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Objectives

Children with cerebral palsy (CP) often have upper extremity (UE) and lower extremity (LE) impairments. While tools measuring separately UE abilities and LE abilities are currently used, activities in which UE and LE are used in combination—the most numerous in everyday life—cannot be assessed because no current instrument allows capturing the global activity performance of children with CP.

The aim of this study was to develop a clinical tool for measuring global activity level (UE, LE, and combination of both) in children with CP using the Rasch model.

Methods

Instrument

ACTIVLIM-CP is a parent-report questionnaire of activities of daily living including upper, lower, or a combination of both extremities:
- Activities have to be completed without technical or human assistance.
- Three-level scale: impossible/difficult/easy.
- Unfamiliar activities = missing values.

Subjects

Parents/caregivers of 214 children with CP (2-18 years, 120 males, 94 females) were asked to fill in the questionnaire.

Data analysis

Conducted by RUMM 2020, Rasch model software. The following analyzed criteria were used to create the final version of 43 items fitting the Rasch model:
- 154 items
  - Response rate ≥ 80%
  - An ordered rating scale
  - The same rating scale structure
  - Uni-dimensionality
  - No local dependency between items
  - No differential item functioning (age, gender, topographical distribution)
- 43 items

Construct validity

Correlation were analyzed with activity scale previously validated: ABILHAND-Kids, ABILCO-Kids, PEDI, self-care section.

Reproducibility

Correlation test-retest were analyzed on 129 parents' answers who scored the questionnaire for a second time within 4 to 6 weeks.

Results

The final scale consisted of 43 items presenting a high reliability (IR=0.90). The item difficulty hierarchy was consistent over time and did not vary with age, gender, or topographical distribution, allowing the follow-up of children from 2 to 18 years old.

ACTIVLIM-CP is a new unidimensional scale specifically developed to measure activities of daily living in children with CP between 2 to 18 years old whatever the topographical distribution of CP (hemiplegic, diplegia, quadriplegic). The final 43 items scale is a reliable tool that can be used to follow children’s evolution regarding upper and lower extremities and combination of both, and document changes related to neurorehabilitation, especially where a combination of UE and LE is targeted. Its responsiveness is still to be tested.

An online analysis of the ACTIVLIM-CP questionnaire will be freely available (www.rehab-scales.org). More information: yannick.bleyenheuff@uclouvain.be