

American Society of Pediatric Nephrology Position Paper on Linking Reimbursement to Quality of Care

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The pediatric ESRD patient is a member of a unique sub-population of ESRD patients. The cause of ESRD in the pediatric patient differs markedly from the adult patient; treatment modality in the pediatric ESRD patient differs substantially from the adult patient; and outcomes such as growth, development, and school attendance are also unique to the pediatric ESRD patient. In addition, the pediatric nephrology workforce differs substantially from the internal medicine nephrology workforce, and the delivery of care to pediatric ESRD patients is recognized to be more complex than the delivery of care to adult patients. The Center for Medicaid and Medicare Services (CMS) acknowledges the complex needs and labor-intensive nature of care of pediatric ESRD patients, and the CMS has had in place for several years a tiered physician reimbursement payment method based on age. Because of the unique characteristics of the pediatric ESRD population, any changes and alterations in reimbursement will need to take into consideration the multiple distinctive characteristics of this population of ESRD patients.

In anticipation of a move toward linking reimbursement to quality of care, the American Society of Pediatric Nephrology (ASPN) formulated this document to address a number of concerns. We review the epidemiology and demographics of pediatric ESRD, the unique characteristics of the pediatric ESRD patient, the pediatric nephrology workforce, and access of the pediatric ESRD patient to care. We also review the current state of guidelines for pediatric ESRD patients that are largely opinion based because of the few quality measures that have actually been investigated in pediatric ESRD patients. Finally, we discuss the potential effects of linking reimbursement to quality of care in pediatric patients and the current lack of tools and methods to establish such a policy in pediatric ESRD patients, and we offer our expertise in addressing the deficit of knowledge of many aspects of pediatric ESRD care.

Epidemiology and Demographics of Pediatric ESRD

Since 1988, the United States Renal Data System has produced an annual report on ESRD, including a pediatric section on ESRD. This report provides valuable information on the demographics, epidemiology, modes of therapy, morbidity, and mortality in pediatric patients with ESRD (1,2). The North American Pediatric Renal Transplant Cooperative Study (NAPRTCS) was organized in 1987 to obtain data on all pediatric renal transplant recipients in North America; NAPRTCS was subsequently expanded to include pediatric dialysis patients in 1992, and the registry was expanded further to include pediatric patients with chronic renal failure (estimated GFR <75 ml/min per 1.73 m² as calculated by the Schwartz formula) in 1994 (3). These two databases of pediatric ESRD patients provide information of the demographic characteristics; modes of therapy; morbidity and mortality; and use of Epogen, growth hormone, and other therapies for children with chronic kidney disease. These databases point out that the cause of ESRD in the pediatric patient differs considerably from the adult dialysis patient.

Children who are younger than 19 yr are always defined as pediatric patients, and adolescents who are aged 19 to 20 yr are also included in the pediatric age range by some organizations and databases (4–7). Children account for 1% or less of ESRD patients (1,2). Although comprising a very small percentage of the ESRD population, pediatric patients have unique characteristics and problems that need to be recognized, understood, and addressed when considering any alteration in ESRD policy or reimbursement. The cause of ESRD in pediatric patients differs considerably from the adult ESRD population (1–3). Although diabetic nephropathy and hypertensive nephrosclerosis have their adult antecedents in childhood, diabetic kidney disease and hypertensive nephrosclerosis are distinctively uncommon as a cause of ESRD during childhood. In contrast, obstructive uropathy with associated renal dysplasia is one of the most common causes of ESRD in children. The cause of ESRD in children varies according to the age of the child (1–3). At all ages, renal dysplasia with or without obstructive uropa-

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thy is a common cause of ESRD, whereas congenital nephrotic syndrome, cortical necrosis, autosomal recessive polycystic kidney disease, and hemolytic uremic syndrome also cause ESRD in infants and young children. ESRD in the school-age child and adolescent is more commonly caused by renal dysplasia with or without obstructive uropathy, glomerulonephritis, focal segmental glomerulosclerosis, and various forms of polycystic kidney disease. In addition to age, the gender and racial group of the child substantially influence the cause of renal failure (1,2). Survival rates also differ by age and modality. For example, by 5 yr after reaching ESRD, 69% of children whose end stage began between birth and 4 yr of age are still alive on dialysis compared with 82% of children in other age groups (1,2). In comparison, children who have received a kidney transplant have a better long-term survival, and transplantation is the preferred modality of renal replacement therapy in children (1,2).

