

Pediatric to adult transition: a personal experience

Transitioning from pediatric to adult transplant programs presents various challenges to the patient, his or her family, and the healthcare staff. In this personal, retrospective account of the issues associated with transitioning, a patient and nephrologist provide insights into some of the problems they confronted. (*Progress in Transplantation*. 2006;16:000-000)

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End-stage renal disease (ESRD) is rare in young adults; less than 1% of adult dialysis kidney transplant recipients are aged between 16 and 20 years in the United States [[AU: United Kingdom?]].¹ The low incidence of ESRD in childhood has led to centralization of services into 7 centers in the United Kingdom, covering large geographical areas. In contrast, adult renal services are widely dispersed amongst 95 separate dedicated adult nephrology centers. Our regional pediatric nephrology center provides ESRD care for a catchment population of more than 5 million, with centralized dialysis and transplant services. The same geographical population is served by 7 individual adult renal units providing maintenance dialysis and transplant care. Pediatric dialysis and transplant centers are small communities with a wide range of multidisciplinary staff who can provide extensive support to the patients and their families.

In contrast, adult renal units are increasingly overstretched with the rapid growth of the maintenance dialysis population and often have limited multidisciplinary staff to provide holistic care. The difference between pediatric and adult renal services is stark and

patients often find they are suddenly transferred from the pediatric environment to a local adult renal unit. Such transfers are extremely difficult for the patients and renal teams involved. Adolescents frequently feel disenfranchised and alienated in the adult unit and are wary of the new multidisciplinary renal team. This article explores the patient's perspective of this transition through a case example, and explores ways to facilitate a coordinated and patient-centered approach to transition.

Case Study Account—Dr. Paul Harden Presentation

Philip presented at age 8 with a 2-week history of malaise, lethargy, abdominal pain, and nausea. His serum creatinine level was 707 $\mu\text{mol/L}$ (8 mg/dL). He was transferred 55 miles to the regional pediatric renal service for emergency dialysis. A biopsy revealed antglomerular basement membrane disease.

Response to Therapy

Unfortunately, Philip remained anuric and dialysis-dependent, despite aggressive treatment with daily

plasma exchange and immunosuppression. He was commenced on maintenance hemodialysis and an arteriovenous fistula was fashioned.

Transplantation

After 9 months of dialysis Philip received a successful deceased kidney transplant. He had an episode of early rejection, which responded to methylprednisolone therapy. At 1 year after transplantation he had good function with a serum creatinine level of 88 $\mu\text{mol/L}$ (1 mg/dL).

Referral

I first became involved in Philip's case in early 1997 when I received a referral letter from his pediatric nephrologist summarizing his clinical details. The pediatrician wrote that Philip's age and maturity were entirely appropriate for transfer to adult care.

First Outpatient Appointment

I saw Philip with both his parents in April 1997. He was an intelligent, fit, and developed 16-year-old who was studying for 10 General Certificate School Examinations (GCSEs). His blood pressure was normal at 110/60 mm Hg and his serum creatinine level was 88 $\mu\text{mol/L}$ (1 mg/dL). His transplant function had been stable for 6 years.

First Year in Adult Care

Philip was seen every 2 months for an outpatient review. His renal function remained stable for 9 months and he successfully obtained 10 GCSE qualifications. In December 1997, he developed a clinically confirmed urinary tract infection and was treated with antibiotics. His serum creatinine level rose to 186 $\mu\text{mol/L}$ (2.1 mg/dL) and was slow to improve. A transplant biopsy revealed acute cellular rejection, which responded to pulsed methylprednisolone.

Identifying Nonadherence

Philip's serum creatinine level improved to a new baseline of 124 $\mu\text{mol/L}$ (1.4 mg/dL) in January 1998. Three months later he was admitted with a rise in his creatinine level to 309 $\mu\text{mol/L}$ (3.5 mg/dL) and a low tacrolimus level of 0.6 ng/dL.

He refused a further biopsy and was treated for suspected acute rejection with pulsed methylprednisolone. His creatinine level stabilized but his allograft was damaged and his baseline creatinine level reset at 239 $\mu\text{mol/L}$ (2.7 mg/dL) after this episode.

