5-20-2019

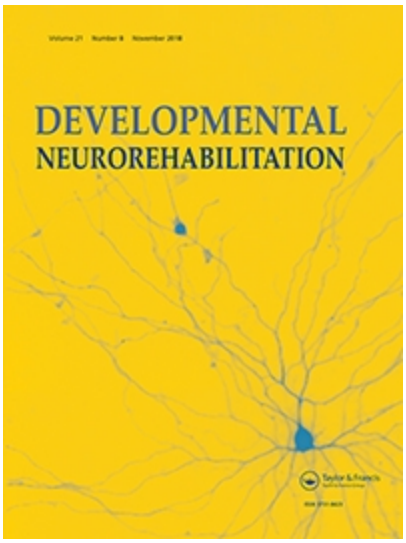
Ease of Caregiving for Children: Re-Validation of Psychometric Properties of the Measure for Children with Cerebral Palsy up to 11 Years of Age.

Mohammed S Alghamdi

Lisa A Chiarello

Lisa Avery

Robert J Palisano



Ease of Caregiving for Children: re-validation of psychometric properties of the measure for children with cerebral palsy up to 11 years of age

Journal:	*Developmental Neurorehabilitation*
Manuscript ID	TPDR-2018-0078.R2
Manuscript Type:	Original Research
Keywords:	Physical caregiving, Family-centered Care, Cerebral Palsy, Ease of Caregiving, Measurement

Abstract

Purpose: To re-validate stability and hierarchal ordering of items, test-retest reliability, and construct validity of the Ease of Caregiving for Children measure for parents of children with cerebral palsy (CP) up to 11 years of age.

Methods: Participants were 613 parents of children with CP between 1.5-11 years of age. Parents completed Ease of Caregiving for Children and both parents and therapists classified children's levels of gross motor, manual and communication functions.

Results: Rasch analysis indicated acceptable fit of items, stable item calibration, and logical ordering of items by difficulty. Test-retest reliability was good: ICC=0.69 (95% CI 0.52–0.81). For construct validity, ease of caregiving was higher for parents of children with higher functioning compared to parents of children with lower functioning, $p<0.001$.

Conclusions: Ease of Caregiving for Children is a unidimensional, reliable and valid measure of physical caregiving for parents of children with CP 1.5-11 years.

of the measure supported the undimensionality and hierarchical ordering of items by difficulty [14]. The measure demonstrated high internal consistency (Cronbach's alpha =was 0.92) [14] and acceptable test-retest reliability, ICC(2,1) = 0.73, (95% CI, 0.50 to 0.86) [14]. Construct validity of the measure was examined using the known-groups method in which the known groups were children's levels of gross motor function [14], according to the Gross Motor Function Classification System [20] (GMFCS). Parents of children without motor delay reported higher ease of caregiving scores compared with parents of children with CP. Among parents of children with CP, parents of children in level I reported the highest ease of caregiving scores followed by parents of children in levels II and II. Parents of children in levels IV and V reported the lowest ease of caregiving compared to parents of children in levels I-III. The ability to measure change over a one-year period was supported for children in levels I-III but not children in levels IV-V [21]. The effect size, however, was small (Cohen's d = 0.49 for children in GMFCS level I and 0.35 for children in levels II-III) [21].

Our research team recognized the need for re-validation of the psychometric properties of the Ease of Caregiving for Children measure for parents of children with CP across a broader age range that includes preschool and school aged children. Inconsistent evidence exists on the effects of children's age on parental caregiving [16-18,22] and thus we were uncertain if the psychometric properties of the measure would change. In addition, available evidence suggests that limitations in motor and communication functions of children with CP are associated with challenges in parental caregiving [4,14,23,24] and it is important to consider both children's age and functional abilities when evaluating the psychometric properties of the measure. The purposes of this study, therefore, were to: 1) determine the stability and hierarchal ordering of items and to create an interval-level scale; 2) examine test-retest reliability; and 3) examine the construct validity using know-groups method in which the known groups were children's levels of

function in gross motor function, manual ability, and communication function and children's age.

2. Methods

2.1. *Design*

A cross sectional design was used. This study was part of two multi-site prospective studies, Move and PLAY and On Track. The Move and PLAY study was conducted to understand determinants of motor abilities, self-care, participation and playfulness of young children with cerebral palsy aged 1.5 to 5 years. The On Track study was conducted to create developmental trajectories and percentile curves for impairments in body structures/functions, associated health conditions, and participation of children with CP up to 12 years of age. Information on both studies can be found at the *CanChild* website (https://www.canchild.ca/en/research-in-practice/current-studies).

