All night long their nets they threw
For the fish in the twinkling foam,
Then down from the sky came the wooden shoe,
Bringing the fishermen home;
’T was all so pretty a sail, it seemed
As if it could not be;
And some folk thought ’t was a dream
They’d dreamed
Of sailing that beautiful sea;
But I shall name you the fishermen three:
Wynken, Blynken, and Nod.

Eugene Field
“Dutch Lullaby”
Pediatric end-stage renal disease patients pose unique challenges to providers and to the healthcare system, which must address not only the disease itself in these patients, but the many extra-renal manifestations that affect their lives and their families. None is more evident than the growth of children with kidney disease. On the next page we show that 65 percent of children with ESRD have a growth rate in the lowest one-fifth of the general population, yet only 30 percent of these children receive recombinant human growth hormone (rhGH), a therapy approved by the FDA for this indication. It is unclear whether providers are paying attention to this area, or whether payment systems are biased against treatment.

Other elements of care in the pediatric ESRD population are also puzzling. Children with secondary glomerulonephritis, for example, have the lowest rates of ESA use prior to initiation of ESRD therapy, the lowest rates of pre-ESRD referral to nephrologists and kidney dietitians, the lowest glycosylated hemoglobin levels at initiation, and the highest triglyceride levels. One explanation for the lack of pre-ESRD care in children with secondary glomerulonephritis may be that sicker patients are referred later by their primary care physicians, after kidney failure has become clear. This issue requires considerable attention, particularly since overall survival in the pediatric population has not improved over the last ten years.

New to the chapter this year are data from the revised Medical Evidence form, assessing pre-ESRD nephrology referral and dietitian care, and the use of dialysis catheters. As in their adult counterparts, catheter use rates are high among children—higher, in fact, than they were five years ago. Because catheters are associated with infectious complications and morbidity, this is a major concern.

As also seen in the adult population, anemia treatment in children with ESRD continues to raise concern as well. Overshooting of target hemoglobin levels is as common here as in adults, placing children at risk of serious complications. Prolonged periods at high hemoglobin levels may compromise dialysis catheter accesses, leading to increased hospitalizations.

Influenza and pneumococcal pneumonia can also, of course, lead to increased hospitalization rates and higher risks of mortality. The low rates of vaccination against these diseases have improved, but still remain far below recommended levels. And there continue to be discrepancies in vaccination rates by modality, with hemodialysis patients more likely to be vaccinated than those on peritoneal dialysis or with a transplant.
As mentioned, there has been no progress in the five-year survival of pediatric ESRD patients. In some populations, in fact, the likelihood of survival declined slightly between the 1991–1995 and 1996–2000 periods. Children with a transplant continue to have the greatest chance of surviving five years, at 0.93 in 1996–2000, compared to 0.79 and 0.82 for hemodialysis and peritoneal dialysis patients, respectively.

Concluding this year’s chapter, we present new information on growth in the pediatric ESRD population, using data collected under the CMS ESRD Clinical Performance Measures (CPM) project. The median height of the ESRD population is at just the 6.7th percentile of that reported for the general population, yet only one in three children are treated with recombinant human growth hormone. And while growth disparities increase with time on dialysis, the prevalence of rhGH treatment is unchanged. Patients without Medicare as primary payor are less likely than those with primary Medicare coverage to receive rhGH.

Predictors of rhGH therapy show areas of concern. Non-white patients, for example, are less likely than white children to be treated, while those who see a pediatric nephrologist are 2.5 times more likely to receive therapy than those who do not. These findings suggest that children are not receiving access to recommended care, which is FDA-approved and is covered by most insurers. This area clearly needs further consideration, since children with kidney disease are already at a substantial disadvantage in terms of their growth and development.

The most striking findings related to pediatric patients center on the lack of improvement in patient survival over the past decade. This is a central concern, as it suggests that care of this population is insufficient. Members of the pediatric kidney disease community need to focus on developing new approaches in treating this most vulnerable population.

