



Pediatric Kidney Disease Fact Sheet

How Does Kidney Disease Impact Children?

Chronic Kidney Disease (CKD) is defined as structural or functional kidney damage over a minimum period of three months. Children with CKD face many unique challenges, including delayed language and motor skills development, growing at a slower rate than their peers, and the loss of bladder control.

End Stage Renal Disease (ESRD), the most severe stage of CKD, is caused by congenital and acquired disorders in the pediatric population. Children with ESRD are at risk for growth failure, frequent hospitalization and significantly higher mortality than the general pediatric population. The majority of children with ESRD will depend on a variety of the available renal replacement therapies throughout their lifetime, including hemodialysis (HD), peritoneal dialysis (PD) and transplantation. All patients with ESRD regardless of age are eligible for Medicare.

Children with kidney disease have additional health care and supplemental services needs, including transportation, nutrition services, and specialized care. Many of which are not covered by the Medicare ESRD bundled payment rate. The majority of individuals with ESRD that survive past age 19 receive at least one kidney transplant, with the majority needing additional transplants over time.

Prevalence and Incidence Rates (2016)

Age Group	Children with CKD	Percent (% of total children in study)	Children with Incident ESRD
Total	5,285	.27	1,372
0-4	1,122	.36	204 cases
5-9	1,027	.23	139 cases
10-13	839	.21	202 cases
14-17	1,085	.26	295 cases
18-21	1,212	.29	532 cases

Increased Hospitalizations and Comorbidities are Common for Pediatric Kidney Patients

Chronic Kidney Disease:

- Children with CKD have hospitalization rates 12 times higher per 1,000 patient-years compared to all children, with children aged 0-4 having the highest frequency of hospitalization.
 - Leading causes of hospitalizations include cardiovascular, infectious or “other causes,” which includes kidney and urinary tract, metabolic, endocrine, nutritional, hematology/oncology, and gastrointestinal diagnoses.
- Common comorbidities for children with CKD include diabetes, hypertension, and cardiovascular disease.

End Stage Renal Disease:

- From 2011-2015, overall rate of hospitalization dropped by 1.8%, from 1,874 to 1,841 admissions per 1,000 patient years.
 - Leading causes of hospitalization include infection (29.2%), hypertension (12.5%), complications of dialysis (6.2%), complications of kidney transplant (5.2%), CVD (2.2%), dehydration (2%), fever (1.8%), and hyperkalemia (1.6%).

Life Expectancy for ESRD Patients by Initial Treatment Modality (2015)

Age Group	Dialysis Patients	Transplant Patients	General Population
0-4	22.0	57.7	77.0
5-9	22.8	56.2	72.1
10-13	23.3	52.1	67.6
14-17	20.6	48.9	63.7
18-21	17.6	45.6	59.8
22-29	15.7	42.3	54.1

Cost of Care

As shown above, children with CKD have extensive health care needs. Based on commercial spending data, between 2006 and 2016, expenditures for children with CKD increased 47.6%, while spending for children without CKD rose by 26.4%. Overall, health care expenditures were 7.6 times higher for children with CKD compared to children without CKD in 2016.

ASPN has raised concerns with the Centers for Medicare and Medicaid Services (CMS) about the inadequacy of payments for pediatric nephrology cases. It is critical that CMS collect accurate data on what is required to deliver quality care to children with ESRD and not limit access to care. The following factors related to pediatric dialysis care should be, but are not currently, included in the pediatric facility payment formula:

- Increased acuity of nursing care compared to adult dialysis patients, especially for smaller, younger pediatric hemodialysis patients
- Need for developmental/behavioral specialists, including Child Life Specialists
- Need for more frequent assessment by pediatric dietitians to adjust formulas and diet for the specialized growth and nutrition requirements of children treated with dialysis
- Need for social workers and other trained individuals designated to intervene with schools to ensure school attendance and optimize school performance among pediatric dialysis patients
- Need for a broader array of dialysis supplies, including a broad range of sizes of dialyzers, tubing, and peritoneal fluid bags, to accommodate infants through young adults