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Development and psychometric properties of the Hand-Use-at-Home questionnaire to assess amount of affected hand-use in children with unilateral paresis

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ABBREVIATIONS

CHEQ	Children's Hand-use Experience Questionnaire
CP	Cerebral palsy
HUH	Hand-Use-at-Home questionnaire
NBPP	Neonatal brachial plexus palsy
PMAL-R	Pediatric Motor Activity Log – Revised

AIM To describe the development of the parent-rated Hand-Use-at-Home questionnaire (HUH) assessing the amount of spontaneous use of the affected hand in children with unilateral paresis, and to test its internal structure, unidimensionality, and validity.

METHOD Parents of children with unilateral cerebral palsy (CP) and professionals participated in the development of the HUH. To examine internal validity, data of 322 children (158 males, 164 females; mean age 6y 7mo, standard deviation [SD] 2y 1mo) with unilateral CP ($n=131$) or neonatal brachial plexus palsy (NBPP) ($n=191$) were collected. Rasch analysis was used to examine discriminative capacity of the 5-category rating scale as well as unidimensionality and hierarchy of the item set. Additionally, data of 55 children with typical development (24 males, 31 females; 6y 9mo, SD 2y 5mo) were used to examine construct validity.

RESULTS The 5-category rating scale was disordered in all items and was collapsed to obtain the best discriminating sum score. Ten misfitting or redundant items were removed. Eighteen hierarchically ordered bimanual items fitted the unidimensional model within acceptable range. The HUH significantly discriminated between the three groups (children with typical development, NBPP, unilateral CP; $H_{(2)}=118.985$, $p<0.001$), supporting its construct validity.

INTERPRETATION The HUH is a valid instrument to assess the amount of spontaneous use of the affected hand in children with unilateral upper-limb paresis.

Unilateral cerebral palsy (CP) and neonatal brachial plexus palsy (NBPP) constitute two of the most common forms of unilateral non-progressive neurological conditions in children. In both unilateral CP and NBPP, repeated failure to perform activities with the affected arm and hand may lead to decreased spontaneous use. Consequently, children with a unilateral paresis often use their affected upper limb less often in bimanual activities than might be expected based on their functional capacities.^{1–4} This discrepancy between capacity and performance⁵ (referred to as developmental disregard) has been reported in unilateral CP^{6,7} and NBPP⁸ and may lead to a vicious circle of decreasing upper-limb use. Despite intensive rehabilitation, parents often report that their children seldom spontaneously use the affected arm and hand at home.² This underuse results in inefficient task performance and, subsequently, may hamper social participation.⁹

Clinicians are challenged to identify differences in upper-limb use between the therapeutic setting and the

home situation. Spontaneous hand-use reflects automatized upper-limb motor control, but currently there is a lack of instruments assessing the amount of spontaneous use in daily life. Clinical tests focus on effective use of the affected upper limb (Assisting Hand Assessment^{10,11}) or on developmental disregard (revised Video-Observation Aarts and Aarts module: Determine Developmental Disregard⁴), but are actually clinical surrogates for daily life performance that is influenced by personal and environmental factors.⁵ A parent-reported measure of the amount of hand-use during everyday activities may be a valuable addition to the existing clinical assessments. Valid and commonly used parent-rated questionnaires measure various aspects of actual daily life performance, but none of them assesses the amount of affected hand-use. The ABIL-HAND-Kids¹² assesses manual ability based on unimanual and bimanual activities, whereas the Children's Hand-use Experience Questionnaire (CHEQ)⁹ focuses on a child's

perspective of affected hand-use in bimanual activities. Currently, the only parent-completed measure of the amount of affected upper-limb use at home is the Pediatric Motor Activity Log – Revised (PMAL-R).¹³ The PMAL-R evaluates the quality ('how well') and frequency ('how often') of affected upper-limb use. However, psychometric properties of the 'how often' subscale have not yet been evaluated¹³ and most of the PMAL-R items (16/22) are unimanual,¹⁴ even though most daily activities are bimanual by nature. Although parent-reported measures are subjective, more objective measures (e.g. accelerometry, video-observation) cannot readily be used in young children,¹⁵ are time-consuming, or influence daily-life behaviour. Against this background, we developed the parent-reported Hand-Use-at-Home questionnaire (HUH) to evaluate how often the affected upper limb is spontaneously used in typical daily life activities of children with unilateral upper-limb paresis, aged 3 to 10 years. In this age group play and self-care activities can easily be observed by parents.

