Chapter 7: ESRD among Children, Adolescents, and Young Adults

- The one-year end-stage renal disease (ESRD) patient mortality among the 0-4 year age group has declined approximately 41.6% over the past decade. (Figure 7.8). The transplantation rate did not account for changes during this time.

- The number of children and adolescents beginning ESRD care is steadily decreasing from a high of 17.5 per million in 2004 to 13.7 per million population in 2015, representing a decrease of 21.7% (Figure 7.1.a).

- As of December 31, 2015, the point prevalence of children and adolescents, 0 to 21 years of age, with ESRD was 9,672, or 99.5 per million population (Figure 7.1.b). An additional, 10,251 adult survivors of childhood onset ESRD contributed to the 2015 point prevalence of ESRD in adults.

- During 2011-2015, the proportion of missing, unknown, and unspecified etiologies of incident ESRD patients was particularly high among the 18-21 age group (27%; Table 7.2).

  Short stature is common in children and adolescents with incident ESRD; this affects the majority of the youngest patients between the ages of 0 and 4 years (52.7%).

---

**Introduction**

End-stage renal disease (ESRD) affects children of all ages. The majority of these children will depend on renal replacement therapies (RRT) over many decades. Consequently, children with ESRD often traverse the entire modality spectrum of hemodialysis (HD), peritoneal dialysis (PD), and transplantation. These children are at risk for growth failure, frequent hospitalizations, and significantly higher mortality than the general pediatric population. This chapter includes an evaluation of growth parameters in children with ESRD.

Children with ESRD are quite different in disease etiology, transplant opportunities, morbidity, and mortality than adults with ESRD. Consequently, this chapter of the Annual Data Report (ADR) focuses on pediatric ESRD. Additionally, we include a section on young adults in order to improve our understanding of the issues surrounding transitions and outcomes in this distinct population, wherein etiology and comorbidities are often more aligned with adolescents than older adults.

**Methods**

The findings presented in this chapter were drawn from multiple data sources, including from the Centers for Medicare & Medicaid Services (CMS), the Organ Procurement and Transplantation Network (OPTN), the Centers for Disease Control and Prevention (CDC), and the U.S. Census. Details of these are described in the Data Sources section of the ESRD Analytical Methods chapter.

See the section on Chapter 7 in the Analytical Methods Used in the ESRD Volume section of the ESRD Analytical Methods chapter for an explanation of the analytical methods used to generate the study cohorts, figures, and tables in this chapter.

Downloadable Microsoft Excel and PowerPoint files containing the data and graphics for these figures and tables are available on the USRDS website.

In this 2017 pediatric chapter, we align etiology classification with typical pediatric classifications, and report new results regarding growth status of children with ESRD. However, there are limitations in the reporting of trends in children 0 to 2 years old due to
the small total number of patients in this age group. These limitations drive the requirement to use larger age groupings for much of the chapter.

**Epidemiology of End-stage Renal Disease in Children**

The number of children and adolescents beginning ESRD care is steadily decreasing from a high of 17.5 per million population (PMP) in 2004 to 13.7 PMP in 2015—a decline of 21.7% (Figure 7.1.a). In 2015, the number and rate of these incident cases varied by age group; there were 211 cases in those aged 0-4 years, 117 aged 5-9, 163 aged 10-13, 336 aged 14-17, and 548 aged 18-21 years, for a total of 1,375 children with incident ESRD. Within these age-based cohorts, incidence rates in 2015 were 9.3 PMP per year for 0-4 year olds, 4.8 for 5-9 year olds, 8.6 for 10-13 year olds, 18.4 for those aged 14-17 years, and 29.8 PMP aged 18-21 years.

As of December 31, 2015, the point prevalence count of children, 0 to 21 years of age, with ESRD was 9,672, or 99.5 PMP (Figure 7.1.b). Overall, the prevalence of ESRD in children in the U.S. has been generally stable for the most recent decade.

**Incidence and Prevalence by ESRD Modality**

Over time, children have consistently initiated ESRD therapy with HD more frequently than PD or transplantation. Data from 2015 demonstrated this pattern, with 714 (51.9%) initiating with HD, 366 (26.6%) with PD, and 293 (21.3%) with transplant. This equates to an incidence rate of 7.5 with HD, 3.8 with PD, and 2.4 with transplant, PMP per year in 2015.

When examined by age, PD was the most common initial ESRD treatment modality for children aged 9 years and younger (Figure 7.2.a). Hemodialysis has become the most common initial modality for patients aged 10 years and older. Similar relationships are shown by patient weight, with PD most commonly prescribed as the initial modality in small children weighing less than 20 kilograms (kg), and initiation with HD becoming more common with increasing patient weight (Figure 7.2.b).

