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

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

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 executive functions (2). Furthermore, in the national Chronic Kidney Disease in Children (CKD) study 80 percent to 40 percent of children with mild-to-moderate chronic kidney disease (CKD) had a lower final educational/training level and cognitive development, educational achievement, and prospects for employment opportunities equal to the general population (3).

The first step in teaching problem-solving skills is to explicitly acknowledge that taking medication 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 mediating 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 adherence.
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Optimizing Adherence

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adherence. This may open the door to a more meaningful conversation about adherence. The second step is to find out what interferes with this particular patient taking her medications on schedule. Some of the most common barriers to adherence cited by parents and patients include forgetfulness and poor planning or scheduling (2, 4). In order to overcome these barriers, parents and patients must work together at home to establish routines and clarify roles and responsibilities in managing the medical regimen. The clinician may help families to find solutions to adherence barriers. Simple solutions work best and may include things like setting cellphone reminders or using a pill box. The key is to help the patient to find their own solutions, rather than to "prescribe" solutions for them. Although this approach is certainly more time consuming, it is much more likely to be effective. When possible, having the patient and caregiver meet with a psychologist can be very helpful. Both the patient and the caregiver need to be reminded that adherence is a process and that difficulties with adherence are not always solved on the first attempt.

Clinicians can encourage ongoing parental support, and may guide the gradual transition of responsibility for medication-related tasks from parent to adolescent. It is helpful to establish realistic expectations and assess how much a patient can really do on their own. The process is not easy, and may involve a certain amount of trial and error. To help parents understand the process, clinicians can make parallels between other life skills that a child will gain in adolescence, like doing chores or learning to drive. These tasks also are learned skills, which take time and effort and are most successfully accomplished with gradually decreasing supervision and support from parents.

Adherence should be discussed explicitly at every visit. Just as we would follow up a rash or the effects of a new medication, clinicians should follow up the results of a plan made with the patient to increase adherence. We must find out what worked and what didn’t, and celebrate small successes. As adolescents develop and face new challenges, we must also try to anticipate new adherence challenges. Changes in routine, such as summer breaks or starting college, can pose disruption and can usually be anticipated and discussed in advance.

Support from family and friends is one of the most important factors promoting adherence. Some patients for whom family support is unavailable may benefit from the involvement of a close friend. Clinic visits should be inclusive to significant others or friends, and patients should be encouraged to bring support with them if they choose to do so. Some families find support in the waiting room. Providing opportunities for caregivers to meet each other and patients to interact can be very valuable by providing opportunities to share experiences and find positive role models.

The best approaches to promote medication adherence in adolescents and young adults are inclusive to the family, patient, and health care team but are individualized, and focused on the patient. Remember to empower the patient to identify their own stumbling blocks and pinpoint ways to overcome them. And, above all, remember that adherence may wax and wane; providers must be attentive and provide consistent support throughout.

Dr. Amaral is affiliated with the University of Pennsylvania and The Children's Hospital of Philadelphia, Philadelphia, PA. Dr. Foster is affiliated with McGill University, Montreal, Quebec, Canada.

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