So I am proud only of those days that we pass in undivided tenderness, when you sit drawing, or making books, stapled, with messages to the world... or coloring a man with fire coming out of his hair. Or we sit at a table, with small tea carefully poured; so we pass our time together, calm and delighted.

ROBERT BLY
"FOR MY SON, NOAH, TEN YEARS OLD"
Pediatric end-stage renal disease patients pose unique challenges to providers and to the health care system, which must address not only the disease itself in these patients, but the many extra-renal manifestations that affect growth and development.

ESRD care in pediatric patients has undergone a number of changes over the last two decades. This year, we present updated information on the demographic characteristics of this population, trends in treatment modalities, the degree of anemia at initiation of treatment, residual renal function at initiation, and evidence of malnutrition and inflammation as represented by low serum albumin levels. We also present data on overall and cause-specific hospitalization and mortality.

Between May of 1995 and June of 2004, more than 4,000 children started therapy for ESRD caused by either primary or secondary glomerulonephritis, and another 3,200 began treatment for ESRD caused by cystic kidney disease, a diagnosis occurring most often in patients younger than age four.

Preventive care measures continue to be underutilized in pediatric patients. Rates of influenza, pneumococcal pneumonia, and hepatitis B vaccinations are far lower in children than in adult patients, as is the percent of patients receiving cardiovascular risk management.

Rates of catheter use are also much greater in children than in adults. Long-term use of these accesses poses significant problems for the pediatric population relative to infectious complications and stenoses of central veins.

The treatment of anemia in this younger population has undergone major changes over the last ten years. Hemoglobin levels, on average, have increased more than 1.5 g/dl. Boys and girls now have similar hemoglobin levels, and racial disparities have narrowed.

Among patients who require erythropoietin therapy, those on peritoneal dialysis continue to have lower hemoglobin levels than do those on hemodialysis, and their erythropoietin doses are considerably lower, most likely due to subcutaneous administration. These lower doses suggest that dosing patterns in peritoneal dialysis patients may not be keeping pace with targeted hemoglobin levels. Additionally, iron dosing in these patients is less than one-fourth that in the hemodialysis population. This would also contribute to the lower hemoglobin levels.

As reported in previous ADRs, infectious complications are an important consideration in the pediatric population. Compared to their adult counterparts, pediatric patients have fewer infectious complications on hemodialysis, but a greater degree of infections following transplant. Interestingly, vascular access complications for internal devices are now similar in the adult and pediatric populations. This is particularly true for infectious hospitalizations secondary to peritonitis, which in pediatric patients seemed
to decline and stabilize in the early 1990s before rising significantly since 1999, while rates in the adult population slowly fell.

Overall hospitalization rates for pediatric dialysis patients are more than double those of the transplant population, with the latter varying to a lesser degree based on the primary cause of renal failure.

When assessing overall survival, the 1994–1998 cohort shows improved survival of pediatric patients compared to the 1989–1993 period. This is true in the overall ESRD population as well as among hemodialysis and peritoneal dialysis patients. Interval death rates in the pediatric population are much more stable over a five-year followup period compared to those in the adult population, with an early hazard followed by a subsequent decline in mortality rates at one to two years, and then a steady rise in the followup period.

Overall, the pediatric population is increasingly treated with hemodialysis as a first modality of treatment. Transplantation, however, is still the dominant therapy, with nearly three in four patients transplanted in the three years after initiation. Dialysis catheters continue to be a major source of complications for children, particularly relative to infectious hospitalizations and sepsis. Anemia treatment has improved, yet the cumulative probability of any infectious complication is significant, particularly in peritoneal dialysis populations, approaching 60 percent at the end of three years. There has been a slight increase in the overall survival of children on ESRD treatment.

There continues to be little information about the nutritional status of pediatric ESRD patients and their growth and development, which was last evaluated in the early 1990s. The USRDS will work with the Centers for Medicare and Medicaid Services’ Clinical Performance Measures group, which is collecting more extensive information on the prevalent pediatric population.