The modality at initiation varied greatly by race, with HD most commonly reported for those of African American/Black race (71.1%) compared to White (50.1%) and those of Other (43.0%) races (Figure 7.2.c). Kidney transplantation accounted for less than 40% of initial modality across all pediatric ages and weights, but was the predominant prevalent ESRD treatment modality used in children (Figure 7.1.b). Of the 9,672 children and adolescents under 22 years of age with prevalent ESRD as of December 31, 2015, kidney transplant was the most common ESRD modality (6,910, 71.4%), followed by HD (1,730, 17.9%) and PD (1,004, 10.4%). This equates to a point prevalence PMP children of 18.2 for HD, 10.6 for PD, and 70.4 for transplant.
vol 2 Figure 7.1 (a) Incidence and, (b) December 31st point prevalence of ESRD among pediatric patients (aged 0–21 years), by modality, 1996-2015

(a) Incidence

(b) Point prevalence

Data Source: Special analyses, USRDS ESRD Database. Peritoneal dialysis consists of continuous ambulatory peritoneal dialysis and continuous cycling peritoneal dialysis. All consists of hemodialysis, peritoneal dialysis, uncertain dialysis, and transplant. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
vol 2 Figure 7.2 Cross-sectional trends in pediatric ESRD modality at initiation, by patient (a) age, (b) weight, and (c) race, 1996-2015

Figure 7.2 continued on next page.
Figure 7.2 Cross-sectional trends in pediatric ESRD modality at initiation, by patient (a) age, (b) weight, and (c) race, 1996-2015 (continued)

(c) Race

Data Source: Special analyses, USRDS ESRD Database. Includes incident ESRD patients in 1996-2015. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Etiology

The leading causes of ESRD in children during 2011-2015 were CAKUT (congenital anomalies of the kidney and urinary tract; 22%), primary glomerular disease (21.8%), cystic/hereditary/congenital disorders (12.5%), and secondary glomerular disease/vasculitis (10.7%). The most common individual diagnoses associated with pediatric ESRD included focal glomerulosclerosis (849, 11.6%), renal hypoplasia/dysplasia (737, 10%), congenital obstructive uropathies (712, 9.7%), and systemic lupus erythematosus (462, 6.3%).

Figure 7.3 shows the distribution of the most common causes of ESRD by age and by year of onset of ESRD. CAKUT and congenital/hereditary/cystic disorders caused more ESRD in young children; primary and secondary glomerulonephritis and other etiologies became more common with advancing age. The distribution of ESRD etiology by age and year of onset of ESRD were consistent between incident years 2006-2010 and 2011-2015. The unspecified, uncertain, and missing reported ESRD etiologies accounted for over 1000 incident cases between 2011 and 2015 (20.6%) and represent an area for future quality improvement initiatives (Tables 7.1 and 7.2).
Figure 7.3 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD, by age in (a) 2006-2010 and (b) 2011-2015

(a) 2006-2010 (period A)

(b) 2011-2015 (period B)

Data Source: Special analyses, USRDS ESRD Database. Abbreviations: CAKUT, congenital anomalies of the kidney and urinary tract; C/H/C, cystic/hereditary/congenital diseases; ESRD, end-stage renal disease; GN, glomerulonephritis
### Table 7.1 Distribution of reported incident pediatric ESRD patients by primary cause of ESRD (aged 0-21 years), and by demographic characteristics

(a) 2006-2010 (period A)

