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Pediatric Chronic Kidney Disease in North Carolina

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Chronic kidney disease (CKD) in children, adolescents, and young adults differs from that in adults both in terms of etiology as well as management. The typical causes of CKD are congenital or genetic in younger children and are acquired in adolescents and young adults.[1] Figure 1 depicts the primary causes of CKD in pediatric kidney transplant patients from the 2007 Report of the North American Pediatric Renal Trials and Collaborative Studies (NAPRTCS), a national representative registry. In addition to routine medical therapy, pediatric CKD management is often complex because it must incorporate the impact of CKD on physical health, growth and development, psychological issues, family dynamics, and educational development. There are a limited number of centers providing comprehensive pediatric nephrology care. Although transplantation is the preferred therapy for nearly all pediatric CKD patients with end-stage kidney failure, many patients remain on chronic dialysis. Similar to adults, treatment of pediatric CKD is expensive and burdensome (to the patient, the patient's family, and the health care system). Pediatric CKD is also associated with higher morbidity and mortality when compared to morbidity and mortality rates in the general pediatric population.[2]

> "With the rising incidence of obesity and type 2 diabetes mellitus in young children and adolescents, the incidence of CKD in adulthood is expected to increase over the coming years."

Across the spectrum of mild to severe disease, the prevalence of pediatric CKD is unknown. The incidence and prevalence of CKD in the most severe stage of end-stage renal disease (ESRD) requiring renal replacement therapy (RRT) via dialysis or transplantation are known. The national incidence of pediatric ESRD is 15 cases per million per year, and the estimated prevalence is 82 cases per million.3 The incidence of ESRD increases with age, from 13.0 to 32.6 per million per year in 13 and 19 year-old patients, respectively.1 Minorities are disproportionally affected by CKD in adolescence and young adulthood in part due to the higher incidence of certain glomerulonephritis in minority populations. The most common causes of CKD in adults (diabetes mellitus and hypertension) often have their origins in childhood but typically do not lead to kidney disease until adulthood. With the rising incidence

of obesity and type 2 diabetes mellitus in young children and adolescents, the incidence of CKD in adulthood is expected to increase over the coming years.

In North Carolina during 2005, there were 407 children, adolescents, and young adults less than 24 years old with ESRD.[1] The Organ Procurement and Transplantation Network (OPTN) reports that from 1988 to 2007, 365 kidney transplants have been performed in North Carolina pediatric patients (representing 2.6% of all pediatric kidney transplants in the US). And as of March 7, 2008, there were 38 active potential recipients on the kidney waiting list.[4]

The cost of ESRD in 2002 for all patients in the US was $25.2 billion (6% of the Medicare budget). North Carolina has the 10th highest prevalence of ESRD in the nation and accounts for 3.4% of the US ESRD population.[1] As of 2006 in NC, 6884 patients of all ages were covered under Medicare/Medicaid for SFY2006 and encumbered $839 million dollars for all medical expenses (Medicaid estimated cost data provided by A. Yow, Division of Medical Assistance, personal communication January 2008). With 1% of ESRD occurring in pediatric patients,1 we can estimate the cost of pediatric ESRD through public insurance at over $8 million in North Carolina for state fiscal year 2006. Private insurance and self-pay contributions are not included in these estimates. The cost of dialysis for children is high: $100,000 annually per patient. This tends to be higher than the cost for adults since a higher staff-to-patient ratio is required for pediatric patients and pediatric nephrologists fees are higher. Medication also contributes to the high costs, eg erythropoietin for anemia may cost $5000-$7000 per year and anti-rejection medication typically costs $7000-$20,000 per year.5·6

Medical and Cognitive Issues of Pediatric CKD

Similar to adults, the onset of CKD may be subtle in children. The signs and symptoms of the primary kidney disease and complications of progressive CKD may masquerade as other common childhood problems. Polyuria, polydypsia and delayed urinary continence are common symptoms of infants and children with congenital structural anomalies such as obstructive uropathy from posterior urethral valves and renal dysplasia. A number of metabolic complications occur, including metabolic acidosis, growth failure, rickets and anemia. Metabolic acidosis results from bicarbonate wasting and retention of organic acids. Uncontrolled metabolic acidosis, anorexia, protein-calorie malnutrition, and resistance to naturally occurring growth hormone in severe kidney disease can contribute to weight and statural growth failure. Impaired growth often leads to impaired self-esteem with lasting effects on overall quality of life in adult survivors of childhood onset CKD. Bone disease due to retention of phosphorus and eventual secondary hyperparathyroidism may cause orthopedic abnormalities such as rickets, genu valgum deformity, or slipped capital femoral epiphysis. Most patients with moderate to severe CKD develop anemia from inadequate erythropoietin production, but the availability of recombinant erythropoietin and iron supplementation provides an effective treatment.

