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
Hemodialysis in children

Unique characteristics of children and adolescents make it imperative to specifically evaluate their different etiologies of renal failure, treatment, mortality, and overall patient and transplant graft survival. (McEnry; Fine, Salusky, et al 1987; Fine 1987; Ettenger 1987). These factors include development of cognition, secondary sexual characteristics and physical growth. It has also been reported that there are differences in immune responsiveness in children (Ettenger 1987; Parekh 1995) which may account for differences in transplant outcomes. For these reasons, the pediatric ESRD population requires special attention, and this chapter will focus on the incidence, prevalence, and modalities of treatment, survival outcomes and cause specific mortality as related to the national pediatric ESRD population.

The reported upper age cutoff for pediatric patients used among the ESRD registries worldwide ranges between 15 and 19 years. As in earlier Annual Data Reports, this 1998 Annual Data Report defined pediatric as all patients less than or equal to 20 years. 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 annual incidence counts for the 1995-96 period (1.087) increased compared to the 1993-94 period (928). Last year's report showed a small increase in incidence in 1995. This was thought to be due more to the inclusion of non-Medicare patients in the 1994-95 incident patient counts reported by HCFA rather than an increase in diagnosis and treatment for younger patients with ESRD. Future incident data will need to be collected to ascertain whether there is an actual increase in incidence for pediatric groups.

Among both the pediatric and adult ESRD populations, rates of ESRD incidence increase substantially with increasing age. The incidence rate of treated ESRD, adjusted for race and sex, is much higher among adults than among children. During 1996 the adjusted ESRD incidence rate per million United States population (in each age group) was 13 for ages 0-19 years, 117 for ages 20-44 years, 542 for ages 45-64 years, 1144 for ages 65-74 years, and 1079 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

Pediatric ESRD Incidence and Prevalence Counts and Rates, 1994-96

Age at Incidence	Incidence		Point Prevalence*	
	Average Counts Per Year	Unadjusted Annual Rate**	Average Counts Per Year	Unadjusted Annual Rate
0-4	158	9	362	20
5-9	137	8	676	36
10-14	242	14	1,284	70
15-19	523	30	2,455	136
All Pediatric (0-19)	1,060	15	4,777	65
Adults (20-44)	12,032	122	69,374	694

**Alive on December 31 of 1994-96. **Per million population (in each group), adjusted for sex and race. Patients in Puerto Rico and U.S. Territories and cases where race is "other" or "unknown" are excluded. Counts are averaged over a three year period. Includes Medicare and Non-Medicare patients. Source: Reference Tables A.3, A.4, B.5, and B.6*

Table VIII-1 ***USRDS 1998***

and race. Table VIII-1 indicates that average incidence rates over the combined years 1994-96 were more than twice as high among children 15-19 years (30 per million) compared to children 10-14 years (14 per million), and more than three times higher than rates for children 0-4 (9 per million) and 5-9 (8 per million) years of age at onset of ESRD. Average annual counts of incident ESRD among children for the years 1994-1996 show that 523 out of the 1060 children newly beginning treatment for ESRD (49 percent) were between the ages of 15 and 19 (Table VIII-1).

Within the pediatric ESRD population, there are large variations in the incidence rates of ESRD by race, as well as by age. The pediatric treated ESRD incidence rates per million United States population per year for the 1994-96 period were 11 for Whites, 26 for Blacks, 14 for Asians/Pacific Islanders, and 21 for Native Americans. The higher overall incidence of ESRD for Black children was primarily the result of an almost three-fold excess of ESRD, in the 15-19-year-old age group among Blacks compared to Whites (62 per million versus 21 per million). Treated ESRD incidence rates in Whites and Blacks differed less in the younger age groups. The incidence rates for Native Americans show a similar pattern compared to Whites, with a rate of 39 per million in Native Americans between the ages of 15-19, almost twice that of Whites in the same age group.

Figure VIII-2 illustrates the incidence of treated ESRD by sex, according to 5-year age groups. Treated incidence rates of ESRD were greater for boys than girls overall. This reflects the higher incidence of congenital disorders including obstructive uropathy and renal dysplasia, which occur more commonly in boys and are the cause of 15 percent of the total incident cases in the pediatric ESRD population.

Causes of Pediatric ESRD

The largest single disease group causing ESRD (Table VIII-3) in children is primary glomerulonephritis (31.7 percent of all reported causes), followed by cystic/hereditary/congenital diseases (24.4 percent). Hypertension only represented 5.0 percent of all pediatric ESRD. Diabetes is an extremely rare cause of ESRD in the pediatric population; only 1 in 2000 patients with ESRD due to diabetes falls in this age group. The distribution of causes of ESRD by age group for the pediatric patients incident during 1992-96 is shown in Figure VIII-3. Among the younger patients, 0-4 years old, cystic/hereditary/ congenital disease was the primary cause of ESRD. Among the older patients, 5-19 years of age at onset of ESRD,

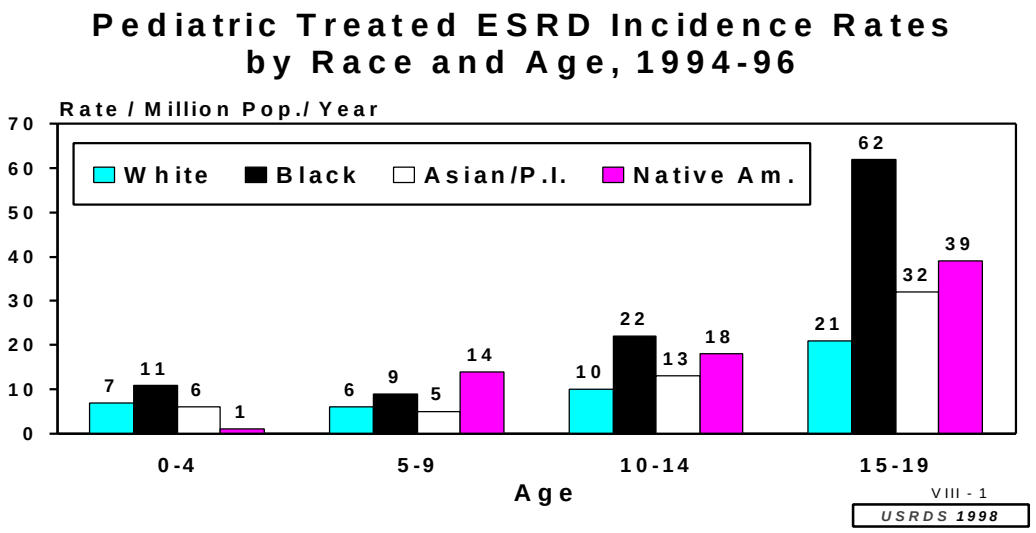

Figure VIII-1

Reported pediatric ESRD incidence rates per million population by age group and race, adjusted for sex. Average rate per year, 1994-96. Includes 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

glomerulonephritis (GN) and collagen vascular diseases was prominent.

