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An Item Analysis of the Instability of Parent Report Scores on the Pediatric Evaluation of Disability Inventory

by

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Dedication

For all my family and friends who provided encouragement and support. Especially for my husband, Scott, who showed tremendous patience and provided extraordinary help through this busy time for me, all at the same time as we continued to take big steps together in our lives. Finally for our growing family who provided inspiration and perspective during the completion of my thesis.

Abstract

Purpose: To evaluate item instability of the Pediatric Evaluation of Disability Inventory – Functional Skills Scale completed by parents. **Methods:** Scoring instability was analyzed between baseline and after 6 months of intervention (T1-T2) on 113 children and between end of intervention and 3 months afterwards (T2-T3) on 101 children. **Results:** Scoring instability was present among children between T1-T2 (19% of children > 5 unstable items) and between T2-T3 (34% of children > 5 unstable items). Ten or more children had unstable scores between both time periods for 21 out of 132 (16%) items. More instability was found between T2-T3, among older children in T1-T2, and among children with less motor limitations in T2-T3. **Conclusions:** Item instability was present, but the magnitude was low. Suggestions for parental scoring on the PEDI-FSS include clarifying the scoring reference, the subjective words, the guidelines for multi-faceted items, and the impact of the outdoor environment.

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Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

Clinical practice in pediatric rehabilitation is changing from an emphasis on impairments to a focus on a child's functional skills.[1] This shift is the result of numerous factors including a change in the theory to explain gross motor development.[1] Previously the neuromaturational theory guided therapeutic interventions to improve impairments (eg, inhibit abnormal muscle tone) and remediate movement skills to obtain normal patterns of movement.[1] These strategies are challenged by interventions influenced by the Dynamic Systems Theory (DST). Using the tenets of DST, therapists are encouraged to focus on the functional abilities of the child and the task in the context of their environment.[2] A child may use different movement strategies in different environments and emphasis is on functional success rather than quality of movement. Combined with an awareness of evidence based practice, this new intervention focus emphasizes the importance of standardized and valid outcome measures to evaluate the functional abilities of children with motor disabilities. Measurement of functional skills rather than isolated developmental domains (eg, motor skills, communication skills) is advantageous because it allows for functional solutions to complete a task, encourages adaptations to an activity such as the use of assistive devices, and emphasizes the importance of considering the child's natural environment or context.[3,4]

Functional measures for children are often administered either by direct observational assessment by a professional or by the judgment of a professional or a parent.[4] Parent or professional judgment can be completed using either a standardized interview or a questionnaire. Traditionally, assessment is considered more objective if completed by direct observation by a professional,[5] but parent report has the benefit of providing information about actual performance as parents observe their children in the context of everyday life.[6] Parents' ability to see their child directly interact with the environmental factors in their life aligns with the description of function in the International Classification of Functioning, Disability, and Health (ICF).[7] With the common application of the ICF as a framework for pediatric rehabilitation,[8] the advantages of parent report are an important consideration for therapists.

PROBLEM STATEMENT

The debate regarding parental report is still present in the literature despite advantages to its use. Strong evidence exists for using parental concerns to identify a problem and using parent report for screening tools,[9] but some researchers conclude parent report for more detailed assessment is not accurate.[10-13] Conclusions are limited by challenges in the parent report literature and by the scarcity of research investigating the use of parent report specific to the assessment of functional skills. The Pediatric Evaluation of Disability Inventory (PEDI)[14] is an outcome measure designed to capture the functional abilities of children with disabilities that is often administered by parent report.[15] Since publication of the PEDI in 1992, it has been cited in the literature extensively and used internationally for clinical and research purposes with varying pediatric diagnoses including cerebral palsy.[15] The stability of parent report on individual PEDI items has not been investigated. Clinically, this issue is important to occupational and physical therapists using the PEDI with parent report for evaluation over time. An evaluation of individual item stability will also contribute generally to the knowledge of the use of parent report. There are still a lot of questions about the accuracy of parent report. The current literature investigating parent report tends to use more general methods, such as evaluation of the degree of association between summary scores on outcome measures obtained from parents and professionals[16] and has not evaluated the consistency of parent report over time at an in-depth level.

