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Identification of adolescent and adult patients receiving pediatric urologic care and establishment of a dedicated transition clinic

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Summary

Introduction
Pediatric patients with chronic urologic conditions frequently require lifelong evaluation and treatment. Transition to adult urologic care is critically important as these patients mature and the goals of care shift to include sexual function, fertility, and reconstruction.

Objective
Our objectives are to (1) quantify and describe the population of young adult patients with congenital or childhood-acquired urologic problems who continue to be followed in pediatric urology clinic, to (2) discuss the numerous obstacles to successful care transition, and to (3) outline the design features of the dedicated transition clinic we established in response to the identification of a sizeable population in need.

Study design
We (1) performed a retrospective review of our electronic health record to identify young adult patients 19–35 years of age seen in pediatric urology clinic over a five year period. Patients without a chronic urologic diagnosis were excluded. We identified each patient's primary diagnosis and status with respect to transition of care. We then (2) established a dedicated transition clinic to facilitate progression to adult care services at our institution.

Results
Among 480 young adult patients seen in the pediatric clinic during the five-year period, 99 patients with an average age of 22.4 years were identified as having a chronic congenital or childhood-acquired diagnoses requiring urologic care. At the end of the five-year period, 40 of 99 patients (40.4%) had successfully transitioned to adult care while 59 patients (59.6%) continued care with pediatric urology. Among patients yet to transition, spinal dysraphism (30%) was the most common primary diagnosis. In this same group, discussion regarding transfer to adult care was documented during at least one visit in only 8 of the 59 patients (13.6%). All patients in this cohort had healthcare needs that included sexual function, fertility, or reconstruction.

Discussion
The present data confirm the presence of sizeable population of young adult patients with chronic urologic problems and maturing care needs who 1) continue to receive exclusively pediatric care, and 2) are rarely engaged in preparatory discussions regarding care transition. Obstacles to successful transition of care are numerous and include limited staff training, lack of identified staff member responsible for transition, financial and psychosocial barriers, and discomfort on the part of physicians, patients and families. We describe the additional challenges that are unique to transition of care in urology. We share a blueprint of our recently-established transition with the hope of prompting additional discussion and facilitating transitional urologic care elsewhere.

Conclusion
Many young adult patients with chronic urologic conditions continue to receive care from pediatric urologists well into adulthood. We hope that our clinic might serve as a model for augmentation of urologic transition services at other institutions. We anticipate a future report evaluating our clinic's impact on long-term follow up, clinical outcomes, and patient satisfaction.

Table The University of Virginia Urology Transition Clinic

Clinic design and objectives
• Clinic is held monthly
• Appointments are blocked for one hour
• Joint visits are attended by pediatric and adult urology faculty
• Psychosocial issues and logistical barriers are addressed
• Sexual health and reproduction is emphasized
• Multidisciplinary input is sought when appropriate
• Progress through clinic is tailored based on condition, cognitive capacity, strengths, limitations and social situation
Pediatric provider obligations
• Accurately assess readiness for transition on an individual basis
• Thoughtfully prepare patient expectations
• Offer joint visits and/or coordinated care until comfort with adult team is assured
• Assure satisfaction and engagement with the adult-care team
• Offer continued availability or additional consultation should these goals not be met

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Introduction

More than 85% of children born today with chronic medical conditions live well into adulthood [1]. Many specialties face the challenge of transitioning adolescents with chronic conditions—disease processes traditionally managed by pediatric specialists—to providers in adult medicine. In urology, advances in neonatal care as well as surgical and non-surgical interventions have increased long-term survival in patients with diverse congenital diseases affecting the genitourinary tract, including spina bifida, bladder and cloacal exstrophy, and posterior urethral valves [2]. Within the spina bifida population, survival to adulthood is now 70–80%, an improvement of 20–30% compared with rates seen 40 years ago [3].