Figure VIII-4 provides the distribution of causes of ESRD within each race group for pediatric incident patients during 1992-96. Primary GN was the primary

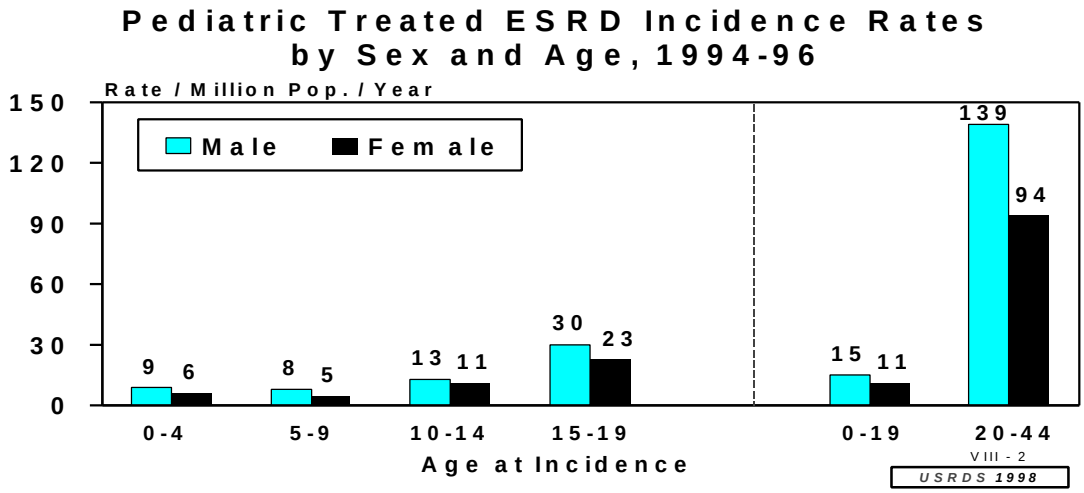

Figure VIII-2

Reported pediatric ESRD incidence per million population by age and sex, adjusted for race. Average rate per year, 1994-96. 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

Incidence of Treated ESRD (%) in Pediatric Patients (Age<20), Median Age, Sex, Race[1], and One Year Transplant and Death Status by Detailed Primary Disease, 1992-1996: *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)	**5,155**	**14**	**57.1**	**63.0**	**27.4**	**37.3**	**2.9**
Diabetes	**83**	**16**	**39.8**	**54.2**	**33.7**	**13.3**	**2.4**
Glomerulonephritis (GN)	**1,635**	**16**	**55.0**	**56.9**	**32.8**	**33.3**	**1.6**
- Focal glomerulosclerosis, focal GN	515	16	60.2	44.5	47.0	30.9	1.2
- Membranous nephropathy	23	16	52.2	*	60.9	13.0	4.3
- Membranoproliferative GN	130	15	45.4	68.5	22.3	36.9	0.0
- IgA nephropathy, Berger's disease	66	17	71.2	69.7	*	28.8	0.0
- Rapidly progressive GN	106	14	39.6	69.8	11.3	33.0	0.9
- Goodpastures Syndrome	34	16	47.1	88.2	*	17.6	2.9
- Unspecified GN	683	16	54.8	59.0	30.3	36.5	2.0
- Other proliferative GN	65	16	53.8	66.2	26.2	33.8	3.1
Secondary GN/Vasculitis	**470**	**16**	**36.6**	**61.7**	**26.4**	**21.1**	**5.5**
- Lupus erythematosus	257	17	24.5	45.9	40.1	10.1	7.0
- Wegener's granulomatosis	28	17	50.0	85.7	*	17.9	7.1
- Henoch-Schönlein syndrome	50	14	52.0	90.0	*	42.0	2.0
- Hemolytic uremic syndrome	99	9	57.6	83.8	*	34.3	3.0
Interstitial Nephritis/Pyelonephritis	**558**	**14**	**63.3**	**76.2**	**17.4**	**45.2**	**2.5**
- Chronic pyelonephritis, reflux neph.	120	16	44.2	80.0	12.5	33.3	0.8
- Nephropathy caused by other agents	71	14	69.0	81.7	*	43.7	2.8
- Nephrolithiasis, Obstruction, Gout	231	12	76.2	74.9	20.3	49.8	2.2
- Chronic interstitial nephritis	123	15	54.5	73.2	16.3	51.2	4.9
Hypertensive/large vessel disease	**258**	**17**	**57.8**	**38.4**	**52.7**	**25.6**	**4.7**
- Hypertension, (no primary renal dis.)	237	17	58.6	35.0	56.1	24.9	4.6
- Renal artery stenosis or occlusion	21	9	47.6	76.2	14.3	33.3	4.8
Cystic/Hereditary/Congenital Diseases	**1,259**	**11**	**66.8**	**72.8**	**19.0**	**43.7**	**2.9**
- Polycystic kidneys, adult (dominant)	128	10	44.5	76.6	14.8	46.1	3.1
- Polycystic, infantile (recessive)	31	3	41.9	74.2	*	6.5	9.7
- Medullary cystic, nephronophthisis	40	13	55.0	85.0	*	35.0	0.0
- Alport's, other hereditary/familial disease	149	16	85.9	70.5	21.5	40.9	0.7
- Cystinosis	39	12	61.5	92.3	*	61.5	0.0
- Congenital nephrotic syndrome	41	1	39.0	65.9	*	17.1	7.3
- Congenital obstructive uropathy	296	11	80.7	69.6	19.6	50.0	2.4
- Renal hypoplasia, dysplasia	472	8	60.8	72.2	20.3	43.9	3.8
- Prune belly syndrome	42	10	100.0	73.8	*	47.6	0.0
- Other Cystic/Hereditary/Congenital Dis.	21	37	278.2	292.9	*	104.5	0.0
Neoplasms/Tumors	**32**	**6**	**50.0**	**65.6**	*****	**15.6**	**18.8**
- Renal or urological neoplasms	31	6	51.6	64.5	*	16.1	19.4
Miscellaneous Conditions	**146**	**13**	**58.2**	**53.4**	**38.4**	**23.3**	**7.5**
- Tubular necrosis (no recovery)	50	10	54.0	70.0	22.0	20.0	6.0
Etiology Uncertain	**418**	**15**	**51.7**	**64.6**	**25.8**	**39.5**	**1.9**
Missing	**296**	**13**	**60.5**	**58.8**	**27.7**	**66.9**	**3.4**

Patients in Puerto Rico and U.S. Territories are included. Medicare and Non-Medicare patients are included. Bolded represent disease category headings. Percentages are expressed relative to the number of patients in each disease (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 total are not listed separately from the corresponding disease group. [3]"1st Year" = 1st year of ESRD therapy; "Tx'ed" = transplanted ***USRDS 1998***

Table VIII-2

cause of ESRD in 40 percent of Blacks, 42 percent of Asians, 38 percent of Native Americans, and 30 percent of Whites. Hypertension was the primary cause of ESRD in 10 and 9 percent of Blacks and Native Americans, respectively and was a rare cause among Whites and Asians.

