Pediatric patients (those aged 0-21 years) account for only 1% of the prevalent population receiving kidney replacement therapy (KRT) but are a unique subset differing from adults in both underlying kidney diseases and treatment needs. The biggest difference is that children must achieve adult maturation through growth and development from birth through adolescence. During this time, they are dependent on adults for care, nurturing, and supervision. Additionally, common comorbid conditions are not diabetes, heart disease, cerebrovascular disease, gout, and smoking, but seizure disorder, cognitive impairment, behavioral abnormalities, and nonkidney congenital anomalies, including congenital heart disease. The complex process of growth and development is adversely affected by chronic kidney disease and especially by dependence on long-term dialysis. Abnormal nutrition, metabolic acidosis, anemia, bone disease, poor muscle strength, and altered growth hormone–insulin-like growth factor–binding protein axis all interfere with normal growth and development. The youngest patients, those younger than 5 years, are the most vulnerable to the vagaries of long-term dialysis and require the most intense care, but all pediatric patients, including adolescents, need specialized care due to ongoing growth and psychosocial development and lack of autonomy.

Special Characteristics of Pediatric KRT Patients

**Kidney Diseases.** Diabetes and hypertension rarely cause pediatric kidney failure. Instead, a broad spectrum of diseases, including congenital anomalies of the kidney and urinary tract, hereditary diseases, and acquired glomerulonephritis/vasculitis are the primary diseases in children (Fig S1). Unlike KRT in adult patients, which has increased in incidence by 60% in the last 2 decades, in the pediatric population (aged 0-21 years), incidence has slowly declined from a peak of 1,741 patients in 2003 to 1,321 in 2017. Technical advances during the last 50 years and better understanding of pediatric therapy for nutrition, infection, hypertension, bone disease, growth failure, and metabolic control have led to improved survival. The overall probability of 5-year survival is now 0.91 for pediatric patients aged 0 to 21 years starting dialysis during 2008 to 2012, with even the youngest patients (those aged 0-4 years) improving to 0.83. Although 50 years ago there was concern for offering dialysis and transplantation, now almost all pediatric patients are expected to be offered all modalities of KRT and they have the potential for the longest survival.

**Modality.** The goal of therapy for all children is a successful transplant, which leads to better growth, development, academic achievement, and quality of life for patients and families compared with long-term dialysis. About 20% undergo preemptive transplantation, and among prevalent pediatric patients in 2017, almost 75% had a functioning allograft compared with 29% of adults (Fig 1). Many children will still need long-term dialysis either before transplantation or as a bridge after a failed transplant. Unlike the adult population, almost 40% of children are maintained with long-term home peritoneal dialysis (PD) (Fig 1), usually with a parent as the caregiver. Home PD is preferred in younger children for better preservation of residual kidney function, avoidance of vascular access, more dietary and fluid freedom, and less disruption of school attendance.

**Growth, Development, and Comorbid Conditions.** Children do not function independently so pediatric dialysis care requires much more intense supervision, not only from parents or guardians, but also from pediatric nephrologists, dialysis nurses, technicians, social workers, child life specialists, and dietitians, all with specialized knowledge of changing needs for age,
growth, development, and underlying disease. Gastrostomy tube feedings and growth hormone therapy are frequently needed to provide adequate nutrition and achieve statural growth. Frequent assessment and dietary adjustments for changes in target weight due to growth or weight loss are imperative. Staffing for hemodialysis (HD) treatments for small size, short attention span, or behavioral issues usually needs to be 1:1 or 1:2 to provide safe care. Home PD care often requires more than 1 monthly visit and frequent telephone support for family caregivers. Caregiver, especially parent, burnout and family dysfunction is common and requires identification and extra multidisciplinary team support. Most pediatric dialysis facilities use child life specialists to promote developmentally appropriate adjustment to the medical environment, teachers to liaise with schools to optimize ongoing education, behavioral specialists to help manage difficult behavior, and psychologists to deal with psychosocial disruption of normal childhood and family life. Pediatric surgeons and urologists must be available for HD or PD access with attention to lifetime access site preservation, gastrostomy tubes, and rehabilitation of the urinary tract for a successful transplant. Coordination of care for other medical comorbid conditions and for developmentally appropriate physical, occupational, and speech therapy creates additional complexity but has led to improved pediatric outcomes, fewer lifelong medical complications, and lower long-term health care expenditures.