The distribution of treatment modality is substantially different in the pediatric patient compared with the adult ESRD patient. Preemptive transplantation is the primary therapy for ESRD in many pediatric patients, and in pediatric patients who undergo dialysis therapy, peritoneal dialysis is used much more commonly than in the adult ESRD population (1–3). Of 6028 children enrolled in the dialysis segment of NAPTRCS, 3609 (59.9%) were maintained on peritoneal dialysis, whereas the remainder were treated with hemodialysis (3).

Unique Characteristics of Pediatric Patients with ESRD

The unique needs of the pediatric patient with ESRD includes emphasis on the importance of growth and development, school attendance and performance, family dynamics, nutrition, and psychosocial adjustment of the child and the family to a chronic disease. Growth failure has long been recognized in children with chronic renal failure, and in the past, most children with renal insufficiency exhibited profound growth retardation (8–11). The need for adequate, sustained growth and normal development set children apart from adults with chronic renal failure. Many factors contribute to growth failure in children with ESRD, including the degree of renal failure, inadequate caloric intake, renal osteodystrophy, intercurrent infections, anemia, metabolic acidosis, and renal tubular defects. Therapeutic intervention with adequate nutrition, correction of metabolic acidosis, appropriate use of phosphorus binders and vitamin D analogues, and growth hormone therapy have been shown to improve growth in children with ESRD (12,13). Provision of adequate nutrition is paramount to achieve optimal growth and requires a multidisciplinary team that includes a dietitian who is trained in providing nutritional advice to pediatric ESRD patients. Appropriate attention to linear growth and growth velocity is very important in pediatric patients with ESRD so that therapy with growth hormone can be considered and instituted at the optimal time. Attainment of normal adult height has substantial implications for the psychosocial well-being of an individual and for subsequent school and job performance.

An important difference in the pediatric patient with ESRD is

development and maturation of the brain, the acquisition of developmental milestones, and neurocognitive development. The role of the uremic environment on neurocognitive development is uncertain and is a vital area for research. Early studies of neurocognitive development were hampered by the inclusion of children's receiving aluminum-containing antacids and inadequate nutrition (14,15). A few recent studies suggested that development and neurocognitive outcome of children with ESRD is improved, but more subtle deficits resulting in poor school performance have been reported in many studies (16,17). Future studies and measurement of neurocognitive outcome in children with ESRD will be critically important to optimize the developmental and neurocognitive outcome of children with ESRD.

The task of childhood is to develop the skills and attitudes required for successful independent adult life. For pediatric dialysis programs, regular school attendance should be a primary goal of the overall success of dialysis therapy. Combining a dialysis schedule and regular school attendance can be difficult. Only 77% of North American children who receive maintenance peritoneal dialysis and 46% of children who are on hemodialysis attend school full time (3). Pediatric dialysis programs use various strategies to optimize educational opportunities for school-age patients. Chronic renal disease results in severe psychologic and social stresses for both the pediatric patient and the family (18,19). The impact of chronic disease on the emotional status of the patient's siblings is also well recognized (20). Given all of these complicated issues, the need for specialized psychological support for the pediatric ESRD patient and family is indisputable (21). The provision of this support by a highly specialized and multidisciplinary pediatric ESRD team can result in normalizing family dynamics despite the presence of a variety of challenging emotional and environmental issues.

The psychosocial impact of transitioning from pediatric ESRD care to adult ESRD care also presents unique challenges for the adolescent and young adult with ESRD, for the pediatric health care team who will transition the care of the adolescent and young adult, and for the health care team who will assume the care of the young adult. Tools and programs need to be developed to ensure that transitioning from a pediatric dialysis center to an adult dialysis center is as smooth as possible and is not disruptive to the medical care or psychosocial well-being of the young adult with ESRD.

