



# Barriers to transition in young adults with neurogenic bladder

G.M. Grimsby<sup>a</sup>, R. Burgess<sup>b</sup>, S. Culver<sup>b</sup>, B.J. Schlomer<sup>b,c</sup>,  
M.A. Jacobs<sup>b,c</sup>

<sup>a</sup>Phoenix Children's Hospital,  
Phoenix, AZ, USA

<sup>b</sup>Children's Health, Dallas, TX,  
USA

<sup>c</sup>Department of Urology,  
University of Texas  
Southwestern Medical Center,  
Dallas, TX, USA

Correspondence to: M.A.  
Jacobs, Children's Health,  
Center for Pediatric Urology,  
2350 Stemmons Freeway, 4th  
Floor, F4.04, Dallas, TX 75207,  
USA, Tel.: +1 214 456 7255;  
fax: +1 214 456 8803

[Micah.Jacobs@Childrens.com](mailto:Micah.Jacobs@Childrens.com)  
(M.A. Jacobs)

## Keywords

Meningocele; Urinary  
bladder; Neurogenic; Transition  
to adult care

Received 27 October 2015  
Accepted 25 April 2016  
Available online 13 May 2016

## Summary

### Introduction

'Transition' not only involves finding an adult healthcare provider, but also includes the process of developing the patient's ability to care for him/herself. Recent literature states that 40% of young adults with special healthcare needs are receiving the tools needed for transition. Pediatric urologists treating patients with complex anomalies, such as spina bifida, often anticipate poor outcomes for patients who are ill equipped for transition to adult care. The goal of this study was to identify potential barriers for young adults with neurogenic bladder when transitioning to independent care.

### Study design

A prospective IRB-approved study was performed on all patients with neurogenic bladder referred to the transitional urology clinic. Reasons for missed appointments were tracked, and all patients were asked to complete the Transition Readiness Assessment Questionnaire (TRAQ) in private prior to an appointment. The TRAQ responses are scaled 1–5, with higher numbers corresponding to higher transition readiness of each individual skill. The mean score for each question was calculated across all patients, and the mean TRAQ score was calculated across all questions for each patient. To assess if certain subgroups were more prepared for transition, mean scores were compared between sexes, patients aged <19 and ≥19 years old, and between

ambulatory and full-time wheelchair users with unpaired *t*-tests.

### Results

A total of 73% (58/79) of patients referred to the transitional clinic came to their appointment. The most common reason for missed clinic appointments was related to health insurance coverage (47%). A total of 42 patients completed the TRAQ at a mean age of 19.5 years old; 90% (38/42) had spina bifida. Females, ambulatory patients, and those ≥19 years old had higher overall mean TRAQ scores, but these differences were not statistically significant. The highest TRAQ scores were related to taking and ordering medications, utilization of medical supplies, communication with healthcare providers, and assisting with household duties. The majority of the patients indicated 'I am learning to do this'. The lowest scores were in response to questions about health insurance coverage, payments for medications or medical equipment, financial help, and utilization of community services. Most patients responded 'I do not know how but I want to learn'.

### Conclusions

Young adults with neurogenic bladder needed the most guidance during transition to independent care, with management of health insurance and finances. Based on these findings, dedicated social work and nurse visits have been included into the transition process.

## Introduction

In a 2002 consensus statement, the American Academy of Pediatrics defined the goal of transition 'to maximize life-long functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood' [1]. 'Transition' not only involves finding an adult healthcare provider, but also includes the process of developing the patient's ability to care for him/herself. This is supported by the Healthy People 2020 initiative, which mandates that 'youth with special healthcare needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence' [2]. Despite these directives, recent literature has uncovered that only 40% of young adults with special healthcare needs are receiving the tools needed for transition [3].

Unfortunately, patients with complex congenital diagnoses are less likely to successfully navigate the transitional process on their own [1]. Specific barriers to transition in these patient populations, such as spina bifida, are largely unknown [4]. What is known is that the majority of adult patients with complex diagnoses do not seek regular urologic follow-up, which places them at risk for higher mortality and more utilization of urgent-care resources [4]. Thus, successful transition is critically important for patients with complex medical diagnoses frequently treated by the pediatric urologist [5].