Incidence of Treated ESRD in Pediatric Patients (Age<20) by Detailed Primary Disease and Race[1], 1992-1996: *Column Percent*

Primary Disease Groups[2]	Total Patients (5 years)	% of Total	# White	# Black	Percent White	Percent Black
All Pediatric ESRD (reference)	**5,155**	**100.0**	**3,250**	**1,414**	**100.0**	**100.0**
Diabetes	**83**	**1.6**	**45**	**28**	**1.5**	**2.1**
Glomerulonephritis (GN)	**1,635**	**31.7**	**931**	**537**	**30.3**	**40.3**
- Focal glomerulosclerosis, focal GN	515	10.0	229	242	7.4	18.2
- Membranous nephropathy	23	0.4	*	*	*	1.1
- Membranoproliferative GN	130	2.5	89	29	2.9	2.2
- IgA nephropathy, Berger's disease	66	1.3	46	*	*	*
- Rapidly progressive GN	106	2.1	74	12	2.4	0.9
- Goodpastures Syndrome	34	0.7	30	*	*	*
- Unspecified GN	683	13.2	403	207	13.1	15.5
- Other proliferative GN	65	1.3	43	17	1.4	1.3
Secondary GN/Vasculitis	**470**	**9.1**	**290**	**124**	**9.4**	**9.3**
- Lupus erythematosus	257	5.0	118	103	3.8	7.7
- Wegener's granulomatosis	28	0.5	24	*	*	*
- Henoch-Schönlein syndrome	50	1.0	45	*	*	*
- Hemolytic uremic syndrome	99	1.9	83	*	*	*
Interstitial Nephritis/Pyelonephritis	**558**	**10.8**	**425**	**97**	**13.8**	**7.3**
- Chronic pyelonephritis, reflux neph.	120	2.3	96	15	3.1	1.1
- Nephropathy caused by other agents	71	1.4	58	*	*	*
- Nephrolithiasis, Obstruction, Gout	231	4.5	173	47	5.6	3.5
- Chronic interstitial nephritis	123	2.4	90	20	2.9	1.5
Hypertensive/large vessel disease	**258**	**5.0**	**99**	**136**	**3.2**	**10.2**
- Hypertension, (no primary renal dis.)	237	4.6	83	133	2.7	10.0
- Renal artery stenosis or occlusion	21	0.4	16	*	0.5	*
Cystic/Hereditary/Congenital Diseases	**1,259**	**24.4**	**917**	**239**	**29.8**	**17.9**
- Polycystic kidneys, adult (dominant)	128	2.5	98	19	3.2	1.4
- Polycystic, infantile (recessive)	31	0.6	23	*	*	*
- Medullary cystic, nephronophthisis	40	0.8	34	*	*	*
- Alport's, other hereditary/familial disease	149	2.9	105	32	3.4	2.4
- Cystinosis	39	0.8	36	*	*	*
- Congenital nephrotic syndrome	41	0.8	27	*	*	*
- Congenital obstructive uropathy	296	5.7	206	58	6.7	4.4
- Renal hypoplasia, dysplasia	472	9.2	341	96	11.1	7.2
- Prune belly syndrome	42	0.8	31	*	*	*
- Other Cystic/Hereditary/Congenital Dis.	21	0.4	16	*	*	*
Neoplasms/Tumors	**32**	**0.6**	**21**	*****	*****	*****
- Renal or urological neoplasms	31	**0.6**	20	*****	*	*****
Miscellaneous Conditions	**146**	**2.8**	**78**	**56**	**2.5**	**4.2**
- Tubular necrosis (no recovery)	50	**1.0**	35	11	1.1	0.8
Etiology Uncertain	**418**	**8.1**	**270**	**108**	**8.8**	**8.1**
Missing	**296**	**5.7**	**174**	**82**	******	******

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 total are not listed separately from the corresponding disease group

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Table VIII-3

Among the Whites, the etiology of ESRD was almost equally distributed in the following categories: primary GN, Cystic/hereditary/congenital diseases, and Other causes. In the Asian/Pacific Islander population, primary and secondary GN accounted for 60 percent of the causes for ESRD. The similar pattern was also seen in the Blacks with 49 percent comprising of primary and secondary glomerulonephritis.

The etiology of pediatric ESRD is substantially different from those causing ESRD in adults.

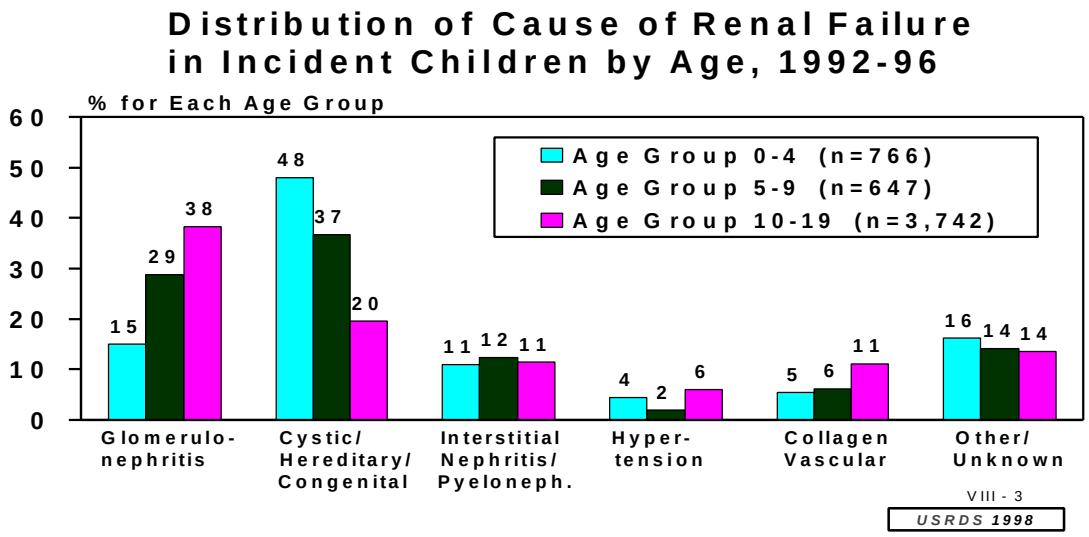

Figure VIII-3

Incident pediatric cases by disease group, by age group (0-4, 5-9, and. 10-19), as a percent of total pediatric ESRD cases within each age group. Numbers on top of bars represent the percent within each age group over a 5-year time period, 1992-1996. Patients in Puerto Rico and U.S. Territories are included. Medicare and non-Medicare patients are included. Source: Special Analysis

Data on mean age, Race group (Black, White), percent male, percent transplanted in the first year and 1-year death status is provided in Tables VIII-2 and VIII-3. Numbers and percentages of Asian and Native American pediatric patients are omitted because the small sample size makes it more difficult to detect true patterns.