Figure 8.1 Between May of 1995 and June of 2004, more than 4,000 children started therapy for ESRD caused by either primary or secondary glomerulonephritis, and another 3,200 began treatment for ESRD caused by cystic kidney disease. Figure 8.7 Forty-nine percent of children beginning therapy have an albumin less than the test’s lower limit. Figure 8.18 By June of 2004, more than three in four pediatric dialysis patients had a mean hemoglobin at or above the K/DOQI target of 11 g/dl. Figure 8.31 Pediatric transplant patients have overall admission rates that are 40 percent lower than those of dialysis patients at six months, and their days in the hospital are approximately half those of the dialysis population.
from May, 1995, to June, 2004, almost 3,000 children began therapy for ESRD caused by primary glomerulonephritis, and 3,264 new patients had a diagnosis of cystic/hereditary/congenital kidney disease; 1,070 had a primary diagnosis of secondary GN (Figure 8.3). Patient distribution by age differs widely; more than half of those with cystic kidney disease, for example, are younger than ten, compared to only 16 percent of the population with primary GN.

Pediatric patients with cystic kidney disease have the highest hemoglobin levels at initiation—9.9 g/dl, compared to 9.0 and 8.8 in patients with primary and secondary GN, respectively—and are also the most likely to receive EPO prior to starting therapy (Figures 8.4–5). Hemoglobin levels are lowest in children with secondary GN. By race, 40 percent of white children have received EPO prior to their ESRD diagnosis, compared to 31 percent of black children. Mean hemoglobin levels show a similar pattern, with an average level of 9.5 g/dl in whites, compared to 9.0–9.1 in blacks and in children of other races.

The mean estimated glomerular filtration rate in children starting ESRD therapy is 10.4 ml/min/1.73 m²—10.8 in whites, 9.9 in blacks, and 9.7 in patients of other races (Figure 8.6). Children with secondary GN have the highest eGFRs, and those with primary GN the lowest.

Forty-nine percent of children beginning therapy have an albumin less than the test’s lower limit (Figure 8.7). By race, however, this ranges from 45 percent of whites to 58 percent of blacks. Patients with secondary GN are most likely to have this marker of nutritional deficiency, and those with cystic kidney disease the least.
While vaccination rates in the pediatric population have been growing over the past decade, they remain strikingly low (Figures 8.8–10). In 2000–2003, for example, only 22 percent of pediatric patients were vaccinated for influenza—far below the HP2010 target of 90 percent. Not even 6 percent of patients received a pneumonia vaccination during that period, and only 7 percent were vaccinated for hepatitis B.

The frequency of lipid testing continues to increase (Figure 8.11). Forty-one percent of hemodialysis patients, and 46 percent of those on peritoneal dialysis, now receive at least one lipid test in a year.

Vascular access use in pediatric patients varies by age and gender, but not as widely by race (Figure 8.12). Catheters, for instance, are used in 78 percent of patients age 12 and younger, but only 44 percent of those age 13 and above; in these latter patients, catheter and fistula use are nearly equal. Forty-four percent of boys have an arteriovenous fistula, compared to only 24 percent of girls. These differences by age and gender may be due to the smaller vasculature of younger and female patients.

Among pediatric patients with a hemodialysis catheter, rates of infection and sepsis are 1.2 and 1.0 per patient year at risk, respectively; event rates for access removal or replacement are 0.2 and 0.5 (Figure 8.13). Event and complication rates are even lower for patients with arteriovenous fistulas or grafts. In the peritoneal dialysis population, the rate of sepsis reaches 1.9 per patient year at risk, while the rate of peritonitis is 0.1 (Figure 8.14).

Event and complication rates are even lower for patients with arteriovenous fistulas or grafts. In the peritoneal dialysis population, the rate of sepsis reaches 1.9 per patient year at risk, while the rate of peritonitis is 0.1 (Figure 8.14).
Hemoglobin levels in hemodialysis patients increase by age, with children age 0–19 having the lowest levels, and adults the highest (Figure 8.15). All age groups, however, have seen a steady increase since 1992–1993—from 16 percent in the youngest patients to 22 percent in children age 15–19. Trends are slightly different for patients on peritoneal dialysis; hemoglobins are highest in adults here as well, but tend to be lowest in the oldest children. Hemoglobin levels differ little by gender, and there are no clear trends by race/ethnicity. The mean hemoglobin for the pediatric population in 2002–2003 was 11.6 g/dl.

