

## ACCEPTED MANUSCRIPT

**Transitioning Young Adults with Neurogenic Bladder – Are We Asking Too Much?**Joshua D. Roth, M.D.<sup>1</sup>Konrad M. Szymanski, M.D., M.P.H.<sup>1</sup>Ethan J. Ferguson, M.D.<sup>2</sup>Mark P. Cain, M.D.<sup>1</sup>Rosalia Misseri, M.D.<sup>1</sup>

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## Summary

### Introduction

Significant numbers of young adults with chronic health conditions fail to transition.

### Objective

We aimed to evaluate how ready urologic patients who have transitioned were actually prepared for that process. **Due to the cognitive impairments frequently seen with spina bifida (SB), we hypothesize that these individuals will be less prepared to transition medical care to adult providers compared to their healthy counterparts.**

### Methods

Participants included consecutive patients in the transitional SB clinic at our institution and controls (college student without obvious physical disability or interest in healthcare related fields aged 18-25). Both groups were administered the Transition Readiness Assessment Questionnaire (TRAQ) over a nine-month period. Five TRAQ domains assess 20 skills necessary to transition. Likert scale responses range from 1 “No, I do not know how” to 5 “Yes, I always do this when I need to” (which we considered appropriate for transitioned patients). Demographics and the number of daily medications taken were collected. Patients and healthy controls were compared using 1) total and domain TRAQ scores, 2) the proportion of non-transitioned skills (“1”) and 3) fully transitioned skills (“5”). Non-parametric statistics were used.

### Results

43 unique SB patients (30.8% shunted, 46.5% female) and 100 controls were enrolled. SB patients were older than controls (21 vs 20 years,  $p < 0.001$ ). **There was no** gender difference **between groups** ( $p = 0.33$ ).

Transitioned patients and college students were fully transitioned only in the “Talking with Providers” domain (**Figure**). College students performed significantly better than patients in the domains of “Appointment Keeping” ( $p = 0.04$ ) and “Tracking Health Issues” ( $p = 0.02$ ). Transitioned patients were less likely to be interested in learning how to perform skills in the domains of “Appointment Keeping” and “Tracking Health Issues” ( $p < 0.001$  for both domains).

## Discussion

We describe the transition readiness of young adults with SB compared to healthy controls and other youths with chronic health conditions. Limitations include the small sample size, potentially limiting generalizability, as well as cross-sectional nature.

## Conclusion

“Transitioned” patients with SB had lower TRAQ scores in some domains compared to healthy college students, who themselves had scores indicating that they were not fully ready for transition. Increased attention to transition readiness in people with SB is necessary, as even healthy young adults struggle with these tasks and are poorly prepared for transition.

**Summary Figure.** Comparison of median TRAQ domain scores between 43 transitioned spina bifida patients and 100 healthy college student controls. \* indicates  $p \leq 0.04$

## Introduction

Transitioning of care from pediatric to adult providers requires delivery of uninterrupted, developmentally appropriate care to patients as they move from adolescence to adulthood[1]. Part of the struggle in transitioning care revolves around system-based issues of identifying adult providers with an interest or willingness to care for patients with complex congenital conditions[2]. However, teaching a patient the skills necessary to advocate for themselves and transition their care is equally important, and can be overlooked by providers as they start to discuss transition.

**Prior studies have revealed that almost 60% of young adults with chronic health conditions fail to transition their care from pediatric providers to adult providers[3]. The problems encountered during transition are frequently related to cognitive impairments that are common in the SB population or the patient's prioritization of body image and perceived "normal" behaviors over their medical care[2]. The failure to transition irrespective of the etiology has been documented to result in higher costs of medical care, more utilization of urgent care resources, and increased rates of mortality[4,5].**

**Transitioning care is important for both healthy adolescents and adolescents with chronic health conditions when transitioning care from pediatric to adult health care providers.** The Transition Readiness Assessment Questionnaire (TRAQ) is a validated tool that measures a young adult's readiness to transition care **by way of 20 skills deemed important for managing one's health care as an adult[6,7].** In a

recent systematic review of all transition readiness tools, the TRAQ was determined to be the best tool due to its content and construct validity. In addition, it is a disease-neutral tool and was designed to test transition readiness in adolescents with any chronic disease[8].