Many aspects of quality renal care, such as therapy for anemia and renal osteodystrophy, dialysis adequacy, and vascular access, apply to both adult and pediatric populations. However, many of these have unique pediatric implications. Importantly, as discussed above, other aspects of quality of care are unique to the pediatric population, including growth and development, school attendance and performance, psychosocial adjustment, and family stress. Thus, any quality assurance program that is applied to this population must be driven by evidence-based outcome data that include measurement of these unique aspects of pediatric care.

Guidelines for Pediatric ESRD Care

Clinical pediatric nephrology has traditionally been hampered by the lack of data regarding the desirable outcomes noted above. In 1999, the ASPN published a paper on the optimal care of the pediatric ESRD patient, which was based largely on expert opinion (22). The Kidney Disease Outcomes Quality Initiative (K/DOQI) guidelines were initiated in 1997 by the National Kidney Foundation and represented the first comprehensive effort to give evidence-based guidance to clinical care teams and lead to improved care of patients in dialysis facilities in the United States. A major goal of K/DOQI is to develop concrete plans that could have a measurable impact on improving the quality of life for dialysis patients. The initial guidelines addressed adequacy of hemodialysis, adequacy of peritoneal dialysis, management of vascular access, and management of anemia. Each of these guidelines except the one for vascular access contained pediatric-specific guidelines. Because of the lack of valid data, the large majority of the pediatric guidelines were opinion based. Subsequent guidelines all have included pediatric-specific guidelines that also are largely opinion based. Several recent guidelines have covered in depth important aspects of care of the pediatric patient with renal disease (4–7). Pediatric K/DOQI guidelines that address nutritional issues, including evaluation of protein-energy nutritional status, management of acid-base status, energy and protein intake for children who are treated with dialysis, and vitamin and mineral requirements, were published in 2000 (4). Classification of stages of renal disease in adult and pediatric patients was published in 2002, guidelines for management of dyslipidemias were published in 2003, and guidelines for BP management were published in 2004 (5–7).

On the basis of the National Kidney Foundation's K/DOQI clinical practice guidelines, CMS funded the development of clinical performance measures (CPM) for adult patients who receive dialysis in the United States, and in 1999, the ESRD CPM project was initiated. The purpose of the ESRD CPM project was and still is to provide ESRD caregivers comparative data on their adult dialysis patients and to assist them in evaluating and improving patient care. At present, there are 13 ESRD CPM: Three measures to assess hemodialysis adequacy, three measures to assess peritoneal dialysis adequacy, three measures to evaluate vascular access, and four measures to examine anemia management. The initial data collection for the ESRD CPM was conducted in 1999, and this effort has continued on a yearly basis. A national random sample is drawn from the adult dialysis population. With the use of standard collection forms, the data are obtained and analyzed and serve as the basis for the annual ESRD CPM project report.

At this time, because of the lack of evidence-based clinical guidelines for children, CPM have not been developed for this patient group. However, CMS believed that it was critically important to collect and analyze pediatric patient data to stimulate improvements in pediatric dialysis patient care. Originally, CMS collected data only on pediatric hemodialysis patients who were between the ages of 12 and <18 yr and receiving in-center hemodialysis. More recently, CMS began to collect data for all pediatric hemodialysis patients who were

<18 yr of age. At present, no data are being obtained for pediatric peritoneal dialysis patients, and, as discussed above, the majority of pediatric dialysis patients are maintained on peritoneal dialysis (1–3). CPM data collected thus far for pediatric patients who are on hemodialysis has been extremely useful in demonstrating clinical practice patterns in this population and hopefully will serve as a template for the development of evidenced-based clinical practice guidelines for all pediatric dialysis patients.