<table>
<thead>
<tr>
<th>Primary Disease Groups</th>
<th>Total Patients</th>
<th>Percent Incidence</th>
<th>Median Age</th>
<th>Percent Males</th>
<th>Percent White</th>
<th>Percent Black/African American</th>
<th>Percent Other Race</th>
</tr>
</thead>
<tbody>
<tr>
<td>All ESRD, (reference)</td>
<td>8221 7340</td>
<td>100 100</td>
<td>16 16</td>
<td>56.6 56.5</td>
<td>66 66.3</td>
<td>24.8 23.9</td>
<td>9.2 9.9</td>
</tr>
<tr>
<td>Cystic/Hereditary/Congenital Diseases</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polycystic kidneys, adult type (dominant)</td>
<td>1662 1617</td>
<td>20.2 22</td>
<td>12 11</td>
<td>69.9 68.7</td>
<td>76.4 74.2</td>
<td>17.1 19.5</td>
<td>6.6 6.2</td>
</tr>
<tr>
<td>Polycystic, infantile (recessive)</td>
<td>721 712</td>
<td>8.8 9.7</td>
<td>11 11</td>
<td>83.4 82.4</td>
<td>74.1 69.9</td>
<td>20.7 24.4</td>
<td>5.3 5.6</td>
</tr>
<tr>
<td>Renal hypoplasia, dysplasia, oligonephronia</td>
<td>745 737</td>
<td>9.1 10</td>
<td>10 10</td>
<td>63.8 59.6</td>
<td>75.8 75.2</td>
<td>16.8 17.9</td>
<td>7.4 6.9</td>
</tr>
<tr>
<td>Chronic pyelonephritis, reflux nephropathy</td>
<td>196 168</td>
<td>2.4 2.3</td>
<td>16 17</td>
<td>43.9 50.6</td>
<td>86.7 88.1</td>
<td>5.1 6</td>
<td>8.2 6</td>
</tr>
<tr>
<td>Cystinosis</td>
<td>954 921</td>
<td>11.6 12.5</td>
<td>14 13</td>
<td>58.8 59.3</td>
<td>79.1 76.9</td>
<td>15.9 15.9</td>
<td>4.9 7.3</td>
</tr>
<tr>
<td>Primary oxalosis</td>
<td>46 48</td>
<td>0.6 0.7</td>
<td>18 18</td>
<td>47.8 39.6</td>
<td>78.3 83.3</td>
<td>19.6 14.6</td>
<td>2.2 2.1</td>
</tr>
<tr>
<td>Congenital nephrotic syndrome</td>
<td>145 151</td>
<td>1.8 2.1</td>
<td>4 1</td>
<td>47.6 49</td>
<td>77.2 79.5</td>
<td>19.3 13.2</td>
<td>3.4 7.3</td>
</tr>
<tr>
<td>Drash syndrome, mesangial sclerosis</td>
<td>113 112</td>
<td>1.4 1.5</td>
<td>13 12</td>
<td>40.7 42.9</td>
<td>89.4 77.7</td>
<td>5.3 12.5</td>
<td>5.3 9.8</td>
</tr>
<tr>
<td>Other (congenital malformation syndromes)</td>
<td>186 162</td>
<td>2.3 2.2</td>
<td>17 17</td>
<td>86.6 87.7</td>
<td>73.1 75.9</td>
<td>20.4 17.3</td>
<td>6.5 6.8</td>
</tr>
<tr>
<td>Sickle cell disease/anemia</td>
<td>59 40</td>
<td>0.7 0.5</td>
<td>13 11</td>
<td>49.2 62.5</td>
<td>96.6 82.5</td>
<td>3.4 12.5</td>
<td>0 5</td>
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<tr>
<td>Primary Glomerular Disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Glomerulonephritis (GN) (histologically not examined)</td>
<td>1985 1603</td>
<td>24.1 21.8</td>
<td>18 18</td>
<td>55.1 55.5</td>
<td>61.1 65.4</td>
<td>31.4 26.9</td>
<td>7.5 7.6</td>
</tr>
<tr>
<td>Focal glomerulosclerosis, focal sclerosing GN</td>
<td>399 290</td>
<td>4.9 4.0</td>
<td>19 19</td>
<td>61.2 58.3</td>
<td>66.2 72.1</td>
<td>24.3 19.3</td>
<td>9.5 8.6</td>
</tr>
<tr>
<td>Membranous nephropathy</td>
<td>1017 849</td>
<td>12.4 11.6</td>
<td>17 17</td>
<td>55 56.8</td>
<td>53.3 59.4</td>
<td>41.5 34.9</td>
<td>5.2 5.8</td>
</tr>
<tr>
<td>Membranoproliferative GN type 1, diffuse MPGN</td>
<td>48 39</td>
<td>0.6 0.5</td>
<td>18 19</td>
<td>45.8 69.2</td>
<td>54.2 61.5</td>
<td>39.6 33.3</td>
<td>6.3 5.1</td>
</tr>
<tr>
<td>Dense deposit disease, MPGN type 2</td>
<td>105 70</td>
<td>1.3 1.0</td>
<td>17 17</td>
<td>43.8 45.7</td>
<td>66.7 75.7</td>
<td>21.9 14.3</td>
<td>11.4 10</td>
</tr>
<tr>
<td>Dense deposit disease, MPGN type 2</td>
<td>33 26</td>
<td>0.4 0.4</td>
<td>16 16</td>
<td>54.5 53.8</td>
<td>90.9 84.6</td>
<td>3 7.7</td>
<td>6.1 7.7</td>
</tr>
<tr>
<td>IgA nephropathy</td>
<td>208 187</td>
<td>2.5 2.5</td>
<td>19 18</td>
<td>65.4 58.8</td>
<td>73.6 74.9</td>
<td>14.9 10.2</td>
<td>11.5 15</td>
</tr>
<tr>
<td>IgM nephropathy</td>
<td>21 15</td>
<td>0.2 0.2</td>
<td>19 19</td>
<td>63.2 60</td>
<td>63.2 66.7</td>
<td>36.8 26.7</td>
<td>0 6.7</td>
</tr>
<tr>
<td>With lesion of rapidly progressive GN</td>
<td>64 47</td>
<td>0.8 0.6</td>
<td>15 16</td>
<td>32.8 27.7</td>
<td>71.9 72.3</td>
<td>15.6 17</td>
<td>12.5 10.6</td>
</tr>
<tr>
<td>Other proliferative GN</td>
<td>92 80</td>
<td>1.1 1.1</td>
<td>16 17</td>
<td>39.1 41.3</td>
<td>76.1 66.3</td>
<td>15.2 30</td>
<td>8.7 3.8</td>
</tr>
</tbody>
</table>

Table 7.1 continued on next page.
<table>
<thead>
<tr>
<th>Primary Disease Groups</th>
<th>2011-2015 (period B)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td><strong>Total Patients</strong></td>
<td>390</td>
</tr>
<tr>
<td><strong>Percent Incidence</strong></td>
<td>390</td>
</tr>
<tr>
<td><strong>Median Age</strong></td>
<td>390</td>
</tr>
<tr>
<td><strong>Percent Males</strong></td>
<td>390</td>
</tr>
<tr>
<td><strong>Percent White</strong></td>
<td>390</td>
</tr>
<tr>
<td><strong>Percent Black/African American</strong></td>
<td>390</td>
</tr>
<tr>
<td><strong>Percent Other Race</strong></td>
<td>390</td>
</tr>
</tbody>
</table>

**Secondary Glomerular Disease/Vasculitis**
- Lupus erythematosus, (SLE nephritis)
- Henoch-Schoenlein (IgA Vasculitis)
- Hemolytic uremic syndrome
- Polyarteritis and other vasculitis
- ANCA-associated vasculitis
- Goodpastures syndrome
- Secondary GN, other
- AIDS nephropathy