As the prefrontal cortex of the brain, responsible for reward-related learning, behavior control and decision making, is not fully developed until the age of 24, healthy adolescents may lack the skills necessary to transition[9-11]. Further, the additional cognitive impairments that are present in those with SB can compound this problem[12-15]. Thus, we aimed to evaluate the readiness to transition among SB patients who have already transitioned to adult care from the care of their pediatric urologist. **While those with SB have more deficits than their healthy counterparts, the process of transition is difficult and often not a focus of care as adolescents become adults. Thus,** we hypothesize that young adults with SB are **less** prepared to transition their care when compared to healthy counterparts.

## **Methods**

A cross-sectional assessment was conducted of consecutive patients with SB in the transitional SB clinic at our institution from August 2017 to April 2018. The transitional clinic is a multidisciplinary clinic specifically for patients over 18 years old with the sequela of SB. **Patients in this transition clinic were provided information regarding the transition clinic and scheduled to be seen there for upcoming appointments after their last appointment in the pediatric multidisciplinary spina**

**bifida clinic. Patients who were discharged from the pediatric clinic prior to the creation of the multidisciplinary clinic were encouraged to attend this clinic from their various Urologists.** Each patient completed a validated TRAQ questionnaire to identify areas to improve the skills needed for a successful transition[7]. Only the first survey was included for patients with multiple clinic appointments over the study period.

Five TRAQ domains (“Managing Medication,” “Appointment Keeping,” “Tracking Health Issues,” “Talking with Providers,” and “Managing Daily Activities”) assess 20 skills necessary for transition. Responses are on a 5-point Likert scale: 1 “No, I do not know how”; 2 “No, but I want to learn”; 3 “No, but I am learning how to do this”; 4 “Yes, I have started doing this”; 5 “Yes, I always do this when I need to”. We considered “5” optimal for transition. In addition, demographics and the number of daily medications were collected.

Additionally, we collected TRAQ responses from controls: young adults aged 18 to 25 at a local college **who would have had to recently transfer care from their pediatrician to an adult provider.** The surveys were collected from a convenience sample of individuals **who were approached at the student union. Individuals** without obvious physical disability or an interest in pursuing a career in health care related fields **were asked to fill out the TRAQ.** Demographics and the number of daily medications were collected as a surrogate for overall health.

Mean overall and domain TRAQ scores were calculated for each subject. Three comparisons of patients and controls were conducted based on: 1) the median of individual total and domain TRAQ scores, and 2) the proportions of non-transitioned skills (“1”) and 3) the proportions of skills consistent with fully transition (“5”). Whenever possible, non-parametric, median-based tests were utilized to avoid potential bias of means-based tests which assume normal distribution. Consequently, continuous variables were compared using the Kruskal-Wallis rank test and categorical variables using Fisher’s exact test.

We also compared SB patient scores to those reported by adults aged 18-26 with other chronic conditions like cystic fibrosis. Since published values for these other populations only include means, rather than medians,[7] a Student’s t-test was used for this comparison. An  $p < 0.05$  was considered significant. All statistics were performed with Stata 12 software (College Station, TX, USA).

## Results

Forty-three consecutive adults with SB aged 18 to 25 participated over a 9-month period. The median age was 21 years (IQR 19-22) and 20 (46.5%) were female. The median number of daily medications taken was 3.0 (IQR 1.0-5.0), 72.1% had shunted hydrocephalus and 90.7% had myelomeningocele. The majority of patients had catheterizable channels (72.1%) or antegrade continence enema **stomas** (67.4%). Almost half of patients had a prior bladder augmentation (48.8%), while a quarter of patients had no prior genitourinary reconstruction (25.6%). Controls were younger (20



vs. 21,  $p < 0.001$ ), were less likely to be white (53% vs. 83.7%,  $p = 0.002$ ), and took fewer daily medications (0 vs. 3,  $p < 0.001$ ) compared to those with SB (Table 1).