In this paper we describe the development of the HUH. Content validity was established by means of a consensus process among professionals and parents. We used Rasch analysis to examine the appropriateness of the items' rating scale and to test whether the items together form a unidimensional and hierarchical construct. Appropriateness of the rating scale refers to whether the parents' ratings on the items can be differentiated as clearly as the points of the rating scale allow. For the assessment of construct validity, we examined if the amount of spontaneous hand-use in children with unilateral CP or NBPP would differ significantly from each other as well as from children with typical development of the same age. We hypothesized that children with unilateral CP or with NBPP obtain lower scores on the HUH compared with children with typical development, and that children with unilateral CP would have a lower score for spontaneous use of the affected hand than children with NBPP.

METHOD

Development of the HUH

To validly assess the amount of spontaneous hand-use, the HUH needed to consist of activities that: (1) are executed at home; (2) are typical of the daily lives of children aged 3 to 10 years; (3) can be observed by parents; and (4) are suitable to test the degree to which the affected arm and hand are used. Activities can be ranked according to the degree to which they elicit a bimanual approach, starting with activities that can easily be performed in consecutive unimanual steps (e.g. fill a glass with water from a tap) up to activities that require the simultaneous use of both hands (e.g. closing a zipper). However, how these activities are ranked according to difficulty level (eliciting spontaneous hand-use) in children with unilateral paresis is unknown.

The first version of the HUH consisted of a broad range of age-related activities derived from interviews with

What this paper adds

- Parent-rated amount of hand-use is a valuable addition to clinical assessment.
- The unidimensional Hand-Use-at-Home questionnaire (HUH) has 18 hierarchically ordered items that assess spontaneous (affected) hand-use in play and self-care activities at home.
- Construct validity of the HUH was established for children with unilateral paresis aged 3 to 10 years.

parents and therapists. Subsequently, parents of 20 children with unilateral CP rated for each activity (1) the frequency of spontaneous use of the affected hand on a 5-category rating scale (never/seldom/sometimes/mostly/always), (2) the importance of the activity on a 3-category rating scale (not at all/somewhat/very important), (3) whether or not it was applicable to their child (never occurs/not applicable due to age), and provided additional comments. Next, an expert-panel of six experienced paediatric occupational therapists determined whether activities (i.e. play, self-care) were relevant for children aged 3 to 10 years and categorized activities as either 'unimanual' or 'bimanual'. For bimanual tasks, it was determined whether activities demanded the use of the affected hand or if they could also be executed unimanually in consecutive steps, as both kinds of activities were deemed necessary in the HUH. In addition, the experts could suggest additional activities and comment on the phrasing of the questions. This yielded a list consisting of 31 activities. A new group of 20 parents of children with unilateral CP completed this 31-item version of the HUH and commented on the questionnaire. This resulted in deletion of the three activities they rated as 'not important at all'. This version, consisting of 28 questions (22 bimanual and 6 unimanual activities), was subsequently reviewed by another small group of five parents, who expressed only one minor concern in the wording. Thus, the final version of the HUH had 28 items, for which frequency of spontaneous use of the affected hand was rated on a 5-category rating scale: '(almost) never', 'sometimes', 'regularly', 'often', and '(almost) always'. Seven items had a 'not applicable' option to reduce possible bias related to age (e.g. 'buttering bread') or sex ('dress a doll or teddy bear') (see Table SI, online supporting information). For the present study, the HUH was available online but, if preferred, a paper version was available as well.