AIM OF THE STUDY

The aim of this study was to evaluate the consistency of parent report on individual items from the PEDI over time. This research project is a secondary analysis of PEDI data collected for a clinical trial of therapy for young children cerebral palsy.[2]

OVERVIEW OF THE THESIS

The thesis follows a paper format and consists of two distinct papers. The first paper is an overview of the issues of parent report related to pediatric rehabilitation (Chapter 2). The second paper is a description of the thesis research project and a summary of the results (Chapter 3). Chapter 4 represents a synopsis of the two papers, clinical implications of the thesis, plans for dissemination of results, and implications for further research.

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Chapter 2: Parent Report in Pediatric Rehabilitation

Outcome measures of children's abilities using parent report are increasing in number and popularity.[1,2] The utility of parental report as an assessment method has been studied for over four decades, beginning in the area of psychology and the assessment of cognitive abilities. Parent report offers distinct advantages over direct assessment by professionals, but controversy regarding the validity of parent report is present in the literature.[2-4] Most of the research has evaluated parent report measures used for screening and identification purposes.[2,5,6] Research has investigated the use of parent report to evaluate their children's health related quality of life compared to child report.[27] The emphasis of the paper is focused on parent report used for assessment purposes of their child's self-care and motor abilities rather than health related quality of life. Investigation into parent report used for evaluative assessment of children's abilities over time is limited,[6,7] even though parent report is used with evaluative measures in pediatric rehabilitation.[8,9] The aim of this paper is to review the issues of parent report for evaluation in pediatric rehabilitation. The first part of the paper discusses the advantages of parent report specific to pediatric rehabilitation and the concerns surrounding the use of parent report across a broad-spectrum of literature. The second part of the paper identifies and describes some measures of self-care and mobility available to pediatric therapists that can be scored by parent report.

PART I: PARENT REPORT - WHAT ARE THE ADVANTAGES AND CONCERNS FOR PEDIATRIC REHABILITION?

Parent report is a potentially efficient method for assessment in terms of cost and time as demonstrated by the use of parent report for screening purposes.[10] If parent report is valid for assessment beyond screening purposes, it could reduce the reliance on professional assessment, theoretically reducing costs of professional assessment and leaving more time for intervention and treatment planning.[11] In addition, therapists consistently identify ‘lack of time’ as a barrier to the consistent use of outcome measures.[12]

Perhaps more important than efficiency, parent report may be the most accurate way to assess ‘real life’ performance and abilities of their children considering parents have the unique opportunity to see their children perform in their daily life circumstances in an array of environments. Direct assessments by professionals often attempt to evaluate a child’s best performance by observing skills in a standardized environment, but the assessments are limited to a specific time period and specific cues such as timing and handling.[13] Parents interact with their children frequently and in different natural environments so their perceptions of their children’s abilities may have more ecological validity compared to professional assessment.[13,14] Typical performance in a familiar environment may be preferable compared to assessment of best performance in an unfamiliar environment because artificial testing environments are not conducive to observing skills that are emerging, complex, or only performed in specific environments.[13] Although therapists are aware of the necessity of considering the child’s daily environment, the constraints of current service delivery models often limit a therapist’s observations to one type of environment such as the rehabilitation centre, the home, or the school. Beyond the physical environment, performance is affected by numerous factors such as time constraints, societal factors, and choice, so it may be difficult to ascertain performance even with observation by a clinician in the child’s natural environment.

Parent report also aligns well with family centered care (FCC) principles and legislation mandating that parents have the opportunity to be involved in their child’s assessment and intervention processes.[1,3,13] Parent report actively involves parents in the therapeutic process and supports the collaborative concept of FCC.[1,14] Considering the principles of FCC that families know their child best, that therapists are collaborators instead of experts, and that goals should be set with parents, the use of parent report in the evaluation component of therapy operationalizes these theoretical principles.[15] Research also suggests that parents have an improved relationship with the professional and are more likely to participate in their children’s treatment when they participate in parent report.[1,13,14]

