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Barriers to transition in young adults with neurogenic bladder

G.M. Grimsby [a], R. Burgess [b], S. Culver [b], B.J. Schlomer [b,c], M.A. Jacobs [b,c]

[a]Phoenix Children's Hospital, Phoenix, AZ, USA

[b]Children's Health, Dallas, TX, USA

[c]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 (M.A. Jacobs)

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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.

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Introduction

In a 2002 consensus statement, the American Academy of Pediatrics defined the goal of transition 'to maximize lifelong 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 difficultly 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