Although healthcare professionals understand the importance of the transition process, they often do not have the tools or resources to assist their patients in these areas. The Transition Readiness Assessment Questionnaire (TRAQ) is a validated tool with which to measure the readiness for transition to independent self-care for youth with special healthcare needs [6]. A recent systematic review of all transition-readiness tools for adolescents with chronic medical conditions found that not only did TRAQ demonstrate adequate validity and consistency, but it had the added benefit of disease neutrality [7]. This tool is applicable to any patient with a chronic medical condition, and has previously been used in patients with congenital heart disease, cystic fibrosis, and diabetes [8–10].

The goal of this study was to identify potential barriers to transition to independent self care in young adults with neurogenic bladder. This was accomplished by examining the reasons why patients did not keep transitional clinic appointments, and by administering the TRAQ tool. In addition, TRAQ scores were compared between patient subgroups to see which were most prepared for transition. The hope was that these results would better assist urologists in guiding patients through the process of transitioning to independent self-care.

## Methods

A prospective Institutional Review Board-approved study was performed on all patients with neurogenic bladder who were referred to a transitional urology clinic from January 2013 to May 2015. The transitional clinic is specifically for young adult patients (>18 years old) with neurogenic

bladder. Prior to the age of 18 the majority of these patients, especially those with spina bifida, were seen at an outside multidisciplinary clinic. Because of the stoppage of care at that facility at age 18, the transitional clinic provides continuity of care with a pediatric urologist for these complex patients from age 18–26 years. A prospective record was made of all patients referred to the transitional clinic, and which patients kept their appointments. Reasons for missed clinic appointments were tracked via chart review and patient phone calls. Patients were listed as 'no shows' if they did not come to three scheduled clinic visits, or they missed two visits and were unreachable by phone.

To determine specific barriers to transition to independent self-care, all patients seen in the transitional clinic were asked to complete the TRAQ on their first visit to the clinic. Patients whose mental capacity prevented them from completing the questionnaire on their own were excluded, as these patients were unlikely to transition to independent self-care. Once informed consent was obtained, the patients completed the questionnaire in private prior to an appointment with an attending urologist.

The questionnaire contains 29 questions in two domains: skills for chronic condition self-management, and skills for self-advocacy and healthcare utilization. Responses are scaled 1–5, with higher numbers corresponding to higher transition readiness of each individual skill: 1 = I don't need to do this; 2 = I don't know how but I want to learn; 3 = I am learning to do this; 4 = I have started doing this; 5 = I always do this when I need to [10]. The mean score for each question was calculated across all patients, and the mean TRAQ score was calculated across all questions for each patient. To assess if certain subgroups were more prepared for transition, mean TRAQ scores were compared between sexes, patients aged <19 and ≥19 years old, and between ambulatory and full-time wheelchair users with Wilcoxon Rank Sum tests. An alpha of <0.05 was considered statistically significant. All statistics were performed with STATA 12 (College Station, TX, USA).

## Results

A total of 73% (58/79) of patients referred to the transitional clinic came to their appointment. Reasons why patients did not come to the scheduled clinic visit are listed in Table 1. The most common reason was related to health insurance (47%). Specific insurance troubles included no insurance, lapse of insurance, or lack of insurance coverage for the present institution. Of the patients who were seen in the clinic, 30 were scheduled for a follow-up appointment during the study period; 60% (18) came to their second clinic appointment. Twelve patients had difficulty returning to the clinic secondary to loss or lapse of insurance coverage or subsequent non-coverage for the present institution. With the assistance of social work, three were eventually able to return to clinic, and one was referred to an adult urologist. Unfortunately the remaining eight patients have been forced to seek care elsewhere.

Fifty patients were screened to complete the TRAQ. Two patients refused to participate and six were unable to complete the questionnaire on their own, leaving 42 patients who completed it. Mean age at the time of TRAQ

**Table 1** Reason for missed initial transitional clinic appointment.

	N (%)
Lack of insurance coverage	10 (47)
No-showed to multiple appointments	7 (33)
Unable to contact patient	2 (5)
Being seen by provider at different institution	2 (5)

completion was 19.5 (18–25) years old. Twenty-five patients (60%) were male, 90% (38/42) had spina bifida as the underlying cause of neurogenic bladder, 43% (18/42) were ambulatory, and 60% (25/42) had undergone previous urologic surgery. The overall mean TRAQ score was 3.0 (SD 0.89). Females, ambulatory patients, and those  $\geq 19$  years old had higher overall mean TRAQ scores, but these differences were not statistically significant (Table 2).