Quality Assurance in the Pediatric ESRD Population

Pediatric nephrologists in general and the ASPN specifically have been involved with improving the care of children with chronic renal failure for many decades. As described above, the ASPN sponsored the development of a paper that addressed the optimal care of children on dialysis (22). Since its inception in 1969, the ASPN has sponsored an annual scientific meeting that is devoted to the advancement of pediatric nephrology. A consistent topic at the annual meeting is the optimal care of infants, children, and adolescents with ESRD with the goal that this information then will be applied to the individual patient. As described above, NAPRTCS was organized by pediatric nephrologists in 1987; this registry was initially devoted to children who had received renal transplants but has since been expanded to include children who receive maintenance dialysis therapy and children with chronic renal failure. More than 90% of children with ESRD are entered into this registry. An annual report is generated yearly to examine multiple characteristics of this population, including survival, anemia, growth, school performance, dialysis adequacy, dialysis access types and complications, and peritonitis rates. Individual centers are also given reports of their patient outcomes to compare with the national outcomes.

The ASPN has also advocated for pediatric representation on regional ESRD network medical advisory boards so that appropriate quality improvement could be extended to children who are on dialysis as well as adults. This advocacy has led to the majority of these boards' having pediatric representation and all having access to pediatric nephrology consultants. The ASPN is striving for representation on all network medical advisory boards. The ASPN also has advocated successfully for pediatric representation on the K/DOQI of the National Kidney Foundation to develop appropriate guidelines for children with ESRD.

On the basis of the previously described unique characteristics of the pediatric ESRD patient, it is compelling that these differences need to be understood and examined in detail before alterations in reimbursement for care of pediatric ESRD patients are considered. Appropriate outcomes measures in pediatric patients are likely to be different in pediatric patients compared with adult patients. The emphasis in most quality efforts in adults with ESRD has focused on improving patient survival, reducing dialysis complications, decreasing cardiovascular disease, and reducing hospitalization. Although these measures may have some validity in children, they are not likely to be the best outcomes measures for pediatric patients.

For example, mortality rates in children who are on dialysis are markedly lower than those in adult dialysis patients, although they are substantially higher than in the general pediatric population. Although a functioning arteriovenous fistula is acknowledged as the optimal dialysis access in pediatrics, only a small percentage of children have a functional arteriovenous fistula, and improving this will be difficult given the current surgical expertise and difficulty with vascular access surgery in small patients. Other outcomes measures, such as growth, development, and school performance, are very likely to be more appropriate in pediatric patients, although the outcomes of these measures are influenced by many factors other than the dialysis prescription and may not be modifiable by efforts of the health care team.

A limited number of studies have shown an improvement in outcome in adults with ESRD. From 1993 to 2003, the percentage of adults who were on dialysis and had a hemoglobin level >11 g/dl increased from 43 to 79%. Similarly, the percentage of adults who were on dialysis and had a $Kt/V >1.2$ increased from 74 to 89%, yet adjusted annual death rates have only declined 1.5%, from 22.7 to 21.2% (23). In children, Morris *et al.* (24) showed that 12 mo of erythropoietin therapy was associated with a decrease in left ventricular mass from 94 to 80 g/m².

Only a few studies in pediatrics have shown improvement in outcomes in children with ESRD to be associated with changes in peritoneal dialysis adequacy, but each study is short term and includes a small number of patients (25,26). No study has examined the effect of change in Kt/V on the outcome of pediatric hemodialysis patients, but one small study in 12 children showed improved growth with increased protein intake and increased urea reduction in pediatric hemodialysis patients (27). A study comparable to the HEMO trial in adults, which examined variations in the dialysis prescription on outcome, has not been performed in pediatric patients (28). In a large group of pediatric dialysis patients, a low serum albumin concentration upon initiation of dialysis was shown to correlate with increased mortality, but this association was not as pronounced as in the adult population (29–31). Similarly, in a large cohort of pediatric ESRD patients, decreased height, growth velocity, body mass index, and increased body mass index were associated with an increased risk for death compared with ESRD patients with more normal anthropometric measures (30). However, no large prospective study has been done in pediatric ESRD patients to show that changing any of these measures alters this risk for death. Thus, without more research, including prospective outcome studies in much larger groups of children on dialysis, it will be difficult to develop and implement appropriate quality outcomes measures in children with ESRD. Several retrospective studies to evaluate clinical performance measures in pediatric patients are currently under way and are likely to provide important information for the care of pediatric ESRD patients in the future (32,33).