Participants and design

Three groups of parents of Dutch children aged 3 to 10 years participated: parents of children with unilateral CP or NBPP and parents of children with typical development. For the unilateral CP group, 11 of the 13 paediatric rehabilitation centres that are part of the Dutch Collaboration for Implementation of the Pirate Concept (LIPIC; <http://piratenconcept.nl>) recruited 131 parents who completed the questionnaire. The NBPP group consisted of 192 parents who completed the HUH as part of a cross-sectional study in children and adolescents with NBPP, that was conducted at the Leiden University Medical

Centre. The children with typical development group consisted of 55 parents who were recruited from the personnel of one rehabilitation centre (Sint Maartenskliniek) and their families, friends, and neighbours. They completed a version of the HUH in which the term 'affected hand' was replaced by 'non-preferred hand'. All participants gave written informed consent.

Data were collected between October 2013 and February 2015 and the study was approved by the medical ethical committee Arnhem-Nijmegen (2013/395), the medical-ethics committee of the Leiden University Medical Centre (P14.071), as well as by the executive boards of the participating institutions.

Statistical analysis

Missing values in the questionnaires were replaced with predicted values using the expectation-maximization technique (IBM SPSS Statistics 20.0) to reduce bias from non-responses. A 'not applicable' score was recorded as 'zero (never)'.

We used Rasch analysis (the partial credit model for polytomous rating scales) to examine the appropriateness of the rating scales and to identify misfitting items. The results from the rating scale analyses guides us how to score the items to obtain the most reliable estimate of a child's ability level. With Rasch analysis, item-measures and person-measures are estimated from the response patterns and are expressed on a common log-odds unit scale. Rasch rating scale analysis¹⁶ was performed to check whether item threshold values were ordered (i.e. increasing threshold values for higher category scores). In case of non-ordered, reversed, thresholds item categories were collapsed until ordered threshold values appeared. To determine whether item scores could be summed, the data were tested for unidimensionality using mean square infit and outfit statistics. Values between 0.71 and 1.4 are considered as a good fit to the model's expectation.^{17,18} A person-item map was plotted to examine the distribution of item- and person-measures to allow identification of levels of spontaneous bimanual hand-use that are poorly assessed by the items. Rasch analysis was performed using the R package eRm (<https://cran.r-project.org/web/packages/eRm/index.html>).¹⁹

Internal consistency of the HUH was examined by calculating Cronbach's α . An α between 0.7 and 0.9 was considered adequate.²⁰

Construct validity was examined by testing the differences in mean HUH sum scores between children with unilateral CP, children with NBPP and children with typical development using Kruskal-Wallis H tests with pairwise comparisons using the Dunn-Bonferroni approach. The variables age, sex, and affected side were compared between groups using the one-way ANOVA and Pearson's χ^2 test respectively. Age, affected side, and sex were correlated with the individual HUH sum scores (Spearman's rank correlation coefficient and point-biserial correlation respectively) to examine whether HUH scores were influenced by these characteristics.

RESULTS

A total of 378 questionnaires were returned. One questionnaire of the NBPP group was discarded because more than half of the scores were missing. Nine questionnaires (2.7%) had one to three random missing values (19 in total) that were imputed using the expectation-maximization method and were included for analysis. Thus, for Rasch analysis, 322 questionnaires from the unilateral CP ($n=131$) and NBPP ($n=191$) groups were available. The children with typical development group was not included in the Rasch analysis. The characteristics of all children are presented in Table I. There were no significant differences in age or sex between the three groups.

Establishing the final HUH item set

Two items ('dress a doll or bear' and 'tie shoelaces') with more than 35% 'not applicable' responses were excluded. Rasch analysis showed that the 5-category rating scales were disordered for most items (see Fig. 1 for explanation) and that some response options were underused. There was not a specific redundant response category that could be deleted. The best solution (guided by Rasch analysis) was to collapse the rating scales in an identical way in all items to calculate a reliable sum score. Thus, the rating scales were collapsed into three categories (i.e. never, sometimes = score 0; regularly, often = score 1; always = score 2), which resulted in ordered category thresholds for all items, except for the unimanual items. For these unimanual items, the scales were disordered to the extent that only dichotomizing was possible. Therefore, these items were deleted. Item 'play at the table' correlated strongly ($r=0.92$) with 'play on the floor', and showed strong inter-item correlations ($r>0.74$) with two other items. Therefore, it was considered redundant²⁰ and omitted. Item 'dress upper body' was removed as it correlated strongly with

