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The Fate of Transitional Urology Patients Referred to a Tertiary Transitional Care Center

Robert Chan, Jason Scovell, Zachary Jeng, Saneal Rajanahally, Timothy Boone, and Rose Khavari

Department of Urology, Houston Methodist Hospital, Houston, TX; and the Scott Department of Urology, Baylor College of Medicine, Houston, TX

Abstract

OBJECTIVE—To determine the changes in management of children with neurogenic bladder (NGB) or genitourinary congenital anomalies as they moved to our transitional care clinic at the Center for Restorative Pelvic Medicine, a multidisciplinary center led by an adult urologic team dedicated to the long-term care of these patients.

MATERIALS AND METHODS—We retrospectively reviewed charts of patients with NGB or genitourinary congenital abnormalities referred between 2010 and 2013. Analysis included patient characteristics, causes of NGB, bladder management, recurrent urinary tract infection, stones, renal function, upper tract studies, video urodynamics, and change in management.

RESULTS—Twenty-four patients with an average age of 22.0 ± 2.7 years were included in analysis. Management was altered in 70.8% of patients ($n = 17$). Surgical management was instituted in 58.3% ($n = 14$ of 24) of patients and included bladder augmentation or urinary diversion ($n = 7$), intravesical botulinum toxin A injections ($n = 5$), cystolitholapaxy, or cystolithotomy ($n = 2$). Conservative management was changed in 12.5% ($n = 3$) of patients and included initiating anticholinergic medication ($n = 2$) or self-catheterization ($n = 1$). Follow-up was 8.9 ± 12.1 months.

CONCLUSION—There is an immense need for transitional care of patients with NGB or genitourinary congenital abnormalities as they grow into adulthood. Nearly 71% of our patients had a change in their bladder management with 38% undergoing a major surgery. This study emphasizes the necessity for a dedicated adult urologic team in conjunction with a comprehensive team to care for these complex patients because their urologic care and needs may vary significantly from their childhood.

The care and management of pediatric patients with congenital genitourinary anomalies transitioning to adulthood is undergoing a period of profound transformation. Owing to improvements in surgical and nonsurgical interventions, children with diverse congenital diseases affecting the genitourinary tract are surviving into adulthood at far higher rates than in the past.¹ As an example, up to 70%–75% of children born with a myelomeningocele and

Address correspondence to: Rose Khavari, M.D., Department of Urology, Houston Methodist Hospital, 6560 Fannin Street, Suite 2100, Houston, TX 77030. rkhavari@houstonmethodist.org.

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consequent neurogenic lower urinary tract dysfunction are living past the age of 20 years.² With these marked improvements in care and favorable outcomes, expectations among patients with congenital genitourinary abnormalities have shifted from simple survival to basic functional goals like bowel and bladder continence and to a desire to have the full range of physical function.^{3,4} These new expectations, especially in the areas of sexual function, fertility, and reproductive health, are creating previously unseen challenges for health care providers attempting to transition adolescents from pediatric to adult care.⁵ As this patient population continues to grow, the transitional process for urologic care of congenital anomalies is progressively becoming a topic of vital importance.

Transition is not simply a move from one provider team or hospital to another but is a critical stage in adolescent development with profound changes in the doctor-patient relationship.³ Transition is a “purposeful, planned process that addresses the medical, psychosocial, and educational need of adolescents with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems.”⁶ Poor transition is linked to noncompliance with follow-up and appointment avoidance, both of which have a negative effect on morbidity, mortality, and socioeconomic performance.^{7,8} A successful transition from pediatric to adult care is crucial in helping pediatric patients become independent adults, being able to rely on their own personal resources to effectively access the health care system.^{9,10}

To address the many challenges facing these patients, the transitional care clinic at the Center for Restorative Pelvic Medicine (CRPM) at Houston Methodist Hospital was established in 2010 to aid the transition of children with neurogenic lower urinary tract dysfunction or genitourinary congenital anomalies to an adult urologic team dedicated to their long-term care. The objective of this study is to highlight the changes in management of patients presenting to a transitional urologic clinic as they move into adulthood.