The complexity of managing CKD and its associated comorbidities in children requires a specialized multidisciplinary medical team. Younger children with CKD require more surgical procedures than adolescents/young adults to treat urinary tract anomalies, orthopedic abnormalities, malnutrition (gastrostomy tube placement), or gastrointestinal dysmotility (fundoplication). The medical treatment of CKD includes phosphorus binders, bicarbonate supplementation, antihypertensives, erythropoietin, vitamin D analogues, recombinant human growth hormone, and immunosuppressive medication for certain forms of glomerulonephritis, autoimmune diseases, and transplantation.

Cardiovascular disease is a particularly concerning cause of morbidity and mortality among adolescents and young adults with pediatric-onset CKD. For patients 15 to 19 years of age, cardiovascular event rates are nearly 1000-fold greater among patients with ESRD when

compared to their age-matched peers from the general population.[7] The cardiovascular risk for survivors of childhood CKD remains very high. Cardiovascular mortality rates among patients with ESRD between the ages of 25-34 years of age are similar to members of the general population who are in their 80s.[8] Monitoring for hypertension and adequate treatment is paramount at all CKD stages for children because of its pivotal role in the development of cardiovascular disease. Left ventricular hypertrophy is a marker of end-organ damage of uncontrolled hypertension in childhood. With normalization of blood pressure, the hypertrophy resolves. Other concomitant cardiovascular risk factors include hyperlipidemia, obesity, type 2 diabetes, tobacco use, and specific disease states such as nephrotic syndrome, systemic lupus erythematosus, and vasculitis require special attention. Unfortunately, lipid testing for all pediatric patients with ESRD is only 56% for Whites and 48% for Blacks.[9]

Risk factors for adult development of CKD and/or hypertension may be seen in childhood. Prenatal events may predict chronic comorbidities later in life by impacting processes such as nephrogenesis that could result in reduced nephron number.[10] In turn, low glomerular number may lead to glomerular hyperfiltration, hypertension, and glomerulosclerosis.[11] The most studied *in utero* risk factors include low birth weight and prematurity. A recent study found that low birth weight was associated with a 70% increased risk for ESRD in a large birth registry from Norway over periods up to 38 years.[12]

Cognitive and academic achievement of children and adolescents are negatively affected by CKD.[13] Cross-sectional and longitudinal cohorts have demonstrated worsening intelligence quotient, memory, and attention as CKD progresses to ESRD.[14,15] These abnormalities are compounded by the presence of anemia, nutritional deficiencies, and uremic toxins. After transplantation, cognitive function often improves but does not completely normalize despite normal kidney function.[16,17]

For pediatric ESRD patients, hemodialysis and peritoneal dialysis are the 2 available forms of chronic dialysis therapy. ESRD patients under the care of pediatric nephrologists receive peritoneal dialysis 2 times greater than hemodialysis.18 Hemodialysis is not ideal, yet it is the more common form of renal replacement therapy among adolescents and young adults in the US[2] (as a great number of them are under the care of internal medicine nephrologists) due to the disruption of school participation with thrice weekly hemodialysis therapy, poor volume and hypertension control with intermittent therapy, and difficult vascular access. In adults hemodialysis access is accomplished optimally by surgical creation of an arterio-venous fistula, but this is not feasible in an infant or small child.[18] Consequently, infants and young children dependent on hemodialysis often utilize a central venous catheter for access. These catheters provide a portal of entry for pathogens with resulting insertion site infections and bacteremia. Typical community-based hemodialysis facilities do not provide services for children. Thus children who are hemodialysis dependent often travel to tertiary care facilities for routine hemodialysis. Parent-provided home peritoneal dialysis requires the surgical placement of a Tenckhoff catheter in the abdomen. Infections of the catheter site and peritonitis are the most common complications of peritoneal dialysis. These can be prevented completely or in part by strict attention to sterile technique. Peritoneal dialysis facilitates more regular school attendance. Nutrition and fluid intake may be more liberal when compared to hemodialysis and volume control improved due to the daily nature of peritoneal dialysis therapy.18

Transplantation is the preferred renal replacement therapy for nearly all children with ESRD, but minorities receive less kidney transplants compared to Whites.[2] Unlike adults, virtually all pediatric CKD patients are transplant candidates, and approximately 50% of pediatric transplants come from living donors. As an infant nears a body weight of 10 kg, renal transplant is feasible. Children typically do well after transplantation with 5-year graft survival rates of approximately 85% for living donor transplants and 80% for transplants from deceased donors.