Frequently, patients with chronic urologic conditions continue to receive care in the pediatric healthcare setting into adolescence and adulthood. Jesus and colleagues recently found that adolescents ($12 < \text{age} \leq 18$ years old) and adults (>18 years old) made up 19.8% and 2.7% of new referrals, respectively, to their pediatric urology clinic during a 1-year period [4]. While nearly half ($n = 49$) of the adolescent patients were referred for diseases presenting in adolescence, all adults ($n = 15$) presented with chronic congenital urologic problems, mainly exstrophy–epispadias complex and neurogenic bladder [4]. Jesus et al. [4] did not describe or suggest a mechanism to facilitate transitioning these patients to adult urology. However, a small number of centers have begun to establish dedicated transition clinics to facilitate progression of adult patients into adult urologic care [5]. Great Ormond Street Hospital in London, for example, began a multidisciplinary clinic in 2010 that enables pediatric and adolescent urology professionals to outline a coordinated care plan for the adult urologist assuming care [6]. No data are yet available to describe the effectiveness of this effort.

We hypothesize that a substantial population of young adult patients with chronic conditions continues to be seen in the pediatric urology clinic at our institution. Additionally, we believe that these patients would benefit from the creation of a clinic dedicated to facilitating the transition to adult urologic care. Our current objectives include (a) identifying and describing this population at our institution, (b) detailing the design of our Urology Transition Clinic created in response, and (c) discussing barriers to successful transition in terms of our early experience with the clinic.

Methods

After institutional review board approval, we performed a retrospective review of our electronic health record system to identify young adult patients aged 19–35 years who had been seen in the pediatric urology clinic between January 2007 and July 2012. Patients without a chronic or congenital urologic diagnosis were excluded, including patients seen briefly for acute problems such as stone disease, uncomplicated urinary tract infection, genital infections, testicular pain or testicular lesions, or incidental benign renal lesions, to name a few. We defined each patient's primary urologic diagnosis and identified those that had transitioned to adult care. For patients who continued to receive care in the pediatric clinic, we determined if discussions to initiate transition were underway.

Quantifying this population allowed us to justify the creation of, as well as plan financially and logistically for, the founding of a dedicated transition clinic designed to facilitate transition to adult urologic care. The clinic was established in late 2012 and is held monthly. Following individualized assessment of readiness and preparatory discussion in the pediatric setting, established pediatric urology patients 18 years or older with one or more chronic urologic condition are invited to follow-up in clinic. New patients are welcome. One-hour blocks are reserved for each patient. Visits are attended by both the pediatric and the adult urology faculty for joint assessment, personalized introduction, and coordinated counsel. We address sexual and reproductive function. Psychosocial issues are evaluated and addressed. Progress through the clinic does not occur at a predetermined pace but is, instead, tailored on the basis of each patient's condition, cognitive capacity, strengths, limitations, and social situation.

Providers prepare patient expectations with respect to timing of transition on an individualized basis. We coach and encourage patients towards personal responsibility and self-care. We seek multidisciplinary input from other specialties including nephrology, gynecology, endocrinology, and psychiatry, among others, when appropriate. Should a clinic patient require surgical intervention or revision, adult and pediatric faculty members perform the operation in concert. Postoperatively, patients receive adult nursing care. We have considered graduation criteria (outlined in Table 1) that must be met before transition can be considered a success (Table 2).

Results

Four hundred eighty young adult patients were seen in the pediatric clinic during the 5-year period. Ninety-nine patients with an average age of 22.4 years had chronic congenital or childhood-acquired diagnoses requiring urologic care. Overall, the most common diagnoses included myelomeningocele (36.4%), traumatic brain or spinal cord injury (15.1%), posterior urethral valves (7.1%), and cerebral palsy (5.1%). Other conditions represented in the cohort included bladder and cloacal exstrophy, voiding dysfunction due to behavioral or psychiatric disorders, and congenital neurologic conditions.

Table 1 Transition clinic graduation criteria.

1. Participate independently in his or her care
2. Establish familiarity and comfort with adult urology physicians and nurses
3. Obtain and maintain healthcare coverage or institutional financial assistance
4. Attend at least one preventative care visit with adult practitioner in past year
5. No delayed or forgone essential visits in the past year