The PROMIS of Assessing Pediatric Spinal Deformity Outcomes

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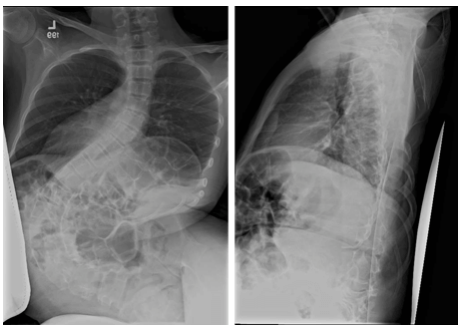

Example X-rays of a patient with neuromuscular scoliosis due to cerebral palsy.

There is a need for high-quality, reliable, valid and responsive PRO instruments in pediatric orthopaedic populations. Only 45 percent of PROM instruments used in pediatric orthopaedic populations were developed for, or had clinical evidence supporting, their use in pediatric patients.

The hypothesis for this study is that the implementation of patient-reported outcomes measurement information system (PROMIS) measures is feasible and that PROMIS measures will be valid, reliable and responsive in pediatric spinal deformity patients. They also hypothesize that the implementation of PROMIS measures in this population will improve patient and provider satisfaction.

The team will identify study population, identify existing evidence (systematic review) and conduct a pilot/feasibility study to: 1). Transition PROMs from static forms to CATs and 2). Validate PROMIS in study population. The initial population of interest is pediatric spinal deformity patients, which includes several subpopulations:

- Adolescent idiopathic scoliosis
- Early-onset scoliosis
- Neuromuscular scoliosis
- Connective tissue-related scoliosis (e.g., Marfan syndrome)

Future directions include:

- Prospectively implement PROMIS measures on a larger scale, to other study populations, using a modular approach.
- Determine whether clinicians find data captured to be satisfying or helpful in caring for patients.
- Determine whether application of PROMIS measures is associated with improved or perceived improvement in outcomes.

This project was presented to the T32 Executive Committee and approved on Sept. 27, 2017.