Prior to data collection, ethical approval of the study protocol was obtained from each university's Institutional Review Boards and, if required, from data recruitment/collection sites' ethics boards. Written informed consent was obtained from parents and assent was obtained from children when applicable.

2.2. Participants

The participants of this study were a convenience sample of 613 children with CP and their parents who were part of the Move and PLAY study (n = 407) and the On Track study (n = 206). Participants from Move and PLAY study were recruited from four regions in the United States (Greater Seattle, WA; Greater Philadelphia, PA; Greater Atlanta, GA, Greater Oklahoma City, OK) and six provinces in Canada (Newfoundland; Ontario; Manitoba; Saskatchewan; British Columbia**;** Nova Scotia). Participants from the On Track study were recruited only from three regions in the United States (Greater Seattle, WA; Greater Philadelphia, PA; Greater Atlanta, GA).

Demographic information on the children and their parents from both studies is presented in Table 1. For the total sample, children were between 1.5 to 11 years of age with a mean age of 4.3 (2.36) years, 56% were boys, and 66% were white. Parents of children were predominantly mothers (90%) with a mean age of 36 (8.17) years, and 76% were white. Forty-two percent of parents were not employed at the time of the study and 72% had an educational level greater than high school.

For the reliability analysis of the measure, a sub-sample of 55 parents participated in the test-retest reliability of the Ease of Caregiving for Children Measure, 33 of which were from the Move and PLAY study. The reliability sub-sample consisted of 35 boys and 20 girls with mean age of 5.4 (2.9) years, and across all GMFCS levels (I= 21; II= 7; III= 8; IV= 8; V= 11). Parents had mean age of 35.8 (8.1) years and were predominantly mothers (80%).

2.3. *Measures*

2.3.1. *Ease of Caregiving for Children Measure*

The Ease of Caregiving for Children [14] is a reliable and valid parent-report measure of physical caregiving for parents of children with CP. Parents rate their level of difficulty when physically assisting their children in 12 activities including mobility, positioning, and self-care. Parents are instructed to rate the level of difficulty of caregiving tasks using a 5-point Likert Scale: 1 = “very difficult”; 2 = “somewhat difficult”; 3 = “little difficulty”; 4 = “no difficulty”; 5 = “no help is needed”. Parents are instructed to consider four factors when rating the level of difficulty: safety, physical demands, time, and confidence. The measure can be competed in a paper-and-pencil format within 5 to 10 minutes. The total summed score of the measure can be converted to an interval level score using the scoring system devised from the Rasch analysis. Higher scores indicate greater ease of caregiving for parents.

2.3.2. Classification Systems

Gross Motor Function Classification System (GMFCS) [20], Manual Ability Classification System (MACS) [25,26], and Communication Function Classification System (CFCS) [27] are 5-level classification systems that are designed for children with CP (2 to 18 years) to classify their self-initiated movement, use of hands in daily life activities, and effectiveness sending and receiving information, respectively. For each classification system, children classified at level I have the highest functioning and children classified at level V have the lowest functioning. The psychometric properties of the three classification systems are summarized in Table 2. The classification systems can be retrieved from the following websites at no cost: GMFCS (www.canchild.ca); MACS (www.macs.nu); and CFCS (www.cfcs.us).

2.4. *Procedure*

Parents completed the Ease of Caregiving for Children measure during the first data collection point in the Move and PLAY and On Track studies. Parents and therapists classified children's GMFCS levels. Parents and therapists from the On Track study additionally classified children's levels of function using the MACS and CFCS. For the Move and PLAY study, therapists classified children's GMFCS level based on observation and discussion with parents on children's abilities. For the On Track study, parents and therapists independently classified children's levels of functions and their classifications were the same or consensus was reached following discussion 98% of the time for GMFCS, 97% for MACS and 94% for CFCS. If consensus was not reached, the research team decided to use parent's classification unless the therapist provided a rational justification [28]. For reliability testing of the Ease of Caregiving measure, a subgroup of parents completed the measure a second time with an interval of 5 to 44 days after the first visit.

2.5. *Data analysis*

Descriptive statistics were computed for all variables. All statistical analyses were conducted using SPSS software (SPSS Statistics for Windows, Version 23.0. Armonk, NY: IBM Corp.), unless stated otherwise.

2.5.1. ***Rasch Analysis***

The Rasch model of item response analysis [29] was used to determine the hierarchical ordering of items by difficulty and to create an interval level scoring system. Model fitting was conducted using the mixRasch package [30] in R 3.2.4, using the Partial Credit Model (PCM) [29].