Overall TRAQ scores were not different between groups (controls 4.1 vs. SB patients 3.7,  $p = 0.09$ ) (Figure 1, Table 2). A score of 4 corresponds to “Yes, I have started doing this.” Therefore, this indicates that, on average, both groups were either learning how to do transition-related tasks or starting to perform them, but were not yet consistently doing so. Both groups were only fully transition-ready, as indicated by an average domain score of 5.0, in the domain of “Talking with Providers.” **Control** college students performed significantly better than **SB** patients in the domains of “Appointment Keeping” (3.7 vs. 3.1,  $p = 0.04$ ) and “Tracking Health Issues” (4.0 vs. 3.5,  $p = 0.02$ ). This indicates that in the “Appointment Keeping” domain, both groups were only learning how to perform these tasks. In the “Tracking Health Issues” domain, the college students have started performing these tasks, while the transitioned SB patients were only learning how to perform these tasks.

Adults with SB reported similar TRAQ scores overall and for each domain irrespective of the number of daily medications or surgical history.

There were no differences between the SB patients and controls when comparing the percentage of young adults who obtained a maximum score of 5 in each domain ( $p \geq 0.09$ ). This indicates that the same proportion of adults, whether with SB or not, reported full transition readiness in each domain and overall. However, **SB** patients

were more likely to have scores of “1” (“No, I do not know how.”) compared to **control** college student controls in the domains of “Appointment Keeping” (14.0% vs. 0.0%,  $p<0.001$ ) and “Tracking Health Issues” (16.3% vs. 0.0%,  $p<0.001$ ). (Table 2).

When comparing **our SB cohort** to 363 adults aged 18-26 with various chronic health conditions[7], several differences were observed. **SB** patients are less ready to transition overall (3.6 vs. 4.0,  $p=0.01$ ) compared to the previously reported populations with chronic conditions like cystic fibrosis. This indicates that, overall, patients with SB were just learning how to perform these tasks, while their counterparts with other chronic medical conditions were starting to perform them. Patients with SB reported less readiness to transition in the “Appointment Keeping” (3.1 vs. 3.8,  $p<0.001$ ), “Tracking Health Issues” (3.3 vs. 3.7,  $p=0.04$ ), and “Managing Daily Activities” (4.0 vs. 4.4,  $p=0.01$ ) domains compared to those with chronic medical conditions (Table 3).

## Discussion

This study represents the first study to administer the TRAQ to young adults without chronic medical conditions. It is also the first study to compare transition readiness in adults with SB who have already transitioned their care to otherwise healthy controls. Interestingly, healthy controls, on average, only scored a “4.1,” indicating that they were only starting to perform tasks necessary for transition. While the total TRAQ scores for young adults with SB was no different from those with other chronic medical conditions[7], differences within individual domains all suggested that those with SB were consistently less ready to transition. One would expect those with more consistent

exposure to the health care field due to frequent SB follow-up to be more ready to tackle the process of transition. However, this was not observed. **These findings indicate that we need to allocate resources to prepare** all adolescents for the process of transition, regardless of underlying disease.

Medical and surgical advancements in ventriculoperitoneal shunts and aggressive management of neurogenic bladder have increased survival to 75-85% in individuals with SB into adulthood[16]. This has created a tremendous need for transitional services due to the multiple urologic, neurosurgical, orthopedic, gastrointestinal, cognitive, and psychologic care people with SB can experience into adulthood. Providers should recognize that health care transition is one small part of the bigger transition from a dependent child to an independent adult[17]. In addition to ensuring a smooth transition of care from a pediatric provider to a transitional or adult provider, we should also ensure our patients have the skills necessary to become a more independent young adult with regard to their medical care, including the skills assessed in the TRAQ. This includes managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities[7,16]. Unfortunately, there is a large population of adults with congenital urologic conditions who continue to receive pediatric care exclusively and rarely engage in transition discussions[18].

Patients with SB performed just as well as healthy controls in the fields of “Managing Medications,” “Talking with Providers,” and “Managing Daily Activities.” However, the only field that reported consistent fully transitioned skills was the “Talking with Providers”

domain. Transitioning skills required to manage medications and manage daily activities should be emphasized more when preparing both healthy adolescents and those with chronic diseases for transition of care.