Despite these advantages, controversy remains in the literature regarding the accuracy of parent report.[2-4,6] A major concern is parent bias because of lack of training in either test administration or observational skills.[3,16] As summarized by Sexton, Miller, and Rotari,[17] studies evaluating parent report reach varying conclusions ranging from acceptable parental agreement with a professional to both over and underestimation of a child’s abilities. Recent studies continue to report disparate findings indicating parent report yields both the same results as professional report[18] and higher scores than professionals.[2] The equivocal results may be due in part to the diversity of the methods used in studies.[6,19] Early studies asked parents to estimate their child's developmental age or predict their child's future functioning.[6,20] In other studies, parents were asked to report on their child's current abilities and their responses were compared to either professional judgment [21,22] or direct professional assessment.[2,4,17-19] These comparisons have been studied using both the same[17-19,21,22] and different measures.[2,4]

Conclusions regarding parental accuracy are mainly based on the amount of agreement parent report has with professional assessment. For this paper the term agreement will be used to refer to the relationship of parent report when compared to professional assessment, because studies discussed consistently compared to some type of professional assessment. The term agreement is used instead of accuracy, because it does not imply professional assessment is superior. Other than the methodology used, varying results across studies may relate to certain factors affecting parent report. The factors identified in the literature that affect the agreement of parent report with a professional are the type of information gathered from parents, child and family characteristics, and the developmental domain assessed. Each of these factors are discussed in the next section.

Parental assessment is considered more accurate when they are asked to report on current abilities of their child rather than recalling past performance. Providing a specific time period, such as 'during the last week', is recommended to improve parent report of current abilities.[6] Parental predictions of their child's future functioning may be inaccurate because a child's future function and 'truth' is not known.[20] Asking parents to estimate the developmental age of their child rather than to report on specific abilities can also be inaccurate.[6] Parents' assessment of their child's current skills may be more accurate when questions are in recognition format (e.g. 'Can your child button and unbutton fasteners on clothes?') rather than identification format (e.g. 'How does your child get dressed?').[6]

The severity of a child's condition influences parent report differently depending on what aspect of the child's functioning is limited. For example, studies evaluating the influence of a child's cognitive ability on parental agreement, report both no effect and better parental agreement with children who have higher cognitive abilities.[4,5,17] Severity of cognitive abilities was defined in one study by the amount of change in cognitive level over time and parents of children with little change were reported to have more agreement with professionals.[19] When a developmental quotient is used to describe the child's severity, greater parental agreement with children who have a higher developmental level is reported.[20] When the influence of a child's motor impairment on parent report agreement was examined, parents of children with less severe motor impairment rated their child's abilities lower than professionals.[23]

Parent report agreement is more consistently influenced by a child's age than by severity of a child's condition. Parents of children older than 2 years have better agreement with professional assessment compared to parents of children less than 2 years old.[5,13] In a study of children aged 6 years to adulthood, the group of children with the greatest discrepancy in parent scores was on average three years younger than the group of children with less discrepancy.[24] The influence of age on parent report is consistently in the same direction with greater parental agreement with older children. However, there is still some evidence that a child's age has little influence on the agreement of parent report as summarized by Sexton et al.[17]

The influence of family characteristics on the agreement of parent report is equivocal.[5,10] Characteristics of the family that improve parental agreement include higher maternal education level,[17] prior experience with children,[25] higher family income[17,26] and higher socioeconomic class.[17,26] These factors are not reported to impact parental agreement in all studies.[6,10,17]

The developmental domain assessed may affect the agreement of parent report.[5] Assessment of children's communication abilities yields more discrepancy between parent and professional assessment compared to other areas of development such as eating, grooming, play, cognition, self-help, and motor skills.[4,6,21] Parents can reliably classify their children's motor abilities using a categorical scale.[7,23] Parents have agreed more with professional assessment when assessing motor abilities compared to cognitive skills perhaps because motor skills are more concrete and easier to observe than abstract cognitive concepts.[18,19]

Discussion

Overall, the literature investigating parent report is inconclusive with evidence of both agreement and disagreement with professionals. Child and family factors may influence the agreement of parent report, but the results are inconsistent. Much of the research is dated and limited by methodological challenges. The different comparisons between parent report measures and professionally assessed measures result in the following limitations. When two different measures are used by parents and professionals, different results could be due to the measures representing different developmental constructs or having different psychometric properties. The best way to evaluate the congruency of parent report and professional scoring is to use the same measure, even if the formats were slightly different. Conclusions from comparisons between parent and professional report on the same measure are also limited because it is difficult to determine whose judgments more closely represent the actual performance of the child. Although direct observation by a professional may provide a more objective view of a child's ability than parent report, the advantages of parents seeing their child frequently and across environments makes it difficult to know which is more representative of a child's actual performance. This contextual advantage of parent report is especially important when assessing children with motor impairments given the consistent evidence that environmental context influences their mobility.[28]

Numerous studies confirm a child's method of mobility and the amount of caregiver assistance needed for mobility are both affected by the environment.