Admitting Nonadherence

I saw Philip with the multidisciplinary team on a ward round when we discussed the management of his clinical rejection. He did not admit to variable adherence with his immunosuppression despite the low

tacrolimus levels. I was convinced that he was nonadherent so I returned to talk to him frankly on a one-to-one basis.

Progressive Transplant Failure

Following the severe late rejection episode, the serum creatinine level remained stable at 248 $\mu\text{mol/L}$ (2.8 mg/dL) for 9 months. Philip regularly attended monthly clinics and had no subtherapeutic tacrolimus levels.

I reviewed him without his parents and we made joint clinical management decisions. His parents were involved when Philip requested. Unfortunately, despite careful monitoring and full compliance with immunosuppression, Philip's transplant function subsequently slowly declined until he resumed maintenance hemodialysis in October 1999—30 months after transfer from pediatric care.

Resuming Hemodialysis

Initially, Philip found the tight dietary and fluid restrictions of hemodialysis difficult. Unfortunately, he had developed 90% panel reactive antibodies after his failed transplantation, making retransplantation difficult. He has matured substantially over the last 4 years and now has excellent blood pressure, fluid, and biochemical control on regular dialysis.

Case Study Account—Philip Nadine Initial Reaction

I was shocked and frightened when I found out about my disease. **[[AU: Edits OK?]]** I was exhausted and just wanted the physicians to sort me out as quickly as possible. I had high expectations of the kidney unit staff and thought I would be back to normal within a few days.

No Way Back

I felt better with dialysis but was worried when my own kidneys failed to recover. I hated the lengthy car drive to the dialysis unit 3 times a week (60 miles, approximately 1.5 hours traveling each way). This was a huge stress on my family and me.

The local community raised money and we were able to buy a home hemodialysis machine and install it in a portable cabin in the garden. Dialysis at home was much better; my family could be with me and I could continue my hobbies and be with friends.

Back to Normal

I was very excited when I heard that I was going to receive a kidney transplant. I was surprised one had become available so soon. It was a huge relief as I anticipated dispensing with dialysis and returning to a normal life.

Within a month or 2 life was great; I was eating

normally, stopped having to be “wired-up” for dialysis, and was leading a normal childhood with family and friends.

Don't Transfer Me

I was alarmed when I was told I would transfer back to the local hospital. I thought it was less important than the regional specialist hospital so I must be less important now. I knew all of the staff and patients well in the pediatric renal unit, but there would be no familiar faces or friends in the adult unit.

First Impressions of Adult Renal Unit

My fears were confirmed, the environment was alien and much less comforting. Most of the other patients looked over age 60, there were new ways of checking in, and having bloods checked that I did not trust **[[AU: Please clarify the last part of this sentence. Having blood taken by people he didn't trust?]]**. Posters of cartoon characters had been replaced by skin cancer alerts. I was embarrassed that my parents were with me, everyone else saw the physician on their own.

Dependence to Independence

Initially, my life changed little as I was working for GCSE qualifications, which I completed within 3 months of transfer. Gradually, I was influenced by a range of different pressures in my life (Figure 1). I was 16 years old and rebellious; I did not want to do what other people told me to do. The renal unit staff and my parents kept telling me to take the tablets. At school I was called “monkey man” because of hair growth on my arms; my face was swollen and I had acne due to the immunosuppressants. I had read that patients could become tolerant of their transplant, which allowed reduction of immunosuppression.

A Model of Nonadherence

I first experimented with vitamin supplements after transferring to adult care. When I stopped taking the vitamins there was no adverse effect so I stayed off them. Next I reduced the prednisolone progressively over a couple of months with no adverse effect. My facial swelling reduced so I stopped the prednisolone completely. Once off the steroids I thought I would try and stop the azathioprine because the tacrolimus seemed the most important drug as levels were measured at each clinic visit. By December 1997 I had stopped the azathioprine completely and was only taking tacrolimus. I had a urinary infection in December 1997 and mild secondary rejection, but my kidney recovered after treatment. In early 1998, I thought I would try and stop the tacrolimus (Figure 2).

Realizing the Consequences

When I was admitted with a more severe episode of rejection in April 1998 I had stopped taking all immunosuppression 3 weeks earlier. My renal function deteriorated more rapidly and remained impaired. I was worried when I started to realize that I could lose the transplant and may need to return to dialysis. Following a ward round, Dr Harden returned to speak to me on a one-to-one basis and I was able for the first time to speak about my nonadherence.