The main assumption of the Rasch model is the unidimensionality of a measure; that all items evaluate a single latent trait. There is no single test to determine unidimensionality; instead this assumption was evaluated using five analyses: 1) the dominant factor method [31]; 2) scree plots; 3) the very simple structure criterion (VSS) [32]; 4) the comparative data (CD) method [33]; and 5) fit of items to the Rasch model. Rubio et al.[31] suggested that a dominant factor is present if the ratio of the first factor's eigenvalue is 5 times the second factor's eigenvalue. The VSS method computes a VSS index, which varies from 0 to 1 for multiple solutions. The solution that maximizes the VSS index is regarded an optimal solution. The fit of items to the Rasch model was analyzed with two statistics, the unweighted average score residual, termed the outfit and the information-weighted residual, the infit. Linacre [34] states the following for infit statistics values: < 0.5 are overly predictable, 0.5-1.5 productive for measurement, 1.5-2.0 unproductive, but not degrading and, >2.0 the noise dominates useful information.

The appropriateness of the rating scale used for the measure (5-point Likert Scale; 1= *very difficulty* to 5 = *no help is needed*) was evaluated by examining the item characteristic curves. The characteristic curves provide visual representation of the performance of the 5-point rating scale to evaluate: 1) the order of the rating options for each item (most to least

difficult); 2) the use of each rating option (most selected option vs. least selected option); and 3) the position of rating options on the continuum of ease of caregiving.

The results of the Rasch analysis are item calibrations (which reveal the item hierarchy) and person measures. Item calibrations (measured in logits) range from negative to positive infinity and are constrained to have a mean of zero. Items with high positive calibration values are associated with more difficult caregiving tasks and items with large negative calibration values are associated with less difficult caregiving tasks. The person measures are based on the total sum score for all items and were re-scaled to lie on the interval of 0 to100. The table to transform raw scores to scaled scores is presented in the Appendix.

The stability of item calibrations was examined by randomly splitting the sample into two distinct sub-samples. Rasch analysis was performed for both sub-samples and Shrout and Fleiss' intraclass correlation ICC_2 was used to compare the agreement in item calibrations between the two sub-samples [35]. A high correlation between the two sub-samples indicates stable item calibrations. Correlation between item estimates reported by Ward et al.[14] and the revised item estimates from this study were examined.

2.5.2. ***Reliability and Validity***

Data of 55 participants from the Move and Play and the On Track studies were analyzed to determine test-retest reliability of the measure. Intraclass correlation coefficient, ICC(2,1), was used to determine test retest reliability of Ease of Caregiving measure. The strength of ICC values were interpreted as follows: less than 0.4 as poor, 0.4 to 0.59 as fair, 0.6 to 0.74 as good, and 0.75 to 1.00 as excellent [36]. Because the time interval between test and retest varied between 5 to 44 days, we conducted a sensitivity analysis for participants (n = 39) who had an interval of 4 calendar weeks or less between test and retest visits. The sensitivity analysis was conducted with an assumption that Ease of Caregiving for Children scores would be more stable with shorter time intervals between test and retest.

Data of the participants from the On Track study were analyzed to determine the construct validity of the measure. Data were missing for two participants and therefore data of 204 participants were used for the analyses. The construct validity was determined by known-groups method using children's age and gross motor function, manual ability, and communication function levels as the known groups. Children were assigned to one of two groups based on their age: *younger children* (1.5 to 5.9 years) or *older children* (6 to 11 years). Children were also assigned to two groups based on their level of function in GMFCS, MACS, and CFCS: *children with higher functioning* (Levels I-II) or *children with lower functioning* (Levels III-V). Three separate two-way ANOVAs were used to examine the effect of children's age and level of function on ease of caregiving scores. The partial eta-squared was used to determine the magnitude of the effect of children's age and level of function on ease of caregiving [37]. Partial eta-squared was interpreted as follows: = 0.01 indicates a small effect, = 0.06 indicates a medium effect, and = 0.14 indicates a large effect size [37]. An alpha level of $p < 0.05$ was used for all analyses, unless stated otherwise.

The assumptions of the two-way ANOVAs were examined; outliers were assessed by visual inspection of boxplots, normality was assessed by Shapiro-Wilk's test for each cell, and the homogeneity of variance was assessed by Levene's test. The assumptions of normality and homogeneity of variance for the two-way ANOVAs were not satisfied. However, because of the large sample size (n = 204) and the ratio of the largest to smallest variance remaining less than 10:1[38], the analyses were deemed appropriate and robust to the violation of assumptions. Outliers were detected by visual inspection of the boxplots but we decided to retain them in the analyses because these were valid cases and only represented 0.04% of the sample size.

