IMPROVING SELF-MANAGEMENT AND ASSOCIATED OUCOMES FOR ADOLECENTS WITH SPINA BIFIDA

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Background
Higher levels of self-management (SM) correlate with better health outcomes and transition preparedness for adolescents with chronic conditions. Currently, there are no evidence-based outpatient clinic interventions to improve SM for adolescents with varying degrees of physical and cognitive impairment such as spina bifida (SB). Developing a clinic process to guide individualized SM plans for SB-related conditions supports the healthcare quality domains of patient-centeredness, effectiveness, and efficiency.

Objectives
We aim to develop a clinic-based intervention to improve SM participation for TCH Spina Bifida Transition Clinic (SBTC) adolescent patients that leads to statistically significant improvement in related health outcomes, SM, quality of life, and patient satisfaction scales by two years.

Methods
With multi-stakeholder input, an initial SB SM Tool was developed, including a questionnaire to determine SM independence levels for bowel, bladder, and skin care, and an algorithm to guide individualized education, goal-setting, and targeted intervention. The tool is used at quarterly SBTC visits. Every 6 months, surveys assessing SM, quality of life, and patient satisfaction are collected. The clinic team meets monthly to review outcomes and plan tool and process improvements.

Results
From November 2016 to January 2018, 53 patients completed baseline measures and 26 have completed 6-month follow up measures. On a scale of 1/low-7/high, SB SM improved significantly (M1=4.23; M2=5.13; p=.003) while non-SB related SM did not (M1=3.36; M2=3.93; p=.105). On a scale of 1/low-5/high, patient care subscales (follow-up coordination, patient activation, practice design, problem solving, and goal setting) all improved, but were not statistically significant (average M1=3.62; M2=3.95 Goal setting trended toward significance (p=.075). On a scale of 0/low-200/high, quality of life subscales for (1) family and independence and (2) bladder and bowel control improved, but the change was not statistically significant (M1=136.2; M2=150; p=.110).

Discussion
Preliminary results suggest that the SB SM Tool can engage patients and improve SM within the time constraints of a complex care visit. Behavioral change evolves slowly and, given the small sample size and number of visits, further implementation and data collection are needed to substantiate these findings. Future interventions aim to improve SM questionnaire validity, increase SM goal implementation, and reduce exacerbations of comorbid conditions.