**Tubulointerstitial Diseases**
- Chronic interstitial nephritis
- Tubular necrosis

**Transplant Complications**
- Kidney transplant complication
- Other transplant complication

**Diabetes**
- Diabetes with renal manifestations Type 2
- Diabetes with renal manifestations Type 1

**Neoplasms/Tumors**
- Renal tumor

**Hypertensive/Large Vessel Disease**
- Hypertensive/Large Vessel Disease

**Miscellaneous Conditions**
- Acquired obstrutive uropathy
- Nephrolithiasis
- Unspecified with renal failure
- Traumatic or surgical loss of kidney(s)
- Other renal disorders
- Nephropathy caused by other agents

**Etiology Uncertain**

**Missing**

Data Source: Special analyses, USRDS ESRD Database. Abbreviations: ANCA, anti-neutrophil cytoplasmic antibody; AIDS, acquired-immune deficiency syndrome; CAKUT, congenital anomalies of the kidney and urinary tract; congenital obstructive uropathy, combination of congenital ureteropelvic junction obstruction, congenital ureterovesical junction obstruction, and other congenital anomalies; ESRD, end-stage renal disease; GN glomerulonephritis; IgA, immunoglobulin A; IgM, immunoglobulin M; incl., including; MPGN, membranoproliferative glomerulonephritis; SBE, subacute bacterial endocarditis. Diagnoses with 10 or fewer total patients for year categories are suppressed.
Table 7.2 Proportion of missing, unknown, and unspecified etiology of ESRD in children and adolescents, by age group.

<table>
<thead>
<tr>
<th>ESRD etiology missing, unknown, or unspecified</th>
<th>0-4</th>
<th>5-9</th>
<th>10-13</th>
<th>14-17</th>
<th>18-21</th>
<th>All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10.9%</td>
<td>14.4%</td>
<td>19.0%</td>
<td>19.3%</td>
<td>27.0%</td>
<td>20.6%</td>
</tr>
</tbody>
</table>

Data Source: Special analyses, USRDS ESRD Database.

### Growth

Children with chronic kidney disease and ESRD are at risk for growth impairment, requiring intensive intervention to optimize growth. In this 2017 ADR, we report growth parameters of short stature (defined as less than the third percentile for age) and body mass index (BMI) at incidence of ESRD.

Over the past 10 years, the 0-4 age group consistently had the highest proportion of children with short stature (Figure 7.4.a). The proportion of incident ESRD patients with short stature decreased in older age groups. In 2015, the percentage of incident ESRD patients with short stature was highest in the youngest patients, at 52.7% in the 0-4 age group, 33% in the 5-9 age group, 29.4% in the 10-13 age group, and 23.8% in the 14-17 age group. The prevalence of short stature in the incident pediatric ESRD population has not improved over the past 10 years.

The youngest children with incident ESRD in the 2011-2015 period, those between 0-4 years of age, had the largest proportion of unhealthy weight status, including being underweight (14.8%) and obese (26.8%; Figure 7.4.b). In total, 55% of children aged 0-4 who were obese at ESRD initiation also had short stature, suggesting that nutritional support alone is insufficient to restore all patients to a normal stature.
vol 2 Figure 7.4 Growth status at the time of ESRD initiation by (a) Stature and (b) Body Mass Index (BMI)

(a) Stature

(b) BMI

Data Source: Special analyses, USRDS ESRD Database. (a) Stature reported for age <21 per growth percentile guidelines. Percentiles for children greater or equal to 24 months of age and up to less than 20 years of age are calculated following Centers for Disease Control and Prevention (CDC) growth charts. Percentiles for children less than 24 months of age are calculated following World Health Organization (WHO) growth charts. Short stature is defined as height less than 3rd percentile for sex and age. (b) BMI categories are defined differently for patients younger than 18 (underweight: BMI < 5th percentile; Normal: 5th percentile ≤ BMI < 85th percentile; Overweight: 85th percentile ≤ BMI < 95th percentile; and obese: BMI ≥ 95th percentile) and patients 18 and older (underweight: BMI < 18.5; Normal: 18.5 ≤ BMI < 25 percentile; Overweight: 25 ≤ BMI < 30; and obese: BMI ≥ 30). Abbreviations: ESRD, end-stage renal disease; BMI, body mass index.
Hospitalizations in Children with Incident ESRD

The first ESRD-year adjusted all-cause hospitalization rates were highest in the youngest children, those 0-4 years of age (Figure 7.5.a). During the 2010-2014 reporting years, the rates of hospitalization rose overall from 1,885 to 2,318 admissions per 1,000 patient years. This increase in hospitalization rates was observed in every age group and for every RRT modality (Figure 7.5.b). While they account for a minority of hospitalizations in children with incident ESRD, we report the one-year hospitalizations associated with cardiovascular disease (CVD) and infection. This provides consistency with previous ADR pediatric chapters and aligns with two leading causes of ESRD-associated mortality in children. Other substantial causes of hospitalization in this population included hypertension (19.8%), complications of kidney transplant (8.6%), complications of dialysis, including access complications (7.2%), dehydration (2.9%), and hyperkalemia (2.4%).

vol 2 Figure 7.5 One-year adjusted all-cause hospitalization rates in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2005-2009 and 2010-2014

(a) Age

(b) Modality

Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2005-2014, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
The first-year CVD hospitalization rates for children less than 22 years of age with incident ESRD were 63 per 1,000 patient-years from 2005-2009, and 48 from 2010-2014 (Figure 7.6.b). The highest rates of CVD hospitalizations in incident patients were observed in children aged 5-9 and 18-21 years (Figure 7.6.a) and in children treated with dialysis (Figure 7.6.b).