Children use different modes of mobility and amounts of caregiver assistance depending on whether they are at home, school, or outdoors and in the community.[7,28-31] This variability in children's mobility across environments is reported for children grouped by age,[29] Gross Motor Function Classification System (GMFCS) level,[29] and highest mobility skill mastered.[30] Because this variability is found across groups of children, therapists cannot make conclusions about a child's mobility status based solely on these child characteristics (age, GMFCS, highest level of function). The consensus across studies is assessment in varied natural environments is necessary.[7,29,30] All the studies used parent report to describe children's mobility performance and suggest the use of parent report to assess across environments. Some of these authors gave the recommendation to use parent report primarily for its feasibility and stated it is an inferior alternative to direct assessment.[7,29]

An assumption exists in the literature that professional assessment is the 'gold standard' of a child's true developmental abilities. Several studies concluded that parents are accurate enough to screen their children for problems, but that professional assessment is still necessary to make a diagnosis or to qualify for services.[17,32,33] Another explicitly stated reason to include professional assessment is that parent report is not specific enough for individual planning.[33] This concept that the professional is the expert has been challenged[5,34] with the argument that utilizing standardized parent report measures can provide specific information and parents may have more accurate information about the actual performance of their children than professionals.

What is ‘truth’; parent or professional assessment?[23,34,35] The parent report literature suggests that future research could be improved by consistently comparing parents and professionals on the same measure, but even using this type of comparison assumes that the professional assessment represents the gold standard. Determining the gold standard for parent report may be one of the most important factors in future investigations, although some authors suggest that it is not possible to know which is more accurate as they are simply different perspectives.[23,34]

It is important to consider the role of parent report. One study concluded that parent assessment of developmental status is accurate enough to substitute professional assessment for children with severe brain injuries at a single point in time.[11] For assessment over time, it has been suggested that parents can be the sole raters as long as the parent perspective is used before and after the intervention.[3] A shift to more emphasis on parent report for assessment in pediatric rehabilitation may help clinicians meet the principles of FCC that families know their child best and that all families are unique. Professional expertise and guidance will always be a necessary component of care for families, but more focus on parent report may improve some aspects of FCC. For example, utilizing parent report for assessment could enhance the collaboration needed between therapists and parents for setting family-centered goals. Parents have reported a need for more input and guidance from professionals in setting goals for young children.[36] With the incorporation of parent report, therapists may have more opportunity to share their clinical expertise with parents and parents may have a clear avenue to provide their valuable input for goal setting, but more research is needed to know the actual effect of parent report goal setting.

Interest in measures of parent report is increasing concomitant with the importance of considering the effect of environmental context on children's performance.[13] Consideration of the environment and including parents as partners in care, suggests parent report for evaluative assessment is a valuable asset to pediatric rehabilitation. Because the literature investigating parent report is not conclusive and fraught with limitations, investigation into parent report specific for pediatric therapists is necessary.

PART 2: PARENT REPORT MEASURES EVALUATING SELF-CARE AND MOBILITY IN REHABILITATION

Children's functional abilities in the domains of self-care and mobility are important to pediatric physical and occupational therapists because the goal of rehabilitation is to improve children's functioning in their everyday lives.[37,38] To determine the success of interventions, outcome measures that evaluate the change of children's functional abilities over time are necessary. By focusing on activities of daily living as the end result, the therapeutic process is more likely to address issues that are important to families and improve quality of life.[38] Measurement of functional abilities can also be used for discriminative purposes, for identification of goals, and for planning interventions that are meaningful to children and families.[37]