MATERIALS AND METHODS

Patients who attended the transitional care clinic at the CRPM were identified for study participation. A retrospective review of patients with neurogenic lower urinary tract dysfunction or genitourinary congenital abnormalities referred to CRPM between January 2010 and October 2013 was performed. The institutional ethics review board provided approval for this study. Demographic and urologic baseline characteristics examined were age, cause of neurogenic lower urinary tract dysfunction or congenital abnormality, bladder management, recurrent urinary tract infections (defined as 3 culture-proven urinary tract infections within a 12-month period), incontinence, urolithiasis, pad usage, prior bladder augmentation, and anticholinergic medication use. Causes of neurogenic lower urinary tract dysfunction or congenital anomaly were classified as spina bifida, spinal cord injury, transverse myelitis, and other. The category other included anoxic brain injury, tethered cord syndrome, sacrococcygeal teratoma resection, pelvic sarcoma followed by chemotherapy and surgery, sacral agenesis, cerebral palsy, conversion disorder, multiple sclerosis, and bladder exstrophy. Videourodynamics and upper tract imaging were obtained on the majority of patients presenting to our clinic as part of a comprehensive evaluation to determine their management. We attempt to assess the risk associated with their neurogenic bladder using

urodynamic studies (UDS), renal function testing, and upper tract imaging. The patient's change in management addressing their upper tract risk and urinary continence was evaluated after presenting to the transitional care clinic.

RESULTS

Twenty-four patients were identified with an average age of 22.0 ± 2.7 years (range, 16–26 years) and were included in our retrospective study. Nine patients were men and 15 were women. The average length of follow-up was 9.0 months (range, 0–50.2 months). The etiology of their neurogenic lower urinary tract dysfunction was spina bifida in 45.8% ($n = 11$ of 24), spinal cord injury in 8.3% ($n = 2$ of 24), transverse myelitis in 8.3% ($n = 2$ of 24), or other in 37.5% patients ($n = 9$ of 24; Table 1). Referring physician data were present for 15 of 24 patients (Supplementary Table 1). The most common referring service was pediatric urology ($n = 6$), followed by transitional medicine clinic ($n = 3$), adult urology ($n = 2$), and adult urogynecology, adult pain management and rehabilitation, and a pediatric hospitalist service ($n = 1$ each).

On presentation, bladder management included clean intermittent catheterization (CIC) 79.2% ($n = 19$ of 24) for a majority of patients, whereas 8.3% patients ($n = 2$ of 24) spontaneously voided, and 12.5% patients ($n = 3$ of 24) had constant leakage. Of the patients who performed CIC, 63.2% ($n = 12$ of 19) catheterized via their native urethra, 31.2% ($n = 6$ of 19) via their stoma, and 5.3% ($n = 1$ of 19) via their vesicostomy. A total of 54.2% of patients ($n = 13$ of 24) had recurrent urinary tract infections, 70.8% of patients ($n = 17$ of 24) were incontinent, 20.8% of patients ($n = 5$ of 24) had urolithiasis, 37.5% of patients ($n = 9$ of 24) were on anticholinergic medications, and 37.5% of patients ($n = 9$ of 24) had already undergone a bladder augmentation (Table 1).

For management, we established a plan of care based on renal function testing, upper tract studies, and videourodynamics to determine hydronephrosis or stones and bladder capacity, compliance, and continence, respectively. Eighteen of 24 patients underwent urodynamics, and 13 of 24 patients had an upper tract study. In the UDS, neurogenic detrusor overactivity with leak was present in 38.9% ($n = 7$ of 18) of the evaluations. Patients with neurogenic detrusor overactivity with leak had a median detrusor leak point pressure of 58 cm H₂O (ranging from 14 to 105 cm H₂O). Leakage was identified in 50.0% ($n = 9$ of 18), and poor compliance was present in 27.8% ($n = 5$ of 18) studies. Of the upper tract studies, 10 patients had no or mild hydronephrosis, 2 had stones, and 2 had hydronephrosis. The average creatinine level was 0.87 mg/dL (0.3–4.1).

In our clinic, patients with neurogenic detrusor overactivity who have significant urgency, frequency, and urge incontinence and have either failed oral therapy or are bothered by side effects are ideal candidates for botulinum toxin A. We also consider treating patients with intra-detrusor botulinum toxin A, who have low capacity and decreased compliance after failing oral therapy. The majority of our transitional urology patients are already managed with self-catheterization; therefore, the increased postvoid residual or urinary retention is not a concern. We consider augmentation cystoplasty for patients who fail medical therapy and

intradetrusor injection of botulinum toxin A and have neurogenic overactivity, decreased compliance, and/or decreased capacity.

Management after transitioning to CRPM was bladder augmentation or urinary diversion in 29.2% of patients (n = 7 of 24), intravesical botulinum toxin A injections in 20.8% of patients (n = 5 of 24) patients, and cystolitholapaxy or cystolithotomy in 8.3% of patients (n = 2 of 24). For conservative treatment, 8.3% of patients (n = 2 of 24) were started on anticholinergics and 4.2% of patients (n = 1 of 24) were started on CIC (Tables 2, 3). Follow-up was 8.9 ± 12.1 months (0–50.2 months). Postmanagement continence data were available for 11 of the 17 patients with incontinence at the time of presentation. Six patients (55%) attained continence after alterations to management, whereas 5 patients (45%) remained incontinent. Three of the 5 patients (60%) who were treated with botulinum toxin A were continent postoperatively. The reasons for change are listed in Table 4.