Young infants and teenagers do less well, the former largely due to technical factors and the latter due to nonadherence to the medical regime.[1]

Successful transplantation resolves many of the problems associated with CKD. Unfortunately, some health conditions persist and others develop such as opportunistic infections, steroid-related impaired growth, osteoporosis, hypertension, and increased risk for malignancy. The medication regime is often complicated, requiring administration of several medications 2 or 3 times a day and contributes to the risk of nonadherence and transplant loss. The transplanted organ is expected to provide kidney function for an average of 12 years but may range from 0 to 30 years.

Pediatric ESRD Mortality, Hospitalizations, and Immunizations

According to the 2007 US Renal Data System (USRDS) report, since 1991 adjusted mortality rates from pediatric ESRD have increased 5% to 26.6 per million population in 2005 with girls having a higher rate than boys (28% related to cardiovascular events and 32% due to infectious diseases). The 5-year mortality rate for children less than 4 years of age on dialysis is 69%, which is higher than rates for children of other age groups.

When compared to adults, all cause hospitalization rates were 14% higher in children (2.1 vs. 17 per patient per year risk) in 2005. Admissions due to cardiovascular conditions increased 54% in boys and 64% in girls from 1993 to 2005. This is very concerning due to these patients' age. The same 2007 USRDS report highlighted the low immunization rate at no more than 30% for influenza, pneumococcus, and hepatitis B.[9]

Family and Psychosocial Issues of Pediatric CKD

Despite medical advances, the current leading cause for kidney transplant loss in adolescents is nonadherence to medical treatment.[19] Adherence among adolescents is compromised by both poor understanding and poor recognition of consequence, leading to inconsistent commitment to treatment regimen. A major impediment is that knowledge about their medical conditions is largely dependent on their parents' literacy. In 1997 the levels of literacy in North Carolina ranked 41st in the US with 52% of its population at a literacy level of ≤2 out of 5 on National Adult Literacy Survey (NALS) literacy scales.[20] People with ≤2 literacy levels cannot perform basic tasks like reading tables, graphs, or maps; and following complicated medical routines may be difficult. We have assessed literacy in 34 parents of children on peritoneal dialysis and demonstrated that children whose parents have lower literacy scores have significantly more peritonitis episodes and worse adherence to treatment than patients whose parents have higher literacy scores. Lower literacy was more prevalent among minorities. (See Figure 2.)

Chronic kidney disease places tremendous emotional, physical, and financial stresses on the family. Work schedules are interrupted as days or weeks are spent with the child in the hospital or attending medical appointments. Siblings often miss school while accompanying parents to medical appointments or feel neglected when the parent(s) spend so much time away from home. They also miss out on activities and emotional support since the parent is frequently immersed in the care of the child with CKD.[21] Time spent traveling to health clinics is a major problem; the financial burden is huge and difficult to measure as only certain costs are covered by medical insurance. There is usually no reimbursement for travel, parking, and meal costs. Physician and pharmacy copays can add up to hundreds of dollars per month. The Medicare Part D “doughnut hole” is a major problem for many families requiring them to pay substantial pharmaceutical costs. Moreover, parents of children with CKD experience high divorce rates.[22]

Respite services for parents of these children are needed but not typically available. Single week kidney camps are available for school age children (National Kidney Foundation Camp Wiwanawi, Camp Kaleidoscope, and Victory Junction Gang Camp) but do not provide consistent opportunities for respite care. Alternative support services such as patient and family support groups may be beneficial in identifying potential resources and for educational opportunities. Given the distance that families travel to see the pediatric nephrologists at tertiary care centers, utilization of parent and patient support groups is low.