From 1992 to 1996, there were 5,155 incident cases of ESRD in children. Fifty seven percent were boys and 63 percent were White. Within the first year of therapy, 37.3 percent were transplanted. This

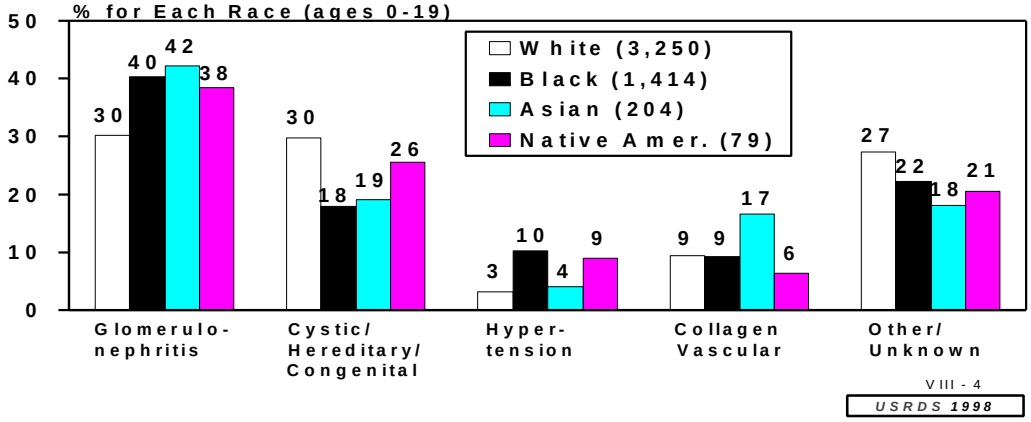

Figure VIII-4

Incident pediatric cases by disease group, and 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 5-year period, 1992-96. Patients in Puerto Rico and U.S. Territories are included. Medicare and non-Medicare patients are included. Source: Reference Tables A.21 and A.22

represents a much higher transplant rate than in the adult population.

By disease category, numerous interesting findings can be observed. Focal segmental glomerulosclerosis (FSGS) comprised the biggest specified diagnosis group (31 percent). In FSGS, 60 percent were boys 47 percent were Black. Lupus ESRD patients, females constituted 75 percent of the group, and Blacks were slightly over-represented. In hemolytic uremic syndrome, 84 percent were White and the median age was relatively young (9 years). Interstitial nephritis was the third most common cause of pediatric ESRD and comprised 12.5 percent of the total incident cases from 1992-1996. Of this group, 63 percent were male and 77 percent were White. This group had the highest transplant rate of 45.2 percent in the first year.

Blacks were particularly over-represented (had a higher than the average percentage of 27.4 percent of the total pediatric ESRD population) among children whose primary cause of ESRD was hypertension (53 percent) and membranous GN (61 percent). Whites had higher than expected percentages of ESRD (i.e., 63 percent) caused by the primary disease groups of interstitial nephritis (77 percent) and cystic/hereditary /congenital diseases (73 percent).

Males predominated overall (57.1 percent) and particularly among pediatric patients with ESRD due to interstitial nephritis (63.3 percent) and cystic/hereditary/congenital diseases (66.8 percent).

The 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, lupus, Wegener's, hypertension, autosomal recessive polycystic disease, and congenital nephrotic syndrome. Mortality was lowest among pediatric patients with ESRD due to primary GN.

The incidence of reported ESRD therapy by detailed primary disease group for pediatric patients is shown in Table VIII-3. Percentages by primary disease groups (boldface 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.

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 prevalence of treated ESRD per million United States are shown in Table VIII-1. The aggregated pediatric numbers (ages 0-19) are compared with data for the 20-44-year age group. 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. For example, 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. Point prevalence rates per million population reveal an approximate doubling of prevalence rates for successively older 5-year age groups (Table VIII-1).

Average point prevalence counts for pediatric patients were higher for the years 1995-96 (67 per million population) than for the 1993-94 (59 per million population; Reference Table B.5). As stated earlier, this increase in point prevalence is attributable to the combined affects of higher incidence counts and decreasing mortality of the pediatric population with ESRD. Future data will aid in detecting a trend, as an increased prevalence will have an effect on needs for health care personnel.

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). Children are more likely to utilize 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; Kohaut). 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). There has been an

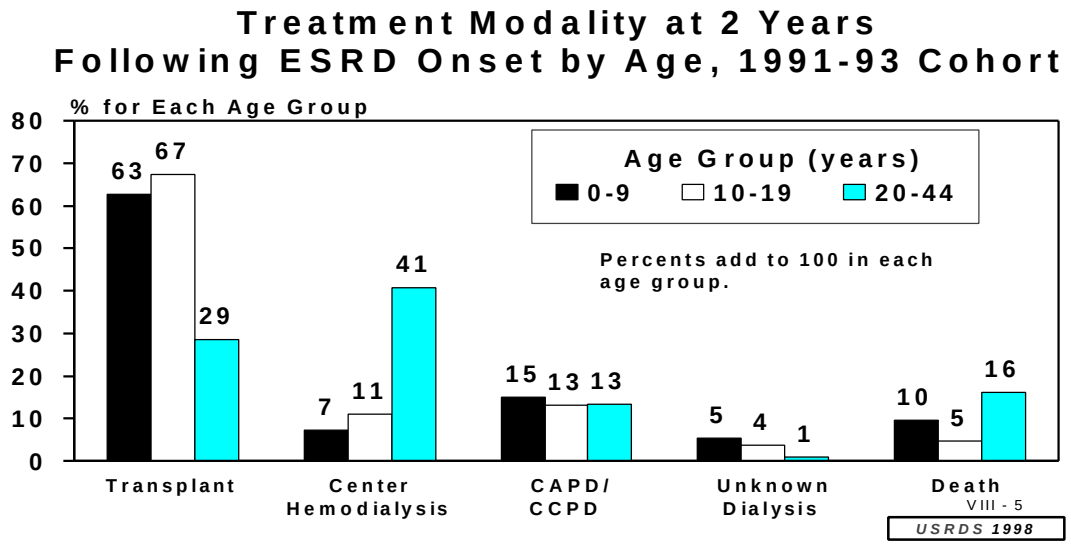

Figure VIII-5

Renal replacement therapy at 2 years (+91 days) post onset of ESRD, by age at onset, 1991-93 cohort of treated incident pediatric 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 Tables C.9 and C.10 and Special Analysis

improvement in survival of infants receiving transplants, so that age is no longer a factor in determining eligibility for transplantation (Kohaut).