The mean results and number of non-responders to each TRAQ question can be seen in Table 3. In the first domain – skills for chronic condition self-management – the highest scores were related to taking and ordering medications and utilization of medical supplies, with the majority of patients indicating ‘I am learning to do this’ (Table 3). The only question in which the majority of patients responded ‘I have started doing this’ was concerning taking medications on their own (Table 3). The lowest scores in this domain were in response to questions about health insurance coverage and payments for medications or medical equipment, with most patients responding ‘I do not know how but I want to learn’ (Table 3).

In the second domain – skills for self-advocacy and healthcare utilization – the highest scores were in response to questions about communication with healthcare providers and household duties, with the majority of patients responding ‘I have started doing this’ (Table 3). The lowest scores in this domain involved obtaining financial help and utilization of community services (Table 3). Overall mean scores were higher in the skills for self-advocacy and healthcare utilization section than the skills for chronic condition self-management domain (Table 3).

## Discussion

With advances in health care, patients with chronic medical conditions, such as spina bifida, now have improved survival, with >75% living into adulthood [11]. Unfortunately, methods for a successful transition to adult health care for

these patients has lagged behind the medical advancements that have allowed them to survive into adult life [5]. In addition to a smooth transfer to an adult healthcare provider, patients with chronic urologic conditions need independence in life skills, self-management, housing, and employment opportunities [5]. Providers must acknowledge that transition in health care is one part of the wider transition from dependent child to independent adult [12]. Unfortunately, there is still a sizable population of young adult patients with chronic urologic conditions who continue to receive exclusively pediatric care and are rarely engaged in discussions regarding transition [13].

The present study was the first prospective use of the validated TRAQ tool to assess for barriers to transition to independent self-care in a dedicated clinic for young adult patients with neurogenic bladder. The TRAQ was easy to administer and interpret in the office setting. The results revealed that young adults in the transitional clinic, the majority with spina bifida, were still in the ‘learning’ stages of condition self-management and healthcare utilization. In most skills areas, patients indicated ‘I do not know but I want to learn’, with the lowest scores relating to health insurance coverage, payments for medications and supplies, and finances. These findings have prompted changes in the transitional clinic, including dedicated social work and nursing visits prior to patients seeing the urologist. These separate visits allow for the urologist to focus on the medical needs of the patient. The separate nursing and social work visits provide extra time for discussion maintenance of health insurance, employment, housing, education options, decision-making, and legal rights. As previous reports have documented, nurses often have much more sustained patient contact than physicians, resulting in additional insights into transition needs and opportunities for counseling [14]. The dedicated social work visits are of particular importance, given that the majority of missed appointments in the transitional clinic were secondary to lack of or loss of health insurance. Even worse, loss of insurance prevented over a third of patients from returning to the transitional clinic for a second scheduled visit, even after establishing care there.

Unfortunately, patients have fewer accessible insurance options available to them as young adults; government programs, such as Medicaid and Children’s Health Insurance Program, that allowed insurance access to them as children are no longer available to them as adults. Even those who qualify for Supplemental Security Income (SSI) as children may not meet the qualifications for adult disability when their case is reviewed prior to their nineteenth birthday. Although the opening of the Health Insurance Marketplace on Healthcare.gov has provided an additional opportunity for people to purchase coverage, families may still find it cost prohibitive. Additionally, they can only purchase a plan during open enrollment or a special 60-day enrollment period immediately following a major life event. Several families in the present group receiving SSI were unaware of the re-evaluation and potential loss if they did not meet adult SSI criteria. Others, who had Medicaid based solely on income and family size, were mistakenly under the impression that the Medicaid would continue until the child was 21 years old. This misinformation led to unexpected loss of Medicaid in several patients. Many of these coverage gaps could be avoided if families understand: (1) when their

**Table 2** Comparison of Transition Readiness Assessment Questionnaire scores between various subgroups.

Subgroup	TRAQ score (mean, SD)	P-value
Male (n=25)	2.8 (0.76)	0.05
Female (n=17)	3.3 (0.99)	
Ambulatory (n=18)	3.3 (0.88)	0.16
Wheelchair user (n=24)	2.8 (0.87)	
<19 years old (n=17)	3.0 (0.80)	0.91
$\geq 19$ years old (n=25)	3.0 (0.96)	