**vol 2 Figure 7.6** One-year cardiovascular hospitalization rates in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality 2005-2009 and 2010-2014

(a) Age (adjusted)

(b) Modality (unadjusted)

*Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2005-2014, surviving the first 90 days after ESRD initiation and followed from day 90. Reference population: incident ESRD patients aged 0-21, 2010-2011. (a) Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. (b) Unadjusted. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.*
The overall rate of hospitalization for infection in the first year of ESRD care was 674 admissions per 1,000 patient years during 2010-2014, which was 11.8% higher than during 2005-2009 (Figure 7.7.b). These first year infection-related hospitalizations in children increased in every modality of RRT in the most recent 5-year reporting window, by 5.7% in HD, 13.1% in PD, and 56.2% in transplant patients. In examining between-modality statistics, children on PD and HD had higher rates of infection-related hospitalizations than did transplanted children (Figure 7.7.b).

**Figure 7.7 One-year adjusted hospitalization rates for infection in incident pediatric patients (aged 0-21 years), by (a) age and (b) modality, 2005-2009 and 2010-2014**

**Data Source:** Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2005-2014, surviving the first 90 days after ESRD initiation and followed from day 90. Adjusted for sex, race, primary cause of ESRD, and Hispanic ethnicity. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
Mortality

During 2010-2014, the one-year adjusted all-cause mortality rate was 27 per 1,000 patient years, a decrease of 30.8% from the 39 per 1,000 patient years seen in 2005-2009 (Figure 7.8.b). Reduced mortality was reported in almost all age categories, with the greatest point estimate of reduced mortality by 41.6% in children age 0-4 years (Figure 7.8.a). The improvement in the one-year mortality in the 0-4 age group was mostly in the infants less than 2 years of age at onset of ESRD (age <2 years: 45% vs age 2 to <5: 32% reduction in mortality).

When comparing the 2005-2009 and 2010-2014 periods, adjusted one-year all-cause mortality rates by modality showed decreases of 27.5% among HD patients, 44.2% among PD patients, and 30.8% among transplant patients (Figure 7.8.b). Despite the overall improvement in the adjusted one-year all-cause mortality from 2010-2014, a difference in mortality by modality remained, with HD- and PD-associated one-year all-cause mortality rates 4.1 and 2.7 times higher than for transplant patients. Across all modalities, the five most common causes of death reported on the Death Notification Form were predominantly attributed to cardiac arrest cause unknown, withdrawal from dialysis, and sepsis for children aged 0 to 21 years. The youngest children had similar reported causes when compared with older children and adolescents.

Assessment of expected remaining lifetime based on age at ESRD incidence and modality is presented in Table 7.3, and compared with published general population estimates from the U.S. Social Security Administration.

vol 2 Figure 7.8 One-year adjusted all-cause mortality rates in incident pediatric patients with ESRD by (a) age with comparison to young adults (aged 0-29 years), and (b) modality (aged 0-21 years only), 2005-2009 and 2010-2014

(a) Age
One-year adjusted all-cause mortality rates in incident pediatric patients with ESRD by (a) age with comparison to young adults (aged 0-29 years), and (b) modality (aged 0-21 years only), 2005-2009 and 2010-2014 (continued)

(b) Modality

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2015. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

Table 7.3 Expected remaining lifetime in years of prevalent patients by initial ESRD modality, 2014

<table>
<thead>
<tr>
<th>Age group</th>
<th>Dialysis patients</th>
<th>Transplant patients</th>
<th>General population</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-4</td>
<td>23.6</td>
<td>56.9</td>
<td>77.1</td>
</tr>
<tr>
<td>5-9</td>
<td>24.3</td>
<td>56.3</td>
<td>72.3</td>
</tr>
<tr>
<td>10-13</td>
<td>24.1</td>
<td>52.2</td>
<td>67.8</td>
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</table>

Data Source: Special analyses, USRDS ESRD Database, USA SSA (Social Security Administration) Period Life Table 2014. Includes period prevalent ESRD dialysis and transplant patients in 2014.
During 2010-2014, the one-year adjusted CVD mortality rate was eight per 1,000 patient years, a decrease of 42.9% from the 2005-2009 period (Figure 7.9.b). The adjusted one-year CVD mortality rate decreased across all age groups (Figure 7.9.a), but remained the highest in children aged 0-4 years.

When examining adjusted one-year CVD mortality across the periods from 2005-2009 and 2010-2014, mortality decreased in all ESRD treatment modality groups but continued to be highest in the dialysis groups, when compared to transplant (Figure 7.9.b).