Achieving Shared Care

I realized what I could lose too late, and my main concern was to keep the transplant working as long as possible. Fifteen months after transfer, I finally trusted Dr Harden and the renal team. I was able to talk frankly about any concerns and agree what treatment to take jointly with the team. Now I took my medication regularly, including the prednisolone and antibiotics. I was angry with myself and felt guilty for both the donor and my supporting family. I was embarrassed about my nonadherence, but now able to talk about it freely with Dr Harden and the transplant nurse specialist.

Resetting the Target

When my transplant failed I was 18 years old and I lost my ambition for the future. Returning to hemodialysis was disruptive and initial adherence to fluid and diet restrictions were difficult. Gradually I came to terms with the loss of the transplant and started to get my life into order. I worked hard as a care assistant to become financially secure, and started a 4-year course in nursing. In September 2004, I graduated as a fully qualified nurse.

Discussion

The abrupt transfer from pediatric to adult renal services demonstrated in this case study is typical of the communication gap that exists between these often geographically distinct nephrology services.² Often, the only communication is a medical referral letter detailing the clinical history, which does not contain all the multidisciplinary aspects of pediatric nephrological care such as social, developmental, and psychological health. The pediatric and adult teams work in completely different environments with vastly different skill mixes of multidisciplinary staff, and frequently have limited insight into the facilities and functionality of each others' departments.

It is not surprising that Philip was wary of the outpatient systems in the adult unit because these would be alien and different to the familiar approach adopted by the regional pediatric unit. The stark difference is clearly demonstrated by the decoration and patient

information literature displayed in the 2 departments. Adult units focus on the autonomous individual and struggle to cope with the strong parental participation encountered in pediatric practice. In the adult care setting, the nephrologist remains a key member of each team, whereas in the pediatric setting, adolescents and their parents have frequently developed a deep sense of trust and continuity of care with an individual pediatric nephrologist. **[[AU: Edits OK?]]** In a survey³ of 101 adolescent diabetic patients transferring to adult healthcare in Melbourne, 97% regarded the adult diabetologist as a key professional. Important characteristics of the adult specialist included someone you can relate and talk to (96%), someone you can see regularly (90%), and someone who allows you to make informed decisions (73%).

It took 15 months for trust to develop between Philip and the adult nephrologist despite regular consultations, resulting in a substantial unintentional reduction in professional support at a time when the adolescent is most susceptible to pubertal pressures. Normal adolescence includes progressive independence and rebellion from parental control with increasing self-determination, experimentation with sexual and social identity, and conformity to considerable peer pressure. A coexisting chronic disease complicates an already confusing time of life, and adherence to treatment regimens becomes increasingly difficult.

Of 20 adolescent kidney transplant recipients transferring at a mean age of 17.3 years from pediatric to adult renal services in Nottingham, 35% developed allograft failure (5% expected **[[AU: Please clarify "expected"]]]**) within 36 months of transfer.⁴ We undertook a similar review of adolescents transferred to adult care in Staffordshire and found 20% allograft failure within 24 months of transfer. **[[AU: Is there a reference for this review? Published results or unpublished materials? If unpublished, please provide the main investigator's name and date of the study.]]** Nonadherence is common in adolescence, although the degree varies between individuals and influence outcome. Philip was actively experimenting with reduction of immunosuppression for more than 12 months without detectable effects. We were only alerted to the process after a late rejection episode and low tacrolimus levels.

Healthcare workers managing transitional patients should carefully watch for clues of persistent nonadherence and develop an accessible and trusting relationship with young adult patients, allowing discussion of the pressures encouraging nonadherence.⁵ It is a tragedy for a young adult to lose a functioning kidney transplant and return to dialysis dependency, particularly as future transplantation may be seriously compromised by sensitization.

