The Transition from Adolescent to Adult Care

Reduced Kidney Transplant Survival in Adolescence and Young Adulthood: Is it Due to Age, Transfer of Care, or Both?

By Susan Samuel, MD, MSc, and Bethany J. Foster, MD, MSCE.

Kidney transplant survival is worse among adolescent transplant recipients compared with older and younger recipients. There are likely complex factors operating at both patient and health care system levels contributing to the increased risk for graft failure in adolescents.

Poor kidney allograft survival was first reported in 1997 by Cecka and colleagues (1). Using the United Network Organ Sharing database, they demonstrated that the 5-year graft survival rate among 13- to 21-year-old kidney transplant recipients was worse than the rates observed in other age groups. Subsequently in 2002, Smith and colleagues (2) showed an increased risk of graft failure in 13- to 17-year-old transplant patients registered in the North American Pediatric Renal Trials and Collaborative Studies database. They also observed that there was a significantly higher number of late acute rejection episodes among those receiving transplants between 6 and 17 years of age compared with younger age groups.

These two studies identified adolescent age at the time of transplant as a determinant of poor graft survival, but did not consider the possibility that it is adolescence itself (a developmental period) that determines graft failure risk. Almost all pediatric transplant patients will eventually enter adolescence—a period of major physical, cognitive, emotional, and social development, and of increasing independence. Adolescence can be a volatile and turbulent time in some patients, which makes this period ripe for complications. It is during this vulnerable developmental stage that almost all adolescents are transferred to adult care—around 18 to 21 years of age in most pediatric institutions across North America. Behavioral changes associated with adolescence and upheaval related to transfer of care may combine to increase the risk of graft failure during this period.

Recently, our group estimated age-specific graft failure rates using the United States Renal Data System (USRDS) database (3), and showed a gradual increase in graft failure rates starting at 11 to 12 years of age, peaking at 19 to 21 years of age, and declining thereafter. Compared with 25 to 29 year-olds with the same time elapsed since transplant, graft failure rates were 20 percent higher among 17 to 24-year-olds, regardless of the age they received the transplant. This study provided strong evidence that graft failure risk is age dependent, and that late adolescence and early young adulthood is a high-risk period. This study did not refute the earlier studies’ conclusions that adolescent age at transplant is a risk factor. Rather, it indicated that individuals transplanted as adolescents enter immediately into a high-risk period. We were unable to account for the effect of transfer of care because transfers are not captured well within USRDS databases.

In 2007, the U.S. Government Accountability Office commissioned a report to investigate whether pediatric transplant recipients are more likely than their adult counterparts to lose access to immunosuppressive medications once Medicare coverage for end stage renal disease (ESRD) ends 3 years after receiving a transplant (4). They used USRDS databases to study this problem. Although the investigators of the report did not find that graft failure was necessarily associated with loss of Medicare, they found that graft failure risk was higher at 3, 5, and 7 years after transplant for patients who had an 18th birthday during observation period compared to older and younger patients. This high-risk group of patients was defined as “transitional” patients as some of them would have been transferred to adult care during the observation interval. This study also could not ascertain the effect of transfer of care due to the limitations of USRDS data. We could postulate that poor transfer of care may have had a role in determining high graft-failure rates in transitional patients. The association between graft failure and age, therefore, has been clearly characterized in these two studies, but further studies are needed to identify the factors mediating the relationship between age and graft failure and, in particular, the role of transfer of care.

The higher graft-failure risk during adolescence and young adulthood has been postulated to be due to a state of net immunosuppression related to some or all of the following factors: puberty-related changes in immune reactivity, de novo exposure to viruses, and under-dosing of immunosuppression medication during a period of rapid growth and nonadherence. Nonadherence with immunosuppressive medications is probably the most widely cited explanation for poor graft outcomes during adolescence. The prevalence of nonadherence among adolescents can be as high as 43 percent. Several studies have shown a greater degree of nonadherence in adolescents compared with older and younger patients. Failing to take immunosuppressants can be a cause for late acute transplant rejection. Therefore, Smith’s finding of increased late rejection and incomplete rejection reversal in the adolescent age group supports nonadherence as a potential mechanism of graft failure in this age group (2).

There are many reasons for nonadherence. Some have suggested that nonadherence may increase immediately following transfer from pediatric to adult care leading to graft failure. This idea was first put forward over a decade ago by Alan Watson, who observed unanticipated kidney transplant failures in seven of 20 patients in the 3 years following transfer of care. Although studies using large USRDS datasets were unable to account for the effect of transfer of care when examining the relationship between age and graft failure rates, a study of Canadian pediatric transplant recipients found a 2- to 5-fold increased risk in graft failure during the period immediately following transfer from pediatric to adult care (5). Nonadherence after transfer of care could not be quantified in this study.

Poorer graft survival after transfer of care suggests that sudden changes in health care system and provider characteristics may create an environment that exacerbates nonadherence and other behaviors that can accelerate graft failure. Medical care for pediatric patients with ESRD generally tends to be intense and multidisciplinary. Staff-to-patient ratios are high and a large amount of time is usually spent on each clinical encounter. Detailed attention is paid to patient compliance with medical appointments and medication. Although such intense support may not be medically necessary for most adult patients, a sudden change in type of care after transfer to adult-oriented care may be disorienting to pediatric patients, who have been accustomed to receiving intensive care and attention all their lives. The shift of focus from family to the individual—with emphasis being placed on the patient’s responsibility for his/her own care—has been identified as a factor which may contribute to impaired adherence to therapy following transfer to adult care.

For individuals with ESRD, adapting to transfer of care may be particularly challenging. On the surface, most adolescent and young adult kidney transplant recipients look like their healthy peers. It is easy to forget that they may have severe cognitive deficits related to childhood exposure to renal failure or other medical problems. It is even easier to forget that even healthy adolescents—while physically fully mature—do not complete frontal lobe development.
The Transition from Adolescent to Adult Care

There is no research that proves the ideal age to transition from pediatric to adult care. In reviewing the current evidence it is difficult to determine a particular age at which the transition should occur, as it depends on the individual patient and their family. The transition process must be adapted for different circumstances, including the patient’s age, the severity of their condition, and their ability to cope with external stressors.

Starting young

There is no research that proves the ideal age to start transition preparation, but many policies and programs suggest starting early without specifying a specific age. One advantage of beginning the transition process early in childhood is that it is easier to gently introduce the idea of adult care and help children understand the concept.

Ensuring knowledge of condition

Conversations about a child’s medical condition should be ongoing and adapted to their developmental stage. These conversations should include discussions about the child’s condition and their own health care. As children enter new phases in their lives—such as starting kindergarten, going into fourth grade, or junior high school—they should be encouraged to take responsibility for some of these issues.

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 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 in what messages are conveyed to families.

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 handbook of information is invaluable, especially if the pediatric team can communicate some of the positives of the new health care relationships.

Developmentally appropriate services for young adults

The demographics of adult hospitals are 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 “babyed” 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.

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References


Nephrology Transition 101

By Miriam Kaufman, MD, FRCP

Pediatric nephrology encompasses 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).

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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 management 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.

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