Table I: Demographic and clinical characteristics of the children

	UCP <i>n</i> =131	NBPP <i>n</i> =191	CTD <i>n</i> =55	<i>p</i> (group differences)
Mean age, y:mo	6:6	6:9	6:9	0.590 ^a
SD	2:2	2:0	2:5	
Range	3:0–10:9	3:0–10:5	3:5–10:11	
Sex, <i>n</i>				
Male/female	63/68	95/96	24/31	0.726 ^b
Affected side, <i>n</i>				
Right/left	75/56	89/102	N/A	0.060 ^b
MACS, ^c <i>n</i> (%)				
I	31 (23.7)	N/A	N/A	
II	52 (41.2)			
III	41 (35.1)			
Lesion extent ^c , <i>n</i> (%)				
C5	N/A	2 (1.0)	N/A	
C5-C6		120 (62.8)		
C5-C7		35 (18.3)		
C5-C8		15 (7.9)		
C5-T1		17 (8.9)		
Not specified		2 (1.0)		

^aOne-way ANOVA. ^bPearson χ^2 . ^cExtracted from the medical record. UCP, unilateral cerebral palsy; NBPP, neonatal brachial plexus palsy; CTD, children with typical development; MACS, Manual Ability Classification System; N/A, not applicable.

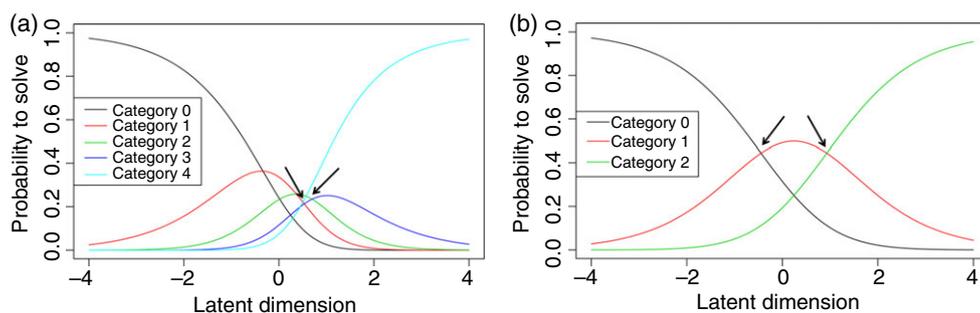


Figure 1: Item characteristic curves plotted (for item ‘remove shirt’) as an example of a disordered rating scale (a) that was amended by collapsing rating categories (b, ordered rating scale). When the data fit the model, item thresholds (i.e. boundaries between response categories indicated with arrows) should monotonically increase. In (a), it can be seen that categories 2 and 3 are underused. In this case a child with person-measure 0.7 has about equal probabilities for a category score 2, 3, or 4 (regularly, often, always) for spontaneous hand-use. After collapsing item categories (b), the thresholds are ordered. At each location of the latent scale, a single item score is more probable. A child with a person-measure between -0.4 and 0.9 logits has the largest probability to obtain a score 1 (regularly, often). With a person-measure greater than 0.9 logits, the probability of a score 2 (always) increases rapidly. [Colour figure can be viewed at wileyonlinelibrary.com].

‘undress upper body’ ($r=0.76$). Thus, 18 items fitted in the final scale with total scores ranging from 0 to 36 points. Item infit statistics (Table SI) were all within the acceptable range indicating good fit to the Rasch model. The highest mean square value was for ‘hold fork cutting’ and indicated that, although within the acceptable range, data from this item were less predictable than the model expected.

Psychometric properties

Table SI and Figure S1 (online supporting information) present the item-measure estimates for scores 1 and 2 after collapsing the response categories into a 3-point item-score. The lowest item-measure indicates score 1 (i.e., the degree to which the activity elicits ‘regular’ or ‘often’ use of the affected hand) and the highest score 2 (i.e., the degree to which the activity ‘always’ elicits use of the affected hand). Item-measures ranged from -2.24 to $+2.86$ logits. Two items (‘throw a ball’ and ‘hold a book’) had equal item-measures; as they each represent a completely different kind of activity (outdoor/gross motor play vs indoor/seated activity), both were kept in the scale.