Pediatric CKD patients require significant amounts of time and effort to coordinate their care. Although many patients have public or private health insurance, care coordination services are not reimbursed. The new North Carolina IMPACC (Improving Pediatric Access through Collaborative Care) program is evaluating the effectiveness of care coordination through case managers located at tertiary institutions. Most but not all pediatric patients become eligible for Medicare when they begin dialysis or receive a transplant. Each center also cares for undocumented immigrants for whom care becomes more complicated. Many are supported, at least in part, by the generosity of programs at the respective institutions and the communities that embrace them. These children are not eligible to receive a renal transplant in the US, so they must remain on dialysis or return to their native country, sometimes where neither dialysis nor transplant is available.

Pediatric Nephrologists in North Carolina

The pediatric nephrologist to population ratio varies greatly across the United States, with some states having no pediatric nephrologists at all, and others having as many as 1 per approximately 350 000 population.[23] In North Carolina, there are currently 9 full-time pediatric nephrologist equivalents providing clinical care, or about 1 pediatric nephrologist per 1 million population. These pediatric nephrologists are located in Chapel Hill, Charlotte, Durham, and Winston-Salem. Most internal medicine nephrologists are uncomfortable seeing children, especially those under age 12, and general pediatricians are not trained to care for the specialty needs of these children. This means that the entire eastern portion of North Carolina has no subspecialty services for children with kidney disease. In fact, based on the North Carolina Medicaid Access patient care-coordination registry at the University of North Carolina at Chapel Hill, the mean number of miles patients travel for nephrology services, (including thrice weekly hemodialysis), is 79.8 (standard deviation 25.2). Figure 3 depicts the home ZIP codes of children who have CKD who are in pediatric nephrology practices in North Carolina; the stars represent the location of these practices.

Transition and Pediatric CKD

Adolescents must begin the process of transition from parent-directed care to disease self-management and eventual transfer to internal medicine nephrology practices. Transition involves patients, families, and pediatric and adult health care providers. It also requires planning and coordination. With the help of a transition coordinator, the University of North Carolina (UNC) Kidney Center has developed and is currently validating tools for the transition process, including a medical passport, a self-administered transition-readiness survey, and the UNC T.RxA.N.S.I.T.I.O.N. Score.[a] The Children and Youth Branch in the North Carolina Division of Public Health is developing a Transition Tool Kit for health care providers, families, and youth with special health care needs (YSHCN) through the Carolina Health and Transition (CHAT) Project. With funding from the US Health Resources and Services Administration (HRSA), the CHAT project targets barriers in the availability of, and access

[a]Information about the Smooth Transition to Adulthood with Renal Disease (STARx) program and its components can be found at http://unckidneycenter.org/hcprofessionals/transition.html.

to, quality health care services by broadening awareness, teaching specific skills, and changing systems of practice for YSHCN, their families, and medical providers.

Once young patients reach age 19 and if they are no longer in school, they typically are no longer eligible for their parent's insurance coverage. These young adults are unlikely to gain employment with medical benefits. This creates a major problem and contributes to morbidity and sometimes to loss of an otherwise successful transplant since the patient cannot obtain the necessary anti-rejection medications.

Opportunities for the Management of Pediatric CKD in North Carolina

Given the shortage of pediatric nephrologists in the US and North Carolina, communication between specialists and primary care physicians is essential for effective co-management of children with chronic health problems.[24-26] Co-management of children with CKD in North Carolina requires effective collaboration, especially when many patients are located far from specialty care. Improving the rate of preventive primary services such as influenza and pneumococcal immunizations and increasing lipid testing rates may in turn decrease morbidity and mortality associated with infectious processes and cardiovascular risk factors.

Systems such as NC health-link (a consultative telephone resource) help with this problem. But despite multiple apparent advances in technology assisted communication (eg, electronic medical records), timely and effective communication is often prevented by delays in completing records, incompatibilities between electronic systems, and the endless pressures of time for both specialists and primary care physicians.[26] Parents are often required to be the primary communicators among physicians.27 Efforts should be made to standardize electronic medical records and emphasize timely, effective communication among providers.

Continued support of outreach education programs by pediatric nephrologists for primary care providers via the NC Area Health Education Centers (AHEC) program and through Internet-based educational modules is paramount. Education of internal medicine nephrologists in the care of certain pediatric problems may be a partial solution to the successful transition of adolescents and young adults into community-based health care.

In addition, acquisition of disease self-management skills in the context of transition will facilitate improved health outcomes among adult survivors of childhood-onset CKD. Culturally-sensitive patient education efforts need to take into consideration the lower literacy levels of some of the patients and families being served. This in turn may increase transplantation rates for underrepresented minorities.

