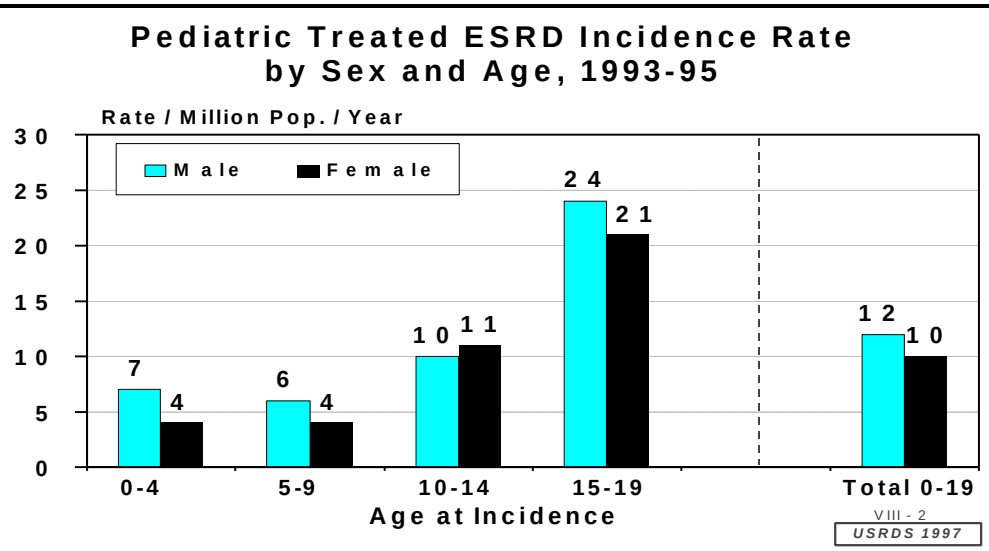

Figure VIII - 2

Reported pediatric ESRD incidence per million population by age and sex, adjusted for race. Average rate per year, 1993-95. Incidence rates for children (ages 0-19 years) are adjusted for race. Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded. Medicare and Non-Medicare patients are included. Source: Reference Tables A.8 and A.31.

Native Americans compared to Whites show a similar pattern, with a rate of 37 per million in Native Americans between the ages of 15-19, more than twice that of Whites in the same age group.

By comparison, the differences in incidence rates by race were even more striking in the adult population (see Chapter II) where there was a four-fold greater incidence of ESRD among Blacks compared to Whites in young adults 20-44 years old, and a more than two-fold greater incidence of ESRD among Native Americans compared to Whites in the same age group (Reference Table A.31). In the adult population, these differences in incidence of ESRD among Whites, Blacks and Native Americans are partly due to the differences in rates of diabetes and hypertension among Whites, Blacks, and Native Americans.

However, diabetes and hypertension together represent only 7.4 percent of the causes of ESRD in the incident pediatric ESRD population, compared to 65.9 percent of incident adults 20-64 years of age.

Figure VIII-2 illustrates the incidence of treated pediatric ESRD by sex, according to 5-year pediatric age groups. Treated incidence rates of ESRD were greater for males than females overall, with the greatest excess in the youngest two age groups. Similar trends are seen in the adult population where, for example, the treated incidence rates among patients 20-44 years of age, adjusted for race, were 121 per million for males and 76 per million for females (Reference Table A.31).

Causes of Pediatric ESRD

The largest single disease group causing ESRD in children was GN (34.1 percent of all reported causes), followed by cystic/hereditary/congenital diseases (24.2 percent). The distribution of causes of ESRD by age among pediatric patients incident during the 1991-95 period is shown in Figure VIII-3. The older patients, 5-19 years of age at onset of ESRD, were over-represented among patients with ESRD due to GN and collagen vascular diseases. The younger patients, 0-4 years old, were over-represented among patients with cystic/hereditary/ congenital disease as the primary cause of ESRD.

Figure VIII-4 provides the distribution of causes of ESRD within each race group for pediatric incident patients during 1991-95. GN (34.1 percent of all pediatric ESRD), was the primary cause of ESRD in 41 percent of Blacks, 41 percent of Asians, and 44 percent of Native Americans. Hypertension (5.7 percent of all pediatric ESRD) was the primary cause of ESRD in 11 and 7 percent of Blacks and Native Americans, respectively. Cystic/hereditary/congenital diseases (24.2 percent of all pediatric ESRD) was the primary cause of ESRD in 28 percent of Whites.

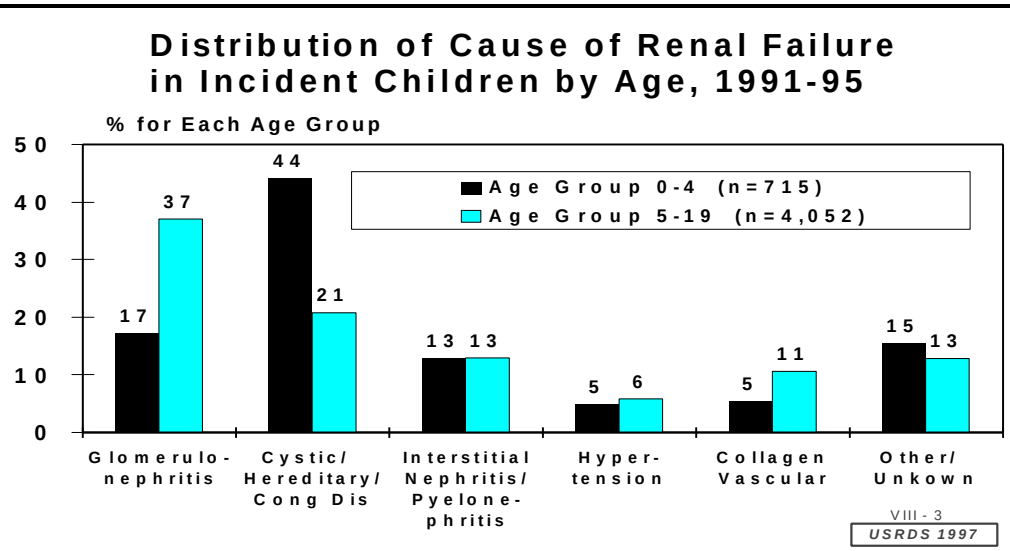

Figure VIII - 3

Incident pediatric cases by disease group, by age group (0-4 vs. 5-19), as a percent of total pediatric ESRD within each age group. Numbers on top of bars represent the percent within each age group over a five year time period, 1991-1995. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Special Analysis.