Table II shows the raw summed scores on the HUH and associated logit measures. Figure 2 shows the distribution of HUH person-measures and item-measures for children with unilateral paresis ($n=322$). The person-measure estimates reflect the extent to which a child spontaneously uses the affected hand. Person-measures ranged from -4.69 to 5.17 logits and were not normally distributed in the sample. Thirteen children had a person-measure below the lowest item-measure of -2.24 logits (raw sum score 0–3). Thirty-five children had person-measures above the highest item-measure of 2.86 logits (scores 33–36). The three children with a score of -4.69 logits were all diagnosed with unilateral CP and scored ‘seldom’ or ‘never’, even on the easiest items (raw sum score 0). The highest HUH score of 5.17 logits (36 points) was obtained by 7% of the sample (23

Table II: Conversion table of sum scores to obtain the HUH score (person-measure) in logits

Sum score	HUH score (logits)	Standard error	Sum score (continued)	HUH score (logits)	Standard error
0	-4.695	N/A	19	0.513	0.37
1	-3.853	1.04	20	0.649	0.37
2	-3.082	0.76	21	0.786	0.37
3	-2.597	0.64	22	0.925	0.37
4	-2.230	0.57	23	1.066	0.38
5	-1.927	0.53	24	1.211	0.38
6	-1.665	0.50	25	1.361	0.39
7	-1.431	0.47	26	1.518	0.40
8	-1.218	0.45	27	1.684	0.41
9	-1.022	0.44	28	1.861	0.43
10	-0.838	0.42	29	2.053	0.45
11	-0.665	0.41	30	2.265	0.47
12	-0.500	0.40	31	2.506	0.51
13	-0.343	0.39	32	2.788	0.56
14	-0.191	0.39	33	3.134	0.62
15	-0.044	0.38	34	3.599	0.75
16	0.098	0.38	35	4.352	1.03
17	0.238	0.37	36	5.174	N/A
18	0.376	0.37			

After recalculating parents’ ratings for the 18 activities from 5 categories into a 3-point item score (i.e. ‘never’/‘sometimes’=score 0; ‘regularly’/‘often’=score 1; ‘always’=score 2) the scores can be summed. This sum score can be converted into a person measure for spontaneous hand-use (the HUH score), expressed in logits. HUH score, Hand-Use-at-Home score; N/A, not applicable.

children with NBPP) who always spontaneously used their affected hand in all 18 activities. The lowest item-measure was for ‘pick up a large ball’, which is the most provoking activity to use the affected hand ‘regularly’ or ‘often’ (achieved by 91.3% of the sample), and ‘hold fork cutting’ was the most difficult item to ‘always’ elicit the use of the affected hand (achieved by 15% of our sample).

Internal consistency (Cronbach’s α) of the 18-item HUH was 0.941. HUH scores showed weak correlations with affected side ($r_{pb}=0.127$, $p=0.023$), sex ($r_{pb}=0.109$, $p=0.051$), and age ($r_s=0.164$, $p=0.003$). Females and