**Predictors of rhGH therapy**

- Non-white patients, less likely
- Pediatric nephrologist, more likely
- Without Medicare, less likely
- Area needs further consideration

**Growth in the pediatric ESRD population**

- Median height: 6.7th percentile
- One in three children treated with rhGH
- Growth disparities increase with time on dialysis
- Prevalence of rhGH treatment unchanged
- Patients without Medicare less likely
- Area needs further consideration

**Highlights**

- No progress in five-year survival among pediatric ESRD patients
- Non-white patients less likely
- Pediatric nephrologist more likely
- Area needs further consideration

**Illustration**

- Standard height quintiles in the U.S. general pediatric population
- Percent with prescription for rhGH
ESA use prior to initiation, by age, race, & primary diagnosis, 2005 incident ESRD patients age 0–19

Nephrologist care prior to initiation, by age, race, & primary diagnosis, 2005 incident ESRD patients age 0–19

Kidney dietitian care prior to initiation, by age, race, & primary diagnosis, 2005 incident ESRD patients age 0–19

HbA1c levels at initiation, by age, race, & primary diagnosis, 2005 incident ESRD patients age 0–19

Total cholesterol at initiation, by age, race, & primary diagnosis, 2005 incident ESRD patients age 0–19

Triglycerides at initiation, by age, race, & primary diagnosis, 2005 incident ESRD patients age 0–19
he revised Medical Evidence form, released in the spring of 2005, contains new fields on pre-ESRD care and biochemical markers.

In 2005, over 45 percent of patients 14 or younger received erythropoiesis stimulating agents (ESAs) before beginning therapy, compared to 30.2 percent of those age 15–19 (Figure 8.2). A higher proportion of white children receive ESAs than African Americans—41.9 versus 28.8 percent. And more than half of those with cystic kidney disease are given ESAs compared to 37.1 and 25.5 percent, respectively, of those with glomerulonephritis (GN) or secondary GN.

In 2005, children age 0–9 were the most likely to be under the care of a nephrologist prior to initiation (70 percent); by race, 63.2 percent of whites and 58.9 percent of African Americans received care (Figure 8.3).

Just over one-third of children age 14 and younger have a renal dietitian prior to starting therapy (Figure 8.4). This type of care, too, is given to a greater proportion of white children than of African Americans—34 versus 26 percent. And 49 percent of children with cystic kidney disease receive dietary care compared to 34.3 and 14.4 percent, respectively, with GN or secondary GN.

Glycosylated hemoglobin (HbA1c) levels are similar across all pediatric age groups, ranging from 5.4 to 5.7 percent, and are higher in African Americans than in whites—6.0 versus 5.4 percent (Figure 8.5). By diagnosis, children with secondary GN have the lowest HbA1c levels, at 4.2 compared to 5.8 and 4.7 percent in those with GN or cystic kidney disease.

With the exception of children with GN, total cholesterol levels are normal to slightly above normal in all age, race, and diagnosis groups (Figure 8.6). The mean level in children with GN is 247 mg/dl—33 and 80 mg/dl higher compared to those with secondary GN or cystic kidney disease.

In 2005, the mean triglyceride level in children age 0–9 was 253 mg/dl—25 and 61 mg/dl higher, respectively, than for ages 10–14 and 15–19 (Figure 8.7). By race, individuals of “other” race have the highest mean levels, at 310.5 mg/dl, approximately 100 mg/dl higher than those found in whites and African Americans. Children with secondary GN have levels of 296 mg/dl, compared to 237 and 191 mg/dl in those with GN or cystic kidney disease.

Among patients age 14 and younger, counts of those with GN increased approximately 26 percent between 1996–2000 and 2001–2005; for those age 15–19, counts increased by 13.6 percent (Figure 8.8). For children with secondary GN, growth in patients counts of 13–15 percent between periods was evident for those age 0–9, and a larger rise of 50–59 percent in those age 10–19. For patients with cystic kidney disease, the population age 15–19 grew 57 percent, compared to 40, 35, and 36.5 percent, respectively, for ages 0–4, 5–9, and 10–14.

Overall, 34.5 percent of children received an ESA prior to initiation during 1996–2000; this rose to 39.1 percent during 2001–2005 (Figure 8.9). Mean hemoglobin levels have grown from 9.1 to 9.7 g/dl overall, and children with cystic kidney disease have the highest level, though it is still well below the 11–12 g/dl K/DOQI target (Figure 8.10).

The mean eGFR increased from 10.0 to 11.1 ml/min/1.73 m² overall in 2005, with increases from 9.3 to 10.5, 11.3 to 12.3, and 10.7 to 11.8, respectively, in patients with GN, secondary GN, and cystic kidney disease (Figure 8.11).