**Table 3** Transition Readiness Assessment Questionnaire scores in young adults with neurogenic bladder.<sup>a</sup>

Domain 1: Skills for chronic condition self-management	Mean (SD)	Non-responders (n)
Do you take meds correctly and on your own?	4.32 (1.23)	1
Do you use and take care of medical equipment/supplies?	3.90 (1.53)	1
Do you reorder meds before they run out?	3.39 (1.55)	1
Do you fill a prescription if you need to?	3.33 (1.39)	0
Do you know the side effects of each med and what to do if you have a bad reaction?	3.02 (1.42)	0
Do you call suppliers when there is a problem with the equipment?	2.88 (1.52)	0
Do you order medical equipment before they run out?	2.88 (1.59)	2
Do you call the doctor's office to make an appointment?	2.81 (1.33)	0
Do you arrange for your ride to medical appointments?	2.81 (1.71)	0
Do you manage your money and household expenses?	2.64 (1.45)	0
Do you call the doctor about changes in your health?	2.63 (1.56)	1
Do you know what your health insurance covers?	2.63 (1.28)	1
Do you follow up on referral for tests, check-ups, or labs?	2.54 (1.40)	1
Do you pay/arrange payments for your meds?	2.29 (1.47)	0
Do you apply for health insurance if you lose your coverage?	2.23 (1.29)	2
Do you arrange payment for the medical equipment and supplies?	2.10 (1.38)	0
<i>Mean</i>	2.9	
<b>Domain 2: Skills for self-advocacy and healthcare utilization</b>	<b>Mean</b>	<b>Non-responders (n)</b>
Do you answer questions that are asked by the doctor/nurse?	4.29 (1.24)	0
Do you tell the doctor/nurse what you are feeling?	4.14 (1.30)	0
Do you keep home/room clean or clean up after meals?	4.07 (1.28)	0
Do you ask questions of the doctor/nurse?	3.83 (1.36)	0
Do you use neighborhood stores and services?	3.69 (1.55)	0
Do you fill out the medical history form with your list of allergies?	3.40 (1.43)	0
Do you help plan or prepare meals/food?	3.19 (1.35)	0
Do you keep a calendar or medical and other appointments?	3.12 (1.57)	1
Do you request and get the accommodations/support you need at school/work?	2.85 (1.64)	1
Do you apply for a job/work/vocation services?	2.71 (1.47)	1
Do you call on and use community support/advocacy services when you need them?	2.14 (1.44)	0
Do you get financial help with school or work?	2.05 (1.41)	2
Do you make a list of questions before a doctor visit?	1.85 (1.31)	1
<i>Mean</i>	3.2	

<sup>a</sup> Responses: 1, I don't need to do this; 2, I don't know how but I want to learn; 3, I am learning to do this; 4, I have started doing this; 5, I always do this when I need to.

current coverage ends; (2) what insurance alternatives are available; and (3) the importance of applying for an alternate insurance in a timely manner.

Unsurprisingly, recent studies have found that patients without insurance or with public insurance have a higher likelihood of not transitioning well [3]. Although any young adult patient may need help navigating health insurance coverage, it is known that young people with special healthcare needs require more resources, assistance, and services to optimize their health and navigate the transition process [1]. The stakes are much higher, as lack of healthcare maintenance in patients with chronic medical conditions can be devastating. Previous reports have found that after the disbanding of a multidisciplinary spina bifida clinic, the majority of patients did not have regular medical or specialty care, and there was an increase in serious morbidity, including amputation and nephrectomy [15].

There are few reports of transition questionnaires in the urology setting. One study administered the validated Care Transition Measure 15 (CTM-15), which assesses the quality of care during transition and the non-validated Transition Care Experience [16]. The authors found that the majority of patients found a transition clinic to be beneficial and felt

that written information would be useful [16]. Another study administered a non-validated questionnaire regarding awareness of the need for transition and long-term urologic follow-up [4]. Not surprisingly, the results revealed that while most parents had thought about the transitional process, <50% of patients had [4].

With regards to the TRAQ specifically, the present data are similar to a study of young adults with a variety of medical conditions, including myelodysplasia, cystic fibrosis, and diabetes, as well as patients seen in an adolescent clinic [10]. As in the present cohort, patients scored highest on questions reflecting daily management tasks such as medications and communication with healthcare providers and lowest regarding health insurance and arranging payments [10]. Patients in the general adolescent clinic had higher mean TRAQ scores than patients in the three subspecialty clinics [10]. The authors also found that older youth and females had overall higher scores [10]. While no difference was found in mean scores between various ages and sexes, this lack of a difference may be secondary to small sample size.