The etiology of pediatric ESRD is substantially different from that of adult ESRD and therefore warrants closer examination. Mean age, race (Black, White), sex, percent transplanted in the first year and 1-year death status is provided in Tables VIII-2 and VIII-3 for a more detailed description of the causes of

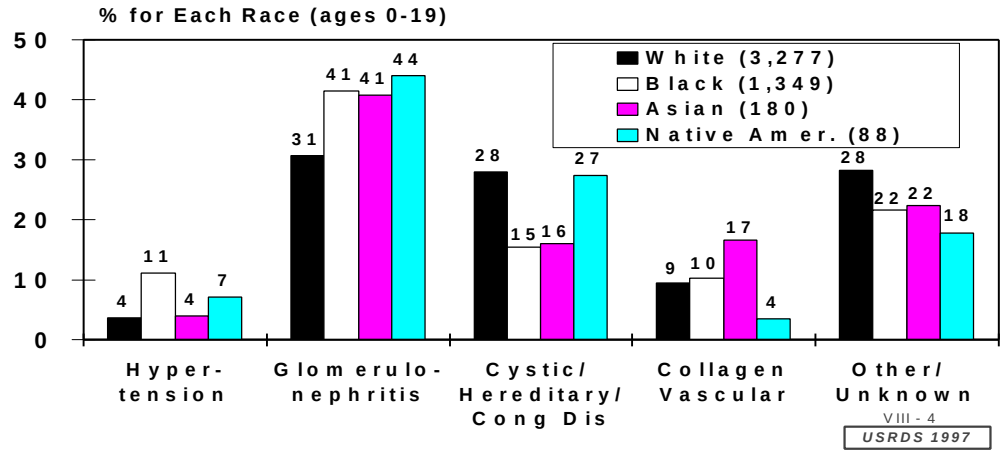

Figure VIII - 4

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, 1991-95. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Reference Table A.21

Treated ESRD Incidence (%) in Pediatric Patients (Age<20), Median Age, Sex, Race[1], and One Year Transplant and Death Status By Detailed Primary Disease, 1991-1995: *Row Percent*

Primary Disease Groups[2]	Total # Patients	Median Age	% Males	% White	% Black	During 1st Year[3] % Tx'ed	During 1st Year[3] % Died
All Pediatric ESRD (reference)	**4,767**	**14**	**57.2**	**64.2**	**27.1**	**42.4**	**3.4**
Diabetes	**78**	**16**	**43.6**	**55.1**	**30.8**	**15.4**	**5.1**
Glomerulonephritis	**1,545**	**16**	**53.7**	**58.8**	**31.8**	**38.5**	**2.4**
. Focal glomerulosclerosis, focal GN	455	15	56.3	44.8	47.3	37.6	2
. Membranous nephropathy	25	16	52	56	44	24	4
. Membranoproliferative GN	123	15	47.2	65	24.4	46.3	0.8
. IgA nephropathy, Berger's disease	29	17	55.2	58.6	*	51.7	0
. Rapidly progressive GN	97	14	40.2	72.2	*	36.1	1
. Goodpastures Syndrome	36	15	50	83.3	*	19.4	0
. Glomerulonephritis (GN)	716	16	54.7	62.2	28.6	39	3.1
. Other proliferative GN	53	15	62.3	73.6	18.9	39.6	3.8
Secondary GN/Vasculitis	**445**	**16**	**36.4**	**62.9**	**27.4**	**22.7**	**5.6**
. Lupus erythematosus	245	17	25.3	46.1	42.9	11	7.3
. Wegener's granulomatosis	29	17	44.8	93.1	*	20.7	6.9
. Henoch-Schonlein syndrome	44	15	50	90.9	*	47.7	2.3
. Hemolytic uremic syndrome	90	9	56.7	87.8	*	34.4	2.2
. Nephropathy from heroin /related abuse	21	14	47.6	47.6	*	47.6	4.8
Interstitial Nephritis/Pyelonephritis	**586**	**14**	**65.7**	**77.6**	**16.9**	**48**	**2.6**
. Chronic pyelonephritis, reflux neph.	88	16	37.5	83	*	45.5	1.1
. Nephropathy caused by other agents	81	14	71.6	79	18.5	45.7	1.2
. Nephrolithiasis, Obstruction, Gout	278	12	78.4	77.3	18	50.7	2.5
. Chronic interstitial nephritis	128	15	54.7	75	17.2	48.4	4.7
Hypertensive/large vessel disease	**260**	**17**	**58.1**	**41.5**	**50.8**	**28.1**	**5.8**
. Hypertension, (no primary renal dis.)	236	17	59.3	37.3	55.1	27.5	5.5
. Renal artery stenosis or occlusion	23	11	43.5	82.6	*	34.8	8.7
Cystic/Hereditary/Congenital Diseases	**1,098**	**10**	**66.3**	**75.5**	**16.7**	**53.1**	**3.2**
. Polycystic kidneys, adult (dominant)	163	10	47.2	80.4	12.9	49.1	3.7
. Medullary cystic, nephronophthisis	22	13	54.5	90.9	*	40.9	0
. Alport's, other hereditary/familial disease	118	16	88.1	73.7	16.1	47.5	0
. Cystinosis	38	11	57.9	92.1	*	73.7	0
. Congenital nephrotic syndrome	20	1	35	70	*	30	10
. Congenital obstructive uropathy	229	10	79.9	69	19.2	58.5	3.5
. Renal hypoplasia, dysplasia	453	8	62.3	75.3	18.5	53.6	4
. Prune belly syndrome	25	10	100	80	*	64	0
Neoplasms/Tumors	**25**	**7**	**56**	**68**	*****	**16**	**20**
. Renal or urological neoplasms	24	6	58.3	66.7	*	16.7	20.8
Miscellaneous Conditions	**100**	**13**	**62**	**55**	**38**	**25**	**9**
. Tubular necrosis (no recovery)	46	10	60.9	71.7	*	17.4	8.7
Etiology Uncertain	**397**	**15**	**53.7**	**67**	**22.9**	**45.1**	**2.5**
Missing	**233**	**13**	**63.1**	**43.3**	**45.1**	**73**	**3.4**

Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Bolded rows represent disease category headings. Percentages are expressed relative to the number of patients in each disease group (row). Source: Reference Table A.21.

* Less than 10 patients per cell.

[1]Percentages for Asian and Native American patients are not shown because of small sample sizes.

[2]Primary diseases with < 20 cases are not listed separately from the corresponding disease group.

[3]"1st Year" = 1st year of ESRD therapy; "Tx'ed" = transplanted.

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ESRD among children (< 20 years). Numbers and percentages of Asian and Native American pediatric patients are omitted because of small sample size.