Among the most worrisome findings of this study are the lower scores among young adults with SB in the domains of "Appointment Keeping" and "Tracking Health Issues," and the 14-16% of these adults having no interest in learning about these transition related tasks (indicated by scores of "1") in these domains. Having a score of "2" indicates that an individual does not know how to perform necessary transition skills but is wanting to learn how to perform those skills. This indicates that despite several discussions and demonstrations which occurred during the transition process to help address issues included in the TRAQ questionnaire, patients with SB were more likely to report no apparent interest in learning or ability in how to perform these tasks. These areas include skills related to making an appointment, following up on test results, calling the doctor about changes in health status, applying for health insurance, filling out a medical history form, and generating a list of questions prior to a doctor's visit. Future work should attempt to understand how to motivate individuals with SB how to want to learn to perform these tasks.

Individuals with SB have much more exposure to health care, e.g., doctor's visits, physical therapy session, etc., than otherwise healthy controls due to the multi-systemic nature of their chronic illness. Compared to other young adults with significant health care exposure due to chronic conditions, young adults with SB scored worse overall and

specifically in the “Appointment Keeping,” “Tracking Health Issues,” and “Managing Daily Activities” domains. It is possible that much of this difference could be attributed to cognitive deficit observed from congenital hydrocephalus[12-15]. More research is needed to address this discrepancy in transition readiness between similarly-aged groups of young adults with different chronic medical conditions. Perhaps neuropsychological testing should be offered to adolescents and young adults to evaluate their cognitive abilities and ability to understand the importance of continued care.

Our results are similar to that of Grimsby et al., who found navigating healthcare coverage to be one of the biggest barriers to transition to independent self-care for patients with neurogenic bladder[19]. This barrier to transitioning is encapsulated in the “Appointment Keeping” domain. Although navigating health insurance coverage is difficult for any young adult, those with special health care needs require more assistance and more resources to achieve this goal[1]. Insurance options become limited as one approaches adulthood. Adults age out of Children’s Health Insurance Program, which provides low-cost health coverage to children in families that earn too much money to qualify for Medicaid, and other public health insurance programs cover nearly half (44%) of children with special health care needs[21]. This may contribute to the 60% of patients fail to transition. This is particularly worrisome as increased serious morbidity is observed in the majority of patients without regular medical or specialty care after their multidisciplinary SB clinic was disbanded[3,22].

There are many obstacles to a successful transition of care. In addition to the issues related to the patient and their family when moving from a family-based care structure to independent management of medical issues, there are also the issues related to barriers in the health care system[2]. Administering the TRAQ has allowed providers in the transition clinic to focus on addressing patient and family barriers to the transition process. Simply administering the tool has generated conversations with patients and families about the process of transition and how to have the patient succeed in independent self-care. This might provide a valuable addition for assessment of young teens before they enter the transition period.

Limitations of the study include its small sample size, potentially limiting generalizability, as well its cross-sectional nature. As our study only captured transition readiness at one point in time, and it should not be interpreted to suggest that addressing the barriers to transition identified in the study could improve transition readiness. Another limitation was a possible response bias as the survey could only be administered to patients who were already enrolled in a transition clinic. **While the survey sought to collect data regarding the patient's skill level at transition readiness, some of the levels may be higher due to parental involvement.** Additionally, a convenience sample was obtained for healthy controls and their responses may not represent the larger population. At the same time, control participants were all college students and therefore more educated than otherwise healthy young adults not attending college. Presuming that education and health literacy plays some part in transition readiness, this seems to suggest that actual

readiness to transition among young adults in the general population may be even lower than reported here.

## **Conclusion**

Transitioned patients with SB had lower TRAQ scores in the domains of “Appointment Keeping” and “Tracking Health Issues” compared to healthy college students, who themselves had scores indicating that they were not fully ready for transition. Compared to young adults with other chronic medical conditions, young adults with SB had lower TRAQ scores overall, **indicating a decreased readiness to transition**. Increased attention to transition readiness is necessary in people with SB, as well as healthy young adults. It appears both groups struggle with these tasks and are poorly prepared for transition.