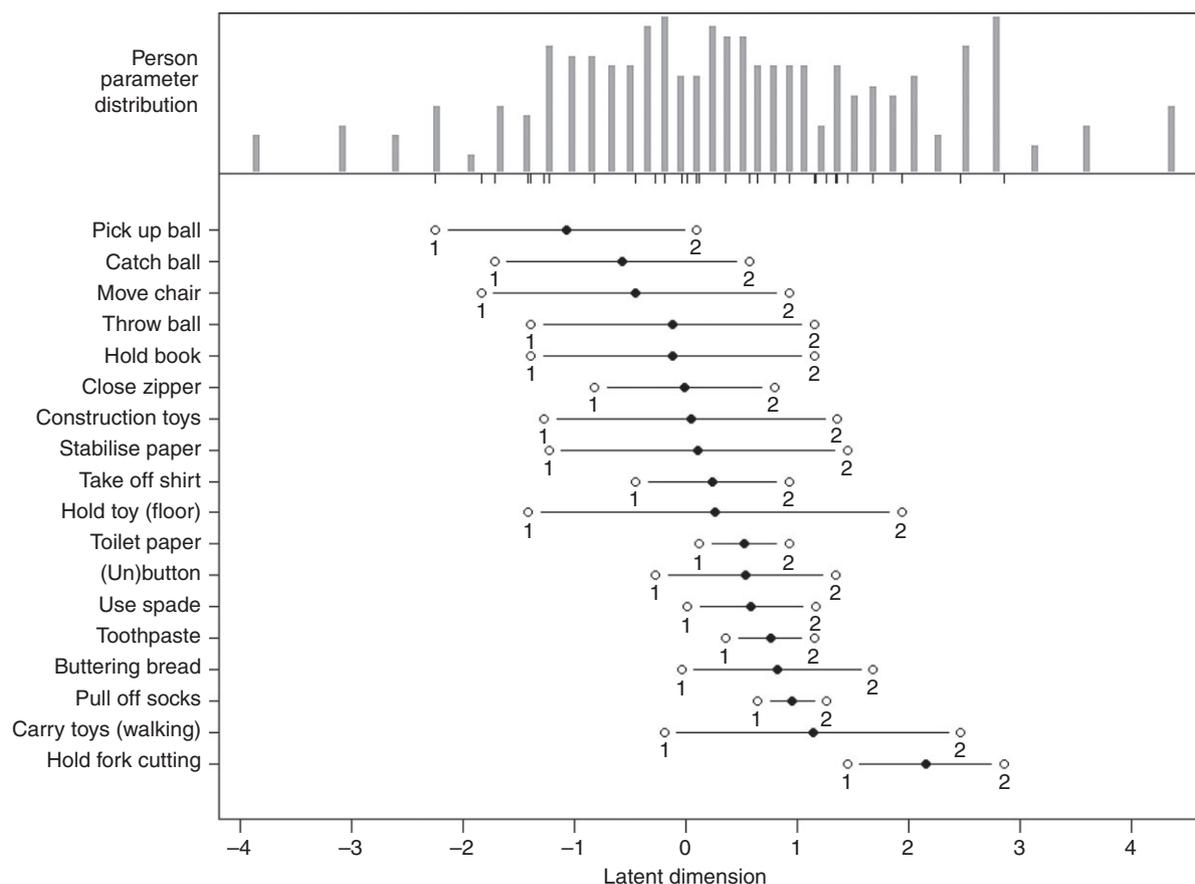


Figure 2: Person-item map; distribution of HUH person-measures and item-measures. Every vertical bar of the person parameter distribution represents a raw total score. The bars for the lowest and highest total scores (0 and 36) are omitted from the figure. Item-measures for scores 1 and 2 for each item are represented by the small stripes below the bars and by the corresponding open dots. Black dots indicate the mean item-measure for each item (item location). Note, the latent dimension on the x-axis is expressed in logits. [Colour figure can be viewed at wileyonlinelibrary.com].

left-side affected children had slightly higher HUH scores and scores increased with age. Equal trends for age and sex were found in children with typical development. Children with a maximum HUH score were aged between 4 years 5 months and 9 years 7 months.

Construct validity

Scores for the amount of spontaneous hand-use differed between groups ($H_{(2)}=118.985$, $p<0.001$). Post-hoc tests showed that all group differences were significant ($p<0.001$). The children with typical development group had the highest amount of spontaneous hand-use (median HUH score: 2.51 logits, range 0.65 to 5.17) with 5.5% of the children obtaining the maximum score. The lowest median HUH score was for the unilateral CP group (-0.343 logits, range -4.70 to 2.79). The NBPP group had an intermediate median HUH score of 1.07 logits (range -3.08 to 5.17).