Parent report may be an ideal method to measure the domains of self-care and mobility because parents observe their child performing these activities in a variety of natural environments. The majority of the parent report literature focuses on outcome measures of traditional developmental domains such as gross motor, fine motor, cognitive and social skills rather than functional abilities. The literature evaluating the validity of parent report on measures of self-care and mobility for children with motor disabilities is sparse. Parent report is used to classify children's motor abilities,[7,23] but these categorical scales are brief and not detailed enough to be considered evaluative instruments. Also, children may not be expected to change categories on these scales as demonstrated in the case of the GMFCS.[39]

Five parent report measures used by therapists to evaluate self-care and/or mobility were identified from the literature; the Vineland Adapted Behavioral Scale (VABS-2),[40] the Activities Scale for Kids (ASK),[35] the Gilette Functional Assessment Questionnaire (FAQ),[41] the Functional Independence Measure for Children (WeeFIM),[42] and the Pediatric Evaluation of Disability Inventory (PEDI).[43] Parent report measures were not included if their main focus was not on mobility and/or self-care activities. For example, measures such as the Life Assessment Questionnaire for cerebral palsy,[44] Assessment of Life Habits for Children,[45] and Children Helping Out; Responsibilities, Expectations and Supports[46] evaluate a child's activity and participation, but their emphasis is more on participation in family and/or school life.

Comparisons of parent report and professional report have been evaluated using one of three methods: 1) parent report compared to direct observation by a professional on the same measure; 2) parent report compared to judgment by a professional on the same measure; and 3) parent report compared to direct observation by a professional using a different measure. Each method has specific limitations but comparison of parent report and direct professional observation on the same measure seems the strongest method to evaluate parent report. For each assessment measure, the method of evaluating parent report and any administration issues of using parent report in pediatric rehabilitation are described.

The VABS-2 is a discriminative and evaluative measure of adapted functioning that is used across many disciplines and it is commonly used for children aged birth to 19 years old with a disability. Domains measured include communication, daily living skills, socialization and motor skills, and an optional maladaptive behaviour domain. Administration of the VABS-2 is by parent interview or parent questionnaire using the Parent Report Form, or by caregiver (person providing care for child that is not the parent) or classroom staff interview. The Parent Report Form is a new component with the introduction of the second edition of the Vineland Adaptive Behavior Scale (VABS) and underwent extensive comparison to parent interview from the original measure to confirm that the two forms of administration had comparable results. Parent report compared to direct observation by a professional on a variety of different measures demonstrated good agreement for related scales and low agreement for unrelated scales.[47-51] The VABS is not used extensively for evaluation of children’s functional abilities in self-care and mobility as it is a multi-domain measure with a broader scope compared to measures that focus primarily on these areas, which are more clinically relevant to physical and occupational therapists.

The ASK is an evaluative measure of self-care, mobility, and aspects of participation such as food preparation, spare time activities, and managing special medical needs. Children 5 to 15 years old with musculoskeletal disorders report on their own function, but if a child is unable to complete the measure, parent report is allowed.[52] It has also been used with other diagnoses including cerebral palsy.[53] The ASK has two different scoring criteria; what a child can do (capability) and what a child actually does do (performance). This is accomplished by having each item presented with different statements: “In the last week, I think I could have fastened my clothes by myself…” and, “in the last week, I fastened my clothes by myself…” Statements are completed by indicating how often the item was completed using a 6 point ordinal scale. Child self-report was compared to parent report with excellent inter-rater reliability (ICC=0.94).[35] When comparing child report to professional assessment based on observations on a subset of items, there was good agreement (r=0.92 and ICC=0.89).[54] The ASK is primarily a self-report measure that was developed with the input of children and parents. Both child and parent-proxy report benefit from the clear parameters for scoring with a time reference and differentiation between distinct aspects of function on the two parts of the measure.

The FAQ was developed as an evaluative measure of functional walking abilities of children with disabilities and developed for children ranging in age from 2 years old to adulthood. Parent questionnaire is used to measure a 10 point ordinal walking scale and 22 items evaluating gross motor skills. Psychometric testing has not been reported on the 22 item gross motor scale.[8] Parent report was compared to a school caregiver's report on the FAQ walking scale with good inter-rater reliability (ICC=0.92).[41] Parent report was also compared to the WeeFIM motor subscale completed by direct observation by a therapist (except for the transfer items which were scored by parent interview) with reports of good concurrent validity (r=.64).[41] Preliminary results suggest parent report is useful for describing children's walking abilities, but the FAQ walking scale is more like a classification system than an evaluative outcome measure.