**vol 2 Figure 7.9 One-year adjusted cardiovascular mortality rates in incident pediatric patients with ESRD (aged 0-21 years), by (a) age and (b) modality, 2005-2009 and 2010-2014**

(a) Age

(b) Modality

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2015. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
During 2010-2014, the one-year adjusted infection-related mortality rate decreased from six to four per 1,000 patient years when compared to the 2005-2009 period (Figure 7.10.b). This mortality rate decreased in those aged 0-4 years by 52.4% (Figure 7.10.a), but it continued to be higher than in other age groups. During 2010-2014 the by mortality rate was quite low, ranging from two to four per 1,000 patient years in children with incident ESRD (Figure 7.10.b).

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2015. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
For patients beginning ESRD therapy during 2006-2010, the probability of five-year survival was 0.90 (Figure 7.11.b). The probability of surviving five years by age was the worst for the youngest and oldest subsets, including 0.85 for ages 0-4 and 0.88 for ages 18-21 years (Figure 7.11.a). Patients initiating ESRD care with transplantation had the highest probability of surviving five years, at 0.96, as compared to 0.81 with HD, and 0.83 with PD (Figure 7.11.b).

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2015. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 0-21, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
Vascular Access

The approach to vascular access in ESRD patients influences both immediate and future patient outcomes. Due to the consequences that central venous catheter (hereafter, catheter) use can have on future access, and because many pediatric patients will require multiple forms of vascular access during their lifetime, vascular access decisions are particularly important in pediatric patients. In this section, we will describe the vascular access practices in incident and prevalent HD patients.

Vascular access in pediatric ESRD patients is approached differently than in adult ESRD patients due to factors such as anatomical differences, transplant waiting times, and transplant rates. The technical challenge of accessing vessels in small children and an expected short waiting time until a kidney transplant becomes available may influence the vascular access experience in children with ESRD. Since 2006, approximately 81% of incident pediatric ESRD patients have started HD with a catheter (ranging from 77.8% to 83.0%; Figure 7.12.a). The initiation of HD with a catheter was observed in the majority of children and adolescents between the ages of 0 and 21 years (Figure 7.12.b). Catheters with a maturing fistula and fistula alone became increasingly more common with advancing age of HD initiation, starting at age 8 years through adolescence.

These trends in initial vascular access remain stable despite concerted efforts, such as the Fistula First Breakthrough Initiative, to increase the utilization of arteriovenous (AV) fistulas in pediatric patients.

vol 2 Figure 7.12 Vascular access type at initiation of incident pediatric hemodialysis patients (aged 0-21 years) by (a) year and (b) age, 2006-2015

(a) Year

Figure 7.12 continued on next page.
When vascular access was examined in prevalent HD patients, there were higher rates of AV fistula and AV graft utilization in children aged 10-13 (29.6%), 14-17 (44.3%), and 18-21 (69.2%) than in children under age 10 (Figure 7.13).

A cross-sectional analysis of point prevalent ESRD patients aged 0-21 years in May 2016 showed that 54.5% of patients had an AV fistula or AV graft as their type of vascular access (Figure 7.13). Age strongly predicted the type of vascular access in use. There was a stepwise increase in the utilization of AV fistula or AV graft with increasing patient age, including 44.3% for those aged 14-17 and 69.2% for those aged 18-21 years.

When examining race and etiology of ESRD in age-adjusted analysis (figures not shown), there were subtle differences in vascular access in the prevalent patients. Blacks had a higher proportion of AV graft use (9.0%) when compared to other races (White 3.8%, and Other 6.0%). Whites and Blacks had similar use of catheters only when compared to Other races, at 45.3% and 45.8% compared to 43.8%. Overall, patients with primary glomerular disease as the etiology of ESRD had the highest proportion of surgical access in place (AV fistula 55.9% or graft 5.9%). In age-adjusted analysis, the highest rate of catheter use was in those with other etiologies of ESRD (51.4%).
Trends in Pediatric Kidney Transplantation

Overall, during 2010-2015, 36.0% of children received a kidney transplant within their first year of ESRD care (Table 7.1), including 37.5% of children with weight greater than 10 kg. In 2015 the rate of transplants was 33.6 per 100 dialysis patient years—a stable trend since 2007 (Figure 7.14.a).

In 2015, 1210 children were wait-listed for a kidney transplant, including 839 patients listed for the first time and 371 patients listed for repeat transplant. The number of patients awaiting a kidney transplant has ranged from 1179 to 1327 since 2004 (Figure 7.14.b). There has been a persistently low median waiting time for those listed for their first transplant over the most recent 10-year reporting period. Over this time, children receiving a repeat transplant have, on average, been on the waiting list at least 3-4 times longer than those awaiting their first transplant. See Figure 6.3 in Volume 2, Chapter 6, *Transplantation*, for trends from 1998-2014 in the percentage of incident patients aged 0-21 who were wait-listed or received a kidney transplant within one year of ESRD initiation.

In 2015, 1023 children received a kidney transplant (Figure 7.14.c). Prior to 2005, kidney grafts in pediatric transplant recipients were most commonly from living donors. There has been a decline, however, in the number of pediatric patients receiving living-donor kidneys since 2009. In 2015, living donors accounted for 38.6% of kidney transplants, an 11.2% decrease since 2009.
vol 2 Figure 7.14 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and kidney transplant rates, (b) kidney transplant counts and waiting list times, (c) kidney transplant counts by donor type, (d) kidney transplant counts, patients 0-17 years, (e) and kidney transplant counts, patients 18-21 years.

