

Dialysis in Children and Adolescents: The Pediatric Nephrology Perspective

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The care of children with end-stage renal disease (ESRD) is highly specialized and often poorly understood by nonpediatric providers and facility/institution administrators. As such, this position paper has been created to offer provider, facility, and institutional guidance regarding the components of care necessary for children receiving dialysis. Key differences between adult and pediatric dialysis units are highlighted. Responsibilities and expectations of the members of the interdisciplinary dialysis team are outlined as they pertain specifically to the care of pediatric dialysis patients. Physical and staffing requirements of the dialysis facility are reviewed, again focusing on unique needs and challenges faced by the pediatric dialysis care team. Among these, vascular access options and proper planning of ESRD care are underscored. Pediatric quality-of-life metrics differ significantly from adult quality variables, and proper tools for assessment must be used. Endorsed by the Council of the American Society of Pediatric Nephrology (ASPN), this position paper serves as a reference tool for the provision of care to pediatric patients with ESRD.

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End-stage renal disease (ESRD) in children is rare, with a prevalence of 8,500 children in the United States according to the most recent US Renal Data System report.¹ Approximately 1,500 children develop ESRD annually in the United States, of whom two-thirds initiate with hemodialysis (HD) and one-third, with peritoneal dialysis (PD) therapy. Subsequently, less than half of all children are maintained on PD therapy, with a small majority maintained on HD therapy. Infants and young children are more frequently maintained with PD therapy as compared with older adolescents, who are more likely to receive HD.

Although this number is small relative to the adult ESRD population, children with ESRD are especially vulnerable because this chronic disease affects all aspects of maturation to adulthood and requires a lifetime of complex and specialized medical care. A further distinguishing element is the need for participation of a parent or adult caregiver in all aspects of the child's medical treatment. Although kidney transplantation is preferred, many children with ESRD are likely to require dialysis therapy initially prior to transplantation and again after eventual loss of a kidney transplant later in childhood or as an adult. The care that these children receive while on dialysis therapy is crucial to minimize life-long medical complications associated with ESRD, to optimize outcomes during time on dialysis therapy and subsequent transplantation, and to maximize overall quality of life (QoL) and social productivity.

Dialysis units with pediatric designation make up <0.1% of the total number of dialysis facilities in the United States, with most located at or near pediatric tertiary-care centers in urban areas of the country.² With the average census approximating 11 children per pediatric dialysis unit, only about half the American children receive care at a pediatric center, with the rest receiving dialysis services at an adult facility. In some regions, more children are dialyzed in adult facilities than in pediatric facilities. For example, in Illinois (ESRD Network 10), of the 227 children being dialyzed as of July 30, 2016, a total of 182 (80%) were treated in nonpediatric facilities, with 42 being treated at pediatric centers (CROWNWeb data accessed courtesy of The Renal Network, Inc on August 30, 2016). Lack of proximity to a pediatric center contributes to why a substantial

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proportion of children receive dialysis care at facilities focused primarily on adults, where members of the interdisciplinary dialysis team may have minimal or no training/experience in pediatric care. Proper understanding of both facility and staffing needs for pediatric dialysis requires familiarity with regulatory aspects of dialysis provision, as well as cognizance of the scope of clinical care needed to effectively treat pediatric patients with ESRD. In this document, the components of care necessary for children (defined here as persons younger than 18 years) on dialysis therapy are enumerated and important distinguishing features between adult and pediatric dialysis units are highlighted.

THE INTERDISCIPLINARY DIALYSIS TEAM

Overview

Members of the interdisciplinary dialysis team work together to plan and coordinate all aspects of individualized dialysis care for each child on dialysis therapy (Box 1). At a minimum, the team must consist of a nephrologist, nurse, social worker, administrator, and dietitian. To meet the specialized needs of children, many pediatric interdisciplinary teams routinely include personnel such as child life specialists, teachers, and psychologists, who play key roles in the child's day-to-day ESRD care and interact with the child and parent/caregiver. Many children have associated urinary outlet disorders requiring the surgical expertise of a pediatric urologist, especially to prepare the child medically for kidney transplantation. Optimally, team members for children on dialysis therapy have training and expertise in both dialysis and pediatrics that has been achieved through both formal and informal mechanisms, such as schooling, internships, networking, and educational conferences. In dialysis units in which team members lack specific pediatric training but nonetheless must care for children with ESRD, ready access to consultative colleagues in their disciplines both trained to care for children and intimately aware of current standards of pediatric dialysis care is imperative. Specifically,

Box 1. Pediatric Dialysis Interdisciplinary Team Members

Required
Nephrologist
Dialysis nurse
Renal social worker
Dietitian
Patient
Parent/guardian
Essential
Child life specialist
Schoolteacher
Psychologist

pediatric providers have expertise in the growth and developmental abnormalities associated with chronic kidney disease (CKD), and formal consultation should be considered in addressing treatment adequacy or proposing alternate therapies. Similarly, referral to a pediatric kidney transplantation center is imperative, and if this involves a different center than the dialysis unit, proper communication between the 2 facilities and the patient/patient's family is paramount.

In delivering comprehensive care, the interdisciplinary dialysis team must involve the family as an integral component of care planning and be mindful of how prescribed care affects the family unit. Unlike adults on dialysis therapy, most children have little autonomy to implement prescribed care routines that occur outside the dialysis unit. The team must strive to involve the child in a developmentally appropriate manner in their dialysis care and must work to make sure that parents/adult caregivers themselves understand the rationale for recommendations.

Medical Director

The medical director of the dialysis unit has ultimate responsibility for all administrative aspects of medical care provided to any child in that unit. This physician must ensure that all state and federal dialysis regulations are being met and that all clinical staff, including other nephrologists, have appropriate qualifications. In the case of an adult dialysis unit treating a child, the medical director should confirm that all members of the interdisciplinary dialysis team are comfortable with the provision of care to a child and that current standards of pediatric dialysis care are met. The specific responsibilities of the dialysis medical director and expected minimal care requirements are outlined in the Conditions for Coverage promulgated by the Centers for Medicare & Medicaid Services (CMS).^{3,4} It is expected by the CMS that a medical director will devote at least 0.25 full-time equivalent to this position. Many responsibilities of the medical director are independent of the dialysis unit census and require significant effort, even in small units. In pediatric dialysis units that generally have low patient volumes and are located in a children's hospital, institutional administrators must recognize this expected full-time equivalent commitment and the need for financial support to cover this portion of that physician's salary.

Nurse Manager and Nursing Services

The CMS expects dialysis units to have a nurse manager familiar with dialysis who oversees nursing services in the facility.⁵ In a facility dialyzing

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