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Peer-reviewed author version

KLINGELS, Katrijn (2017) The iterative process in the development of a parent-reported questionnaire for children with unilateral paresis. In: DEVELOPMENTAL MEDICINE AND CHILD NEUROLOGY, 59(9), p. 885-885.

DOI: 10.1111/dmcn.13468

Handle: <http://hdl.handle.net/1942/24985>

The iterative process in the development of a parent-reported questionnaire assessing amount of hand use in children with unilateral paresis

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Developmental disregard¹ is a matter of concern to most parents of children with unilateral upper limb paresis. It is a term describing the vicious circle of not using - or disusing - the latent capacity of the affected hand in daily life. This phenomenon even becomes more apparent when moving into adolescence. To capture the degree of developmental disregard, clinician-reported outcome measures on both unimanual capacity as well as bimanual performance should be accompanied by a parent-reported outcome measure. This is in order to provide information on relevant activities of daily life that cannot otherwise be observed in a clinical or research setting.

The paper of Geerdink et al.² presents the development and psychometric properties of the Hand-Use-at-Home (HUH), a parent-reported questionnaire evaluating the amount of spontaneous use of the affected hand in play and self-care activities in children aged 3 to 10, with unilateral cerebral palsy and neonatal brachial plexus palsy. The paper's premise is interesting as it presents the thorough and challenging job of balancing the need for psychometric robustness as well as clinical relevance in the developmental process of a new outcome measure. The consensus process of the HUH, involving an expert panel of occupational therapists as well as parents, guaranteed the clinical meaningfulness of the included items. Modern psychometric statistics on the other hand ensured the robustness and unidimensionality of the instrument. The final questionnaire lists 18 bimanual items to be scored on a five-category rating scale, later collapsed into a three-category rating scale as a result of the Rasch analysis. This short questionnaire gives a unique perspective on how often the child uses their affected hand during bimanual play and self-care activities.

Development of an outcome measure is an iterative process and further research is warranted. Future work should involve the translation into other languages followed by sample testing in different countries to establish the cross-cultural validity of the HUH. Secondly, test-retest reliability needs to be investigated. Third, a table or online tool for conversion of the raw scores directly to a 0 to 100 scale based on logits should become available to facilitate the interpretability of the scores by clinicians and parents. Finally, sensitivity to change should be explored. To interpret individual changes as well as changes on a group level, the smallest detectable difference (SDD) and minimal clinically important difference (MCID) are two important benchmarks. While the SDD is a measure of the variation due to measurement error, calculated based on test-retest data, the MCID is defined as the smallest measured change score that can be perceived to be clinically relevant. The latter can be determined by the anchor-based mean change technique in which the parent needs to categorize how much the child's function has changed.³ This makes determining MCID more challenging and likely to be different for children at different ends of the ability scale.⁴

These further steps in the developmental process need to confirm that the HUH is a reliable, valid and responsive outcome measure that will facilitate the dialogue between therapists, parents and children in delineating treatment goals and setting targets. Secondly, longitudinal data of the HUH

should be collected to monitor the developmental disregard over time. Finally, the HUH could be used to evaluate the efficacy of both therapeutic and medical interventions as their ultimate goal should be to improve bimanual performance, thus increasing functional independence and impacting on the quality of life in children with unilateral upper limb paresis.

Acknowledgement

Katrijn Klingels received funding from Research Foundation Flanders (FWO project, grant G087213N) and KU Leuven (Special research fund, grant OT/14/127).

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