Several factors have contributed to differences between the adult and pediatric ESRD treatment modality use. These include the relatively greater availability of living kidney donors (particularly parental) for pediatric transplantation (Bloembergen), limitations on educational, social and emotional support for patients treated with center hemodialysis, problems associated with small vessels for vascular access for dialysis and less constraints on dietary and fluid intake with peritoneal dialysis compared to hemodialysis.

The largest difference in methods of treatment for the pediatric versus the adult ESRD population is seen in transplantation. Thirty-seven percent of children starting ESRD therapy during the 1992-96 period received a transplant during the first year (Table VIII-2), compared to only 8.7 percent of patients 20-64 years of age at ESRD incidence.

The methods of treatment used at 2 years following onset of ESRD for 2,639 pediatric patients incident in 1991-93 and a cohort of incident adults aged 20-44 years old are shown in Figure VIII-5. Sixty-three percent of children between the ages of 0-9 years and 67 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 twenty seven percent of children 0-9 years old and twenty-eight percent of children 10-19 years receiving some form of dialysis (the sum of hemodialysis, CAPD/CCPD, and unknown dialysis modalities in Figure VIII-5) at 2 years into ESRD. In contrast, only twenty-nine percent of adults in the 20-44 age group had a functioning graft after 2 years of ESRD therapy and fifty-six percent were receiving some form of dialysis. Ten percent of children 0-9 years of age and 5 percent of children 10-19 years of age died within 2 years of onset of ESRD. By comparison, 16 percent of incident ESRD patients between 20-44 years had died within 2 years of onset of ESRD.

The differences in patterns of treatment between younger and older children are no longer as striking as reported for earlier years. Overall, the most favored renal replacement modality is transplantation in all pediatric age groups. However, older children aged 10-19 are more likely to be treated with center hemodialysis than the younger patients.

Number of Pediatric Renal Transplants

The number of pediatric renal transplants performed in 1995-96 is plotted in Figure VIII-6

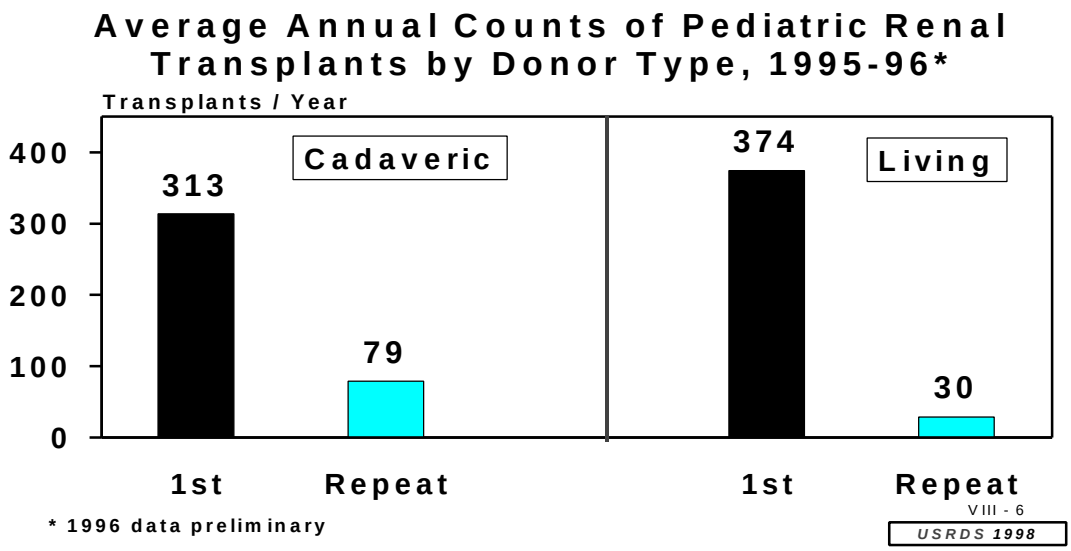

Figure VIII-6

Average annual counts of pediatric renal transplants by donor type (cadaveric or living) and transplant number (first or repeat) performed during 1995-96. Patients in Puerto Rico and U.S. Territories are included. Medicare and non-Medicare patients are included. Source: Special Analysis

according to the transplant number (first or repeat) and type of donor (cadaveric or living). Living transplants constitute both living related and unrelated. In the pediatric population, the number of first living transplants slightly outnumbered cadaveric transplants. This is in marked contrast to the adult population, for whom first cadaveric transplants are 2 to 6 times more common than first living donor transplants (Reference Table F.26). Repeat cadaveric transplants were more numerous than repeat living donor 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

This section further characterizes the patients who received kidney transplants, according to the type of donor (cadaveric or living) as well as the age, sex, and race of the transplant recipient. Shown in Figure VIII-7 are pediatric transplantation rates by donor type and recipient age at time of transplantation, for transplants occurring in 1994-1996. The transplant rate is calculated as the number of total transplants (first and repeat) performed for a given cohort of patients per 100 dialysis patient years. Data came from the same cohort of patients for the dialysis years (used in the denominator) and the number of transplants (used in the numerator). The small number of patients who were transplanted without receiving prior dialysis contribute only to the numerator. Dialysis patient years at risk represent the duration (measured in days and converted to years) that children in the same age, sex, and race group received dialysis therapy during calendar year 1996.

Figure VIII-7 indicates that for children ages 0-19 years, there were 25 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 at 10 and 12 per 100 dialysis patient years for living and cadaveric transplants, respectively. Rates of living and cadaveric transplantation were highest among patient's 5-9 years of age. Although, there appeared to be a slight decrease in transplant rates in children aged 5-9 years in 1996 compared to 1995. Living related transplants were more common than cadaveric transplants in children 0-4 years old. Transplantation rates for cadaveric versus living transplant were similar in the 5-9, 10-14, and 15-19 age groups. The older teenagers had the lowest transplant rate for all pediatric age groups.