DISCUSSION

Although underuse of the affected limb in children with unilateral paresis is recognized as an important

problem,^{7,21} there is no valid and reliable measure to assess daily-life amount of hand-use. We developed the parent-rated HUH to assess the amount of spontaneous hand-use at home in 3- to 10-year-old children. We examined its internal structure, unidimensionality, and construct validity. The results showed that 18 bimanual activities fitted the unidimensional partial credit model after collapsing the rating scale categories. HUH scores clearly discriminated between children with unilateral CP or NBPP and children with typical development, supporting its construct validity. Compared with the constructs of the CHEQ (perceived quality of performance) and ABILHAND-Kids (manual ability), the HUH adds an important aspect of upper-limb performance: the amount of spontaneous hand-use. Parents' ratings will provide good information for clinical use, inducing a dialogue between therapists and parents about parents' observations and expectations and about the possibilities to enhance spontaneous hand-use, in the home environment. The calculated HUH score objectifies the amount of spontaneous hand-use on an interval scale between -4.70 and +5.17 logits and is useful for research and to evaluate treatment outcome.

The PMAL-R is the only measure with a subscale for amount of hand-use, but the overrepresentation of unimanual items in this interview-based assessment does not reflect the large proportion of bimanual activities that children encounter in daily life. In our study we examined six unimanual items (Table SI) and found that some of the categories of the rating scale were used infrequently or not at all. No adequate reordering of the rating scales could be established for these items. For most unilateral items, the frequencies for score 0 ('never', 'sometimes') in children with typical development were very high (60–80%). Altogether, we concluded that unimanual activities are not suitable to measure spontaneous use of the affected hand in our target groups.

The spread of the item-measures (Fig. 2) indicates that the activities were adequately eliciting spontaneous hand-use ranging from 'easy' to 'difficult'. The HUH scores (person-measures) had a much wider range, which could indicate floor and ceiling effects, although effects smaller than 15% are usually considered acceptable.²² With only 4% of our sample reaching a sum score below -2.24 logits, the floor effect is negligible. Yet, 9.2% of the children scored above 2.86 logits and these children (all NBPP) always used their affected hand in at least 15 of the 18 HUH items. It indicates that extra items might be needed to differentiate in the upper part of the scale for children with NBPP, although in this group normal hand-use may reflect spontaneous recovery occurring in about 70% of the cases.²³

Our results showed that the HUH sum score discriminates between children with typical development and children with unilateral upper-limb paresis. Although the results confirmed that children with typical development had the highest scores, only three children (5.5%) had a maximum score indicating that children with typical development did not always use both hands in all bimanual activities either. Moreover, in only six activities the score 'always' was attained by 95% of the children with typical development (Table SI). This suggests that not every bimanual activity is always provoking bimanual task

execution, not even in children who are able to use both hands simultaneously and well-coordinated. Therefore, we suggest that 100% bimanual task execution in children with unilateral CP or NBPP cannot be expected.

The HUH was designed as a measure of spontaneous hand-use from a parental perspective. Parents can be considered as experts of the abilities and needs of their children,²⁴ especially in young children, and are therefore a valid source of information. It must be acknowledged, however, that the comparison between children with typical development and children with unilateral CP or NBPP might be influenced by parents of the children with typical development needing to focus on the non-preferred hand during bimanual activities. Because these parents were not accustomed to observing their child's use of the non-preferred hand, it often took them substantially more time to observe their child and complete the HUH.

In conclusion, the amount of spontaneous hand-use of a child with unilateral paresis performing daily activities at home can be validly quantified by the HUH. Parents report on spontaneous hand-use by their children in 18 bimanual activities using a 5-category rating scale. Item scores are recalculated to obtain the most reliable sum score. The HUH seems to be a valuable addition to current clinical assessments. Future studies should (further) establish its construct validity, test-retest reliability, sensitivity to change, and should address cross-cultural validation.

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The authors have stated that they had no interests which might be perceived as posing a conflict or bias.

SUPPORTING INFORMATION

The following additional material may be found online:

Table SI: HUH items with item-measure estimates and fit statistics

Figure S1: Hierarchically ordered item-measures for score 1 ('regularly', 'often') and score 2 ('always') of the 18 HUH items.

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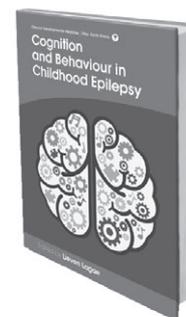
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