Though per-kilo doses of EPO are much higher in children, mean weekly doses for adults and children age 15–19, in both dialysis therapies, have increased 82–97 percent since 1992–1993 (Figure 8.16). Patients on peritoneal dialysis continue to receive considerably less EPO each week than their hemodialysis counterparts.

Carnitine is a compound known to be extremely important in the breakdown of fatty acids. The USRDS has previously reported that carnitine deficiency may play a major role in the increasing prevalence of congestive heart failure, cardiomyopathy, and sudden death, seen particularly in black children. Carnitine testing in the pediatric population does appear to be rising, but still reached only 3.7 percent in 2003 (Figure 8.17). The percent of patients receiving L-carnitine injections reached its peak in 2000; since then a slight decline has taken place.

By June of 2004, more than three in four pediatric dialysis patients had a mean hemoglobin at or above the K/DOQI target of 11 g/dl (Figure 8.18). The average EPO dose is now close to 16,000 units per week.

Pediatric patient distribution by hemoglobin level has followed the same pattern over time for both whites and blacks (Figure 8.19).

Mean hemoglobin levels have undergone a dramatic correction and are now comparable to those found in adults, and black children have recently achieved parity with whites; in order to achieve these levels, however, they require more EPO (Figure 8.20).

The use of iron therapy in the pediatric dialysis population varies little by gender; there are, however, wide variations by age and modality (Figure 8.21). Seventy-eight percent of children age 15–19, for example, were given iron sometime in 2003, compared to 60 percent of those age 10–14. And nearly nine in ten hemodialysis patients received iron—a level three times higher than that seen in the peritoneal dialysis population.
8.18 Mean hemoglobin (g/dl) & trends in mean hemoglobin & weekly EPO dose in period prevalent dialysis patients age 0–19

8.19 Mean hemoglobin (g/dl), by race in period prevalent dialysis patients age 0–19

8.20 Mean hemoglobin & EPO dose, by race in period prevalent dialysis patients age 0–19

8.21 Patients receiving iron during the year in prevalent dialysis patients

(Figures 8.15-16) period prevalent dialysis patients age 0–19 with at least one EPO claim during the prevalent year. Doses adjusted for inpatient days. For Hispanic patients we present data beginning in 1996, the first full year after the April 1995 introduction of the revised Medical Evidence form, which contains more specific questions on race & ethnicity. (Figure 8.17) prevalent dialysis patients who survive the year; values show the percent of patients with at least one carnitine lab test or levocarnitine claim during the year. HCPCS code J3955 is used for levocarnitine, & 82379 for the carnitine lab test. The code for carnitine testing was first used in 1999. (Figures 8.18–20) period prevalent dialysis patients age 0–19 & with EPO claims. The distribution of patients by hemoglobin group (sand diagrams) represents quarterly averages, while hemoglobin levels & EPO doses (line graphs) represent monthly averages. EPO doses in 2004 are not adjusted for inpatient hospital days. (Figure 8.21) prevalent hemodialysis & peritoneal dialysis patients who remain alive, on their current modality, & with Medicare as their primary payor for the entire calendar year.
Infectious complications

Among adult ESRD patients, the rate of infectious hospitalization is highest in patients on hemodialysis, and has been increasing steadily since the early 1990s (Figure 8.22). Pediatric patients on hemodialysis, in contrast, generally have the lowest rates of admission for infection, and children with transplants the highest.

Because of the small cohort size, hospitalization rates in the pediatric population are subject to wide variability. Admission rates for bacterial infections, however, are clearly far lower in pediatric patients (Figure 8.23). Since 1996, for example, rates for children on hemodialysis have been less than 45 per 1,000 patient years at risk, compared to 117–139 in the adult population.

In both the pediatric and adult populations, admission rates for urinary tract infections (UTI) are highest in patients with preemptive transplants, but rates are considerably higher in children (Figure 8.24). Since 1991, admissions for UTIs in pediatric patients average nearly 150 per 1,000 patient years at risk, compared to 67 among adults.

Given the variability in rates due to the small number of pediatric patients, admissions for infections related to an internal device do not differ widely between pediatric and adult patients (Figure 8.25).