3. Results

3.1. Rasch Analysis

3.1.1. Unidimensionality: The dominant factor and scree plot methods indicated a single factor underlying the Ease of Caregiving for Children measure. For the dominant factor method, the ratio of the first eigenvalue (7.22) was 4.9 times the second eigenvalue (1.46). For the scree plot method, visual inspection of the plot indicated a single dominant factor. The comparative data (CD) method indicated that a four-factor structure minimized the root mean square residual eigenvalue (RMSE =0.06) compared to a single factor solution (RMSE = 0.17). For the VSS method, when items were allowed to load only on a single factor, the VSS index for the single factor solution was 0.94 and the VSS indices for the 2, 3 and 4-factor solutions varied from 0.57-0.37. The fit of items to the Rasch model also supported the unidimensionality of the measure; results are presented in the following sections.

3.1.2. Item characteristic curves: Visual inspection of the item characteristic curves indicated that the 5-point rating scale (1= very difficult to 5= no help is needed) is properly ordered. The 'Somewhat Difficult' rating option was the most under-used option; however, it was a rating option for several of the items. Therefore, this rating option was deemed appropriate and the 5-point rating scale was retained. Figure 1 shows the item characteristic curves for item 10 "to eat".

3.1.3. Item fit and item hierarchy: Item calibrations (logits) and Infit and Outfit values are presented in Table 5. The item calibrations (average item logits) varied from -0.88 to 0.78 and reflect the average item difficulty. Overall, the item infit statistics are all within an acceptable range. Item 7, put on/take off orthosis, displayed the highest infit value (1.85). The item-response map for the Ease of Caregiving for Children is presented in Figure 2. Items are ordered along the Y-axis according to the difficulty of the caregiving tasks, based on parent response at the highest rating (no help needed), with item "to bathe" being ranked as most difficult task and item "position for sleeping" being ranked as least

difficult task. The numbers plotted across the map correspond to the actual rating options of the measure. The placement of the numbers on the X-axis corresponds to the Ease of Caregiving scaled score at which the probability of achieving at least that score or higher is 50%, i.e. Thurstone thresholds [29]. The item endorsement map indicates a spread of calibrations owing to multiple rating options within each item.

3.1.4. Stability of item calibration: Using the Partial credit model, the correlation of the item estimates generated from two independent sub-samples (n=306, 307) was ICC(2,1) = 0.98, (95% CI, 0.94 to 0.99).

3.1.5. Correlation between original and revised item estimates: Correlation between original item estimates [14] using the Rating Scale Model and the revised item estimates using Partial Credit Model was $r = 0.94$, (95% CI, 0.80 to 0.98).

3.2. Reliability of the Ease of Caregiving for Children Measure

For the subgroup of parents who completed the measure twice, the ICC(2,1) was 0.69, (95% CI, 0.52 to 0.81) indicating good reliability. For the sensitivity analysis of test-retest reliability with a time interval of 4 calendar weeks or less, the ICC(2,1) was 0.75, (95% CI, 0.57 to 0.86), indicating excellent reliability.

3.3. Construct validity of the Ease of Caregiving for Children Measure

Descriptive statistics for parental ease of caregiving by children's age and level of function for each of the three classification systems are presented in Table 3. For the influence of children's age and level of function on parental ease of caregiving, there was only one significant interaction: children's age and gross motor function level, $F(1,200) = 5.57$, $P = 0.019$, partial = 0.027. No significant interaction was found between children's age and manual ability level ($F(1,200) = 0.65$, $P = 0.42$, partial = 0.003) or between children's age and communication function level ($F(1,200) = 3.76$, $P = 0.54$, partial = 0.018). Given that the interaction effect is significant for children's age and gross motor function level, an analysis

of simple main effects for gross motor function level was conducted with Bonferrnoi adjustment and alpha level $P < 0.025$. There was a significant difference in mean ease of caregiving scores between *parents of younger children with higher functioning* (M = 57.6, SD = 14.77) and *parents of older children with higher functioning* (M = 64.3, SD= 17.11), F*(1,200)* = 6.71, $P = 0.01$, partial = 0.032. However, no difference in mean ease of caregiving between *parents of younger children with lower functioning* (M = 44.7, SD = 8.92) and *parents of older children with lower functioning* (M = 42.9, SD = 8.21), F*(1,200)* = 0.53, $P = 0.47$, partial = 0.003.