For each detailed diagnosis, the percentage distributions by sex, race, and transplant and death status are shown in Table VIII-2 relative to the number of patients in each disease group, i.e., the total for that row. The distribution of diagnoses

Treated ESRD Incidence in Pediatric Patients (Age<20) By Detailed Primary Disease And Race[1], 1991-1995: *Column Percent*

Primary Disease Groups[2]	Total Patients (5 years)	% of Total	# White	# Black	Percent White	Percent Black
All Pediatric ESRD, (reference)	**4,767**	**100**	**3,062**	**1,290**	**100**	**100**
Diabetes	**78**	**1.7**	**43**	**24**	**1.5**	**2**
Glomerulonephritis	**1,545**	**34**	**908**	**491**	**30.7**	**41.4**
. Focal glomerulosclerosis, focal GN	455	10	204	215	6.9	18.1
. Membranous nephropathy	25	0.6	14	11	0.5	0.9
. Membranoproliferative GN	123	2.7	80	30	2.7	2.5
. IgA nephropathy, Berger's disease	29	0.6	17	*	0.6	*
. Rapidly progressive GN	97	2.1	70	10	2.4	0.8
. Goodpastures Syndrome	36	0.8	30	*	1	*
. Glomerulonephritis (GN)	716	15.8	445	205	15	17.3
. Other proliferative GN	53	1.2	39	10	1.3	0.8
Secondary GN/Vasculitis	**445**	**9.8**	**280**	**122**	**9.5**	**10.3**
. Lupus erythematosus	245	5.4	113	105	3.8	8.9
. Wegener's granulomatosis	29	0.6	27	*	0.9	*
. Henoch-Schonlein syndrome	44	1	40	*	1.4	*
. Hemolytic uremic syndrome	90	2	79	*	2.7	*
. Nephropathy from heroin /related abuse	21	0.5	10	*	0.3	*
Interstitial Nephritis/Pyelonephritis	**586**	**12.9**	**455**	**99**	**15.4**	**8.4**
. Chronic pyelonephritis, reflux neph.	88	1.9	73	*	2.5	*
. Nephropathy caused by other agents	81	1.8	64	15	2.2	1.3
. Nephrolithiasis, Obstruction, Gout	278	6.1	215	50	7.3	4.2
. Chronic interstitial nephritis	128	2.8	96	22	3.2	1.9
Hypertensive/large vessel disease	**260**	**5.7**	**108**	**132**	**3.6**	**11.1**
. Hypertension, (no primary renal dis.)	236	5.2	88	130	3	11
. Renal artery stenosis or occlusion	23	0.5	19	*	0.6	*
Cystic/Hereditary/Congenital Diseases	**1,098**	**24**	**829**	**183**	**28**	**15.4**
. Polycystic kidneys, adult (dominant)	163	3.6	131	21	4.4	1.8
. Medullary cystic, nephronophthisis	22	0.5	20	*	0.7	*
. Alport's, other hereditary/familial disease	118	2.6	87	19	2.9	1.6
. Cystinosis	38	0.8	35	*	1.2	*
. Congenital nephrotic syndrome	20	0.4	14	*	0.5	*
. Congenital obstructive uropathy	229	5.1	158	44	5.3	3.7
. Renal hypoplasia, dysplasia	453	10	341	84	11.5	7.1
. Prune belly syndrome	25	0.6	20	*	0.7	*
Neoplasms/Tumors	**25**	**0.6**	**17**	*****	**0.6**	*****
. Renal or urological neoplasms	24	0.5	16	*	0.5	*
Miscellaneous Conditions	**100**	**2.2**	**55**	**38**	**1.9**	**3.2**
. Tubular necrosis (no recovery)	46	1	33	*	1.1	*
Etiology Uncertain	**397**	**8.8**	**266**	**91**	**9**	**7.7**
Missing	**233**	******	**101**	**105**	******	******

Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Bolded rows represent disease category headings. Percentages are expressed relative to the number of patients in race, i.e., total adds to 100% for the column. Source: Reference Table A.22.

* Less than 10 patients per cell.

**Percent distribution excludes missing.

[1]Counts and percentages for Asian and Native American patients are not shown because of small sample sizes.

[2]Primary diseases with < 20 cases are not listed separately from the corresponding disease group.

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among children varied by age. Compared to average values for pediatric patient characteristics in the top row of Table VIII-2, congenital nephrotic syndrome and renal or urological neoplasms were associated with the lowest median age. Hypertension, lupus erythematosus, Wegener's granulomatosis, and IgA nephropathy, Berger's disease were all associated with the highest median age (17 years).

Blacks were over-represented (had a higher than average percentage of a given disease compared to their percent of the total pediatric ESRD population) among children whose primary cause of ESRD was hypertension, GN (focal glomerulosclerosis and membranous nephropathy), and lupus erythematosus (Table VIII-2). Whites had higher than expected percentages of ESRD caused by the primary disease groups of interstitial nephritis and cystic/hereditary /congenital diseases. Asians were over-represented for lupus erythematosus and rapidly progressive GN. Native Americans were over-represented for diabetes. Data for Native American and Asian patients are not shown by detailed diagnosis because of the limited number of patients.

Table VIII-2 also reveals that males predominated overall (57.2 percent) and particularly among pediatric patients with ESRD due to obstruction (interstitial nephritis) and cystic/hereditary/congenital diseases. Females predominated among patients with ESRD due to secondary GN/vasculitis and diabetes.

Frequency of kidney transplantation within 1 year of onset of ESRD also varied by primary disease, with evidence of higher than average rates of transplantation for diseases associated with cystic/hereditary/congenital diseases and interstitial nephritis/pyelonephritis. The fraction of pediatric ESRD patients who died within 1 year following onset of ESRD was highest among those with neoplasms, congenital nephrotic syndrome, hypertension, lupus erythematosus, and Wegener's granulomatosis. Mortality was lowest among pediatric patients within the primary disease groups of interstitial nephritis/pyelonephritis and GN.

Table VIII-3 presents the column percent for incidence of reported ESRD therapy by detailed primary disease group for pediatric patients. Percentages by primary disease groups (bold-face print) add to 100 percent in each column. Counts and percentages for Asian and Native American patients are not presented due to small sample size. The two most common causes of ESRD among White pediatric patients are GN and renal hypoplasia. The two most common causes of ESRD among Black pediatric patients are focal glomerulosclerosis and GN.

No adjustments have been made to the estimates shown in Table VIII-2 and VIII-3 for differences in age, race, sex, and modality of care across these disease groups.

Prevalence of Reported Pediatric ESRD

Point prevalence counts and age specific rates of treated ESRD per million United States are shown in Table VIII-1 for the four pediatric age groups. To allow comparison to young adults, the aggregated pediatric numbers (ages 0-19) are also shown with data for the 20-44-year age group. A child incident (i.e., new to ESRD) at age 4 in 1987 would be counted as prevalent in the 10-14-year age group (age 12), if still alive in 1995. As children grow older, they will be counted as prevalent in successively older age groups, which explains the higher prevalence rates among older age groups, despite the fact that incidence rates were similar for children aged 0-4 and 5-9. Point prevalence rates per million population (adjusted for race and sex) reveal an approximate doubling of treated prevalence rates for successively older 5-year age groups (Table VIII-1).

Almost 50 percent of the 1993-95 point prevalent pediatric ESRD cohort was in the 15-19-year age group. Therefore, aggregate descriptions and outcomes associated with the pediatric ESRD population are strongly influenced by the experience of children in the oldest 5-year pediatric age group. Compared to young adults, the ESRD prevalence in children is relatively small.

