Chronic Kidney Disease in Early Life: The Impact on Cognition, Education, and Workforce Integration

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The majority of children affected by chronic kidney disease (CKD) will survive to adulthood (1, 2). Adult survivors of childhood onset end stage renal disease (ESRD) will carry with them a legacy of ESRD and its attendant complications, including effects on cognition, education, and employability.

Children with ESRD are at risk for cerebral atrophy, silent and symptomatic cerebrovascular infarctions, and ischemia. However, the cognitive function of children with CKD may be impaired despite normal results on brain imaging. ESRD has been shown to have a negative impact on IQ, memory, and attentional functions (2). Furthermore, in the national Chronic Kidney Disease in Children (CKiD) study 30 percent to 40 percent of children with mild to moderate CKD (estimated glomerular filtration rate 40 to 90 ml/min/1.73 m2) scored more than 1 standard deviation below the healthy population normative mean in measures of IQ, academic achievement, attention, memory, and executive function (3). Pilot data have shown that IQ improves by an average of 12 points in children with ESRD after receiving a kidney transplant (4). This finding suggests that some of the cognitive impairments demonstrated in dialysis-dependent children with ESRD may improve with resolution of uremia.

Education is often disrupted in children with ESRD due to medical appointments, procedures, and illnesses. Given the documented challenges to cognitive function and chronic illness, one would expect that 40 percent to 45 percent of children with ESRD would receive special education services. Unfortunately, children with ESRD have the same 15 percent placement rate in special education programs as the general United States population of children (5). Additional research is required to assess the type and value of special education services for children within the CKD/ESRD continuum.

Employment status has been evaluated in adult survivors of childhood-onset ESRD (6). In a Dutch cohort, 67 percent of the patients in the study were employed, which is substantially greater than published employment rates of 25 percent to 50 percent of adults with adult-onset ESRD in several other studies (6–10). Compared with healthy age-matched controls, adult survivors of childhood-onset ESRD were more likely to be unemployed involuntarily (19 percent versus 11 percent) and to be employed in positions requiring a lower level of training or education (6). Another study found that adult survivors of childhood-onset ESRD had a 10 point to 15 point decrement in IQ compared with their healthy age-matched counterparts and tended to have a lower final educational/training level than the general population (11). It is hypothesized that health-related disruptions in typical developmental experiences and in education contribute to these findings.

Although additional investigation is required to bolster our understanding of the factors that contribute to the cognitive and educational challenges experienced by children with CKD, we now have evidence documenting the resilience of adult survivors of childhood-onset ESRD based on their employment rates. Our next step is to identify effective intervention strategies to maximize cognitive development, educational achievement, and prospects for employment opportunities equal to the general population.

References

Optimizing Adherence in Youth With Kidney Transplants

By Bethany J. Foster, MD, MSCE, and Sandra Amaral, MD, MHS

Adhering to a strict medication regimen is difficult for anyone, but for the particularly challenging for adolescents and young adults. Adherence is a skill that must be learned, and it requires organization, advanced planning, and good problem-solving skills, tools that adolescents and young adults are still developing. In fact, the part of the brain responsible for planning and for considering the impact of actions taken (or not taken) is not completely developed until one reaches their mid-20s! In addition, adolescence is a time for testing limits, trying new things, and exploring different identities—activities that are not particularly compatible with sticking to a strict medication schedule.

Perhaps, not surprisingly, studies that compared medication adherence in teenagers and young adults with that in younger children and older adults have been unanimous in their conclusions: medication adherence is worse among teens and young adults. Unfortunately, a few missed doses can have significant and irreversible consequences for young kidney transplant recipients. Teens and young adults who miss medications and experience rejection episodes are less likely to achieve complete reversal, leading to loss of kidney function and often complete graft loss. Youth between the ages of 17 and 24 years have the highest risk of renal allograft failure of any age group, regardless of their age at transplant (1).

Although poor adherence is not the only factor mediating graft loss among youth, it certainly plays a major role.

But what can we do to try to improve medication adherence among adolescents and young adults with kidney transplants? Think of the African proverb “It takes a village to raise a child.” To meet the challenge of medication adherence in this age group requires a collaborative team effort from health care providers, the patient, and their family (2, 3). A number of risk factors for poor adherence have been identified, including factors related to the medication regimen, the health care team, and social aspects. A multifaceted approach is needed to address these risk factors. As clinicians, anything we can do to simplify a patient’s medication regimen—from fewer pills per dose to fewer doses per day—may help young people become more adherent with their treatments. It is also important to ask about side effects. An open and nonjudgmental attitude on the part of health care providers is crucial to promote trust and may also result in better adherence. Adolescent and young adult patients should be interviewed independently from their parents and asked directly about their adherence practices. Questions should be open ended and acknowledge that taking medications every day is difficult. Social factors associated with adherence may be more difficult for a health care team to address. A clinical care team cannot change a family’s structure or financial situation. However, clinicians can provide resources and help families think ahead to prevent lapses in insurance and the supply of medications. Whenever possible, the consistent involvement of a social worker is recommended.

There is no known sure-fire method of improving medication adherence. Education aimed at improving patients’ understanding of their medications, how they work, and why they need to be taken regularly is certainly believed to be necessary, but education alone is clearly insufficient in promoting adherence. Adherence experts suggest that we must not only provide our patients with knowledge, but teach them the skills they need to be adherent, including organizational and problem-solving skills. The first step in teaching problem-solving skills related to medication adherence is to explicitly acknowledge the challenges of consistent medication...