Across all analyses, there were no significant main effects for children's age on parental ease of caregiving, $P > 0.05$. There were significant main effects for children's level of function on parental ease of caregiving for *gross motor function*, F*(1,200)*= 91.24, $P < 0.001$, partial = 0.31; *manual ability*, F*(1,200)* = 81.32, $P < 0.001$, partial = 0.29; and *communication function*, F*(1,200)* = 66.7, $P < 0.001$, partial = 0.25. For all three classification systems, parents of children with higher functioning had a higher mean ease of caregiving compared to parents of children with lower functioning, $P < 0.001$. Table 4 provides differences in parental ease of caregiving scores based on children's levels of function.

4. Discussion

The findings indicate that the Ease of Caregiving for Children is a unidimensional, reliable, and valid measure of physical caregiving of parents of children with CP 1.5 to 11 years. Across the five methods that were used to assess the unidimensionality, the findings indicate that the Ease of Caregiving for Children is measuring a single latent trait, physical caregiving. The Rasch analysis indicated that items (caregiving tasks) fit the Rasch model and have a stable and logical hierarchy. Although the fit of items to the Rasch model was acceptable, we reflected on the relatively higher infit value of item 7, put on / take off an orthosis, and decided to retain the item because the infit value was still below the Linacre's threshold of noise item that

dominates useful information. We also believe that this item is of importance especially to parents of children who wear orthotics. The hierarchy for caregiving tasks (items) in the current study remained relatively stable compared to the original Rasch analysis reported in Ward et al.'s study [14]. The stability of item hierarchy is statistically supported by the observed high correlation between original and revised item estimates and visually evident in the item response map. This finding suggests that the perceived level of difficulty of caregiving tasks reported by parents is not dependent on children's age. For example, putting on/taking off clothes was a harder caregiving task and positioning a child for sleep was an easier caregiving task across both studies.

The partial credit model enabled us to generate an item response map (Figure 2) that provides useful information regarding the probability of achieving each caregiving task. Overall, parents with higher scaled scores completed more caregiving tasks with less difficulty and, therefore, have greater overall ease of caregiving. A scaled score of 20 indicates that there is a 50% likelihood that all 12 tasks are "somewhat to very difficult". A scaled score of 40 indicates that there is a 50% likelihood that easier tasks (e.g. positioning for sleeping) are performed with "no difficulty" and harder tasks (e.g. bathing) with "a little difficulty". A scaled score of 60 indicates that there is a 50% likelihood that children require "no help" for easier tasks and assistance is provided by parents with "no difficulty" for harder tasks.

The intervals on the item response map between scores corresponding to the ratings "somewhat difficult", "a little difficult", "no difficulty", and "no help needed" represent the average increase in score needed to move from one level of difficulty to the next. The large intervals between scaled scores corresponding to the ratings "no difficulty" and "no help needed" for most items suggest that providing no help, particularly for harder tasks, may not be easily attainable for children with CP due to their functional limitations. In contrast, the intervals between scaled scores that correspond to the ratings "somewhat difficult", "a little

difficult", and "no difficulty" are smaller and similar across tasks reflecting that provision of physical assistance would be expected from parents of children with CP and the progression from one level of difficulty to the next is more readily attainable.

Differences in parental ease of caregiving based on children's levels of gross motor function, manual ability, and communication functions illustrate the measure's ability to discriminate between known groups, thus supporting the construct validity. As expected, parents of children with higher functioning (gross motor, manual, and communication functions) reported greater ease of caregiving compared to parents of children with lower functioning. Our findings for the influence of children's gross motor and manual functions on parental ease of caregiving are consistent with earlier research [14,16,24]. Communication and speech impairments in children with CP have been linked to low parent-child interaction [39]. Our study adds that children's communication function does influence parent's ability to physically assist their children in daily life activities. The findings suggest that children's level of mobility, use of hands to manipulate objects, and ability to communicate with parents can determine the need and extent of parental physical assistance. These findings have implications for service providers to provide anticipatory supports and services (e.g. parent education, training, and use of assistive technology) that optimize parents' caregiving experience.