The causes underlying the loss of Philip's functioning kidney transplant are undoubtedly multifactorial and include family and peer pressure, adolescent rebellion, and striving for independence. However, a sudden transition to adult renal services and a new renal team at a critical age also may have contributed adversely and facilitated nonadherence. Healthcare professionals should strive to minimize the disruption of adolescent transition through the development of a planned program of transfer agreed between the patient and the pediatric and adult healthcare teams.^{6,7}

There are no evaluative data to ascertain which model of transition of pediatric to adult care is most effective.⁸ Miller⁹ proposes that the adult nephrologist and dedicated nurse practitioner should meet the adolescent in the pediatric environment on several occasions before transfer. **[[AU: Edits OK?]]** A progressive shift of care from the pediatric to the adult team can be customized to each individual in the setting of a joint transition clinic.⁹ This will allow time for the adolescent and his or her parents to develop a relationship with the adult team and to foster the development of patient-team trust. In addition, the adult team can assess developmental suitability for transfer to the adult clinic environment.

An individualized transition plan can be formulated between the patient, his or her family, and the pediatric and adult nephrology teams between the age of 14 to 16 years.¹⁰ This would include a comprehensive assessment of educational, developmental, psychosocial, and medical status to determine timing and preparation required for transition to adult services. Programmed visits to the adult unit before transfer can provide a nonthreatening introduction to the adult service for adolescents and their family. Peer support activities can ease the transition by providing role models to vulnerable adolescent patients and foster self-advocacy skills. Some adult centers have established young adult clinics to enhance peer support and manage these patients with a small dedicated nursing and medical team to foster good continuity of care and health team-patient relationships.

Conclusion

More than 90% of children with ESRD will survive successfully into adult life.¹¹ It is important that healthcare professionals develop care models that optimize the seamless and timely transition of adolescents from pediatric to adult renal services in an attempt to minimize the disruption to individual patient care.

References

1. USRDS Annual Report 2005. Incidence and Prevalence. Available at: <http://www.usrds.org>. Accessed August 20, 2006.

2. Cameron JC. The continued care of children with renal disease into adult life. *Pediatr Nephrol.* 2001;16:680-685.
3. Court JM. Outpatient-based transition services for youth. *Pediatrician.* 1991;18:150-156.
4. Watson AR. Non-compliance and transfer from pediatric to adult transplant units. *Pediatr Nephrol.* 2000;14:469-472.
5. Meyers KEC, Thomson PD, Thomson WH. Non-compliance in children and adolescents after renal transplantation. *Transplantation.* 1996;62:186-189.
6. Reiss J. Health care transitions: destinations unknown. *Pediatrics.* 2002;110:1307-1314.
7. National Service Framework. *Getting the Right Start: The National Service Framework for Children, Young People and Maternity Services.* London, United Kingdom: Department of Health; 2003
8. Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health care systems for adolescents with chronic conditions. *J Adolesc Health.* 1993;14:570-576.
9. Miller S. Transition of care in adolescence. *Pediatr Nurs.* 1996;8:14-16.
10. Betz C. Adolescents with chronic conditions: linkages to adult service systems. *Pediatr Nurs.* 1999;25:473-476.
11. Blum R. Transition in adult health care: setting the stage. *J Adolesc Health.* 1995;17:3-5.

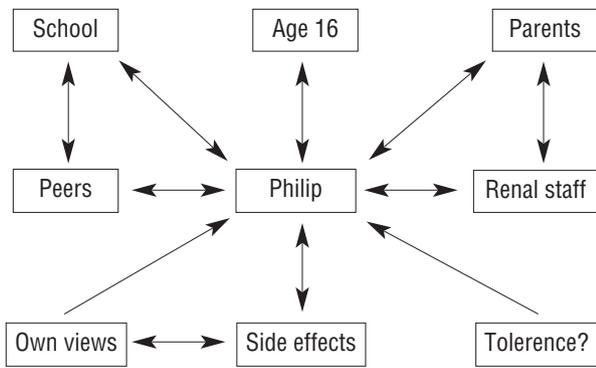


Figure 1 Patient-perceived pressures to become nonadherent

Stage 1

Buildup of feelings → Missed vitamin doses → No effect

Stage 2

Reduce prednisolone → Look much better → No effect

Stop prednisolone

Stage 3

Stop antibiotic → No effect → Stop azathioprine

⇒ Urinary tract infection ⇒ Rejection

Stage 4

Reduce tacrolimus → Rejection ⇒ Worried!

Figure 2 Personal map of nonadherence