As discussed previously, the logical quality measures for current use are the K/DOQI guidelines with the caveat that these pediatric guidelines are based almost exclusively on opinion or are not available. Some guideline goals may not be

achievable given the current therapies available; for example, there are very limited options for reducing cholesterol in children compared with adults as many drugs have not been tested for efficacy and safety in children, and, as noted above, arteriovenous fistula as a primary access is technically very difficult to create in small children. In addition, a fistula may not be the optimal access in a child who is maintained on hemodialysis for only a short time before transplantation.

A recent survey of pediatric nephrologists determined that <100 centers with pediatric nephrologists directly deliver dialytic care to children as opposed to many thousand dialysis centers that deliver care to adult ESRD patients (ASPEN survey, unpublished data). The average pediatric center has approximately 15 patients. Thus, changes in only a single patient can significantly change the percentage of any quality measure derived by aggregating patients. As a group, adolescents are the least compliant patients, making some quality measures difficult to achieve, such as serum phosphorus and BP goals, despite good intentions and active interventions on the part of the nephrologists and the health care team. These are just two examples of the difficulties that could lead to poor quality measure outcomes and consequently to reduced payments to physicians who care for pediatric patients. This is especially true when outcome rather than process measures are used for reimbursement, which in turn could impair access to dialysis facilities for pediatric patients who already have very limited choices. Many pediatric patients live great distances from a pediatric center and are dialyzed in an adult center that is closer to home. A reduction in payment when delivering care to pediatric patients could limit further the number of centers that are available to pediatric patients. Finally, no consensus has been achieved as to whether payment should be linked to attainment and maintenance of a quality measure or to continuous improvement in that measure. Furthermore, to use the Donabedian construct, there is no consensus as to whether the emphasis should be on improving structural measures, process measures, or outcome measures (34).

Despite these uncertainties and difficulties, the pediatric nephrology community continues to work to acquire information to improve the care of children with chronic kidney disease. The National Institutes of Health (NIH) clinical trial of therapy for focal segmental glomerulosclerosis and the NIH longitudinal Chronic Kidney Disease (CKiD) study of children with chronic kidney disease, each of which is currently under way, are good examples of efforts by the pediatric nephrology community to advance knowledge of kidney disease in pediatric patients. However, more studies that examine large numbers of children with ESRD are needed to obtain the data that will supply the optimal benchmarks for which to strive, perhaps by linking payment to this process.

Pediatric Nephrology Workforce

The care of children with kidney disease requires a coordinated multidisciplinary team approach that includes pediatric nephrologists, pediatric urologists, pediatric surgeons, vascular surgeons, transplant surgeons, renal dietitians, skilled pediatric nephrology nurses, social workers, child life specialists, and

transplant coordinators. Studies of the workforce who cares for patients with ESRD identified two major differences between the practice of pediatric nephrologists and that of internal medicine nephrologists (35,36). First, children and adolescents with ESRD require greater clinical time and supervision than adults with ESRD as a direct result of greater disease acuity and changing maturational and developmental status. Second, the vast majority of pediatric nephrologists work as full-time academic faculty or maintain significant affiliations with academic medical centers and do not devote all of their time to clinical activities (35,36). In addition, the distribution of pediatric nephrologists in North America is not uniform, and access to a pediatric dialysis unit is variable in different regions of the country (37). A few states, such as Wyoming and Montana, do not have a pediatric nephrologist, whereas California has 50 and New York has 57 pediatric nephrologists who are members of the ASPN (active, emeritus, and fellow ASPN members). On the basis of the most recent U.S. Census data and the membership of the ASPN (which may not reflect accurately the pediatric nephrology workforce in some states and areas), the number of pediatric nephrologists per capita is variable in different areas of the country (Table 1). The result is that in many areas

of the country, access to a pediatric nephrology dialysis facility that is staffed by a pediatric nephrologist requires significant travel by the pediatric patient. In addition, many pediatric dialysis units have small numbers of patients, and the demographic characteristics of the pediatric patient population in different geographic areas can be variable. Thus, determining the quality of care in an individual small pediatric dialysis unit can be substantially affected by a few patients who are outside the norm.