Body mass indices at initiation were highest in African Americans, at 24.1 kg/m² in 2006 compared to 22.2 and 21.1 in whites and individuals of other races, respectively (Figure 8.12).
8.13 Incident & prevalent counts, by modality ESRD patients age 0–19

8.14 Incident & prevalent rates, by modality ESRD patients age 0–19

8.15 Prevalent patient distribution, by modality prevalent ESRD patients age 0–19

8.16 Patients informed at initiation of transplant options, by age, race, & primary diagnosis incident ESRD patients age 0–19

8.17 Time to first transplant, by age & race incident ESRD patients age 0–19
M

odality choices for the incident pediatric population have changed dramatically since 1978 (Figure 8.13). The number of children placed on peritoneal dialysis, for example, rose from 52 in 1980 to 314 in 1990, while transplant counts in 1990 were nearly three times higher than in 1980, at 175 versus 60. Peritoneal dialysis and transplant counts continue to rise, and since 1990 have increased 28 and 34 percent, respectively. These increases are reflected in the prevalent population—In 2005 the number of children with a transplant was 5,104, four times higher than the number on hemodialysis.

Between 1995 and 2005, incident and prevalent rates rose 7 and 9 percent for hemodialysis, and fell 8 and 5 percent for peritoneal dialysis (Figure 8.14). The transplant rate fell 3.9 percent in incident patients, but grew 24 percent among prevalent patients. Among pediatric ESRD patients prevalent in 2005, the percentage of patients on peritoneal dialysis at 18 and 24 months was slightly higher than in 2000, but this difference disappeared in later months.

In 2005, 71–75 percent of pediatric patients were informed of their transplant options prior to initiating ESRD therapy (Figure 8.16). By race, 71 percent of whites received information, compared to 82 percent of African Americans. Children with a primary diagnosis of glomerulonephritis are the most likely to be informed, at 82 percent.

Time to first transplant appears to be increasing. During 1996–2000, 75 percent of children age ten or younger and 90.3 percent of those older than ten received a transplant within five years of initiation; during 2001–2005, the numbers fell to 70 and 79 percent, respectively (Figure 8.17).

Children under a nephrologist’s care prior to ESRD are far less likely to start hemodialysis with a catheter compared to those without such care, at 38.5 versus 70 percent (Figure 8.18). The proportion with catheters increases with age, from 30.4 percent in patients age 0–9 to 64.1 percent in those age 15–19.

The proportion of pediatric patients using catheters grew by 10 percent between 1999–2001 and 2002–2004, while infectious event rates increased by 27 percent; fistulas and graft infectious event rates were approximately 60 percent lower. At six months post-initiation, only 5 percent of patients with a fistula suffer an access infection compared to 36 percent of those with a catheter (Figures 8.19–21).
anemia & overshooting of target hemoglobin levels

**8.22** Patient distribution by mean quarterly hemoglobin (g/dl), & trends in mean monthly hemoglobin & weekly EPO dose period prevalent dialysis patients age 0–19

**8.23** Patient distribution by mean quarterly hemoglobin (g/dl) & age period prevalent dialysis patients

**8.24** Mean monthly hemoglobin & weekly EPO dose, by age period prevalent dialysis patients

**8.25** Patients receiving IV iron, by age, gender, & modality period prevalent dialysis patients
emoglobin levels in children have improved since 1991, and in 2005 more than 75 percent had a mean quarterly hemoglobin meeting or exceeding the K/DOQI target of 11–12 g/dl (Figure 8.22). This increase is certainly a significant achievement, but also demonstrates that additional efforts are needed in order to approach 100 percent K/DOQI compliance.

The rise in hemoglobin is attributable to a major rise in mean weekly EPO dose over time. In January, 1991, for instance, the mean dose was 5,517 units per week. This rose to 11,705 units at the end of 1995, and, as of December, 2005, was 16,628 units—more than a three-fold increase over the entire period.