Our finding on the interaction between age and gross motor function suggests that children's age alone should not be considered a determinant of parental ease of caregiving for children with CP between 1.5 to 11 years of age. Differences in ease of caregiving based on children's age were evident only for parents of children with higher functioning (GMFCS levels I-II) with parents of older children (6-11 years of age) reporting greater ease of caregiving than parents of younger children (1.5-5 years of age). It can be expected that older children with higher gross motor function may have achieved independence in fulfilling many daily life activities and thus parents can anticipate greater ease in caregiving. In contrast, no

differences in ease of caregiving based on children's age were found for parents of children with lower functioning (GMFCS levels III-V). We believe that the lack of difference in ease of caregiving based on children's age for children with significant mobility limitations may be attributable to the complex interaction of parent, child, and environmental factors such as parent's capacity for helping their children, children's physical size and level of independence in daily life activities, and availability of formal or informal support.

Our finding of lack of differences in ease of caregiving based on children's age extends the findings of Ward et al. [14] that ease of caregiving did not differ by children's age for parents of children with CP between 1.5 to 5 years of age. In contrast, two previous studies reported a positive association between children's age and caregiver's perceived difficulty of caregiving for parents of children with CP aged 2 to 22 years [16,17]. Given that we only studied ease of caregiving for parents of children up to 11 years of age, we believe that differences in ease of caregiving based on children's age might be notable when children reach adolescence and their physical growth becomes more prominent.

Implications for practice

Service providers are encouraged to use Ease of Caregiving for Children as part of their assessment of children with CP during the initial and follow-up examinations. Ease of Caregiving for Children is a short measure that can be competed in 5 to 10 minutes and can help service providers to objectively document and guide interventions for ease of caregiving of parents of children with CP. Regardless of the practice setting, Ease of Caregiving for Children can be used to gain information about parents' perception of ease of caregiving. It also can be used to guide discussions with parents to identify their individual strengths, needs and concerns related to caregiving for their children, assist with anticipation of progression in parent's ease of caregiving for harder tasks, and to establish parent goals and focus of intervention. The updated version of the measure now includes spaces for parents to share their

experiences related to each item and for service providers to documents their notes. The updated version can be found at the On Track study webpage: https://www.canchild.ca/en/research-in-practice/current-studies.

Limitations and recommendations for research

A limitation of this study is that we only re-validated selective psychometric properties of the measure (test-rest reliability, construct validity, and stability and hierarchal ordering of items). We also did not examine parent (e.g. self-efficacy) or environmental factors (e.g. availability of assistive technology), which would have added meaningful context to the findings. The sensitivity and responsiveness of the measure need to be established for parents of children and youth with CP before it can be used to measure change over time. Research on the Ease of Caregiving for Children is also needed to determine validity of the measure for parents of children and youth with other disabilities and health conditions. **Conclusion**

Our findings indicate that the Ease of Caregiving for Children is a reliable and valid measure that can be used to assess physical caregiving for parents of children with CP between 1.5 to 11 years of age. This study used a rigorous measurement approach to determine logical ordering of items, to re-validate the interval-level scoring system, and to support the construct validity of the measure. The Rasch analysis, using the Partial Credit Model, indicated that the items (caregiving tasks) are logically ordered and vary in difficulty. Across the three function classification systems (GMFCS, MACS, CFCS), parents of children with higher functioning reported greater ease of caregiving compared to parents of children with lower functioning. Differences in ease of caregiving based on children's age were evident only for parents of children with higher functioning (GMFCS levels I-II) with parents of older children reported greater ease of caregiving than parents of younger children. We encourage service providers to use the Ease of Caregiving for Children in conjunction with conversation to identify caregiving tasks that are of concern and to partner with families to develop individualized plans of care.

Acknowledgments

This research was supported by Canadian Institutes of Health Research (MOP-81107 & MOP-119276), U.S. Department of Education, National Institute of Disability and Rehabilitation Research, (H133G060254) and Patient-Centered Outcomes Research Institute (5321). We acknowledge the Move and PLAY and On Track study teams, participating sites, children and their families.

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Table 1. Demographic information for participants from Move and PLAY and On Track studies