The WeeFIM is an evaluative and discriminative measure of functional abilities developed for children with developmental disabilities aged 6 months to 7 years; it can also be used with older children with disabilities if their functional abilities are below those of a 7 year old without a disability. A 7 point ordinal scale measures amount of caregiver assistance in three domains: self care, mobility, and cognition. Methods of administration include parent interview, caregiver interview, professional report, direct professional observation, or information from medical records. Parent report compared to direct observation on the WeeFIM yielded no significant differences and good agreement for total score (ICC=0.93), domain scores (ICC=0.93 for motor; ICC=0.75 for cognitive), and subscales (ranged from ICC=0.66 for social subscale to ICC=0.94 for locomotion).[18] Agreement for individual items varied (ICC=0.41-0.98). Also, parent report was compared to direct observation on a measure of play skills with high agreement (r=0.77) and on a measure of language with moderate agreement (r=0.41-0.42).[55] There is strong evidence that parent report is an accurate method of administration of the WeeFIM, but less agreement for specific items (social interaction, problem solving, memory, comprehension, toilet transfers, dressing lower body, and grooming) suggests the need for further investigation.

The PEDI is an evaluative and discriminative measure of functional abilities for children between the age of 6 months and 7½ years old; it can also be used with older children who have a disability if their functional abilities are lower than typically developing 7½ year olds.[43] It can be scored by parent questionnaire, parent interview, interview with a professional or by professional report based on knowledge of the child.[43] The PEDI evaluates the domains of mobility, self-care, and social function in two main parts: the Functional Skills Scale (FSS) measures whether the child is capable of completing functional skills and the Caregiver Assistance Scale (CAS) determines the amount of caregiver assistance typically required.[43] Three studies compared parent report to professional report on the PEDI and reported good agreement for the domain summary and scaled scores on the FSS (ICC=0.84-0.96 for Self Care, ICC=0.81-0.96 for Mobility, ICC= 0.72-0.89 for Social Function).[22,43,56] More inconsistent results were found for the CAS: two studies reported good agreement in two domain summary scores (ICC=0.84-0.91 for Self Care, ICC=0.90-0.96 for Mobility) and variable results for the Social Function domain, with low agreement in one study (ICC= 0.33) and high agreement in another (ICC=0.74).[22,43] Further analyses in one study demonstrated varying agreement for specific content areas (ICC=0.15-0.93) and normative scores (ICC=0.12-0.75) of the FSS and CAS.[22]

Comparisons of parent report to direct observation by a professional on numerous other measures demonstrated agreement with related scales.[22,43,57,58] Parent report has consistently been shown to be in good agreement with professional assessment on the PEDI (except the PEDI CAS Social Domain). Similar to the WeeFIM, parent report on certain content areas are less accurate by parent report suggesting further research is needed.

Discussion

The method of evaluating the accuracy of parent report varied among the measures reviewed. Of the five measures, only the WeeFIM demonstrated parent agreement with the strongest methodology of comparing parent report to direct observation on the same measure. Future research comparing parent report to the professional on the same measure is needed. The PEDI and the FAQ compared parents to professional judgment on the same measure with varying agreement (ICC=0.33-0.94 compared to ICC=0.92, respectively). These varying results may be more dependent on the different raters used for professional judgment than conclusions regarding the validity of parent report. Occupational therapists and physical therapists were used in the PEDI studies compared to a school staff member, usually a teacher, who scored the FAQ. Previous literature suggests that teachers tend to rate children higher than clinicians,[56,59] suggesting overall conclusions regarding parent report based on professional's judgments are difficult when the raters vary. Comparing parents to professional judgment may have more limitations than comparing to direct professional observation, but even using professional direct observation as the 'gold standard' has limitations as it may not represent true ability and performance. The evaluation of parental report on the ASK was different than the typical methods used and this unique comparison implies parental accuracy. Comparing parent report to the child's own perception may be an interesting way to evaluate parent report and a possible consideration for future research.