Levels of hemoglobin differ across pediatric age groups and when compared to adult levels (Figure 8.23). At the end of 2005, 70.0 percent of children age ten and younger met or exceeded the K/DOQI target, compared to 76 and 85 percent, respectively, of those age 10–19 and adults age 20 and older (Figures 10.23–24). One item of interest is the overall trend of EPO dose versus actual hemoglobin level over time. The average dose in children age 10 and younger, for instance, has historically been lower than the doses used in children age 10–19 and in adults. This is in part related to size, but it is associated with a slower rise in hemoglobin levels toward the K/DOQI target. Once achieved, however, it appears that the target hemoglobin is maintained with less EPO in this younger group, as evidenced by a 7 percent decrease in weekly EPO dose since 2000 compared to 11 and 24 percent growth in children age 10–19 and adults 20 and older.

In the pediatric population, older children are more likely to receive iron during the year. In 2005, nearly 80 percent of children age 15–19 were given iron compared to 65.4, 70.3, and 92.0 percent, respectively, of children age 0–9, those age 10–14, and adults (Figure 8.25). Slightly more males than females receive iron—79.2 versus 74.4 percent—and the proportion of children on hemodialysis receiving iron is much higher than in those on peritoneal dialysis, at 77.1 and 17.8 percent, respectively.

Figures 8.26–28 show that overshooting of hemoglobin levels in children is comparable to that reported in adults. While the absolute levels are slightly lower—children tend to achieve lower hemoglobin levels than adults—overshooting is clearly present, and the time exceeding a target of 12 g/dl is similar to that found in adults.

**Figure 8.22–24:** Period prevalent dialysis patients (in Figure 8.22, age 0–19) with EPO claims. Sand diagrams: distribution of patients by hemoglobin group represents quarterly averages; line graphs: hemoglobin levels represent monthly averages, & EPO doses represent monthly averages of weekly doses. EPO doses are adjusted for inpatient hospital days. **Figure 8.25:** Period prevalent dialysis patients who remain alive, on their current modality, & with Medicare as primary payor for the entire calendar year. **Figure 8.26** dialysis patients, age 0–19, incident between July 1, 2001, & June 30, 2005, with Medicare as primary payor, receiving EPO during the first six months after day 91, & achieving a hemoglobin of 11+ g/dl during that period; probabilities calculated using Kaplan-Meier method. **Figure 8.27** point prevalent dialysis patients, age 0–19, 2005, with Medicare as primary payor, & receiving EPO in each of the first six months after January 1, 2005; **Figure 8.28** dialysis patients, age 0–19, incident between July 1, 2001, & June 30, 2005, with Medicare as primary payor, & receiving EPO during the first six months after day 91.
accinations against influenza in pediatric ESRD patients increased noticeably between the 1998–2001 and 2002–2005 periods (Figure 8.29). In whites, for example, the proportion of patients receiving the vaccine rose from 18.2 percent in the early period to 30.1 percent in the latter period. A similar increase—from 17.8 to 28.4 percent—was evident for African Americans. Pediatric patients on hemodialysis are more likely than peritoneal dialysis or transplant patients to be vaccinated, regardless of race. During 2002–2005, 37.5 percent of white hemodialysis patients were vaccinated compared to 32.5 percent of peritoneal patients and 24.6 percent of those with a functioning graft. Among African Americans, 33.1 percent of hemodialysis patients received a vaccination, compared to 27.9 and 22.1 percent.

The proportion of pediatric ESRD patients who receive pneumococcal pneumonia vaccinations has increased, but continues to remain alarmingly low (Figure 8.30). In the latter study period of 2002–2003 and 2004–2005, for instance, only 7.8 percent of white patients and 7.6 percent of African American patients received a vaccination. By modality, those on hemodialysis are the most likely to be vaccinated against pneumonia, at 11.4 and 9.9 percent of white and African American patients, respectively. In the peritoneal dialysis population these numbers fall to 10.3 and 8.2 percent, and in the transplant population they are even lower, at 4.1 and 3.8 percent.

Between 1998–2001 and 2002–2005, vaccinations against hepatitis B in the pediatric ESRD population grew only slightly (Figure 8.31). Overall, only 6.9 percent of white patients, and 9.0 percent of African Americans, were vaccinated in the latter period. By modality, hemodialysis patients are again more likely to be vaccinated than their counterparts on peritoneal dialysis or with a functioning graft. In 2002–2005, 15.9 percent of white children on hemodialysis received the vaccine compared to 8.3 and 1.8 percent, respectively, of those on peritoneal dialysis or with a transplant. And among African Americans, 15.2 percent of those on hemodialysis are vaccinated, compared to 7.3 and 2.3 percent.
Lipid testing increased across races and modalities between the 1998–2001 and 2002–2005 study periods (Figure 8.32). In the latter period, 56.2 percent of white pediatric patients were tested compared to 48.6 percent of African Americans. In contrast to vaccination rates, rates of lipid testing are highest among children with a functioning graft, at 61.2 and 57.1 percent, respectively, in the white and African American populations. Among patients on hemodialysis, rates are 49.7 and 44.9 percent; and they are 52.1 and 42.1 percent for children treated with peritoneal dialysis.