**Pediatric Facility.** The typical pediatric facility is located in a children’s hospital, serves a small medically complex census from a geographically widespread area, and requires a broad range of specialized equipment and supplies to deliver dialysis to the spectrum of body sizes from infants to adolescents. To provide safe extracorporeal HD blood volumes and appropriate small PD exchange volumes, a variety of sizes of lines, dialyzers, PD bags, and both HD and PD catheters must be available, resulting in a low-volume high inventory of disposable supplies. Historically, specialized pediatric equipment and supplies are more expensive, subject to wastage from long shelf life when activity is low, and prone to limited availability or lapses in production due to the small market. Although medication doses may be smaller compared with adults, the formulation often needs to be child accessible in liquid or sprinkle form, which frequently requires special compounding and increases cost.

**History of Pediatric Dialysis Payment**

Just like adults, children are eligible for coverage by the Medicare End-Stage Renal Disease program, except children 0 to 21 years old qualify through their parents accruing Social Security credits and constitute one of the few subsets of pediatric Medicare beneficiaries. Since the Medicare End-Stage Renal Disease Program began in 1972, pediatrics was recognized as an atypical population, requiring more intensive services (Table S1). When the Omnibus Budget Reconciliation Act (OBRA 1981) established dialysis payment by the composite rate, an exception policy for higher payment based on documented higher costs was allowed for pediatric facilities, which came to be defined as those with >50% of patients aged 0 to 18 years. As early as 1983, a few pediatric dialysis facilities applied and were granted pediatric exception. Thereafter, the exception window was available only when the base composite rate was adjusted by acts of Congress, which occurred just 5 times from 1983 to 2003. At each opening of the window, some additional pediatric facilities applied and were granted pediatric exception. Instead, pediatric facilities without the exception rate provided specialized pediatric dialysis care usually at a financial loss, but as the right thing to do for this special population.

**Figure 1.** Kidney replacement therapy modality for pediatric (Ped) and adult patients for 2017. Transplantation (Tx) is the major modality for prevalent pediatric patients and 21% of incident patients underwent preemptive transplantation. Of prevalent pediatric patients receiving long-term dialysis, 38% (974/2,582) were maintained with home peritoneal dialysis (PD) compared with only 10% (51,656/518,155) of adult patients. Based on data for pediatric patients aged 0 to 21 years and adult patients 22 to 75 years and older in the 2019 Annual Data Report from the US Renal Data System, Tables D.7-10. Abbreviation: HD, hemodialysis.
The Medicare Modernization Act (MMA 2003) required that separately billable dialysis-related drugs, laboratory tests, and other items be included as part of the composite rate and led to the basic case-mix adjustment methodology effective January 1, 2005. The MMA ended application for pediatric exception but improved pediatric reimbursement. Under basic case-mix adjustment, the Centers for Medicare & Medicaid Services (CMS) elected to cover all pediatric patients younger than 18 years in any setting (pediatric or adult unit) using a 1.62 multiplier based on the historical exception rate for pediatric facilities. CMS rightly surmised that pediatric patients required more costly care and that failure to provide the right adjustment could impair access to care. The modifier was fair although deemed temporary until more pediatric cost data could be obtained. When the Medicare Improvements for Patients and Providers Act (MIPPA 2008) changed reimbursement to the current bundled prospective payment system implemented in 2011, the 1.62 pediatric multiplier was discontinued and replaced by much lower pediatric adjusters (1.033-1.277) based on age (<13 and 13-17 years) and dialysis modality (HD and PD). Modeling for pediatric adjusters was constrained by the small number of patients and limited data. The model eventually focused on lower volumes of PD fluid and doses of drugs for small patients compared with adults but did not take into account higher costs for specialty items and much higher nursing and ancillary service costs.

Impact of Policy Change

The current bundled prospective payment system once again underreimburses pediatric dialysis. With current medical economics, pediatric facilities are forced to consider closing or outsourcing pediatric dialysis, posing a threat to specialized care for this vulnerable population. Only 0.5% of prevalent dialysis patients are pediatric, with yearly incidence declining over the last decade. Children already are treated more often with home dialysis and transplantation, goals of the Advancing American Kidney Health Initiative 2019. Appropriate dialysis reimbursement will not make children’s hospitals or pediatric providers rich but will ensure that the longest survivors have access to proper specialty care to maximize outcomes and minimize lifelong complications. Most children’s hospitals have been unable to accurately represent the cost of pediatric specialty services and supplies in Medicare cost reports and claims data, sometimes putting extra costs under overhead when no other line item is appropriate. Likewise, the cost of care for the few pediatric patients dialyzed in multiple adult facilities is buried in facility costs dominated by adult care. Better ways of accurately collecting pediatric cost data and an ongoing dialogue between CMS and pediatric providers with commitment to realign payment with actual delivery of care is paramount to achieve correct reimbursement for pediatric dialysis.

**Supplementary Material**

**Supplementary File (PDF)**

**Figure S1:** Primary kidney diseases causing kidney failure in pediatric patients.

**Table S1:** Major legislation and regulations impacting pediatric dialysis reimbursement.

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