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Figure 1: Comparison of median TRAQ domain scores between transitioned SB patients and healthy college student controls. \* indicates  $p \leq 0.04$

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Table 1: Demographics of Transitioned SB Patients and Healthy College Student Controls

	Transitioned Patients N=43	College Students N=100	p-value
Age in years, median (IQR)	21 (19-22)	20 (19-21)	<0.001
Gender, # female (%)	20 (46.5%)	53 (53.0%)	0.33
Race (% White)	36 (83.7%)	53 (53.0%)	0.002
Ethnicity (% Hispanic)	4 (9.3%)	15 (15%)	0.31
# of Daily Medications, median (IQR)	3 (1.0-5.0)	0.0 (0.0-1.0)	<0.001
<b>Disease Process</b>			
Myelomeningocele	39 (90.7%)		
Lipomeningocele	1 (2.3%)		
Meningocele	1 (2.3%)		
Myelomeningocele and cloacal extrophy	1 (2.3%)		
Lipomeningocele and cloacal extrophy	1 (2.3%)		
<b>Prior Surgeries</b>			
VP Shunt	31 (72.1%)		
Bladder augmentation	21 (48.8%)		
Bladder stone surgery	18 (41.9%)		
Kidney stone surgery	5 (11.6%)		
Bladder neck sling	13 (30.2%)		
Urethral sling	1 (2.3%)		
Artificial urinary sphincter	1 (2.3%)		
Bladder neck reconstruction	9 (20.9%)		
Bladder neck closure	1 (2.3%)		
Catheterizable channel	31 (72.1%)		
Antegrade continence enema	29 (67.4%)		
No genitourinary	11 (25.6%)		

reconstruction			
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Table 2: TRAQ scores by domain and overall for 43 transitioned spina bifida patients and 100 healthy college student controls.

		Median (IQR)	Mean (SD)	% Minimum Score	% Maximum Score
Overall TRAQ Score	Transitioned Patients	3.7 (2.8-4.5)	3.6 (1.1)	0.0%	7.0%
	College Students	4.1 (3.6-4.4)	4.0 (0.6)	0.0%	4.0%
Managing Medications	Transitioned Patients	4.0 (3.1-4.6)	3.8 (1.1)	2.3%	16.3%
	College Students	4.2 (3.8-4.8)	4.1 (0.8)	0.0%	14.0%
Appointment Keeping	Transitioned Patients	3.1 (2.0-4.4) <sup>a</sup>	3.1 (1.4)	14.0% <sup>c</sup>	14.0%
	College Students	3.7 (3.1-4.2)	3.7 (0.8)	0.0%	10.0%
Tracking Health Issues	Transitioned Patients	3.5 (2.5-4.5) <sup>b</sup>	3.3 (1.4)	16.3% <sup>c</sup>	14.0%
	College Students	4.0 (3.5-4.5)	3.9 (0.8)	0.0%	12.0%
Talking with Providers	Transitioned Patients	5.0 (4.5-5.0)	4.7 (0.6)	0.0%	65.1%
	College Students	5.0 (4.5-5.0)	4.6 (0.6)	0.0%	63.0%
Managing Daily Activities	Transitioned Patients	4.3 (3.0-5.0)	4.0 (1.1)	2.3%	34.9%
	College Students	4.7 (4.0-5.0)	4.4 (0.6)	0.0%	33.0%

a: p=0.04

b: p=0.02

c: p<0.001

All other p values are > 0.09

Table 3: TRAQ scores by domain and overall for 43 transitioned spina bifida patients from this cohort compared to 363 adults aged 18-26 with various chronic health conditions from the Wood et al. cohort.

	Roth et al. Spina Bifida Patients, Mean (SD)	Wood et al. ≥18 yo, Mean (SD)	p-value
Overall TRAQ Score	3.6 (1.1)	4.0 (1.0)	0.01
Managing Medications	3.8 (1.1)	4.1 (1.1)	0.09
Appointment Keeping	3.1 (1.4)	3.8 (1.2)	<0.001
Tracking Health Issues	3.3 (1.4)	3.7 (1.2)	0.04
Talking with Providers	4.7 (0.6)	4.6 (0.9)	0.48
Managing Daily Activities	4.0 (1.1)	4.4 (0.9)	0.01