Average year-end point prevalence counts for pediatric patients were higher for the years 1993-95 than for the 1990-92. A portion of this increase is likely due to the new inclusion of non-Medicare patients in data reported for 1993-95. See Chapter II for more details.

ESRD Treatment Modalities for Pediatric Patients

Children with ESRD 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; Mehls). Several factors have contributed to differences between the

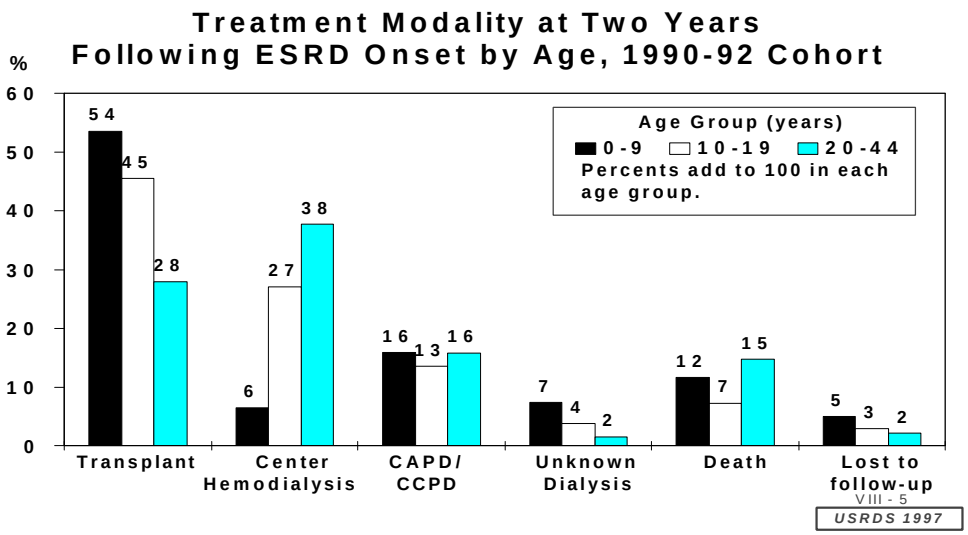

Figure VIII - 5

Renal replacement therapy at two years past onset of ESRD by age at onset, 1990-92 cohort of treated incident patients. Percentages within each age group add to 100. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Reference Table C.10 and Special Analysis.

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, problems associated with small vessels for vascular access, and less constraints on dietary and fluid intake with peritoneal dialysis compared to hemodialysis. Evidence of reduced growth rates for children receiving dialysis compared to those receiving a transplant (Turenne; Tejani) also contributes to a strong preference for kidney transplantation for children (Alexander; Webb).

The largest difference in methods of treatment for the pediatric versus the adult ESRD population was seen in transplantation. Forty-two percent of children starting ESRD therapy during the 1991-95 period received a transplant during the first year (Table VIII-2), compared to 10 percent of patients 20-64 years of age at ESRD incidence.

Figure VIII-5 profiles the methods of treatment used at 2 years following onset of ESRD for 2,706 pediatric patients incident in 1990-92 and a cohort of incident adults aged 20-44 years old. Fifty-four percent of children between the ages of 0-9 years and 45 percent of children 10-19 years of age had a functioning graft after 2 years of ESRD therapy. Children received dialysis less frequently than adults, with only 29 percent of children 0-9 years old and 44 percent of children 10-19 years having received some form of dialysis (the sum of hemodialysis, CAPD/CCPD, and unknown dialysis modalities in Figure VIII-5). In contrast, only 28 percent of adults in the 20-44 age group had a functioning graft after 2 years of ESRD therapy and 56 percent were receiving some form of dialysis. Twelve percent of children 0-9 years of age and 7 percent of children 10-19 years of age died within 2 years of onset of ESRD. By comparison, 15 percent of incident ESRD patients between 20-44 years had died within 2 years of onset of ESRD. Five percent of children between 0-9 years are considered lost to followup 2 years after onset of ESRD, compared to 3 percent of children 10-19 years and 2 percent of adult patients aged 20-44 years. Overall, differences in treatment utilization are more striking when comparing younger children, 0-9 years old, with adults 20-44 years old.

The differences in patterns of treatment between younger and older 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, children in the youngest age group are more likely to die within the first 2 years of ESRD than are older children.

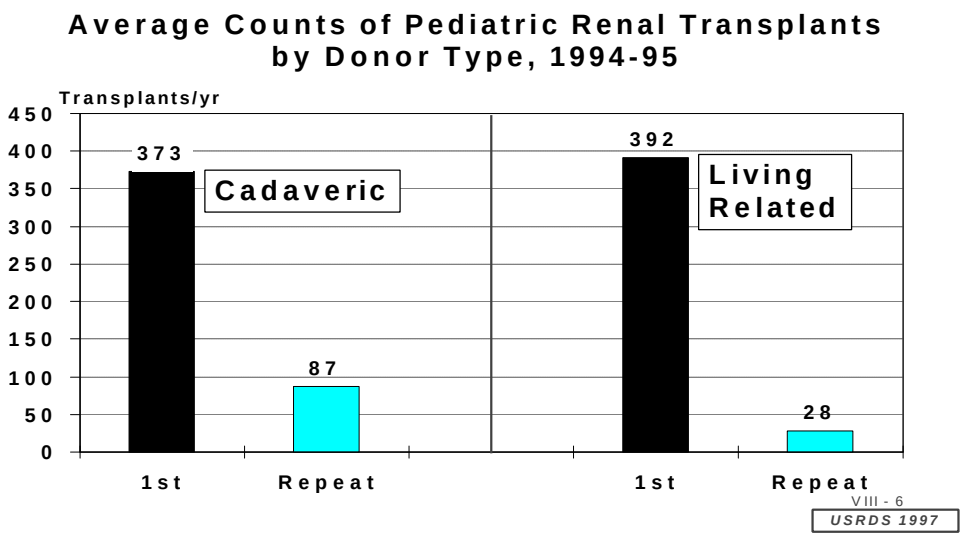

Figure VIII - 6

Average annual counts of pediatric renal transplants by donor type (cadaveric or living related) and transplant number (first or repeat) performed during 1994-95. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Reference Table F.11 and Special Analysis.

Number of Pediatric Renal Transplants

The number of pediatric renal transplants performed in 1994-95 is plotted in Figure VIII-6 according to the transplant number (first or repeat) and type of donor (cadaveric or living related). In the pediatric population, the number of living related transplants slightly outnumbered cadaveric transplants. This is in marked contrast to the adult population for whom first cadaveric transplants are 1.5 to 6 times more common than first living related donor transplants. Repeat cadaveric transplants were more numerous than repeat living related transplants for both pediatric and adult patients, although the difference was greater among some adult age groups than among pediatric patients.