COMMENT

Today, >90% of patients with chronic diseases are reaching adulthood,¹¹ representing a dramatic advancement in care. This improvement is evident comparing the 25-year survival rates from a cohort of spina bifida patients in the 1960s (25%)¹² with a recently published cohort of spina bifida patients in 2011 (82%).¹³ This improvement brings new challenges regarding management as these patients often have multisystem disorders, with urologic complications present in 24%–94% of adults with spina bifida.² Care into adulthood for patients with complex congenital urogenital anomalies is becoming a recognized need in transitional care medicine. Along with the challenges of transitioning patients from a pediatric to adult team, there is scant evidence to guide clinical decision making.

As evidenced by our experience, and those around the country,^{1,3,14–16} there is a growing need for transitional care clinics to handle the treatment and management of patients with neurogenic lower urinary tract dysfunction and genitourinary congenital anomalies. At our institution, we work closely with the pediatric care teams, an active partnership, which has been shown to improve patient care and satisfaction.¹⁵ The benefit of transitioning from the pediatric to an adult team is clearly evident based on the changes in management detected by regular testing and evaluation. We found that nearly 71% of patients had a change in their bladder management with 38% undergoing a major surgery with either bladder augmentation or cystectomy. One hypothesis for why these patients are requiring such a shift in care is that some pediatric urologists may be hesitant to perform these types of procedures in adult patients causing a delay in appropriate management. Other possibilities include change in patients' insurance and having limited accessibility to adult reconstructive urologist, changes in patients' compliance with management plans as they transition to teenage years and adulthood and become more independent vs parents directing all care during childhood.

More than 20% of our patients were treated with intravesical botulinum toxin A injections after transitioning to our clinic. There are currently 2 trials investigating botulinum toxin A in the pediatric population.^{17,18} However, many pediatric urologists do not routinely perform botulinum toxin A injections or offer it as early as adult neurourologists do particularly in a

clinic setting. Additionally, some other aspects of management are generally outside the scope of a pediatric urologist's practice such as pelvic organ prolapse repair. The prevalence of poor compliance in 5 of the patients treated at our institution is concerning. We do not believe that this is a result of suboptimal care, but more likely due to the fact that, as pediatric patients grow into their teen and adult years, they tend to see their physicians less frequently. When transitioning to our adult clinic, we were able to see these patients with a fresh perspective and identify new issues as a part of a thorough initial workup. We hope that these results will provide the basis for increased communication with the pediatric urologists to transition their patients earlier to a team able to provide the necessary care for long-term genitourinary and pelvic floor health.

It is important to note that many of our patients transitioned directly from their pediatric urologists as we have a close relationship with both the academic and private pediatric urologists in the region; however, some of our patients had been away from urologic care for a period of time. These differences highlight 2 issues regarding this population. Transitioning the patients who came directly from pediatric urologic care shows the value of an institution such as the CRPM. Patients who had lapsed in their urologic care most likely "fell through the cracks" of our medical system due to lack of access to appropriate health care and the high cost of care.

Urodynamic testing is a critical component in the long-term survival of patients with neurogenic lower urinary tract dysfunction.¹⁹ We performed UDS on 75% of patients for further evaluation; however, it is important to address the fact that a significant portion of patients were not assessed using these diagnostic tests. We recommend initial UDS, renal function labs, and upper tract imaging for all patients entering the transition clinic. Some patients may have already performed testing within a year and have the report or the tracing that we believe should be sufficient. In other instances, due to insurance limitations some patients were not able to afford this testing. This population provides a unique challenge with regard to following renal function and risk of deterioration. In this study, we report serum creatinine; however, due to the limited muscle mass in these patients, this is not a particularly accurate measurement. We have switched to using the estimated and calculated glomerular filtration rate (GFR) for most of our patients. Weighing the wheelchair-bound patients to obtain a more accurately calculated GFR has remained a major limitation in our clinical practice. In addition, we acknowledge that there is no well-established method of measuring renal function and GFR in wheelchair-bound patients, particularly patients with myelomeningocele.

It is important to acknowledge the limitations of this descriptive study. The retrospective nature of this study has the inherent flaws associated with this study design. Although patients have a variety of underlying etiologies for their congenital bladder dysfunction, our findings highlight the broad need for multidisciplinary care regardless of specific diagnosis in this population. Furthermore, a validated quality of life questionnaire would have been useful in determining the impact of our interventions on improving our patient's daily function. This study lacks a control group, which would have provided additional information on the benefit of integrated adult care on adult care. Because our population is unique and heterogeneous, it is difficult to compare these patients with other populations

with bladder disorders. Others have shown the benefit of transitional care for the urologic patients, but a prospective approach examining the reasons behind a change in management and what risk factors may predict a need for a change in care would be useful in answering the important questions.