(a) ESRD incident and kidney transplant rates

(b) Kidney transplant counts and waiting list times

Figure 7.13 continued on next page.
Figure 7.14 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and kidney transplant rates, (b) kidney transplant counts and waiting list times, (c) kidney transplant counts by donor type, (d) kidney transplant counts, patients 0-17 years, (e) and kidney transplant counts, patients 18-21 years (continued)

(c) Kidney transplant counts by donor type

(d) Kidney transplant counts, patients 0-17 years

Figure 7.14 continued on next page.
vol 2 Figure 7.14 Trends in pediatric transplantation (aged 0-21 years), by (a) ESRD incident and kidney transplant rates, (b) kidney transplant counts and waiting list times, (c) kidney transplant counts by donor type, (d) kidney transplant counts, patients 0-17 years, (e) and kidney transplant counts, patients 18-21 years

(e) Kidney transplant counts, patients 18-21 years

Data Source: (a) Reference Tables A1, E9, and M1. The rate of ESRD per million among the U.S. population aged 0-21 years and the rate of transplantation in dialysis patients aged 0-21 years at the time of transplant, 1996–2015. (b) Special analyses, USRDS ESRD Database. The waiting list count provides the number of pediatric candidates aged 0-21 years on the Organ Procurement and Transplantation Network kidney transplant waiting list on December 31 of each year for first and subsequent kidney alone or kidney plus pancreas transplantation. Candidates listed at more than one center on December 31 are counted only once. There are no data available for median waiting list time for patients with prior transplants listed after 2012. (c-e) Reference Tables E8, E8(2), E8(3). This figure represents kidney alone and kidney plus pancreas transplant counts for all pediatric candidates. Abbreviations: ESRD, end-stage renal disease; pt, patient; Tx, transplant; yrs, years.

Overall, the transplant rates in each of the age groups have remained stable during 1996-2015. In 2015, patients 5-9 and 10-13 years old had the highest rates of 52.5 and 56.8 transplants per 100 dialysis patient years, and those 18-21 years old had the lowest rate at 20.9 (Figure 7.15.a).

In 2015, males with ESRD were transplanted at a higher rate than females, at 37.7 versus 29.6 per 100 dialysis patient years. The transplant rate remained lower in Black dialysis patients compared with Whites, at 20.7 versus 36.9 per 100 dialysis patient years (Figure 7.15.b). Analyses for Native and Asian Americans were excluded due to the low number of transplants in these populations.
vol 2 Figure 7.15 Annual rates of living and deceased donor transplants in pediatric dialysis patients (aged 0-21 years), by (a) age and (b) race, 1996-2015

(a) Age with living donor

(b) Age with deceased donor

Figure 7.15 continued on next page.
The trend in median waiting time to transplant for incident patients on dialysis has been improving. In 2002, the median waiting time peaked at 22.1 months then began to decline, with the most dramatic improvement occurring after 2005 (Figure 7.16.a). This coincided with a change in the OPTN organ allocation policy. Since 2005, the median waiting time for incident dialysis patients has continued to decrease, and was at its lowest in 2014, at 11.2 months. Since 2007, the waiting times for incident patients on dialysis have been similar for HD and PD. In 2014, the median waiting time to transplant for HD patients was 11.1 months, and for PD patients was 11.7 months.

Kidney transplant waiting times varied by age and ESRD etiology. In patients younger than 18 years old, the median time from incident dialysis to transplant has been improving from 1996 to 2014 in most age groups. An exception was for those 0-4 years old (Figure 7.16.b). These youngest children have had stable waiting times, which may result from the surgical complexities in this age group. Since 1996, patients aged 18-21 years old have shown the largest improvement with waiting times. In 2014, the median waiting time for children 0-4 years old surpassed that of patients 18-21 years old. Patients with congenital anomalies of the kidney and urinary tract (CAKUT) as the cause of their ESRD had the longest median waiting time to first transplant, with a median of 13.7 months in 2014 (Figure 7.16.c).

In 1996, White patients were wait-listed for an average 35% shorter period than Blacks (Figure 7.16.d). Since then, the average time on the transplant list has improved significantly for all patients, and the gap between races has narrowed substantially. Consequently, most recent median waiting times were now similar between groups (Whites 10.8 and Blacks 13.5 months). With the resolution of the waiting-time gap between Black and White pediatric ESRD patients, improving the transplant disparity observed in dialysis-dependent Black children may be addressed through efforts to improve the listing rate in these children.
The median transplant wait time for a deceased donor type has decreased steadily since 2010, such that the difference in waiting time between living and deceased donor organs was less than three months in 2014 (Figure 7.16.e).