Transplantation rates by recipient race and sex are shown for both cadaveric and living related donors in 1994-96 (Figure VIII-8). For females rates of

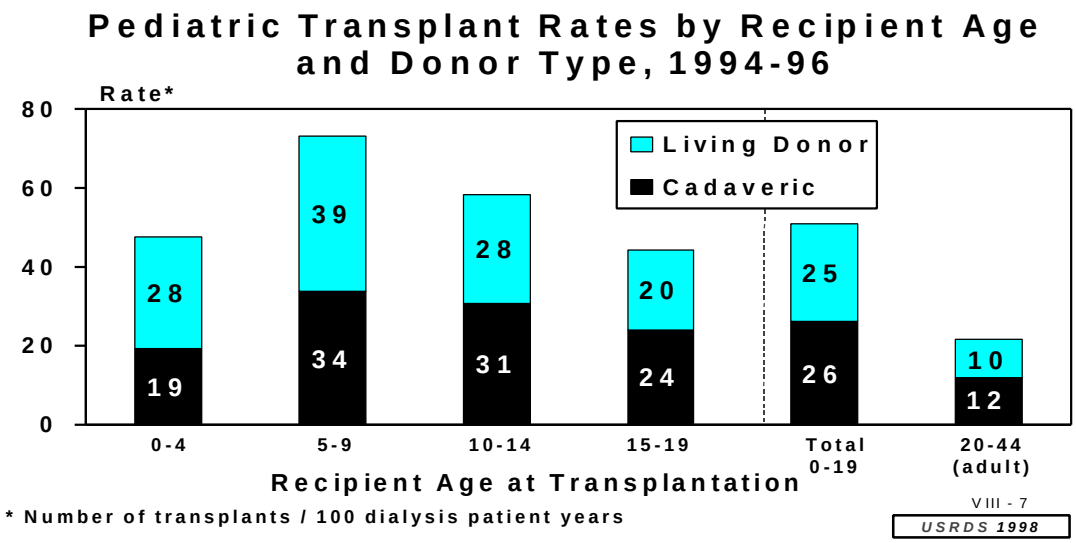

Figure VIII-7

Pediatric renal transplantation rates (per 100 dialysis patient years) by recipient age (on December 31 of transplant year) and donor type, 1994-96. Patients in Puerto Rico and U.S. Territories are included. Medicare and non-Medicare patients are included. Source: Special Analysis

pediatric cadaveric transplants were lower in Black patients than in White patients, while they were similar for males. The rate of pediatric living donor transplantation was lower in Black patients of both sexes than for White patients and the rate for Black females was lowest of the four groups. Females in both races received fewer cadaveric and living donor transplants than males.

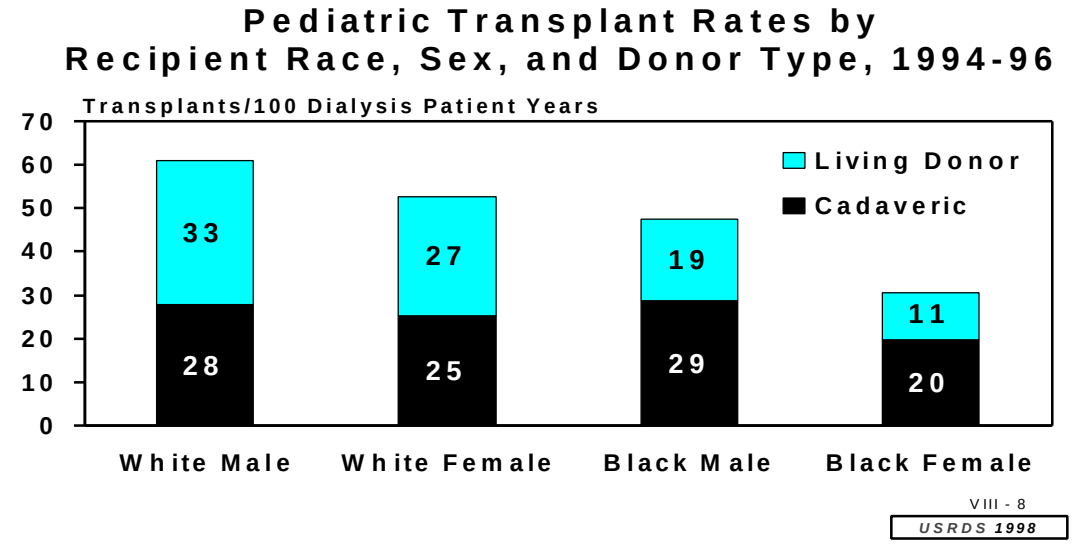

Figure VIII-8

Average pediatric renal transplantation rates (per 100 dialysis years) by donor type, recipient race and sex, 1994-96. Patients in Puerto Rico and U.S. Territories are included. Medicare and non-Medicare patients are included. Source: Special Analysis

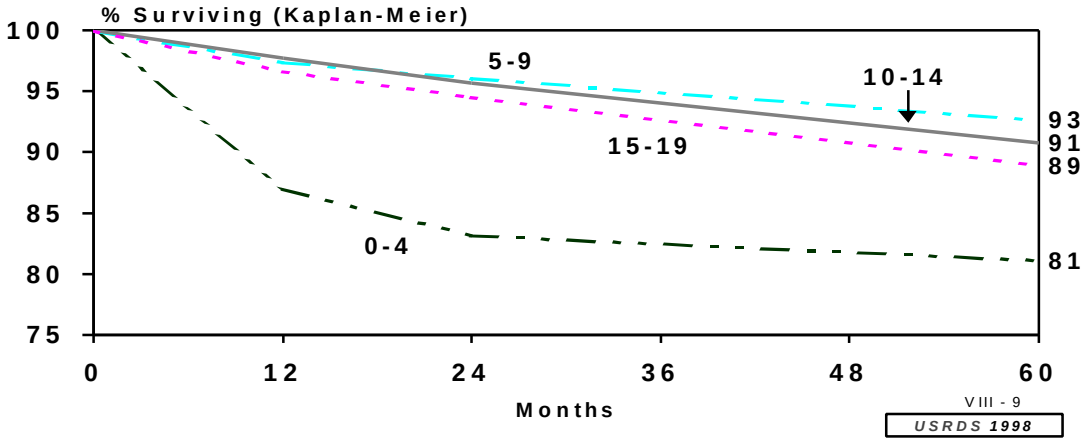

Figure VIII-9

Pediatric Kaplan-Meier 5-year survival estimates (percent) by age group, 1990-91 incident cohort. Survival starting at day 91 following onset 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.2, E.14, E.16, and E.18

Patient Survival for All Renal Replacement Therapies

Figure VIII-9 depicts patient survival by 5-year age groups for all pediatric ESRD patients (includes

