Cross-sectional evaluation of transition readiness in the interdisciplinary spina bifida clinic

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**Limits: 300 words, no figures/tables**

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Introduction

Preparing adolescents with spina bifida (SB) for transition to adult healthcare is a critical process that requires ongoing evaluation and individualization. The Transition Readiness Assessment Questionnaire for SB (TRAQ-SB) is a validated, patient-centered questionnaire, with a SB-specific domain, that evaluates patients’ readiness for transition to adult care.

Methods

The TRAQ-SB was administered to all patients >13 years old at their annual SB Clinic visit starting in June 2016 (n=155). Survey results for the first 24 months of administration were reviewed. Higher TRAQ-SB scores suggest greater transition preparedness (maximum score: 160).

Results

The TRAQ-SB was completed 136 times (87.7% completion) by 121 patients. The mean patient age was 20.3 years (IQR 16.0-21.7). 64 patients (52.9%) were female. Most patients had myelomeningocele and shunted hydrocephalus.

The mean total score was 109 (SD: 29.0, range: 31-160). Mean subscores were: Managing Medications: 13.6 (4.7, 4-20); Appointment Keeping: 19.5 (8.4, 7-35); Tracking Health Issues; 10.9 (4.7, 4-20); Talking with Providers: 9.1 (1.36, 2-10); Managing Daily Activities: 11.3 (3.1, 3-15); SB Activities: 44.4 (12.9, 0-60).

The Total TRAQ-SB Score was significantly higher in females (113.8 vs. 103.1, p=0.03), as were the Managing Medications, Tracking Health Issues, and Managing Daily Activities subscores. The Managing Daily Activities subscore varied significantly by anatomic lesion level and was significantly higher in patients with a diagnosis other than myelomeningocele. The SB Activities subscore was significantly higher in patients with myelomeningocele (45.9 vs 35.7, p=0.0009) and hydrocephalus (47.0 vs 34.4, p<0.0001). Neither the total TRAQ-SB score, nor any of the subscores, significantly correlated with age.

Among 29 patients with repeat TRAQ-SB scores, the mean change was +7.7 points. The greatest gains were in Appointment Making (+2.9) and SB Activities (+2.8) (not statistically significant).

Conclusions

The TRAQ-SB has the potential to focus transition education and facilitate transition to adult care.

Table 1. Demographics

|  |  |
| --- | --- |
| **Characteristic** | **n= 121** |
| Age, y | 20.3 (6.35) |
| Female, n (%) | 64 (52.9) |
| Diagnosis, n (%) |  |
|  | Myelomeningocele | 106 (87.6) |
|  | Other | 15 (12.4) |
| Hydrocephalus, n (%) | 97 (80.2) |
| Lesion Level, n (%) |  |
|  | Thoracic | 38 (31.4) |
|  | Lumbar | 70 (57.9) |
|  | Sacral | 13 (10.7) |

Table 2.

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Managing Medications** | **Appointment Keeping** | **Tracking Health Issues** | **Talking With Providers** | **Managing Daily Activities** | **Spina Bifida Activities** | **Total** |
| **Gender** |  |  |  |  |  |  |  |
| Female | 14.3\* | 20.7 | 11.9\* | 9.2 | 12.0\*\* | 45.8 | 113.8\* |
| Male | 12.7\* | 18.1 | 9.9\* | 9.0 | 10.4\*\* | 42.9 | 103.1\* |
|  |  |  |  |  |  |  |  |
| **Diagnosis** |  |  |  |  |  |  |  |
| Myelo | 13.5 | 19.3 | 10.6 | 9.1 | 11.0\* | 45.9\*\*\* | 109.5 |
| Other | 14.3 | 21.4 | 12.7 | 9.5 | 12.6\* | 35.7\*\*\* | 105.3 |
|  |  |  |  |  |  |  |  |
| **Hydrocephalus** |  |  |  |  |  |  |  |
| Yes | 13.5 | 19.2 | 10.6 | 9.1 | 11.1 | 47.0\*\*\* | 110.6 |
| No | 14 | 20.7 | 12.1 | 9.2 | 12 | 34.3\*\*\* | 102.3 |
|  |  |  |  |  |  |  |  |
| **Functional Level** |  |  |  |  |  |  |  |
| Thoracic | 13.7 | 18.6 | 9.9 | 9.2 | 10.4\* | 46.5 | 108.2 |
| Lumbar | 13.1 | 19.3 | 11.1 | 9.0 | 11.5\* | 43.4 | 107.5 |
| Sacral | 15.4 | 22.9 | 12.8 | 9.5 | 12.6\* | 43.8 | 116.8 |

\* p<0.05, \*\*p<0.01, \*\*\*p<0.001