Recognition of the complexity involved in treating children with CKD is essential and requires an interdisciplinary approach with care coordinators to facilitate disease management. Yet, the number of pediatric nephrology care coordinators in NC is low and reimbursement for case management-related services is poor. An interdisciplinary approach to pediatric CKD, one that includes nutritionists, social workers, nurses, psychologist, educators, physician extenders, and physicians, indeed has been established as standard of care. Yet many of the team members needed for a successful interdisciplinary care are not always available. Similarly, access to care is hindered by patients' limited access to tertiary care centers.

Early detection of pediatric kidney disease may minimize complications, improve care, and decrease costs. One method may be to expand the reporting of estimated glomerular filtration rate (eGFR), the most direct reflection of overall kidney function, from laboratory reports of serum creatinine. The provision of an eGFR for adults appears to have improved recognition of kidney function impairment in adults. This could be accomplished with an automated identification program such as Schwartz eGFR auto-calculator.

Prevention of congenital causes of pediatric CKD is difficult, but early detection with prenatal ultrasound leading to early interventions will improve outcomes for many of these children. Recognition of urinary tract infections to identify children with urinary tract anomalies is critical, as is screening siblings of patients with vesico-ureteral reflux. Other preventive/early identification efforts should include screening children of adult patients with hereditary kidney disease.

Some forms of acquired kidney disease can be avoided such as obesity-related nephropathy, type 2 diabetes mellitus, and diabetic nephropathy, many of which begin during the pediatric ages. Early detection of children with hypertension will allow more effective treatment and may decrease cardiovascular morbidity later in life. Accurate measurement of blood pressure requires standardized techniques, availability of appropriate size cuffs at primary care clinics, and automated blood pressure percentile calculators.

Understanding the increase in the last 16 years in cardiovascular-related hospitalizations and deaths in pediatric CKD patients is paramount. A statewide registry of pediatric CKD cases would provide longitudinal information to track incidence, prevalence, disease progression, financial/physical/family impact, hospitalization, and morbidity/mortality rates. The registry could also track the transition process for these patients—while low in number—need care that poses significant costs to the state. A population-based registry may validate generally accepted but incompletely validated decision support algorithms, and may provide insight related to the increase in hospitalization and mortality rates that pediatric ESRD patients are experiencing.