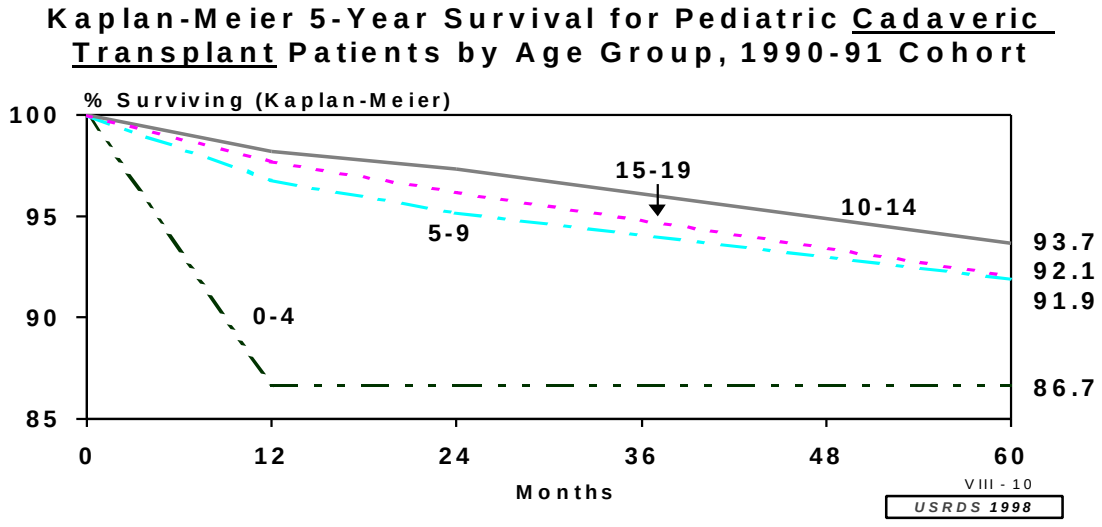

Figure VIII-10

Pediatric Kaplan-Meier 5-year survival estimates (percent) by age groups for cadaveric transplant patients, 1990-91. Survival followup starting from date 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.62, E.64, and E.66

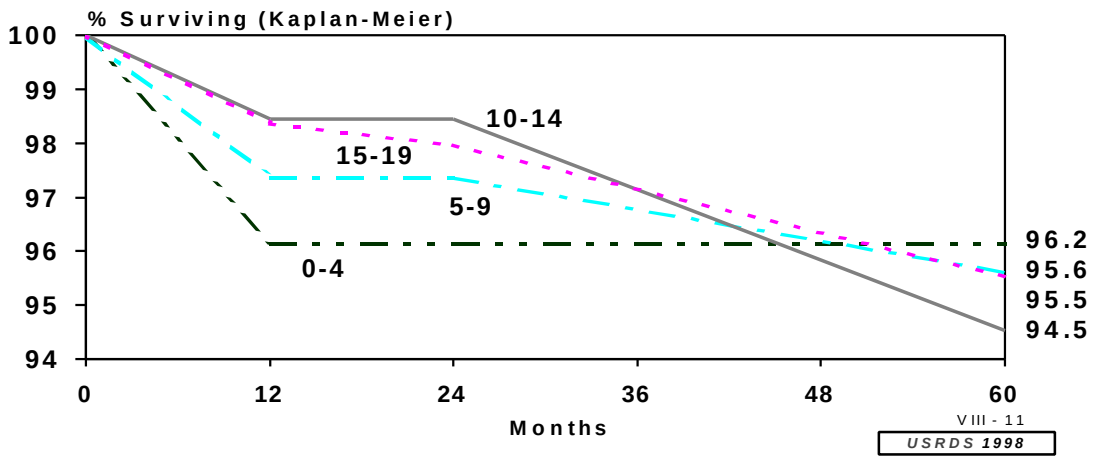

Figure VIII-11

Pediatric Kaplan-Meier 5-year survival estimates (percent) by age groups for living donor transplant patients, 1990-91. Survival followup starting from date 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.78, E.80, and E.82

dialysis and transplantation) in the 1990-91 cohort.

Five-year survival estimates for treated pediatric ESRD patients have been relatively constant. The youngest age group (0-4 years) experienced the lowest 5-year survival of 81 percent. For the three remaining pediatric age groups (5-9, 10-14, and 15-19 years) 5-year survival estimates were similar, with values of 93 percent, 91 percent and 89 percent, respectively.

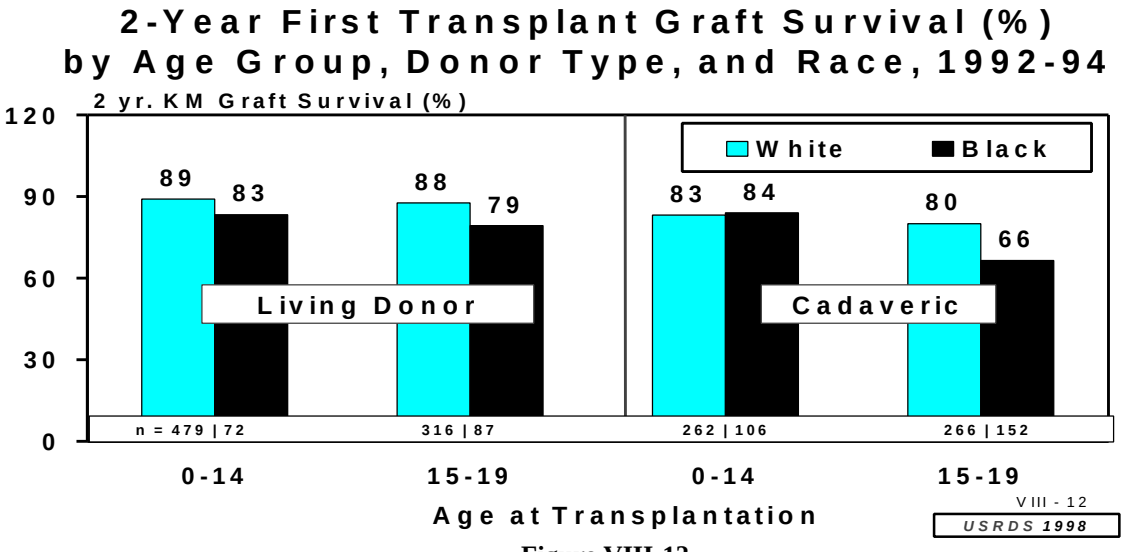

Figure VIII-12

Two-year Kaplan-Meier kidney graft survival (percent) by donor type, recipient age group, and recipient race for first transplants, 1992-94. The number of patients is 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.