The WeeFIM and PEDI CAS measure the level of independence in terms of caregiver assistance and suggest parents are valid reporters of the amount of caregiver assistance their child requires. Parent report of caregiver assistance may be one of the most accurate types of information provided by parents as they are reporting on an aspect of their child in which they are typically directly involved. The amount of assistance required is an essential component of a child's function, but it is considered an indirect measure of performance and does not capture the entire picture of a child's function.[60] Caregiver assistance alone may neglect other factors that affect performance. For example choice is an important factor as a child may choose not to do an activity even though they are able to do the activity with caregiver assistance. The amount of skill can be much different than the amount of caregiver assistance typically required and emphasizes that therapists need to consider the specific aspect of function measured by outcome measures.

The evidence for using parent report for assessment of their child's functional ability is not as strong as for caregiver assistance. This may be due to the limitation of parent report measures of functional skills. Of the five measures, the WeeFIM and PEDI CAS measure caregiver assistance, the FAQ focuses on walking ability, the VABS is a multi-domain measure, and the ASK is primarily a child report measure, leaving the PEDI FSS as the only comprehensive parent report measure focused primarily on functional skills in self-care and mobility. The evidence for parent report on the PEDI FSS is promising however the methodology of comparing parent report to professional report is not as strong as the comparison used with the WeeFIM.

All investigations into the evaluation of parent report on these five measures have been at a single point in time. Longitudinal evaluation of parent report of functional skills could determine if parental assessment is accurate over time and predictive of future functional limitations. Recently one of the first longitudinal studies of functional skills in school aged children with cerebral palsy was published.[61] This research uses the PEDI FSS administered by parent interview as an outcome measure and evaluated children between the ages of 5 to 7 years old over a 2 year span. It would be interesting to determine if this type of research has a similar application that the evaluation of gross motor function by direct observation has shown for the prognosis of a child’s future function.[62] To determine if following the course of parent report of functional skills over time has this potential, it would be useful for future research to follow parent report over a period longer than 2 years, to sample a greater age range of children with cerebral palsy, and to use a comparison measure for parent report (either throughout the study or as a final outcome).

CONCLUSION

Parent report is an attractive option for therapists given the importance of FCC and the emphasis on activity focused assessment in the context of the child's typical environment. The development of parent report measures specific to self-care and mobility is limited, but the emerging evidence of parental agreement on current functional outcome measures is promising. The challenge is determining what the gold standard should be for evaluating parent report. When considering what is 'truth' there is currently no gold standard for who is best to measure disability as pointed out by the authors of the ASK. They propose that children may be the best reporters on their disability.[16] Further evidence is needed to support child self-report for various ages and disabilities. Even with child self-report, parent report is needed as a proxy when children are unable to report for themselves. Other than comparing parent report to the child's own perspective, further research into parent report validity could consider other novel solutions such as comparing parent report to direct observation by parents themselves or to video recordings of the child performing skills of daily life.

With the current use of parent report, it is advantageous for therapists and researchers to include specific parameters for parents. Defining a specific time frame for parents such as "in the last two weeks" is important when they are reporting on their child's current function and is exemplified in the ASK. Clearly defining the construct being measured is necessary, because different aspects are intertwined in function as seen with caregiver assistance providing useful but limited information. The wording of the questions must also be considered as different results are obtained on the ASK by stating “could you…” compared to “did you…” Including these specific parameters, determining the role of parent report and potential benefits for the quality of care for families, and evaluation of the validity of parent report for functional skills are important steps for parent report use in pediatric rehabilitation.

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Chapter 3: An Item Analysis of Parent Report Scores on the PEDI

Children with cerebral palsy receive rehabilitation intervention to improve their overall function. Outcome measures that evaluate a child's functional abilities are important because they are specific to the goal of therapy, they focus on the task, and they usually consider the context of the child's environment.[1] Parent report measures are beneficial when assessing a child's function because parents have the opportunity to see a child's typical performance across different settings.[2] However, the literature investigating the accuracy of parent report is inconclusive. Parents are reported to provide accurate information about their child's abilities in some studies, but found to over or underestimate their child's abilities in others.[3] The Pediatric Evaluation of Disability Inventory (PEDI)[4] is a comprehensive functional outcome measure that can be scored by parent questionnaire, by interview with a parent or a professional, or by professional judgment based on knowledge of the child. The PEDI is commonly used to evaluate functional changes in children with a variety of disabilities including cerebral palsy.[5]