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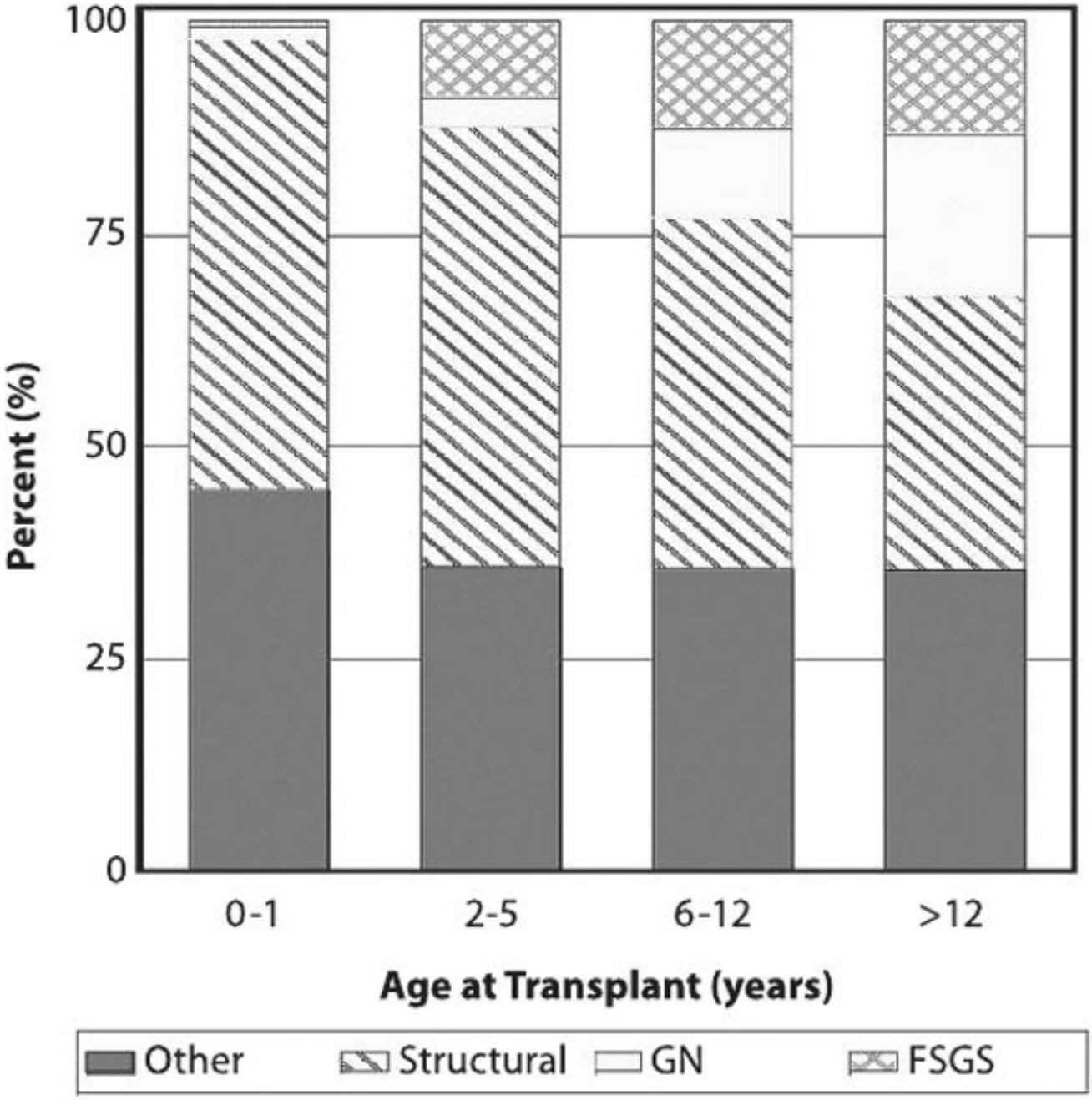

Figure 1. Transplant and Primary Diagnosis by Age, 2007, Among Pediatric Patients
Structural - includes congenital abnormalities of the kidneys, ureters, or bladder; GN - glomerulonephritis; FSGS - focal segmental glomerulosclerosis.

