

Gait Outcomes Assessment List (GOAL): Development of a patient priority-centered outcome measure for children with ambulatory cerebral palsy

Falisha Karpati^{1,2}, Shannon Weir² BSc, MSc, Unni Narayanan^{1,2,3} MBBS, MSc, FRCS(C)

¹Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital;

²Child Health Evaluative Sciences, Sickkids Research Institute;

³Division of Orthopaedic Surgery, The Hospital for Sick Children

Background: Children with cerebral palsy (CP) undergo major interventions to preserve or improve their gait efficiency, optimize their physical function and participation in life activities. Qualitative research identified children's and parents' expectations of these interventions, and generated 48 items across 6 domains for a new priority-based outcome instrument (GOAL[®]Questionnaire) for this population.

Research Questions: What are the importance of each item and domain of the GOAL from child and parent perspectives? How can the GOAL be classified using the ICF framework? Does the GOAL possess face, content and construct validity?

Methods: The GOAL was administered to 51 children (7-16yrs) with ambulatory CP (GMFCS levels I-III) and their parents. Participants rated the importance of each item as an individual goal. Children's and parents' responses were compared using the paired t-test, and stratified by GMFCS level. Each item was classified to identify the ICF domains covered by the GOAL.

Results: All but 3 items were rated above a threshold level of importance by children and parents. Children's priorities correlated with their parents'; however parents rated all items as more important goals than their children. Overall, the domain of "Gait Appearance" was rated most important followed by "Gait Function/Mobility". Increased severity of CP (higher GMFCS level) was associated with lower GOAL domain and total scores, and higher importance of Activities of Daily Living/Independence domains. Items of the GOAL questionnaire represented concepts from all ICF domains.

Conclusions: The GOAL[®]Questionnaire has face and content validity, based on the importance ratings of items and the coverage of all ICF domains. Some items will be dropped and the revised questionnaire tested in a larger sample for internal consistency, test-retest reliability, and construct validity.

Relevance: The GOAL has the potential to become a much needed priority –based outcome measure for children with ambulatory CP undergoing various gait interventions.

Falisha Karpati

Falisha Karpati is in her final year of an Honours Bachelor of Science program at the University of Toronto, with a specialist in Neuroscience, major in Psychology and minor in Biology. She has worked on several research projects over the past two years, and began working on the GOAL project this past summer through the Ward Summer Student Program at Holland Bloorview. During this summer program, Falisha participated in the Hospital for Sick Children Summer Student Symposium and received the Outstanding Presentation award. She is now continuing her work on the GOAL project through an independent project course offered through the University of Toronto. After graduation, she plans to pursue a Masters degree in Neuroscience with the goal of obtaining a career in research.