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# An Innovative Nurse-Managed Transition Clinic for Adolescents and Young Adults with Spina Bifida: A Pilot Study


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**Presenter Information**

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## AN INNOVATIVE NURSE-MANAGED TRANSITION CLINIC FOR ADOLESCENTS AND YOUNG ADULTS WITH SPINA BIFIDA: A PILOT STUDY

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**Background.** Transition from pediatric to adult care for patients with complex illness is challenging. The Spina Bifida Center at Boston Children's Hospital (SBC) has approximately 650 patients, of which 25% (N=162) are ≥ 18 years of age. The SBC has not had a structured paradigm for successful transition. A first transition clinic with our pediatric and adult care urology partners was initiated in August 2016.

**Methods.** A 20 question (TRAQ: Transition Readiness Assessment Questionnaire) paper survey was distributed to patients in the first Spina Bifida Transition Clinic at Boston Children's Hospital. TRAQ is a validated, patient-centered questionnaire which providers and families can use to assess youths' readiness to transition to adult care.

**Results.** Seven young adults participated in the Spina Bifida Transition Readiness Assessment Questionnaire (TRAQ). Of the seven patients who took part in the TRAQ survey, 85.7 % (n=6) were males and 14.3% (n=1) were females. 85.7% were white-non-Hispanic or Latino, and 14.3 % were white-Hispanic or Latino. The participants' mean age was 28.1. Of the patients who completed the questionnaires, 61.4 % reported a positive response ("Yes, I have started doing this," or "Yes, I always do this when I need to.") related to their ability level regarding managing medications, appointment keeping, tracking health issues, talking with providers, and managing daily activities. 16.4% reported a negative response ("No, I do not know how,") related to the domains mentioned above, and 22.1% had a negative response but were either willing to learn or already learning how to manage and develop skills needed for the transition to adult care.

**Conclusion.** Transition is a multi-step process. We found that successful transition for the patient and family requires investment from pediatric and adult providers, involvement of social work and the support of local spina bifida association.

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