As described above, pediatric nephrologists and pediatric dialysis facilities are limited in number, and changes in the payment system that might result in less income could potentially reduce the number of viable pediatric dialysis centers and further impair the ability of pediatric patients to be cared for in a pediatric-specific facility. Dialysis units that predominately serve patient populations that are known to have problems with adherence to a medical regimen, such as adolescents and inner-city children, would tend to do poorly in models that pay on the basis of attainment of a certain measure that requires compliance. Adversely affecting the income of such units could cause further restrictions of access of this group of patients to appropriate dialysis care.

Conclusion

A major goal of the ASPN is to achieve the highest quality of care for all pediatric ESRD patients, and the ASPN strongly supports efforts to improve the care of pediatric dialysis patients. As described previously, there are compelling reasons to expect that linking quality to reimbursement in the pediatric dialysis population will need to be structured differently than in the adult dialysis population. The ASPN encourages the development of appropriate, reproducible, and easily measurable quality indices that improve the health and care of pediatric ESRD patients. This will require more research in large groups of children who receive maintenance dialysis to identify quality parameters and to test the validity of such measures. In formulating such quality measures, the unique characteristics of children who are on dialysis will need to be considered in detail by experts in the field. Once suitable quality measures for pediatric patients are identified and confirmed by testing, appropriate and due consideration can be given to linking payment to quality of pediatric dialysis care.

The nephrology community at large agrees with the ASPN on this issue. The American Society of Nephrology/National Kidney Foundation position paper on Payment for Quality I End-Stage Renal Disease states that some segments of the ESRD population will pose a challenge in terms of quality-based incentives. They specifically state that pediatric dialysis facilities are a particular challenge because they are few in number, have few patients, and have patients who tend to have multiple medical and psychosocial problems that require significantly more resources (38). Similarly, the Renal Physicians Association (RPA) position paper on Legislative Issues Related to Linking Reimbursement to Quality Measures in ESRD Care urges Congress to direct CMS to recognize that the unique characteristics of the pediatric dialysis patient population requires special consideration and that the likelihood that a performance-based

Table 1. Number of pediatric nephrologists per capita population in selected states on the basis of the most recent US Census data and the number of ASPN members in each states^a

Region	<i>n</i>
East	
Massachusetts	1 per 318,965
New York	1 per 333,532
New Hampshire	1 per 1,259,181
Pennsylvania	1 per 616,692
South	
Alabama	1 per 1,116,089
Florida	1 per 819,825
Tennessee	1 per 382,668
Virginia	1 per 598,977
Midwest	
Kansas	1 per 1,347,320
Missouri	1 per 351,856
Minnesota	1 per 414,357
Ohio	1 per 454,954
Mountain	
Colorado	1 per 1,104,428
Texas	1 per 561,184
West	
California	1 per 710,022
Nevada	1 per 702,024
Oregon	1 per 578,811
Washington	1 per 460,613
Canada	1 per 1,852,095

^aData from reference 37. ASPN, American Society of Pediatric Nephrology.

incentive system is inappropriate for these patients is significant (39).

Linking reimbursement to quality of care of pediatric dialysis patients is a worthy goal that is shared by the ASPN and CMS but will require a concerted effort to identify appropriate and reliable quality measures outcomes and processes. The ASPN looks forward to ongoing interactions with CMS and the NIH so that appropriate research can be conducted to develop valid quality measures in pediatric ESRD patients and in patients with earlier stages of chronic kidney disease.

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