Between the 1995–1998 and 1999–2002 periods, the cumulative incidence of infectious hospitalizations at 36 months after ESRD initiation increased in both children and adults (Figure 8.33). In the earlier period, 45.2 percent of children and 53.7 percent of adults were hospitalized for any infection, compared to 52.8 and 56.2 percent, respectively, in the later years. Children and adults on peritoneal dialysis are most likely to be hospitalized—58.6 and 56.5 percent, respectively, in the most recent period—compared to 49.9 and 56.3 percent of those on hemodialysis, and to 44.8 and 41.0 percent of patients with a transplant. The incidence of hospitalization for pneumonia, while low in both populations, increased slightly in pediatric patients but was virtually unchanged in adults.

Between study periods, the cumulative incidence of hospitalization for an infection due to internal device grew from 21.0 to 31.3 percent in children and from 18.6 to 23.7 percent in adults. By modality, an increase from 22.2 to 30.4 percent occurred in children on hemodialysis, and from 18.6 to 23.5 percent in their adult counterparts. In the peritoneal dialysis population, growth was 19.3–34.3 percent in children and 20.2–29.3 percent in adults.

Figure 8.29: point prevalent ESRD pts, 1998–2005, age 0–19 prior to January 1 of each year, & initiating therapy 90 days prior to September 1 & living through December 31 of each year; includes only pts with Medicare inpatient/outpatient & physician/supplier primary payor coverage. Vaccinations tracked between September 1 & December 31. Figure 8.30: point prevalent ESRD pts with 90-day rule, age 0–19 prior to January 1 of the first year of the two-year study period, & living through December 31 of the second year; includes only pts with inpatient/outpatient & physician/supplier primary payor coverage during the entire period. Vaccinations tracked in each study period. Age calculated at end of second year. Figure 8.31-32: point prevalent ESRD pts, 1998–2005, with 90-day rule, age 0–19 prior to January 1 & living through December 31 of each year; includes only pts with inpatient/outpatient & physician/supplier primary payor coverage during each year. Vaccinations & lipid testing tracked in each year. Figure 8.33: incident dialysis & first-time, kidney-only transplant pts with Medicare as primary payor, 1995–2002 combined.
little change occurred between 1993 and 2005 in the rate of hospital admissions for children on dialysis (Figure 8.34). Rates overall increased less than 1 percent, with only slight changes of 2.33, -0.93, and 1.34 percent, respectively for primary diagnoses of glomerulonephritis (GN), cystic/hereditary disease, and other diagnoses. Hospital days have fallen 11 percent overall, and 17.1 and 21.7 percent in children with GN or cystic/hereditary disease.

In contrast to admissions in dialysis patients, those for transplant patients grew 10 percent overall (Figure 8.35). The largest increase occurred in patients with GN, at 15.4 percent compared to 10.6 and 6.7 percent, respectively, in those with cystic/hereditary disease or another diagnosis. Hospital days per patient year have decreased nearly 4 percent overall, with the largest change of 9.2 percent occurring in children with cystic/hereditary disease. Rates have increased by nearly 3 percent in children with GN.

By modality, admission rates for hemodialysis and peritoneal dialysis patients are similar, at 2.03 and 1.95 per patient year in 2005 (Figure 8.36). Hospital days overall have fallen by 11.1 percent since 1993, with decreases of 13.3 and 7.7 percent, respectively, in the hemodialysis and peritoneal dialysis populations.

No progress has been made in five-year survival among pediatric ESRD patients (Figure 8.37). Indeed, in some populations, the probability of a child surviving the first five years of therapy fell slightly between the 1991–1995 and 1996–2000 periods. Patients with a transplant continue to have the highest survival probabilities—0.93 in the latter period, compared to 0.78 and 0.82 for those treated with hemodialysis and peritoneal dialysis.

