

E6

Validation of the GOAL questionnaire: an outcome measure for ambulatory children with cerebral palsy

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Background/Objectives: Children with cerebral palsy (CP) undergo a variety of interventions to preserve or improve their gait and gait related function. Current outcome measures of these interventions do not adequately reflect the priorities of these children. The Gait Outcomes Assessment List (GOAL©) questionnaire (48 items across 7 domains) was developed through an iterative process involving ambulatory children with CP and their parents, to incorporate their priorities and goals related to their gait differences. Health care professionals from multiple disciplines were surveyed to refine the questionnaire. The purpose of this study was to test the reliability and validity of this revised GOAL© for use as a meaningful outcome measure for this population.

Study Design: Outcome measure development & validation study.

Study Participants and Setting: Ambulatory children (5–18yrs) with CP (GMFCS I– III) and their parents recruited from a children's rehabilitation hospital and a tertiary children's hospital.

Materials/Methods: 51 children with CP, GMFCS I (11); II (24); III (16), mean age 13.2 years (SD: 3.4), and their parents were invited to complete the child and parent versions of the GOAL, concurrently with the Gillette Functional Abilities Questionnaire (FAQ) and the Functional Mobility Scale (FMS). 25 children & parents completed the GOAL 2 weeks after the first to measure test-retest reliability using Intraclass Correlation Coefficient (ICC). Internal consistency was measured using Cronbach's alpha. Children's and parents' responses were compared using paired t-tests. GOAL scores were compared between GMFCS levels using ANOVA. GOAL total and domain scores were correlated with the FAQ and FMS using Spearman's correlation coefficient.

Results: The test-retest reliability of the GOAL total score was excellent, ICC: 0.93 (95% CI: 0.78–0.98) & 0.98 (95% CI: 0.96–0.99) for the child and parent versions respectively. ICCs for domain scores ranged from 0.69 to 0.93. Internal consistency for each domain ranged from 0.74 to 0.97. The mean GOAL total score for the child responses for the entire CP group was 60.7 (SD:16.7) distributed over a wide range of scores (25.1–88.9) and for the Parent was 50.9 (SD: 17.1) over a wide range (19 to 86). As hypothesized, both children's and parents' mean GOAL total scores decreased significantly with increasing severity of GMFCS level ($p < 0.01$). Children's GOAL total scores positively correlated with their parents' scores ($R = 0.86$; $p < 0.1$) but consistently rated themselves higher across all domains than their parents did ($p < 0.01$). GOAL total scores correlated positively with the FMS

($r = 0.76$; $p < 0.01$) and the FAQ level ($r = 0.85$; $p < 0.01$) with the highest correlations between expected domains of the GOAL and the FAQ & FMS respectively.

Conclusions/Significance: The GOAL questionnaire is reliable, internally consistent, and demonstrates construct (known groups) and convergent validity with other outcomes that measure similar constructs. Scores are spread over a wide range with no evidence of floor or ceiling effects for this population. The GOAL questionnaire is ready for wider testing of validity and longitudinal assessment to determine sensitivity to change, and has the potential to serve as a much needed goal based outcome measure for children with ambulatory CP.

E7

The development of a pilot tool to assist primary care providers in identifying risk and optimising physical function in ambulant adults with cerebral palsy

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Background/Objectives: The health disorders experienced in adults ageing with cerebral palsy (CP) frequently differ from those encountered in the general population and in those ageing with acquired disability in terms of prevalence, age of onset, rate of progression, degree of severity and presenting manifestations. These disorders are also more likely to be multiple and complex in those with CP. Although around 90% of adolescents with CP are ambulant entering adulthood, many experience premature decline in mobility and function resulting in adverse consequences and potential for increased need for care and support. Adults with CP have identified challenges in accessing timely and appropriate services to meet their health needs. Primary care practitioners are typically responsible for providing advice and health services to adults with CP, yet frequently do not have awareness of or ready access to evidence to guide decision making.

Study Design: Instrument development.

Study Participants and Setting: Fifteen expert and generalist practitioners providing a health related service for adults with a diagnosis of CP were recruited from both the public and private health sectors to participate in a modified Delphi study. Feedback from three adults with cerebral palsy to provide consumer input to the final version of the pilot tool was also sought.

Materials/Methods: A qualitative analysis of transcripts from audiotaped semi-structured interviews with participants was undertaken. Firstly, a comprehensive list of defined problems was identified, secondly, options for management were explored, thirdly, suitable outcome measures were proposed and finally referral processes were considered. Responses were synthesised, and a second round of feedback from practitioners was sought. Information from relevant systematic reviews and consumer feedback was incorporated into the final version of the instrument.