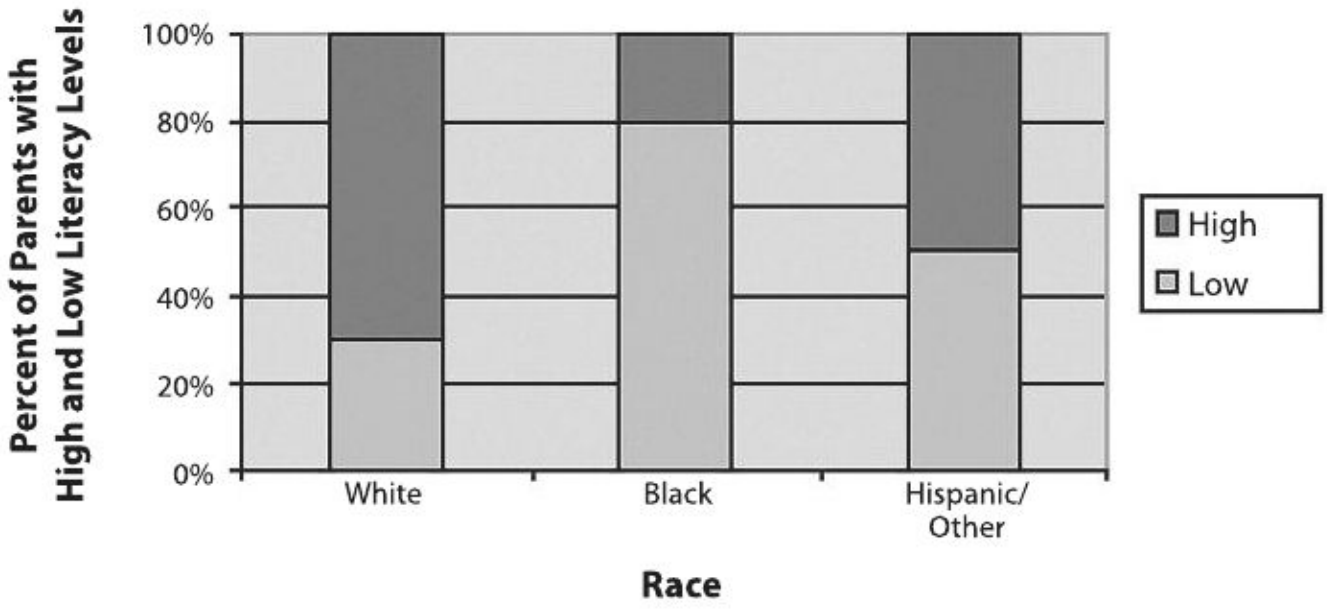

Figure 2. Literacy Levels in Parents of Pediatric Peritoneal Dialysis

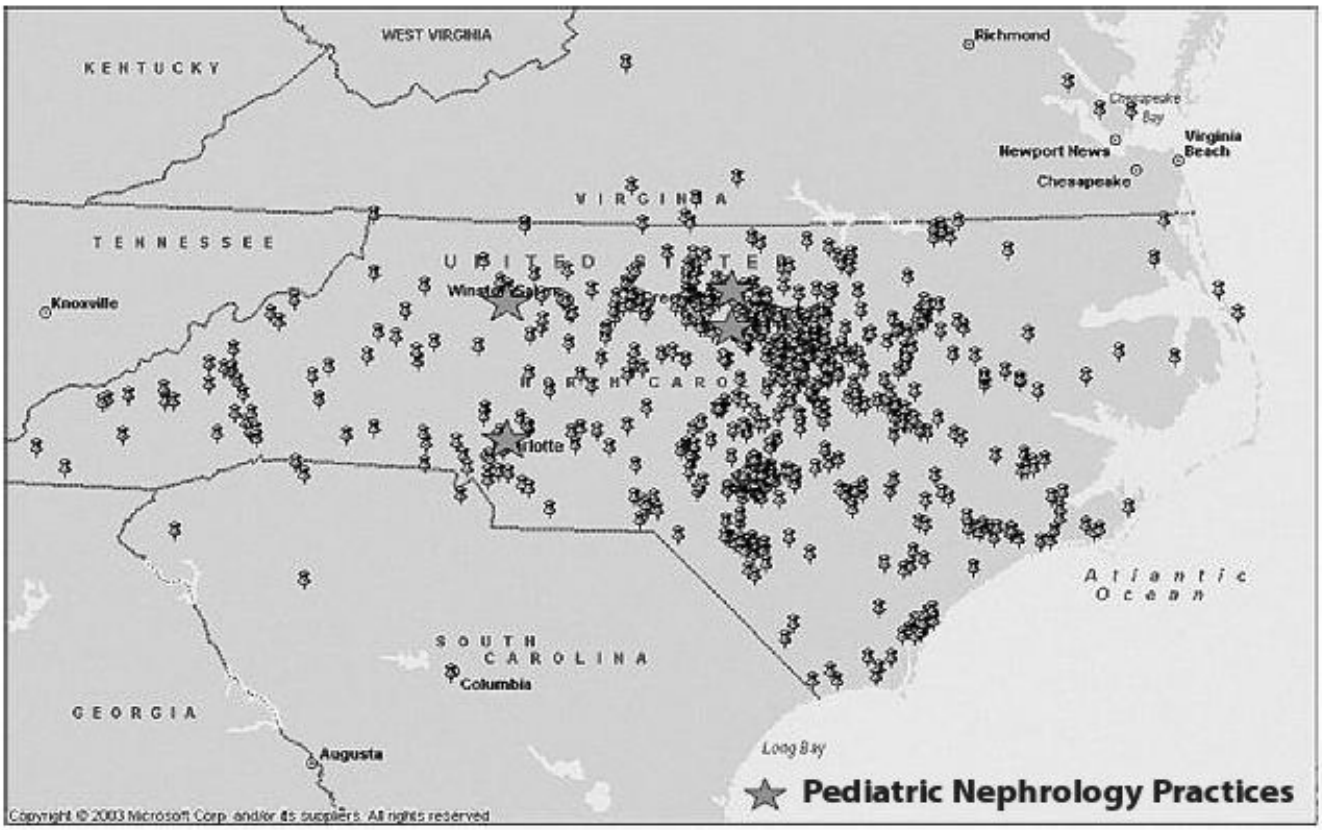

Figure 3. Home ZIP Codes of Children Who Have CKD and Who Are in Pediatric Nephrology Practices in North Carolina