Access to Kidney Transplantation: Transplantation Rates

The previous section presented the total counts of pediatric renal transplants performed in 1994-95. 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 the transplant recipient. Shown in Figure VIII-7 are pediatric transplant rates by donor type and recipient age at time of transplantation, for transplants occurring in 1995. The transplant rate is calculated as the number of total transplants (first and repeat) for a given cohort of patients 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). The small percentage of patients transplanted without prior dialysis contribute only to the numerator. Dialysis patient years at risk represent the duration (converted to years) that children in the same age, sex, and race group received dialysis therapy during calendar year 1995.

Figure VIII-7 indicates that for children of all ages, there were 27 living related transplants per 100 dialysis patient years, and 26 cadaveric transplants per 100 dialysis patient years. Rates of transplantation were considerably lower in adult patients 20-44 years of age: 5 and 11 per 100 dialysis patient years for living related and cadaveric transplants, respectively. Rates of living related transplantation were highest among patients 5-9 years of age, and rates of cadaveric transplantation were highest among patients 10-14. Living related transplants were also more common than cadaveric transplants in children 0-9 years old.

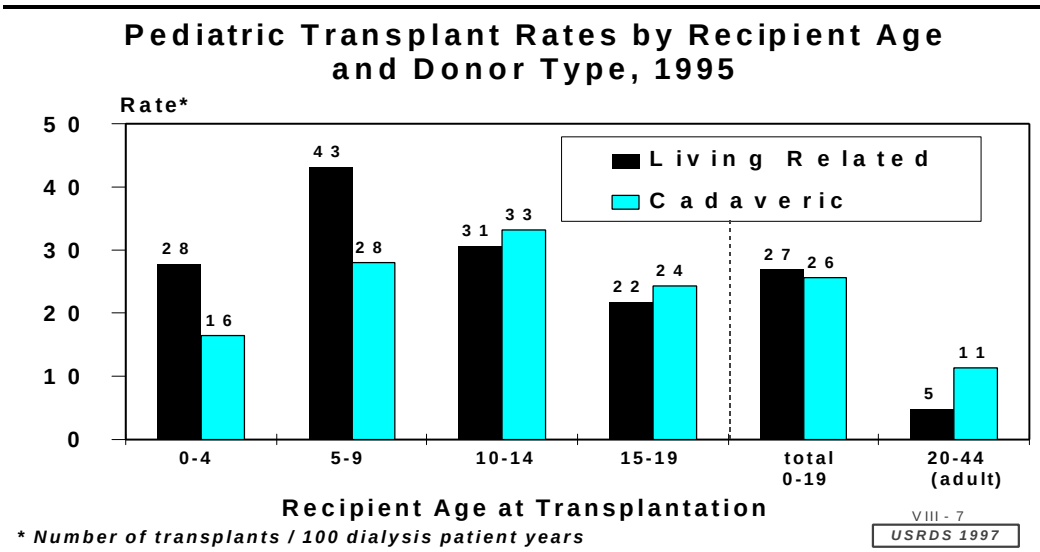

Figure VIII - 7

Pediatric renal transplantation rates (per 100 dialysis patient years) by recipient age (on December 31 of transplant year) and donor type, 1995. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare and Non-Medicare patients are included. Source: Reference Table F.32.

All pediatric patients ever transplanted are shown as a percentage of all prevalent pediatric patients by recipient age at transplant in Figure VIII-8 (patients with failed transplants are included in this analysis). This figure demonstrates the strong propensity of the pediatric nephrology community to choose transplantation as the preferred modality of treatment for children with ESRD. In 1995, 79 percent of prevalent ESRD patients 10-14 years had received at least one transplant compared to 32 percent of ESRD patients of all ages. The percentage of patients ever transplanted decreased with each age group after ages 10-14.

Transplantation rates by recipient race and sex are shown in Figure VIII-9 for both cadaveric and living related donors. Rates of pediatric cadaveric

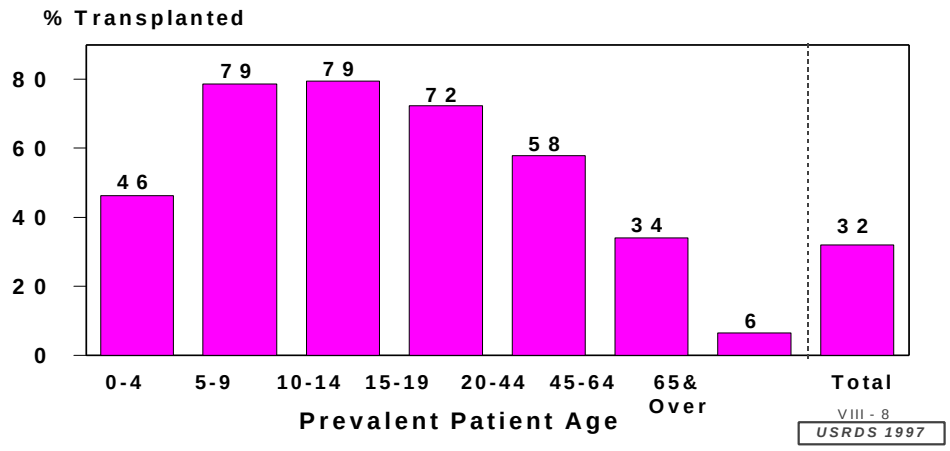

Figure VIII - 8

Patients ever transplanted as a percent of all prevalent patients alive on December 31, 1995. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Reference Table F.33.

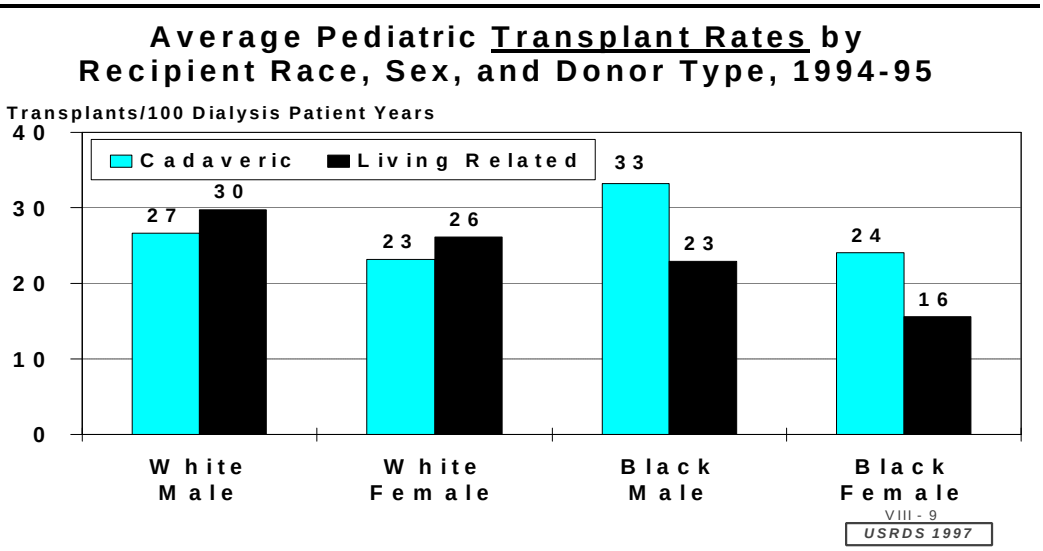

Figure VIII - 9

Average pediatric renal transplantation rates (per 100 dialysis years) by donor type, recipient race and sex, 1994-95. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Special Analysis.

transplants were higher in Black patients than in White patients. This finding is seen in males and in females, but differs from previous reports, which showed higher cadaveric transplant rates for White compared to Black pediatric patients. It is not known if the apparent increase in cadaveric transplant rates for pediatric Blacks indicates a true change in transplantation rates or if it is a data artifact, since the data source for the USRDS has recently changed to include non-Medicare patients (see Chapter VII). Any increase in transplantation rates for Blacks could possibly be the result of under-utilization of living related transplants, with cadaveric transplants becoming the "default" option.