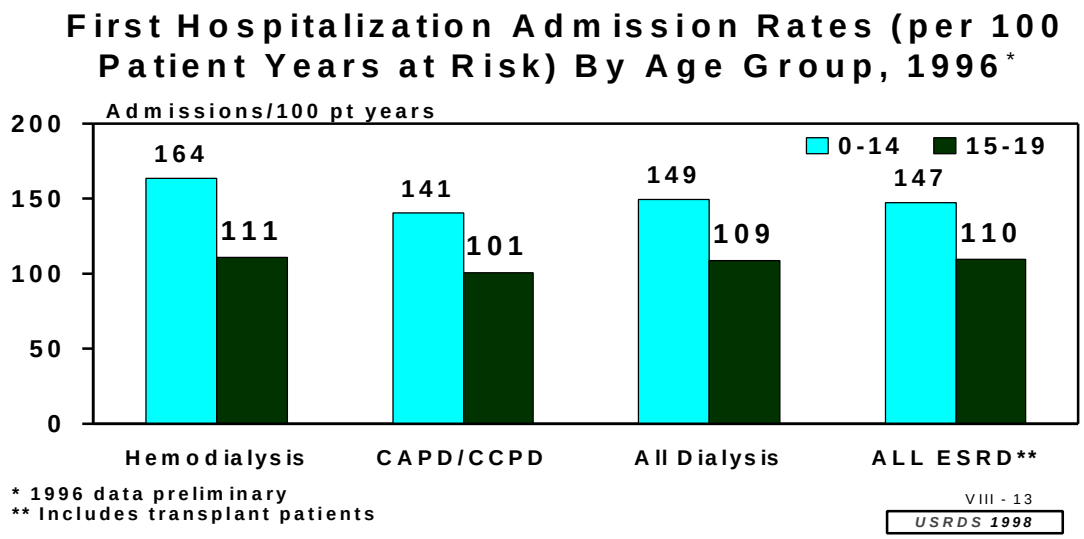

Figure VIII-13

Pediatric first hospital admission rates per 100 patient years at risk, by age and modality, 1994-96. Medicare patients only. Source: Reference Table H.1

Patient Survival by Modality

Unadjusted Kaplan-Meier 5-year survival estimates for the pediatric patients receiving cadaveric and living transplant recipients are shown in Figure VIII-10 and Figure VIII-11.

Overall, living donor recipients had a higher unadjusted 5-year survival estimate in the 1990-91 cohort compared to the cadaveric transplant patients. 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.

Among cadaveric transplant patients, the youngest age group 0-4 had the lowest 5-year survival of 86.7 percent. The other 3 age groups had similar 5-year survival estimates, which ranged from 92-94 percent. Pediatric living donor transplant recipients (1990-1991 cohort) in all age groups had a 5-year survival of 94-96 percent. There was a minimally lower survival in the patients ages 10-14. The youngest age group (age 0-4) had an initial drop in survival in the first year and subsequently leveled off.

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.

Renal Graft Survival

Kaplan-Meier 2-year kidney graft survival estimates are shown in Figure VIII-12 by age, donor type, and race for all children transplanted between 1992-94. The total count of transplants for each cohort appears at the base of the bars. Grafts transplanted from living related donors have higher 1 and 2-year survival rates than grafts originating from cadaveric donors. For both age groups and donor types, White children had better graft survival than Black children. Except in the age group 0-14 of cadaveric transplant patients, there was a similar graft survival. Graft survival estimates for recipients of other races are less precise due to small sample sizes and therefore are not depicted.

Hospitalizations

Figure VIII-13 depicts the first hospitalization admission rate per year per 100 patient years at risk in 1996. Among dialysis patients, there were more hospital admissions for the patients receiving hemodialysis than peritoneal dialysis (excluding admissions for transplant.) This may reflect a selection bias of patients initiated on hemodialysis as peritoneal dialysis is still the preferred choice in the pediatric population. A more detailed study is

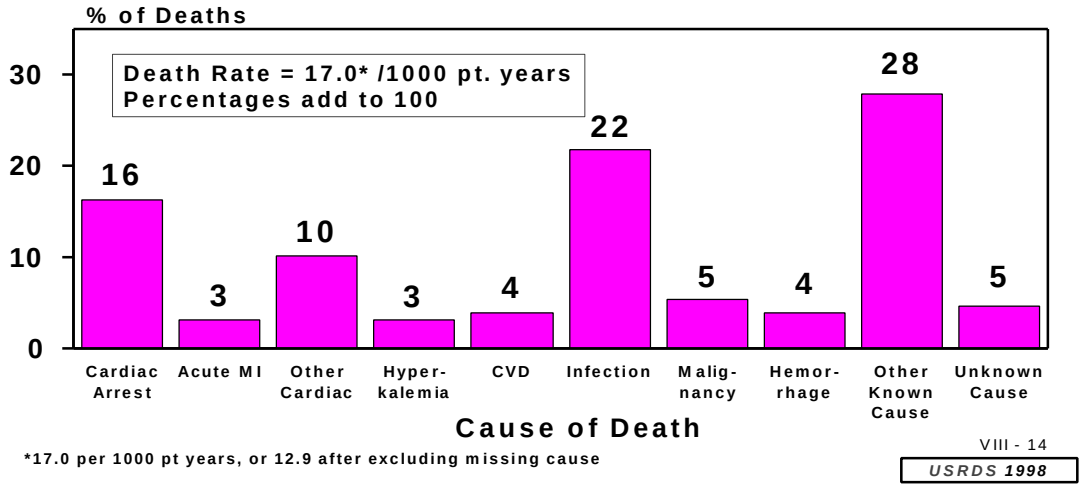

Figure VIII-14

Distribution of causes of death, pediatric patents age 0-19, 1994-96. 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

warranted to evaluate this aspect. In dialysis patients, the younger patients also had a significantly higher admission rate than the older age group of 15-19. All patients with ESRD (including transplant patients) had similar first admission rates in both age groups than the dialysis only groups.

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 1994, 1995, or 1996 were followed until death or until the end of the calendar year (see Reference Table D.4). The overall death rate was 17.0 per 1000 patient years for patient's 0-19 years, substantially lower than the rates for adult patients aged 20-44 years (55.9 per 1000 patient years).

Figure VIII-14 provides the distribution of causes of death during 1994-96 for patients aged 0-19 years old. Chapter V provides a more detailed explanation of causes of death. Infection was the most common cause of death in children (22 percent), followed by cardiac arrest (16 percent). The combination of cardiac arrest with other cardiac deaths accounted for 33 percent of patient deaths. Interestingly, the summation of cardiac arrest and other cardiac causes of death do not include hyperkalemia, which is listed separately as a cause of death. Hyperkalemia, acute MI, arrhythmia, and cerebrovascular disease contribute approximately 3 percent each to the total percent of deaths in the pediatric ESRD population. It is not clear if the method of reporting deaths may have affected this number but more accurate reporting may reveal higher percentages for cardiac causes of death. It should be noted that these percentages for cause of death include only reported deaths. Cause of death data are missing for 194 cases (1 percent) of pediatric deaths. Information pertaining to more precise 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 1996 was 3.8 per 1000 patient years. Pediatric patients aged 0-14 years with functioning transplants had a substantially lower rate of 0.4 deaths per 1000 patient years. For adolescent patients (15-19 years), death rates for patients on dialysis or with a functioning transplant were 2.8 and 0.8 per 1000 patient years respectively. However, these data do not adjust for the possible effect of the sicker patients remaining on dialysis, perhaps not being offered a transplant, or having failed transplant.

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