By primary diagnosis, pediatric dialysis patients with glomerulonephritis continue to have the best outcomes, with a five-year survival probability of 0.86 on hemodialysis and 0.89 on peritoneal dialysis. Probabilities are among the lowest for children with secondary glomerulonephritis or vasculitis, at 0.77 and 0.75, respectively.

Since 1991, adjusted mortality rates in prevalent pediatric patients have increased 5 percent, to 26.6 per million population in 2005 (Figure 8.38). Rates are highest for hemodialysis and peritoneal dialysis patients, at 57.8 and 42.8, respectively. In the transplant population, mortality rates are three- to four-fold lower than for the two dialysis modalities, demonstrating the advantages of this mode of ESRD therapy.

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**Adjusted hospital admissions & days**

**Admissions per patient year at risk**

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<th>Year</th>
<th>Glomerulonephritis</th>
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**Hospital days per patient year at risk**

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**Admissions per patient year at risk**

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**Figures 8.34–8.36** Period prevalent ESRD patients. ESRD patients age 0–19, 2001, used as reference cohort. **Figures 8.34–35** adjusted for gender & race; “all” group also adjusted for primary diagnosis. **Figure 8.36** adjusted for gender, race, & primary diagnosis. “All” group includes patients with unknown dialysis & those who switch modalities, while hemodialysis & peritoneal dialysis groups are censored at modality change. **Figure 8.37** incident ESRD patients, age 0–19. All probabilities are adjusted for age, gender, & race; overall probabilities are also adjusted for primary diagnosis. ESRD patients age 0–19, 1996–1997 combined, used as reference cohort. Dialysis patients are followed from day 90 after initiation; transplant patients are followed from the transplant date. **Figure 8.38** period prevalent ESRD patients, age 0–19; adjusted for age, gender, & race. ESRD patients age 0–19, 2001, used as reference cohort.
8.37 Adjusted five-year survival, by modality & primary diagnosis incident ESRD patients age 0–19

8.38 Adjusted mortality, by modality period prevalent ESRD patients age 0–19

Abnormalities specific hospital admissions

by age period prevalent dialysis patients
by gender period prevalent dialysis patients age 0–19
by race/ethnicity period prevalent dialysis patients age 0–19
In comparison to those of adults, all-cause hospital admission rates in 2005 were 14 percent higher in children—at 2.0 versus 1.8 per patient year at risk (Figure 8.39). By age, admissions are highest in children age 0–9, at 2.9 compared to 1.9 for ages 10–19. Cardiovascular admissions are 13.5 percent lower in children than in adults, but admissions across age groups are on the rise. And hospitalizations for infection are noticeably higher in children than adults—46 percent in 2005.

Overall admissions in pediatric patients fell 2.9 percent in males between 1993 and 2005, and grew 4.9 percent in females (Figure 8.40). Cardiovascular admissions have changed in both boys and girls, with growth of 53.6 and 64.4 percent, respectively—a somewhat alarming development given the age of these patients. In 2005, admission rates in all categories were lower in males compared to females, by 13.6, 17.4, 14.4, and 11.5 percent for all-cause admissions and those related to cardiovascular disease, infection, and other causes, respectively.

By race and ethnicity, all-cause admissions increased 5.7 percent in white pediatric patients between 1993 and 2005, and 2.6 percent in Hispanics; rates fell, in contrast, 3.1 percent in African Americans and 32 percent in patients of other races (Figure 8.41). Admissions for cardiovascular disease show a 75 percent increase in white patients, compared to 35.7 percent in African Americans. Admissions for infections rose the most in Hispanic patients, compared to 35.7 percent in patients of other races (Figure 8.41). Differences in cause-specific rates are apparent as well. The 2005 rate of cardiovascular mortality among white pediatric patients fell 2.9 percent in males compared to females, by 13.6, 17.4, 14.4, and 11.5 percent for all-cause admissions and those related to cardiovascular disease, infection, and other causes, respectively.

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All-cause and cause-specific mortality rates by age are noticeably similar across pediatric age groups, but differ significantly from those in the adult population (Figure 8.42). In 2005, for example, the mortality rate for all causes was 55.3 per 1,000 patient years in children, compared to 226.6 in adults—a fourfold difference. Differences in cause-specific rates are apparent as well. The 2005 rate of cardiovascular mortality was 23.4 among children and 101.1 among adults; rates of infectious mortality were 8.5 and 29.9, respectively. Cardiovascular mortality among pediatric patients, moreover, has been rising, from 17.7 deaths per 1,000 patient years at risk in 1991 to 23.4 in 2005.