The rate of pediatric living related transplants was lower in Black patients of both sexes than for White patients, and the rate for Black females was lowest of the four groups (Figure VIII-9).

Average cadaveric transplant rates by age in

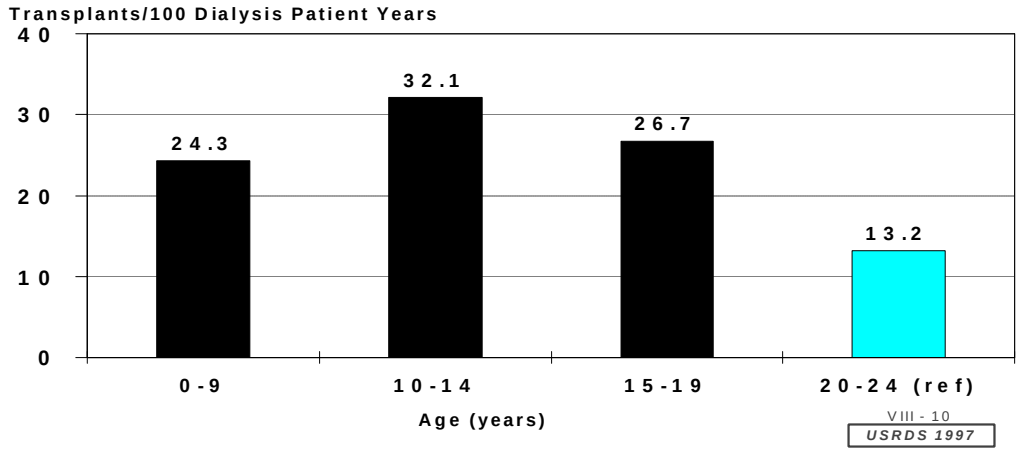

Figure VIII -10

Average pediatric cadaveric renal transplantation rates (per 100 dialysis patient years), 1994-95. Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Special Analysis.

One-Year and 5-Year Survival for Pediatric ESRD Patients by Age and Year, Unadjusted

Figure VIII -11

Pediatric one- and five-year Kaplan-Meier patient survival (percent), starting at day 91 following onset of ESRD, by time period. Estimates are derived from one-year cohorts, and averaged over the two years in each time period. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare and Non-Medicare patients are included. Source: Reference Tables E.1, E.2, E.14, E.16 and Special Analysis.

1994-95 are reported in Figure VIII-10. Rates were highest in pediatric patients 10-14 years of age. Rates for all pediatric age groups were markedly higher than those for adults aged 20-24.

Patient Survival for All Renal Replacement Therapies

Figure VIII-11 depicts 1- and 5-year patient survival by 5-year pediatric age groups. Both 1-year and 5-year survival is estimated using unadjusted Kaplan-Meier survival estimates, calculated as the weighted average of two 1-year incident cohorts.

One- and 5-year survival probabilities for treated pediatric ESRD patients were relatively constant from 1985-86 to 1993-94. The youngest age group (0-4 years) experienced the lowest 1-year survival. For the three remaining pediatric age groups (5-9, 10-14, and 15-19 years) 1-year survival estimates were similar, with values fluctuating around 97 percent. By comparison, the 1-year survival for 1994 incident patients in the 45-64 age group was 84 percent (Reference Table E.18).

Similar to 1-year survival, 5-year survival was lowest in the youngest age group (0-4 years). The 5-9-year age group the 10-14-year age group had almost identical 5-year survival probabilities, which varied between 87 and 95 percent. Five-year survival for patients 15-19 years old fluctuated between 86 and 89 percent.

Patient Survival by Modality

Death rates in the first year of ESRD for pediatric patients by 5-year age groups and treatment modality are shown in Figure VIII-12. The percentage of deaths was compared within each age group for those receiving dialysis or receiving a kidney transplant from a cadaveric or living related donor from start of treatment during 1994. Followup for dialysis patients was censored on the day of first transplant.

Transplant patients had lower death rates than dialysis patients overall, with the largest relative benefit of transplant observed in the youngest patients (0-4 years). Pediatric patients with a living related graft had slightly lower death rates than patients with a cadaveric graft. Since there was no adjustment 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.

This analysis of patient deaths by modality does not consider other important patient outcomes, such as quality of life, which may also vary by modality. Any judgment concerning the relative success of a particular modality of care in addressing the needs of children with ESRD should consider differences in growth and quality of life in addition to survival. According to the USRDS Special Study on growth in children with ESRD, there was greater growth for those treated with transplant than for those treated

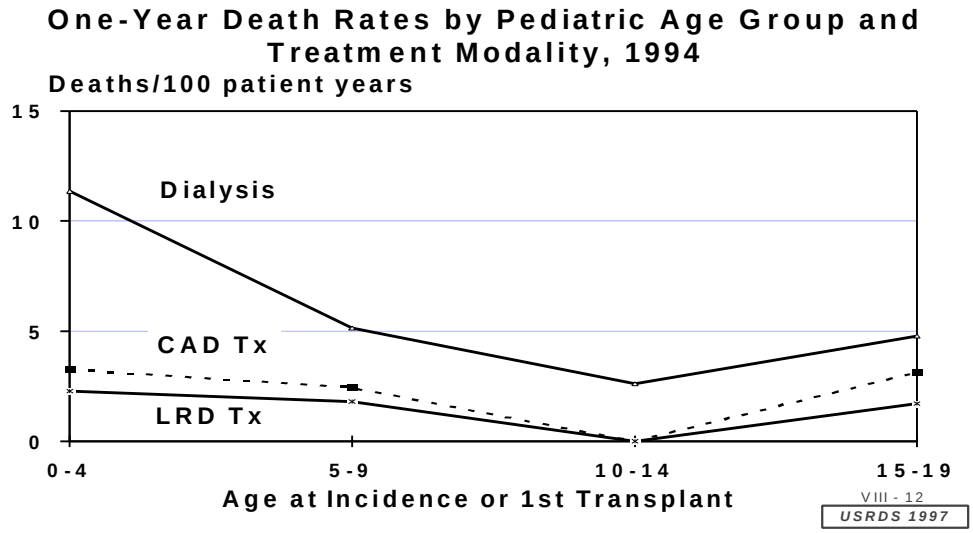

Figure VIII -12

Pediatric patient one-year Kaplan-Meier death rates (percent) by 5-year age groups and treatment modality, 1994. Survival follow-up starting from day 91 following onset of ESRD for dialysis patients incident in 1994 and from date of transplant for patients transplanted in 1994. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare and Non-Medicare patients are included. Source: Reference Tables E.30, E.38, and E.46

with either peritoneal dialysis or hemodialysis (Turenne).