The evidence describing the need for transitional urologic clinics is new but growing. Our findings add urgency to the community of all urologists that there is likely a large population of patients who previously existed at a much lower volume and who require complex care and bladder management as they continue to realize longer life expectancies. Many of these patients present with multiple organ system anomalies, and our experience has been that a discussion between the adult and pediatric teams allows for appropriate adult management of these patients. Our findings highlight the need for a dedicated urology team in coordination with a multidisciplinary medical team when treating these complex patients as their management and treatment options may, and often will, change as they grow into adulthood.

CONCLUSION

There is an immense need for transitional care of patients with neurogenic lower urinary tract dysfunction or genitourinary congenital abnormalities as they grow into adulthood. At our institution, a majority of the patients had either a change in management or reconstructive surgery after their transition to the clinic. These findings emphasize the value and necessity of a dedicated urologic team working in coordination with a multidisciplinary team. We hope that by highlighting an unmet need in the urology community, there will be an increase in awareness and action in the management of this special patient population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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APPENDIX. Supplementary Data

Supplementary data associated with this article can be found, in the online version, at <http://dx.doi.org/10.1016/j.urology.2014.08.022>.

Table 1

Demographics of patient population

Demographics of Patient Population	Value	Range
Gender, n		
Male	9	
Female	15	
Age $\pm$ SD, y	22.0 $\pm$ 2.7	16–26
Follow-up, mo	8.97 $\pm$ 12.1	0–50.2
Cause of neurogenic bladder or congenital anomaly, n		
Spina bifida	11/24	
Spinal cord injury	2/24	
Transverse myelitis	2/24	
Other (anoxic brain injury, tethered cord syndrome, sacroccocygeal teratoma resection, pelvic sarcoma, sacral agenesis, cerebral palsy, conversion disorder, multiple sclerosis, and bladder exstrophy)	9/24	
Management on presentation, n		
Self-catheterization (CIC)	19/24	
CIC via native urethra	12/19	
CIC via stoma	6/19	
CIC via vesicostomy	1/19	
Anticholinergic medications	9/24	
Prior augmentation cystoplasty	9/24	
Recurrent UTI	13/24	
Incontinence	17/24	
Urolithiasis	5/24	
Upper tract studies	13/24	
No/mild hydronephrosis	10/13	
Moderate/severe hydronephrosis	2/13	
Urolithiasis	2/13	
Videourodynamics	18/24	
NDO with leak	7/18	
Mixed urinary incontinence	9/18	
Poor compliance	5/18	
Vesicoureteral reflux	3/18	

CIC, clean intermittent catheterization; NDO, neurogenic detrusor overactivity; SD, standard deviation; UTI, urinary tract infection.

Table 2**Management by etiology**

Etiology	Change in Management
Spina bifida (n = 11)	<ul style="list-style-type: none"> Oral anticholinergics Botulinum toxin A Botulinum toxin A, coaptite injection Cleared for renal transplant Cystectomy with creation of ileal conduit Cystectomy with creation of ileal conduit Cystolitholapaxy Cystolithotomy Modified Indiana augmentation cystoplasty, hysterectomy, uterosacral ligament suspension, and autologous pubovaginal sling Recommended modified Indiana augmentation cystoplasty: patient's family opposed None
Spinal cord injury (n = 2)	<ul style="list-style-type: none"> Modified Indiana augmentation cystoplasty None
Transverse myelitis (n = 2)	<ul style="list-style-type: none"> Anticholinergics, initiated self-catheterization Botulinum toxin A
Other (n = 9)	<ul style="list-style-type: none"> Botulinum toxin A Botulinum toxin A, initiated self-catheterization Botulinum toxin A, coaptite injection Maximizing oral anticholinergic dose Modified Indiana augmentation cystoplasty Reinstituted self-catheterization None None None

Table 3

Management after transitioning to transitional care clinic at the Center for Restorative Pelvic Medicine

Intervention	Number of Patients
Surgical interventions, n	
Bladder augmentation or urinary diversion	7/24
Intravesical botulinum toxin A injections	5/24
Cystolitholapaxy or cystolithotomy	2/24
Conservative measures	
Started on anticholinergics	2/24
Started on CIC	1/24

Abbreviation as in Table 1.

Table 4

Reasons for change in management

Reason for Change in Management	Number of Patients
Renal function preservation	7
Social continence	9
Ease of care	1
Other	2
Recurrent UTI	1
Hematuria and enterovesical fistula	1

Abbreviation as in Table 1.