Finally, Table 7.2 displays the ten-year kidney transplant outcomes. The ten-year outcomes remained stable in terms of all-cause graft failure and death for both deceased and living donor transplants.
vol 2 Figure 7.16 Median waiting time from incident hemodialysis or peritoneal dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, (d) race, and (e) donor type, 1996-2014 (continued)

(b) Age

(c) Primary cause of ESRD

Figure 7.16 continued on next page.
Median waiting time from incident hemodialysis or peritoneal dialysis to first transplant, by (a) modality, (b) age, (c) primary cause of ESRD, (d) race, and (e) donor type, 1996-2014 (continued)

(d) Race

(e) Donor type

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant with the 60-day rule. Includes pediatric patients (aged 0-21 years) starting initiation of HD or PD in 1996-2014 and having the first transplant before 12/31/2015. Abbreviations: CAKUT, congenital anomalies of the kidney and urinary tract; C/H/C, Cystic/Hereditary/Congenital disease. ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis. Note that the percentage of unknown donor type is 1.32% in 1996, 1.11% in 1997, 0.44% in 1998, 0.54% in 1999, 0.22% in 2000, 0.10% in 2001, 0.30% in 2002, 0.10% in 2003, 0.10% in 2004, 0.23% in 2006, 0.14% in 2011, and 0% in 2005, 2007-2010, 2012-2014.
Table 7.4 Adjusted ten-year outcomes for kidney transplants in pediatric patients (aged 0-21 years), by donor type and year, 1996-2005

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<td>All-cause graft failure</td>
<td>Return to dialysis or retransplant</td>
<td>Death</td>
<td>All-cause graft failure</td>
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Data Source: Deceased: Reference Tables F6, F18, I30. Live: Reference Tables F12, F24, I36. Probabilities for all-cause graft failure and return to dialysis or repeat transplant are adjusted for age, sex, race, primary cause of ESRD, and first versus subsequent transplant. All-cause graft failure includes repeat transplant, return to dialysis, and death. The death outcome is not censored at graft failure, and includes deaths that occur after repeat transplant or return to dialysis. Probabilities of death are adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. The reference population for all-cause graft failure and return to dialysis or repeat transplantation is all pediatric patients receiving a kidney alone transplant in 2011. The reference population for death is incident pediatric ESRD patients in 2011. Abbreviation: ESRD, end-stage renal disease.

Young Adults

Because of improvements in the care of pediatric patients with ESRD, a larger percentage of these children are surviving into adulthood. The transition of these patients into adulthood represents a unique process; their specific needs have resulted in the development of transition programs to improve health care for these individuals. As of December 31, 2015, there were 10,251 young adult survivors of childhood onset ESRD in the U.S. These prevalent patients were dependent on HD (34.4%), PD (5.8%), and transplant (59.6%).

In addition to the survivor cohort, the young adult incident ESRD cohort includes individuals aged 22-29 years old at the time of ESRD onset. This section highlights the incident young adult population, focusing on modality and CVD trends.

The overall incident rate of ESRD in the young adult cohort has been slowly decreasing (Figure 7.17). In 1996, the rate was 72.5 PMP in the young adult census population, while by 2015 the ESRD incident rate had reduced to 62.5. In 2015, the rates of incident HD, PD, and transplant were 49.5, 9.8, and 3.1 patients PMP.

Since 2008, there has been a trend in increased utilization of PD as the incident ESRD modality. The point prevalence of young adults with ESRD (figure not shown) was 448.3 patients PMP in 2015. The use of ESRD modality within this 2015 point prevalent population included 204.1 HD, 44.8 PD, and 198.3 transplant patients PMP.
Cardiovascular health has been a major concern in the young adult ESRD population. The overall CVD hospitalization rate during 2010-2014 was 127 admissions per 1,000 patient years (Figure 7.18). The rate of CVD hospitalizations remained highest in those on HD compared with other ESRD modalities. However, there was a 19.5% decline in CVD hospitalization in HD patients in the most recent reporting years. Between 2010 and 2015, the one-year adjusted CVD mortality was 11 per 1,000 patient years, a decrease of 21.4% from the 2005-2009 period (Figure 7.19). The adjusted one-year CVD mortality rate decreased across all modalities.
vol 2 Figure 7.18 One-year unadjusted cardiovascular hospitalization rates in young adults with incident ESRD (aged 22-29 years), by modality, 2005-2009 and 2010-2014

Data Source: Special analyses, USRDS ESRD Database. Includes incident pediatric ESRD patients in the years 2005-2014, surviving the first 90 days after ESRD initiation and followed from day 90. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.

vol 2 Figure 7.19 One-year adjusted cardiovascular mortality rates in young adults with incident ESRD (aged 22-29 years), by modality, 2005-2009 and 2010-2014

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2015. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 22-29, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
One-year adjusted mortality rates for young adults initiating ESRD between 2010 and 2014 was 48 per 1,000 patient-years. (Figure 7.8.a). The probability of five-year survival was 0.81, which was lower than the 0.90 five-year survival in younger patients aged 0-21 years (Figure 7.20). Young adult transplant patients had the highest probability of surviving five years (0.95) compared to 0.74 seen in HD patients, and 0.81 in PD patients. (See Volume 2, Chapter 5, Mortality for adult survival statistics by age and modality)

Vol 2 Figure 7.20 Adjusted five-year survival probability of young adults with incident ESRD (aged 22-29 years), by modality and months after initiation, 2006–2010

Data Source: Special analyses, USRDS ESRD Database. Incident dialysis and transplant patients defined at the onset of dialysis or the day of transplant without the 60-day rule; followed to December 31, 2015. Adjusted for age, sex, race, Hispanic ethnicity, and primary cause of ESRD. Reference population: incident ESRD patients aged 22-29, 2010-2011. Abbreviations: ESRD, end-stage renal disease; HD, hemodialysis; PD, peritoneal dialysis; Tx, transplant.
Notes