Variable	Description	Study	
		Move and PLAY (n= 407)	On Track (n= 206)
Child age (Years)	Mean (SD)	3.43 (1.6)	5.96 (2.7)
Child Sex	Boys	228 (56%)	117 (56.8%)
	Girls	179 (44%)	89 (43.2%)
Child Race	African American	31 (7.6%)	32 (15.9%)
	Asian/ Pacific Islander	17 (4.2%)	9 (4.5%)
	Hispanic/Latino	18 (4.4%)	16 (7.8 %)
	Native American	11 (2.7%)	
	White	284 (69.8%)	123 (59.7%)
	Other	46 (11.3%)	21 (10.2%)
Child GMFCS	Level I	146 (35.9%)	52 (25.2%)
	Level II	47 (11.5%)	46 (22.3%)
	Level III	51 (12.5%)	25 (12.1%)
	Level IV	73 (17.9%)	40 (19.4%)
	Level V	90 (22.1%)	43 (20.9%)
Child MACS	Level I	—	29 (14.1%)
	Level II		76 (36.9%)
	Level III		36 (17.5%)
	Level IV		41 (19.9%)
	Level V		24 (11.7%)
Child CFCS	Level I	—	58 (28.2%)
	Level II		35 (17%)
	Level III		42 (20.4%)
	Level IV		39 (18.9%)
	Level V		32 (15.5%)
Parent age (Years)	Mean (SD)	34.6 (8.1)	39.1 (7.5)
Parent Race	African American	34 (8.4%)	32 (15.9%)
	Asian/ Pacific Islander	19 (4.7%)	8 (4.0%)
	Hispanic/Latino	23 (5.7%)	11 (5.5 %)
	Native American	9 (2.2%)	
	White	319 (78.4%)	146 (72.6%)
	Other	3 (0.7%)	4 (2.0%)
Parent relationship to child	Mother	371 (91.1%)	182 (88.4%)
	Father	21 (5.1%)	16 (7.8%)
	Others	15 (3.6%)	6 (2.9)
Total household income	Less than 30,000	86 (21.1%)	23 (16%)
	30,000 to 44,999	51 (12.5%)	14 (6.8%)
	45,000 to 59,999	55 (13.5%)	13 (6.3%)
	60,000 to 74,999	46 (11.3%)	18 (8.7%)
	75,000 or more	155 (38.1%)	96 (46.6%)
	Prefer not to answer/missing	14 (3.4%)	32 (15.6)
Parent education	High school or less	131 (32.1%)	36 (17.5%)
	Community college diploma; technical degree	110 (27%)	48 (23.3)
	University/graduate degree	166 (40.7%)	119 (57.8%)

Table 2. Psychometric properties of the classification systems

Psychometrics	GMFCS [a]	MACS [b]	CFCS [c]
Reliability	Reliability has been investigated for children with CP 2- 18 years of age [20]. • Moderate inter-rater reliability (κ = 0.55) for children younger than 2 years of age. • Substantial inter-rater reliability (κ = 0.75) for children older than 2 years of age.	Reliability has been investigated for children with CP 2- 18 years of age [25,26]. • Moderate inter-observer reliability (κ = 0.55) for children under 2 years of age; and good inter-observer reliability (κ = 0.67) for children 2-5 years of age [26]. • High inter-rater reliability (ICC = 0.97) for children 4-18 years of age [26].	Reliability has been investigated for children with CP 2- 18 years of age [27]. • Good inter-rater reliability between professionals (κ = 0.66). • Moderate inter-rater reliability between parents and professionals is moderate (κ = 0.49). • Very good test-retest reliability (κ = 0.82).
Validity	Content and construct validity have been supported for children with CP 2- 18 years of age [20].	Content and construct validity has been supported for children 4- 18 years of age [25].	Content and construct validity has been supported for children 4- 18 years of age [27].

a. Gross Motor Function Classification System
b. Manual Ability Classification System
c. Communication Function Classification System

Table 3. Ease of Caregiving scores (mean and standard deviation) across function and age groups						
	GMFCS		**MACS**		**CFCS**	
Age groups	Levels I-II	Levels III-V	Levels I-II	Levels III-V	Levels I-II	Levels III-V
Younger Children (1.5 to 5.9 years)	57.6 (14.77) (n= 47)	44.7 (8.92) (n= 40)	57.8 (13.77) (n= 52)	42.5 (7.99) (n= 35)	57.5 (14.67) (n= 44)	45.7 (10.33) (n= 43)
Older Children (6 to 11 years)	64.3 (17.11) (n= 49)	42.9 (8.21) (n= 68)	62.0 (16.74) (n= 52)	43.7 (10.91) (n= 65)	63.1 (16.77) (n= 48)	44.0 (10.90) (n= 69)
Total	61.0 (16.27) (n= 96)	43.5 (8.49) (n= 108)	59.9 (15.39) (n= 104)	43.3 (9.96) (n= 100)	60.4 (15.96) (n= 92)	44.7 (10.67) (n= 112)

