

opment until their mid-to-late 20s. Given these challenges, it may be difficult for the adolescent ESRD patient to cope with expectations of increased self-management and independence in the adult care system. Therefore, the high-risk period of adaptation to adult care may be a critical window during which intense support is warranted.

We can conclude that the relationships and interactions between age, graft-failure risk, and transfer of care are complex. In reviewing the current evidence it is difficult to distinguish graft-failure risk attributable to age from that conferred by transfer of

care. Patient and health care system factors may all contribute to age-related graft-failure risk. Perhaps, the most important question is how to improve graft outcomes in this vulnerable age interval. This is most likely to be achieved by providing care that is well matched with the developmental needs of this age group. The first step will be to identify patient-, provider-, and system-level factors associated with better outcomes. Then trials need to test multi-component interventions at the patient, provider, and system levels to optimize care for this group of patients. ●

Drs. Samuel and Foster are affiliated with McGill University, Montréal, Quebec, Canada.

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Nephrology Transition 101

By Miriam Kaufman, MD, FRCPC

Pediatric nephrology encompasses such a wide variety of conditions and illness severities that it may be hard to imagine that any one transition model could fit for all of nephrology. While it is true that transition programs must be adapted for different populations, there are basics that apply to them all. These include starting young, ensuring knowledge of one's condition, promoting self-management, introducing the patient and family to the adult system, facilitating appropriate transfer planning/documentation, and providing young adult care that is developmentally appropriate (this last factor is discussed in another article in this issue).

Starting young

There is no research that proves the ideal age to start transition preparation, but many policy statements and consensus papers strongly suggest starting early without suggesting a specific age. One advantage of bringing up the idea of transfer to adult care early is that it gives parents hope that their child will survive into adulthood and that plans are being made—they won't just be “kicked out” when the time comes. Some young people also get the idea that they won't have their condition when they grow up, since they only see other children at their clinic appointments; raising the issue of transfer and transfer planning from the time of diagnosis may prevent this thinking. One tool for early transition and self-management is the *Ready, Set... Good 2 Go* nephrology timeline (http://www.sickkids.ca/pdfs/Good2Go%20Transition%20Program/33902-42487%20sign%20G2Go_Nephrology.pdf). Adapted from work done at Seattle Children's Hospital, the timeline can be distributed to parents at time of diagnosis, and it includes suggestions for promoting important skills in a number of domains, including social, self-care, education, and medical/health. The suggestions are aimed initially at parents caring for their young children during three key develop-

mental periods (ages 0 to 3, 4 to 7, and 8 to 11 years) and then shift to providing guidance to young people (ages 12 to 15 and 16 years and up). Many of the suggestions include practices that parents naturally follow with their healthy children but, in the interests of protecting their child with a kidney condition, might not pursue.

Ensuring knowledge of condition

Conversations about a child's medical condition are usually conducted with parents, and although the child is often present during these talks many children aren't capable of understanding the information or believe that it isn't important that they know it. This can discourage young people from developing a sense of ownership of their condition and their own health care. To move into the adult system, youth must have a basic understanding of their condition and their course through it, as well as an ability to describe important aspects to new health care providers. As children enter new phases in their lives—such as starting kindergarten, going into fourth grade, or junior high and high school—developmentally appropriate information should be reviewed with them. At age 12 or 13 years, they can learn a Three Sentence Summary (3SS) that will let them easily transmit information. The 3SS is similar to how medical trainees present a case to their staff, and can be reviewed and practiced a few times a year. Patients can also make a MyHealth Passport (<http://www.sickkids.ca/myhealthpassport>) with the assistance of a nurse or doctor. This online program allows patients or parents to easily enter their health information and then both print a wallet-sized card and save a PDF to store on their computer or other device.

Promoting self-management

Although parents often envision themselves as taking care of their child forever, it is important that young people take charge—as

much as possible—of their medication, diet, treatments, and other aspects of their care. Even children who have significant learning problems or cognitive delays can take responsibility for some of these issues. There is no gold standard for self-management in children yet, although some are using groups, online programs, and individual counseling to help young people become more responsible for their own care.

Introduction to the adult system

The fear of the unknown is common, and this can be exacerbated for children and parents who often hear from pediatric providers and patients that the adult system is a horrible place where parents will be ignored and young people are not welcome. Clearly, pediatric nephrologists need to be careful of what messages are conveyed to families. Having an introduction to adult providers and clinics before transfer can be extremely helpful in dispelling myths and “setting the stage” for new health care relationships. This can take the form of a joint clinic at the adult or pediatric clinic; a transition education event attended by members of both programs, patients, and families; or a virtual tour and introductions to adult providers.

Appropriate transfer procedures

Although transfer is but one point in the transition process, it is essential that a complete (yet succinct) medical, nursing, psychosocial, and pharmacological history is communicated to adult care providers, along with a copy for the young person. If possible, a verbal handover of information is invaluable, especially if the pediatric team can communicate some of the positives of the young person's personality or behavior. Young people should be given information about where the new clinic is, who to call in case of an emergency, and any other important details. Insurance issues need to be dealt with before the transfer. The transfer checklist used at the Hospital for Sick Children

can be found on the Good 2 Go Transition Program's website (<http://www.sickkids.ca/Good2Go/Transition-Interventions-Tools/Readiness-checklists/index.html>).

Developmentally appropriate services for young adults

The demographics of adult hospitals are clearly skewed towards the geriatric age range. Clinic staff who recognize that young people are still finishing their brain development—and whose executive functions are therefore not fully mature—will be able to approach the young person in a way that recognizes that they are no longer children but have needs that are different from adults. This does not mean that young people must be “babied” but rather that they will still need help in developing the skills that they need to be self-managing, self-advocating members of their health care team.

When does transition end?

The many life transitions that happen at the end of childhood have different end points (graduation from high school or postsecondary education, finding a life partner, getting a job with good benefits, and becoming autonomous in medical management) and are also met at different ages, sometimes with backward steps along the way. Many adult providers talk about the clinic visit where the “light bulb went on” for a young person in their mid-20s. This could be considered to be the moment when the health care transition ends. Many times there won't be such a clear-cut event, but rather a gradual move towards maturity and responsibility. A patient-centered approach should incorporate the changing needs of the now-mature patient and the health care challenges that go with being an adult with a chronic health condition. ●

Dr. Kaufman is affiliated with The Hospital For Sick Children, Toronto, Ontario, Canada.