Girls tend to have higher mortality rates than boys—in 2005, 28 percent overall, 20 percent for cardiovascular mortality, and 32 percent for infectious mortality (Figure 8.43).

More on hospitalization & mortality: p.20–25, Emerging Issues chapter, Chapter Six, 8.34–38 (previous page).
is not surprising that U.S. pediatric hemodialysis patients are of significantly shorter stature when compared to the general U.S. pediatric population (Figure 8.44). This phenomenon is relatively consistent across demographic groups, and is most prominent in patients who have been on dialysis for a longer period of time (Figures 8.45–47). Overall, 37.2 percent of pediatric hemodialysis patients are more than two standard deviations below the standardized mean for their age, gender, or race/ethnicity group. Of these, only 14.6 percent receive a prescription for recombinant human growth hormone (rhGH). More males than females fall below the standardized height—39.0 versus 34.9 percent—and of these 16.1 and 12.6 percent, respectively, are prescribed rhGH. By race/ethnicity, 45.7 percent of Hispanics fall below the standardized mean height, and 19.6 percent of these receive rhGH. In whites and African Americans, prescriptions are provided to 19.7 of 39.4 percent and only 8.9 of 34.7 percent, respectively.

Thirty-five percent of children below the standardized mean height have a diagnosis of cystic kidney disease, and only 4.3 percent of these children are prescribed rhGH. And of the nearly 39 percent with other congenital complications, 19.5 percent receive a prescription, as do 14.9 of 29.9 percent with glomerulonephritis and 12.8 of 33.7 percent diagnosed with focal glomerulonephritis.

Children who have been on hemodialysis four or more years are the most likely to fall below the standardized mean height compared to those on the therapy for less than one year or for 1–3 years—58.2 versus 21.9 and 37.5 percent, respectively—and, of these, 27.9, 6.7, and 13.0 percent, respectively, are given a prescription for rhGH. Nearly 41 percent of children with hemoglobins less than 11 g/dl are more than two standard deviations below the standardized mean height, and 15.4 percent of these patients received a prescription for rhGH (Figure 8.48). Comparatively, 34.6 percent of those with hemoglobin of 11–<12 g/dl and 35.8 percent with hemoglobins of 12 g/dl and above are below the standardized mean height, and 14.2 and 13.6 percent, respectively, are prescribed rhGH.

Urea reduction ratios (URR) below 65 percent indicate inadequate dialysis therapy. Of children with substandard URRs, nearly 26 percent are more than two standard deviations below the standardized mean height, with 12 percent receiving an rhGH prescription (Figure 8.49). In those with URRs of 65 percent or greater, 39.3 percent are below standard height and 15.1 percent are prescribed rhGH.
Albumin levels do not appear to be associated with height differences (Figure 8.50). In children with albumins below the test’s lower limit of normal, 38.8 percent are below the mean standardized height compared to 36.8 percent of those with normal albumin levels. Of these, 11.1 and 15.3 percent, respectively, have a prescription for rhGH.

Low levels of calcium/phosphorous products appear to be most highly associated with abnormal height in children. In those with a level below 30.8, for example, 76.9 percent fall more than two standard deviations below the standardized mean height, and of these 19.2 percent receive a prescription for rhGH. In patients with calcium/phosphorous products of 30.8–53.4 and 53.4 or greater, percentages with a prescription for rhGH are significantly lower for younger, white patients with longer vintage and who are under the care of a pediatric nephrologist.

Table 8.a shows that, among children who are two or more standard deviations below the standardized mean height, the adjusted odds of having a prescription for rhGH are significantly higher for younger, white patients with longer vintage and who are under the care of a pediatric nephrologist.

Odds ratio of receiving a prescription for recombinant human growth hormone hemodialysis patients age 0–19; ESRD CPM data

Reference groups: age 15–19, male, white, cystic kidney disease/other/unknown, adult nephrologist, non-Medicare primary payor, hemoglobin <11 g/dl, Kt/V ≤1.2, URR <65%, albumin <LL, PTH/calcium/phosphorus out of range.