In the late 1990s, peritonitis admissions for peritoneal dialysis patients were similar in adults and children (Figure 8.26). Since then, however, rates for children with this diagnosis have increased.

By the end of the first three years following initiation of ESRD therapy, 42 percent of children on hemodialysis are hospitalized for some kind of infection—lower than the 53 percent incidence seen in the...
In these first three years, more than one in five children treated with either hemodialysis or peritoneal dialysis is admitted for an infection related to an internal device. Rates of admission for a bacterial infection, however, are higher in patients on hemodialysis, reaching 10 percent by 36 months of followup.

Admissions for bacterial and viral infections reach 12.6 and 15.6 percent, respectively, in children with a transplant—greater than the rates of 7.2 and 10.6 percent occurring in the adult population.

(Figures 8.22–26) incident dialysis patients (in Figure 8.26, peritoneal dialysis only) & first-time, kidney-only transplant patients with Medicare as primary payor; unadjusted. Infectious hospitalizations represent inpatient claims with a principal diagnosis code for infection. (Figure 8.27) incident hemodialysis patients with Medicare as primary payor, 1991–2000 combined. (Figure 8.28) incident peritoneal dialysis patients with Medicare as primary payor, 1991–2000 combined. (Figure 8.29) first-time, kidney-only transplant patients with Medicare as primary payor, 1991–2000 combined.
interval analyses of hospital admissions and days in pediatric dialysis patients show that at month six the lowest rates occur in patients whose ESRD is caused by glomerulonephritis (Figure 8.30). Admission rates and hospital days are 42 and 36 percent higher, respectively, at month 30 than at month six, and at month 30 patients with cystic/hereditary/congenital diseases have the highest admission rates and spend the most time in the hospital.

Pediatric transplant patients have overall admission rates that are 40 percent lower than those of dialysis patients at six months, and their days in the hospital are approximately half those of the dialysis population (4.6 versus 8.9; Figure 8.31). Rates by primary diagnosis reveal that, during the early intervals, transplant patients with cystic/hereditary/congenital disease are most likely to be hospitalized, but as time with a functioning graft increases the highest admission rates occur in patients with glomerulonephritis.

Admission rates at month six are 21 percent higher for hemodialysis patients than for those on peritoneal dialysis, and this difference increases to 33 percent at month 30 (Figure 8.32). When compared to those of peritoneal dialysis patients, hospital days at month six are 12 percent higher and increase over the next two years, at which time the relative difference between the two populations is 56 percent.

Volatility in admission rates and hospital days throughout the study interval is high due to the small population size in these patients. Interpreted results should therefore be viewed with caution.

Five-year survival in pediatric patients has changed little since the early 1990s (Figure 8.33). Nearly 88 percent of all children beginning therapy in 1989–1993 survived five years, similar to the 89.3 percent of patients initiating in the 1994–1998 period. Survival remains highly dependent on modality: 81 percent of children starting on hemodialysis or peritoneal dialysis survive five years, compared to 92 percent of those beginning ESRD therapy with a renal transplant.
By primary diagnosis, pediatric patients with glomerulonephritis or with cystic/hereditary/congenital disease have the greatest probability of surviving five years. Survival probabilities for patients with secondary glomerulonephritis or vasculitis remain among the lowest, with 78 percent of those beginning on hemodialysis, and 73 percent of those starting on peritoneal dialysis, surviving five years after initiation.

The small size of the pediatric population means that mortality rates can be quite volatile. Interval analyses of mortality rates in children do show the same sharp fall between months six and twelve seen in the overall population (Figure 8.34). After one year, however, average rates do not rise steadily as they do in older patients, but tend to remain relatively stable.

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Adjusted cause-specific hospital admissions, by age

Adjusted cause-specific hospital admissions, by gender

Adjusted cause-specific hospital admissions, by race/ethnicity
Overall hospitalization rates in incident dialysis patients younger than 20 are highest in younger patients (those up to age 9) and, following month six, exceed those found in adult patients by 15–29 percent (Figure 8.35). For the cause-specific hospitalizations studied, admission rates at month six for infections are nearly twice as high in these younger patients compared to those age 10–19, and the same holds true after one year when comparing this younger age group to patients that are age 20 and older. These higher rates may be attributable to infections due to internal devices, namely peritoneal catheters, since these younger patients are more apt to be on peritoneal dialysis as their initial modality.