Results: The majority of practitioners who participated were physiotherapists (n = 7), highly experienced (>10 years, n = 8), with eleven participants providing services through publicly funded assessment and intervention multi-disciplinary clinics. Seventeen problems were identified as being relevant to consider when providing health care to ambulant adults with CP. The top ranked issues for inclusion in the instrument were mobility change, function, fatigue, pain and falls. Support for the inclusion of spasticity/contracture, medication, feet/footwear, and continence was also strong. Suggested options for management, either research evidence-based or expert-consensus, was provided with possible suitable outcome measures proposed. A flow chart to assist decision making was developed.

Conclusions/Significance: Primary care practitioners need information to assist in the provision of quality health care for ambulant adults with CP. This study has provided content for an instrument to assist primary care providers in the identification of risk, and delivery of evidence based care for ambulant adults with CP. The instrument is now ready for piloting to assist further refinement of content.

E8 Responsiveness of the Pediatric Evaluation of Disability Inventory - Computer Adaptive Test in measuring functional outcomes for inpatient pediatric rehabilitation

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Background/Objectives: Measuring functional outcomes using valid and responsive measures is critical for determining program effectiveness of inpatient pediatric post-acute rehabilitation programs. The Pediatric Evaluation of Disability Inventory (PEDI) has been used frequently to report functional changes in inpatient pediatric rehabilitation; however, the administration time is lengthy and for some older children or those with less severe disabilities there can be a ceiling effect. The PEDI-Computer Adaptive Test (PEDI-CAT) was developed to address these issues. The objective of this study was to evaluate the responsiveness of the PEDI-CAT for youth admitted to a pediatric post-acute care hospital.

Study Design: Instrument development and validation study.

Study Participants and Setting: Inpatients at a pediatric post-acute hospital admitted to the inpatient rehabilitation program, ages 2–21 years, with a length of stay of ≥5 days and with both admission and discharge scores were included.

Materials/Methods: The PEDI-CAT was administered by occupational, physical and speech therapists as part of their admission and discharge evaluations. PEDI-CAT scores from Feb 2013 through November 2014 were included. The difference between mean admission and discharge PEDI-CAT scaled scores were analyzed using paired t-tests. Effect sizes, standard response mean (SRMs), and minimal detectable change values (MDC95) were calculated. Score comparison between diag-

nostic subgroups (Traumatic Brain Injury, Neurological, Orthopedic, Medical) and age groups (≤5yrs, >5yrs) were evaluated for the Mobility domain.

Results: Sample size differed by domain because therapy departments had different dates for initiating use of the PEDI-CAT: Mobility scores (n = 48), Daily Activities (n = 23), Social/Cognitive (n = 10) and Wheelchair subdomain (n = 9). Significant differences were found for all domains when mean admission and discharge scores were compared. Large effect sizes and SRMs were found for the Mobility and Daily Activities domains and Wheelchair subdomain. A small effect size but large SRM was found for the Social/Cognitive domain. MDC values were as follows: Mobility = 0.93, Daily Activities = 0.75, Social/Cognitive = 1.58. The Mobility domain was also responsive to mobility skill changes for all diagnostic groups and age groups.

Conclusions/Significance: The PEDI-CAT was responsive to functional changes for youth discharged from an inpatient pediatric rehabilitation hospital. The PEDI-CAT Mobility domain was responsive to changes in functional mobility skills for patients with a wide range of diagnoses and ages. This study focused on distribution-based methods for evaluating responsiveness of the PEDI-CAT. Future research is needed using anchor-based methods to determine Minimal Clinical Important Difference of the PEDI-CAT for inpatient pediatric rehabilitation.

E9 The Quality Function Measure: a study evaluating rater reliability and agreement when a new measure of gross motor performance is used in ambulant children with hyperkinetic movement disorders

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Background/Objectives: Hyperkinetic movement disorders (HMD) are associated with excessive involuntary movements & are seen frequently in children with neurological conditions. Although children typically have problems with both motor function & impaired quality of movement, movement disorder scales & clinical measures of gross motor function may be insensitive to important changes in the quality of motor performance. Discrepancies are noted, both in the deep brain stimulation (DBS) literature & in our movement disorder service, between patient report & clinical assessment data, suggesting the scales in current use are not always adequately capturing changes following DBS in children.

The Quality Function Measure (QFM) is a new observational assessment designed to evaluate gross motor movement quality in children with cerebral palsy (CP). It is hoped the QFM might allow us to capture qualitative changes in gross motor performance following DBS in children with HMD, & to determine the relationship between changes in movement quality & gross motor function & activity & participation goals.