There are many obstacles to successful transition, including financial and psychosocial barriers, discomfort on



the part of physicians, patients and families, and lack of training of providers [13,14]. Inclusion of the TRAQ in the present transitional clinic assisted providers in identifying where patients stood with regards to independent self-care and identified barriers. It is hoped that the tool itself also alerted patients and their families to the concept and importance of the transition process. Finally, the results allowed changes to be implemented in the transitional clinic structure that are hoped will better prepare the patients for an effortless shift to an adult provider and independent self-care. Future study of this cohort with serial administration of the questionnaire will hopefully uncover if the patients with higher TRAQ scores do successfully transition to independent care.

Limitations of the study included the small sample size and utilization of the original 29-item TRAQ [6] as opposed to the newer 20-item version [17]. It is believed that the 29-item version is superior for patients with neurogenic bladder as it assesses use of, and payment for, medical equipment and supplies (i.e. catheters), while the newer version does not. In addition, patients who could complete the survey on their own only completed the questionnaires, as these patients were the ones that would most likely become independent. Strengths of the study included the use of a validated transitional survey, a prospective nature, and inclusion of only patients with neurogenic bladder.

## Conclusion

The TRAQ results and explanation of the majority of missed visits in the transitional clinic both firmly emphasized that navigation of healthcare coverage is one of the biggest barriers to transition to independent self-care for patients with neurogenic bladder. Based on these findings dedicated social worker and nurse visits have now been included in the transition process.

## Conflict of interest

The authors have no conflicts of interest to declare.

## Funding source

None.

## Ethical approval

The Institutional Review Board (IRB) of the University of Texas Southwestern Medical Center, Dallas, TX, approved this study.

## References

- [1] American Academy of Pediatrics, P. American Academy of Family and Community Physicians-American Society of Internal Medicine. A consensus statement on healthcare transitions for young adults with special healthcare needs. *Pediatrics* 2002; 110(6 Pt 2):1304–6.
- [2] U.S. Department of Health and Human Services, O.o.D.C.a.P. Healthy People 2020. Available at: [www.healthypeople.gov/node/4887/data\\_details](http://www.healthypeople.gov/node/4887/data_details) [last accessed 21.05.15].
- [3] McManus MA, et al. Current status of transition preparation among youth with special needs in the United States. *Pediatrics* 2013;131(6):1090–7.
- [4] Stephany HA, et al. Transition of urologic patients from pediatric to adult care: a preliminary assessment of readiness in spina bifida patients. *Urology* 2015;85(4):959–63.
- [5] Le JT, Mukherjee S. Transition to adult care for patients with spina bifida. *Phys Med Rehabil Clin N Am* 2015;26(1):29–38.
- [6] Sawicki GS, et al. Measuring the transition readiness of youth with special health care needs: validation of the TRAQ—Transition Readiness Assessment Questionnaire. *J Pediatr Psychol* 2011;36(2):160–71.
- [7] Zhang LF, Ho JS, Kennedy SE. A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. *BMC Pediatr* 2014; 14(4).
- [8] Mackie AS, et al. Healthcare transition for youth with heart disease: a clinical trial. *Heart* 2014;100(14):1113–8.
- [9] Okumura MJ, et al. Improving transition from paediatric to adult cystic fibrosis care: programme implementation and evaluation. *BMJ Qual Saf* 2014;23(Suppl. 1):i64–72.
- [10] Sawicki GS, Kelemen S, Weitzman ER. Ready, set, stop: mismatch between self-care beliefs, transition readiness skills, and transition planning among adolescents, young adults, and parents. *Clin Pediatr (Phila)* 2014;53(11): 1062–8.
- [11] Bowman RM, et al. Spina bifida outcome: a 25-year prospective. *Pediatr Neurosurg* 2001;34(3):114–20.
- [12] Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child* 1999;81(3): 271–5.
- [13] Timberlake MD, et al. Identification of adolescent and adult patients receiving pediatric urologic care and establishment of a dedicated transition clinic. *J Pediatr Urol* 2015;11(2):62.
- [14] Sharma N, et al. Transition care: future directions in education, health policy, and outcomes research. *Acad Pediatr* 2014;14(2):120–7.
- [15] Kaufman BA, et al. Disbanding a multidisciplinary clinic: effects on the health care of myelomeningocele patients. *Pediatr Neurosurg* 1994;21(1):36–44.
- [16] Shalaby MS, et al. Assessment of the introduction of an adolescent transition urology clinic using a validated questionnaire. *J Pediatr Urol* 2015;11(2):89.
- [17] Wood DL, et al. The Transition Readiness Assessment Questionnaire (TRAQ): its factor structure, reliability, and validity. *Acad Pediatr* 2014;14(4):415–22.