By gender, girls on average have higher hospitalization rates overall and for cardiovascular disease, infection, and other causes—approximately 25 percent higher than those found in boys (Figure 8.36).

Hospitalizations for all causes are 22–39 percent higher in black children compared to whites, Hispanics, and individuals of other races (Figure 8.37). Rates for cardiovascular disease in blacks are on average 57 percent higher than those found in whites and Hispanics, and admissions for infections are 28–42 percent higher than those found in all other racial and ethnic groups.

Mortality rates—both overall and for mortality due to cardiovascular disease, infection, or another cause—remain significantly lower in pediatric patients compared to their adult counterparts (Figure 8.38). Overall mortality in month 60, for example, reaches 148 deaths per 1,000 patient years for adult patients, compared to 41 in patients age 19 and younger. Rates for cardiovascular mortality are 75 and 8, respectively.

In the five years after day 90, rates tend to be slightly higher in the youngest children, and in girls compared to boys (Figure 8.39).

![Figure 8.35](image1.png)

**Figure 8.35** Adjusted cause-specific mortality, by age incident dialysis patients, 1997–2001 combined.

![Figure 8.36](image2.png)

**Figure 8.36** Adjusted cause-specific mortality, by gender incident dialysis patients, 1997–2001 combined.

![Figure 8.37](image3.png)

**Figure 8.37** Adjusted cause-specific mortality, by gender incident dialysis patients, 1997–2001 combined.
**Figure 8.3** Between May of 1995 and June of 2004, more than 4,000 children started therapy for ESRD caused by either primary or secondary glomerulonephritis, and another 3,200 began treatment for ESRD caused by cystic kidney disease.

**Figures 8.4–5** Pediatric patients with cystic kidney disease have the highest hemoglobin levels at initiation—9.9 g/dl, compared to 9.0 and 8.8 in patients with primary and secondary glomerulonephritis, respectively—and are also the most likely to receive EPO prior to starting therapy. **Figure 8.7** Forty-nine percent of children beginning therapy have an albumin less than the test’s lower limit.

**Figures 8.8–10** While vaccination rates in the pediatric population have increased over the past decade, they remain strikingly low.

**Figure 8.12** Catheters are used in 78 percent of patients age 12 and younger, but only 44 percent of those age 13 and above; in these latter patients, catheter and fistula use are nearly equal.

**Figure 8.16** Patients on peritoneal dialysis continue to receive considerably less EPO each week than their hemodialysis counterparts. **Figure 8.18** By June of 2004, more than three in four pediatric dialysis patients had a mean hemoglobin at or above the K/DOQI target of 11 g/dl. **Figure 8.20** Mean hemoglobin levels have undergone a dramatic correction and are now comparable to those found in adults, and black children have recently achieved parity with whites; in order to achieve these levels, however, they require more EPO.

**Figure 8.23** Since 1996, rates of hospitalization for bacterial infection in children on hemodialysis have been less than 45 per 1,000 patient years at risk, compared to 117–139 in the adult population. **Figure 8.27** By the end of the first three years following initiation of ESRD therapy, 42 percent of children on hemodialysis are hospitalized for some kind of infection—lower than the 53 percent incidence seen in the adult population. **Figures 8.27–28** In the first three years of therapy, more than one in five children treated with hemodialysis or peritoneal dialysis is admitted for an infection related to an internal device.

**Figure 8.31** Pediatric transplant patients have overall admission rates that are 40 percent lower than those of dialysis patients at six months, and their days in the hospital are approximately half those of the dialysis population. **Figure 8.33** Five-year survival in pediatric patients has changed little since the early 1990s. Nearly 88 percent of all children beginning therapy in 1989–1993 survived five years, similar to the 89.3 percent of patients initiating in the 1994–1998 period.

**Figure 8.37** Hospitalizations for all causes are 22–39 percent higher in black children compared to whites, Hispanics, and individuals of other races. **Figure 8.38** Mortality rates—both overall and for mortality due to cardiovascular disease, infection, or another cause—remain significantly lower in pediatric patients compared to their adult counterparts.