Table 4. Differences in Ease of Caregiving scores (estimated marginal mean and confidence interval) based on children's levels of function				
Function Levels		**Estimated Marginal Mean**	**95% Confidence Interval**	***P* value**
GMFCS	Levels I-II	61.93	[58.40 - 63.46]	$P < 0.001$
	Levels III-V	43.78	[41.30 - 46.25]	
MACS	Levels I-II	59.91	[57.40 - 62.42]	$P < 0.001$
	Levels III-V	43.10	[40.41 - 45.78]	
CFCS	Levels I-II	60.27	[57.54 - 62.99]	$P < 0.001$
	Levels III-V	44.86	[42.32 - 47.39]	

Table 5. Item measures (logits) and item fit for Ease of Caregiving for Children measure

Item	Logits	S.E.	Infit	Outfit
moving at home/community	0.34	0.05	0.90	0.90
position for sleeping	-0.88	0.06	1.01	0.83
position for feeding	-0.53	0.06	0.80	0.75
position for bathing	0.19	0.05	0.78	0.73
position for playing	-0.57	0.05	0.79	0.68
put on/take off clothes	0.68	0.06	0.93	0.99
put on/take off orthosis	0.07	0.05	1.85	2.26
to bathe	0.78	0.06	0.80	0.82
to use the toilet	0.27	0.06	1.03	1.03
to eat	-0.44	0.06	1.02	1.00
to drink	-0.67	0.06	1.04	0.89
in and out of car	0.76	0.05	0.98	0.98

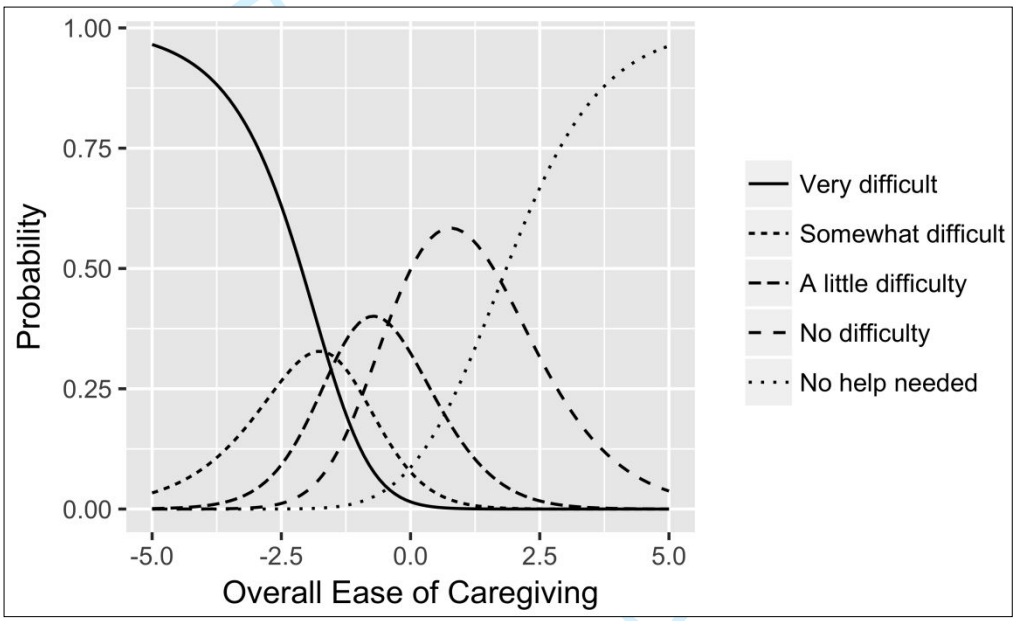

Figure 1. Item Characteristics Curve for Item #10 *(how difficult is it for you to safely help your child to eat)*

Figure 2. Item Response Map

Appendix

Scoring System of Ease of Caregiving for Children Measure

Summed Score	Scaled Score	Summed Score	Scaled Score	Summed Score	Scaled Score
60	100.0	43	46.3	26	32.4
59	87.9	42	45.3	25	31.6
58	80.6	41	44.3	24	30.8
57	75.6	40	43.3	23	30.0
56	71.5	39	42.5	22	29.0
55	68.0	38	41.5	21	28.1
54	64.9	37	40.8	20	27.1
53	62.3	36	39.9	19	25.9
52	59.9	35	39.1	18	24.6
51	57.8	34	38.3	17	23.2
50	55.9	33	37.6	16	21.4
49	54.2	32	36.9	15	19.2
48	52.7	31	36.2	14	16.0
47	51.2	30	35.4	13	10.7
46	49.8	29	34.7	12	0.0
45	48.6	28	34.0		
44	47.4	27	33.2		