One-year survival probabilities by modality (Figures 13-15) are estimated using the Kaplan-Meier method. Estimates for each 2-year period are calculated as the weighted average of the two 1-year incident cohorts.

For pediatric dialysis patients 5-19 years of age, 1-year survival increased from approximately 85 percent in 1985-86 to 95 percent in 1993-94 (Figure

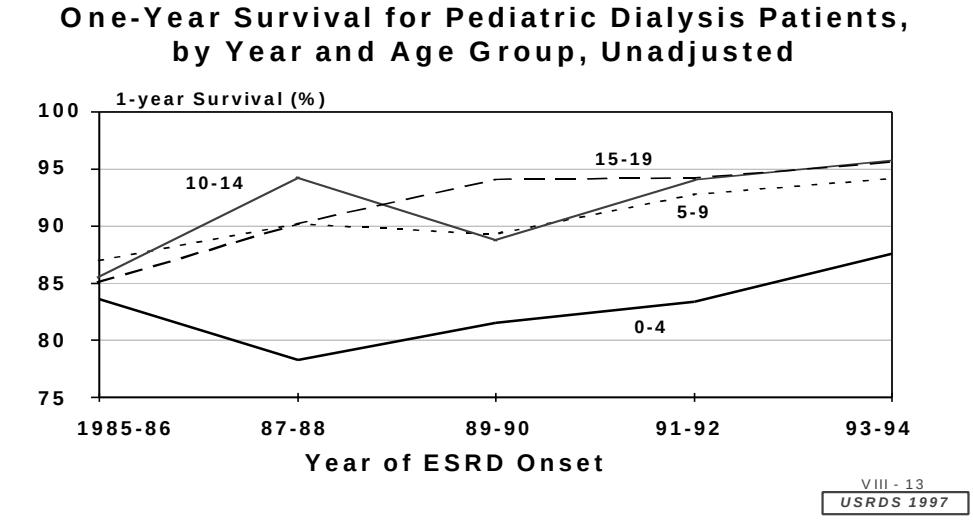

Figure VIII -13

Pediatric dialysis patient one-year Kaplan-Meier survival (percent) by 5-year age groups, and 2-year incident cohorts, 1985-94. Survival estimates are weighted averages of two 1-year cohorts, with survival followup starting at day 91 of ESRD. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare and Non-Medicare patients are included. Source: Reference Tables E.5, E.30 and Special Analysis.

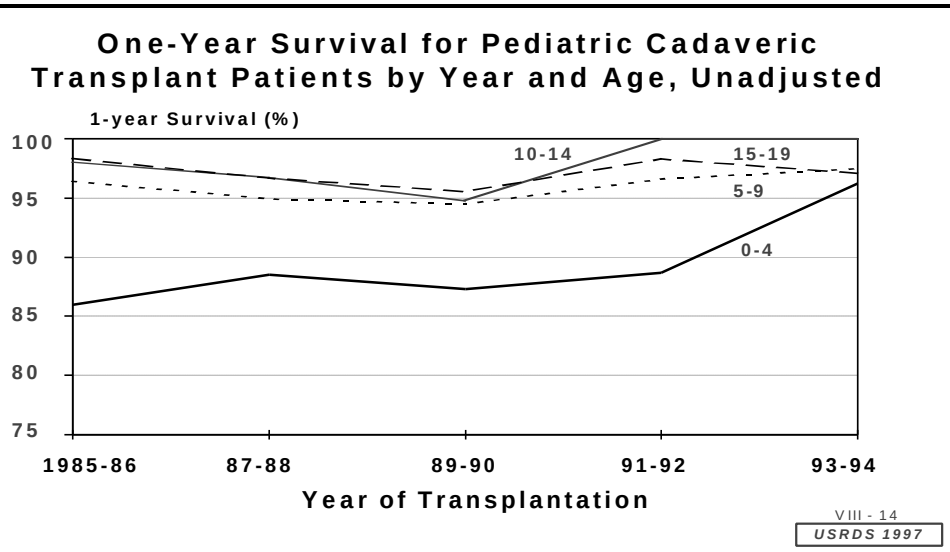

Figure VIII -14

Pediatric cadaveric transplant one-year Kaplan-Meier survival (percent) by 5-year age groups, and 2-year incident cohorts, 1985-94. Survival estimates are weighted averages of two 1-year cohorts, with survival followup starting at day of transplant. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare and Non-Medicare patients are included. Source: Reference Tables E.7, E.38 and Special Analysis.

VIII-13). In dialysis patients 0-4 years of age, 1-year survival improved from approximately 84 percent in 1984 to 88 percent in 1994.

Cadaveric transplant patients in the youngest age group (0-4 years) had markedly improved 1-year survival, with an increase from 86 percent in 1985-86 to 96 percent in 1993-95 (Figure VIII-14).

One-year survival changed very little in older cadaveric transplant patients. One-year survival for patients with a living-related transplant (Figure VIII-15) appeared to show little change between 1985-86 and 1993-94, although values fluctuated.

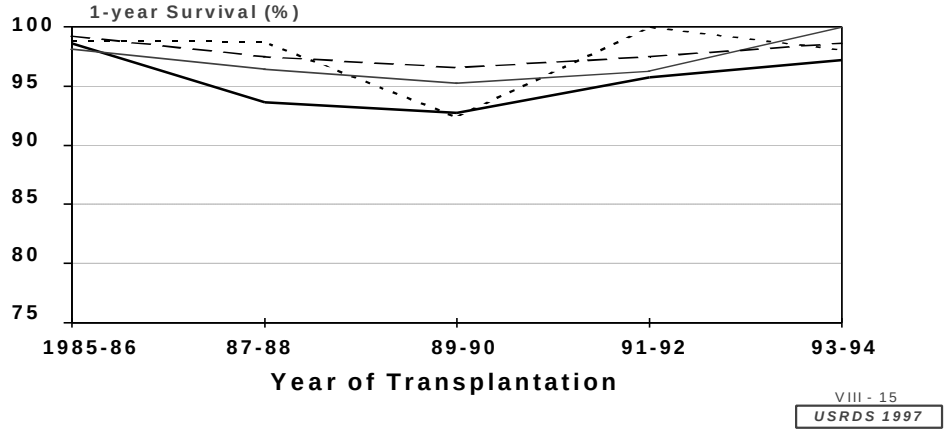

Figure VIII -15

Pediatric living donor transplant one-year Kaplan-Meier survival (percent) by 5-year age groups, and 2-year incident cohorts, 1985-94. Survival estimates are weighted averages of two 1-year cohorts, with survival followup starting at day of transplant. Patients in Puerto Rico and U.S. Territories are included in estimates. Medicare and Non-Medicare patients are included. Source: Reference Tables E.9, E.46 and Special Analysis.

