RESEARCH LETTER

A Nephrology Pediatric to Adult Transition Clinic: A Pilot Program

To the Editor:

Young adults with chronic kidney disease are living longer, with a 10-year survival rate > 80%, thus resulting in an increase in patients requiring a transition of care from pediatric to adult-based practices.1 This transition of care most often occurs between ages 18 and 24 years, a time at which young adults experience unique challenges and when there is a substantial risk for nonadherence and poor outcomes.2-4 Historically, transition recommendations were focused on pediatric practitioners, but the vital role of the adult clinicians has become more evident in recent years.5-7 The consensus statement by the International Society of Nephrology and International Pediatric Nephrology Association supports care coordination between lead clinicians in pediatric and adult nephrology units to ensure a smoother transition.7 Despite this recommendation, adult care providers often feel ill equipped to facilitate a successful transition and most centers do not have protocols in place.2

Northwestern Medicine Nephrology implemented a pilot transition-of-care program for young adults with kidney disease transitioning from Lurie Children’s Hospital to Northwestern Medicine and we report on the first 3.5 years. This program provided coordination of care between pediatric and adult nephrology teams through a formal transition process. This was done as part of a quality improvement project and thus was exempted from institutional review board approval.

The adult nephrology transition team included a lead nephrologist, physician assistant, and social worker, all credentialed at Lurie Children’s Hospital specifically for this program, allowing for documentation in the pediatric chart and for billing. The pediatric nephrology team identified eligible patients and set transfer appointments. Kidney transplant recipients were not included as they were seen through a separate transition program. Before the transfer visit, the teams reviewed the patient history, including identification of potential psychosocial transition barriers.

The transfer visit occurred at Lurie Children’s Hospital with subsequent visits at Northwestern Medicine. Patients’ medical independence and knowledge were assessed, helping to identify those patients at higher risk for nonadherence and requiring additional support. There was opportunity for parental involvement, as well as one-on-one time with the adult providers for young adults making independent health care decisions. A follow-up appointment with the nephrologist or physician assistant was scheduled before the transfer visit was completed. Monthly reviews were conducted to determine whether proper follow-up had occurred and if not, procedures of enhanced follow-up in the form of calls, e-mails, and/or texts were implemented. The pediatric team assisted in contacting any patient who could not be reached. The social worker aided with pertinent insurance and psychosocial issues. Additional specialties were incorporated in the comprehensive care of the patient as needed.

Characteristics of the transition participants are summarized in Table 1. A total of 75 patients were seen in a 3.5-year period, with an initial age range of 18 to 21 years. We noted a wide range of kidney pathologies, as seen in Table 1, many not historically treated by adult nephrologists.

We defined a successful transition as a patient having returned for follow-up at Northwestern Medicine at least once after the initial transfer visit at Lurie Children’s Hospital. Transition outcomes are summarized in Table 2, with 71% successful transition and 9% pending follow-up (has an upcoming visit). A total of 16% of patients had an unsuccessful transition, and 40% of patients required enhanced follow-up of at least 1 reminder to schedule a missed visit.

Table 1. Transition Participants Characteristics

| Participants in Transition Program (n=75) |
|-----------------------------------------|
| Women                                  | 37 (49%) |
| Men                                    | 38 (51%) |
| Age range at enrollment, y             | 18-21    |
| Diagnoses                              |
| Glomerulonephritis                     | 20       |
| Urologic disorders                     | 17       |
| Hypertension/fibromuscular dysplasia    | 10       |
| Genetic tubular interstitial disorders  | 7        |
| Nonkidney organ transplant–related CKD| 6        |
| Chemotherapy-related CKD               | 4        |
| Polycystic kidney disease              | 4        |
| Type 1 DM with microalbuminuria        | 2        |
| Tuberous sclerosis                     | 2        |
| Hydronephrosis                         | 1        |
| Alport syndrome                        | 1        |
| ANCA vasculitis                        | 1        |

Note: Values expressed as number or number (percent).

Table 2. Transition Outcomes

| Outcome                  | Transition Program Participants (n=75) |
|--------------------------|---------------------------------------|
| Successful transition    | 53 (71%)                              |
| Unsuccessful transition  | 12 (16%)                              |
| Lost to follow-up        | 7 (9%)                                |
| Insurance loss/change    | 5 (7%)                                |
| Pending follow-up        | 7 (9%)                                |
| No longer requiring follow-up | 3 (4%)                      |

Note: Values expressed as number (percent).
Our nephrology transition clinic was effective, with 71% of patients successfully transitioned to adult care. This is significantly higher than reported in the literature. For example, Raina et al.\textsuperscript{1} surveyed 49 nephrology centers that reported only 27% successful transition. Although there is no formally recognized standard for what constitutes a “successful” transition, these numbers give a general impression of the effectiveness of our strategies.

We postulate several factors contributing to our high successful transition rate. A key factor was having a dedicated multidisciplinary transition team, enabling us to provide the additional support services and access that these young adults require. As noted in the major guidelines, close communication between the adult and pediatric team is essential.\textsuperscript{2,6-8} We found that conducting the transfer visit at the pediatric location aided in patient comfort with the process. One-on-one time with the providers during the transfer visit enabled patients to express any confidential transition concerns, including social situation and drug use. Many patients required enhanced follow-up/reminders for missed visits after transfer; we believe that without this protocol-based intervention, most of these patients would not have successfully transitioned. Lurie Children’s Hospital and Northwestern Medicine are adjacent to one another, minimizing location change as a substantial barrier. Finally, both institutions use the same electronic medical record, which greatly aided in information exchange.

A limitation to our findings is the limited length of our pilot program; that is, 3.5 years. In addition, there is no universally agreed-on definition of successful transition. For future research, we will be looking at factors influencing drop out.

Based on our pilot experience, transition of care from pediatric to adult nephrology providers can be successfully facilitated with a model such as ours, with collaboration between the teams educated on and engaged in the process.

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