8.51 Bone & mineral values in children more than two SD below standardized height hemodialysis patients age 0–19; ESRD CPM data

8.44–7 & table 8.a, ESRD CPM data, 2002. Heights standardized by age & gender using a CDC method & based on CDC 2000 growth charts. Figures 8.44–51 & Table 8.a include patients with a standardized height > two standard deviations below the mean. Biochemical data & information in rhGH prescriptions obtained from 2002 CPM supplement. Percentage with an rhGH prescription based on patients below the standardized height. Insurance status in Figure 8.47 obtained for patients also in the USRDS database. “MPP” refers to Medicare Primary Payor. *cystic/ hereditary/congenital disease.
patient characteristics at initiation

In 2005, over 45 percent of patients 14 or younger received erythropoiesis stimulating agents before beginning therapy, compared to 30.2 percent of those age 15–19. Among patients age 14 and younger, counts of those with glomerulonephritis increased approximately 25 percent between 1996–2000 and 2001–2005; for those age 15–19, counts rose 13.6 percent.

modality

Between 1995 and 2005, incident and prevalent rates in the pediatric ESRD population rose 7 and 9 percent, respectively, for hemodialysis, and fell 8 and 5 percent for peritoneal dialysis. The transplant rate fell a slight 3.9 percent in the incident population, but grew 24 percent among prevalent patients. In 2005, 71–75 percent of pediatric patients were informed of their transplant options prior to initiating ESRD therapy. By race, 71 percent of whites received information, compared to 82 percent of African Americans. Time to first transplant appears to be increasing. During 1996–2000, 75 percent of children age 10 or younger and 90.3 percent over 10 received a transplant within five years of initiation; during 2001–2005, these numbers fell to 70 and 79 percent.

vascular access

Children under a nephrologist’s care prior to ESRD are far less likely to start hemodialysis with a catheter compared to those without such care, at 38.5 versus 70 percent. Catheter use in pediatric patients grew 10 percent between 1999–2001 and 2002–2004, while infection rates for fistulas and grafts were 60 percent lower and 27 percent higher, respectively, than in those with catheters. At six months post-initiation, only 5 percent of pediatric patients with a fistula suffered an access infection compared to 36 percent of those with a catheter.

anemia & overshooting of target hemoglobin levels

Hemoglobin levels in children have improved since 1991, and in 2005 more than 75 percent had a hemoglobin meeting or exceeding the K/DOQI target of 11–12 g/dl. In the pediatric population, older children are more likely to receive iron during the year. In 2005, nearly 80 percent of children age 15–19 were given iron compared to 65.4, 70.3, and 92.0 percent, respectively, of children age 0–9, those age 10–14, and adults. Overshooting of hemoglobin levels in children is comparable to that reported in adults. While the absolute levels are slightly lower—children tend to achieve lower hemoglobin levels than adults—overshooting is clearly present, and the time exceeding a target of 12 g/dl is similar to that found in adults.

preventive care


infectious complications

Between the 1995–1998 and 1999–2002 time periods, the cumulative incidence of infectious hospitalizations at 36 months after ESRD initiation increased in both children and adults.

overall hospitalization & mortality

Little change occurred between 1993 and 2005 in the rate of hospital admissions for children on dialysis. Rates overall increased less than 1 percent, with only slight changes of 2.33, -0.93, and 1.34 percent, respectively, for primary diagnoses of glomerulonephritis, cystic/hereditary disease, and other diagnoses. No progress has been made in five-year survival among pediatric ESRD patients. Since 1991, adjusted mortality rates in pediatric patients have increased 5 percent, to 26.6 per million population in 2005.

cause-specific hospitalization & mortality

When compared to those of adults, all-cause hospital admission rates were 14 percent higher in children in 2005—at 2.01 versus 1.76 per patient year at risk. Admissions for cardiovascular disease increased 53.6 percent in boys and 64.4 percent in girls between 1993 and 2005, a somewhat alarming development because of the age of these individuals. Girls tend to have higher mortality rates than boys—in 2005, 28 percent overall, 30 percent for cardiovascular mortality, and 52 percent for infectious mortality.

growth & development

A high percentage of pediatric hemodialysis patients have short stature. Less than 15 percent of these patients, however, are receiving recombinant human growth hormone (rHGH). Pediatric hemodialysis patients are more likely to receive rHGH if they are younger, white, with a longer ESRD vintage, or are under the care of a pediatric nephrologist.