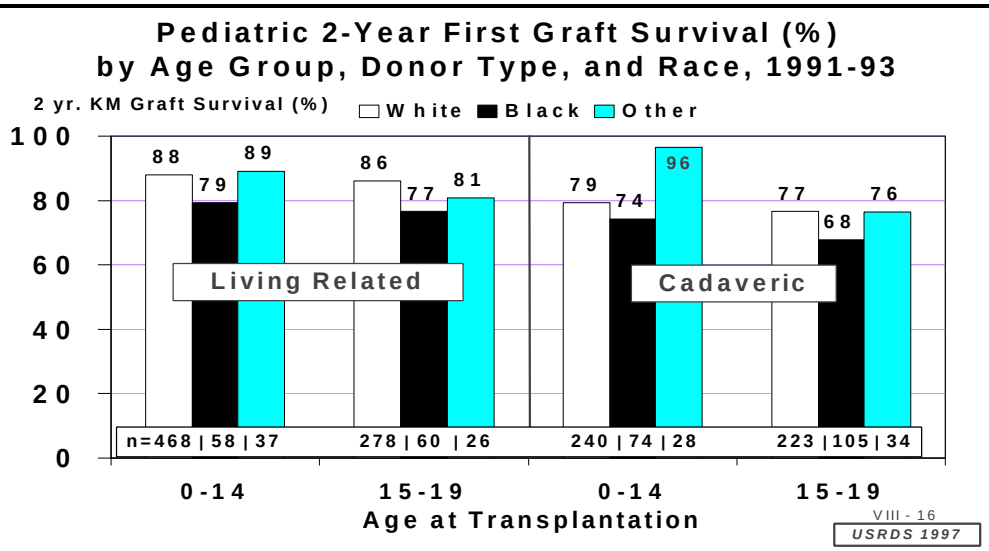

Figure VIII -16

Two year Kaplan-Meier kidney graft survival (percent) by donor type, recipient age groups and recipient race for first transplants, 1991-93. The number of patients are shown at the bottom of each column. Patients in Puerto Rico and the U.S. Territories are included in estimates. Medicare and Non-Medicare patients. Source: Special analysis.

Renal Graft Survival

Kaplan-Meier 2-year kidney graft survival estimates are shown in Figure VIII-16 by age, donor type, and race for all children transplanted between 1991 and 1993. The total count of transplants for each cohort appears at the base of the bars. Grafts transplanted from living related donors have higher survival rates than grafts originating from cadaveric donors. For both age groups and donor types, White children had better graft survival than Black children, a pattern by race that is also observed among adult recipients. Graft survival estimates for recipients of

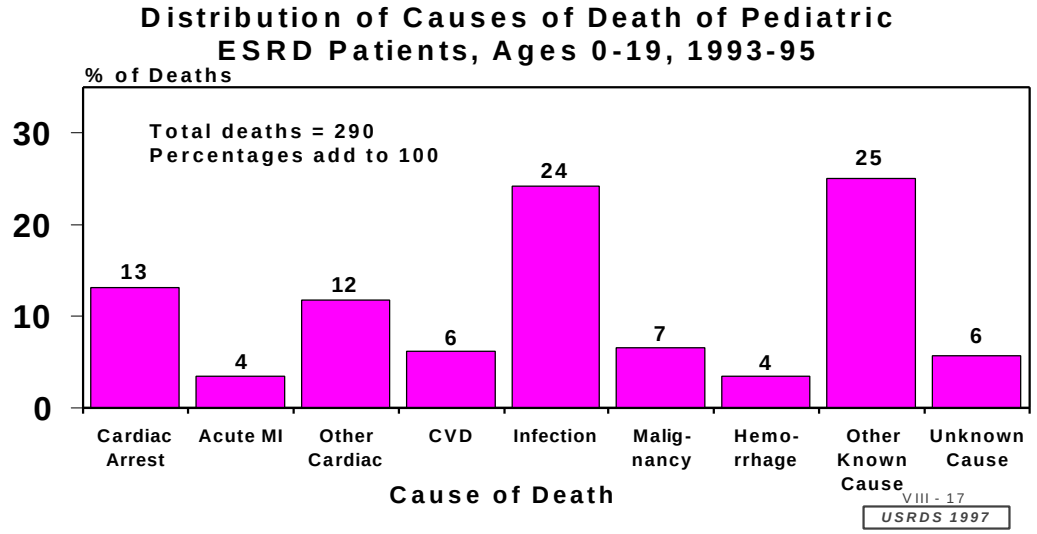

Figure VIII -17

Distribution of causes of death, ages 0-19, 1993-95. These percentages are calculated excluding those patients with missing data. Patients in Puerto Rico and the U.S. Territories are included. Medicare and Non-Medicare patients are included. Source: Reference Table D.4.

other races are less precise due to small sample sizes.

Mortality and Causes of Death

Deaths per 100 patient years at risk were analyzed by cause of death for all prevalent ESRD patients aged 0-19 years. Pediatric patients alive at the start of 1993, 1994, or 1995 were followed until death or until the end of the calendar year (see Reference Table D.4). The overall death rate was 2.0 per 100 patient years for patients 0-19 years, substantially lower than the rates for adult patients aged 20-44 years (5.9 per 100 patient years), 45-64 years (14.2 per 100 patient years), and 65 years or more (33.5 per 100 patient years).

Figure VIII-17 provides the distribution of causes of death during 1993-95 for patients 0-19 years old. Infection was the most common cause of death in children (24 percent), followed by cardiac arrest (13 percent). Cardiac arrest and other cardiac deaths combined accounted for 25 percent of patient deaths. In comparison, 15.5 percent of deaths among adults 20 years of age and older were attributed to infection, and 36.7 percent to cardiac deaths. It should be noted that these percentages for cause of death include only reported deaths. Cause of death data are missing for 17 percent of pediatric deaths; information pertaining to cause specific death rates would be significantly improved with more complete reporting of cause of death by the treating nephrologists.

Comparisons of death rates for pediatric dialysis and transplant patients also yield interesting results (see Reference Table D.2). The death rate for young pediatric dialysis patients (0-14 years), during 1995 was 4.3 per 100 patient years. Pediatric patients aged 0-14 years with functioning transplants had a substantially lower rate of 0.5 deaths per 100 patient years. For adolescent patients (15-19 years), death rates for patients on dialysis or with a functioning transplant were 3.4 and 1.1, respectively, per 100 patient years. However, these data do not adjust for the possible selection bias of the sicker patients who remain on dialysis, being the ones not offered a transplant, or who have a failed transplant.

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