The PEDI describes a child's functional status in the domains of mobility, self-care, and social function. These domains are evaluated in two main parts: the Functional Skills Scale (FSS) and the Caregiver Assistance Scale (CAS). Numerous studies have reported good reliability and validity of the PEDI.[4,6-11] The FSS measures a child's capability which is defined as a child's competence or mastery in functional skills. The scale consists of items representing functional skills which are organized into specific content areas each with a checklist of related items listed in order of difficulty through Rasch analysis. Individual items are scored as either ‘capable’ (score=1) if the child is able to complete the skill in most situations or ‘unable’ (score =0) if the child has not yet demonstrated the skill. Parent report is obtained on the PEDI FSS either by parent interview with a trained assessor or by parent questionnaire, with parents completing a checklist independently followed by a brief review of their responses by a person familiar with the PEDI. The PEDI FSS is often administered by parent questionnaire for clinical and research use, even though it was most commonly administered by parent interview during its development and analyses of psychometric properties. The PEDI FSS is frequently used to document change over time and information regarding the stability of parent report scores is important.

The stability of parent report on the PEDI FSS has been evaluated in two previous studies. Wright and Boschen[9] evaluated the test-retest (intra-rater) reliability of parents’ scoring their child with cerebral palsy over a three week period (method of administration not indicated) and Nichols and Case-Smith[8] evaluated test-retest reliability of scores for children with a disability (including children with cerebral palsy and other diagnoses) over a one week period using parent interview. Both studies found good reliability (ICC=0.81-0.98) for the total domain score for self-care and mobility, although the latter study reported less reliability (ICC= 0.67-0.79) of certain content areas (washing face and body; upper and lower body dressing; and indoor locomotion distance, speed and carrying objects). Neither study evaluated the stability of individual items.

Identification of the unstable items by parent report may identify items that many parents score inconsistently. Identification of these items, if any, would alert therapists to items that they need to discuss with parents before they complete the PEDI to ensure that they understand the meaning of the item. Clinically, identifying PEDI items with scoring instability is useful to clinicians using the PEDI with parent report for evaluation over time. ‘Instability’ is defined as a decrease in parent score on an item from ‘1’ (capable) to ‘0’ (unable) between two sequential assessments when such a loss of ability is unlikely. For instance, young children with a diagnosis of cerebral palsy are often seen over time in pediatric rehabilitation. It is unlikely that they would lose the ability to complete a functional skill although children with cerebral palsy older than 7 years old with more severe motor impairments may show some decline in their gross motor function over time.[12] The PEDI scores of children with other diagnoses (e.g. degenerative conditions or brain injury) may truly change from a ‘1’ to a ‘0’ over time. Given the hierarchical order of the functional skills on the PEDI, younger children with cerebral palsy should remain capable on skills they previously attained unless they experienced an illness or medical intervention that affected their function.

PURPOSE

The purpose of this study is to evaluate item instability of the PEDI FSS when parents provide responses in a questionnaire format.

The specific research questions are:

1. Are children's scores by parent report on items on the mobility and self-care domains of the PEDI FSS unstable between two assessments?
2. Are specific items on the mobility and self-care domains of the PEDI FSS more unstable than others?
3. Are the instances of instability different between two distinct time periods?
4. Are the instances of instability affected by a child's age or severity of motor limitation?
5. Are the instances of instability different between the domains of self-care and mobility on the PEDI?

METHODS

This descriptive research study was completed by secondary analyses of PEDI data collected during a clinical trial of children diagnosed with cerebral palsy.[13] Ethics approval was obtained from the university Research Ethics Board for both the initial study and the secondary analyses.

Subjects

Children receiving care at 19 rehabilitation centers across Alberta and Ontario between September 2006 and June 2008 participated in the original study. They all had a diagnosis of cerebral palsy and were between 12 months old and 5 years 11 months at the time of recruitment. Children's motor abilities represented all five levels of the Gross Motor Function Classification System (GMFCS).[14] Children were excluded if they had a planned medication or surgical intervention that would affect their motor function. After obtaining parental consent, children followed their treating occupational therapist or physical therapist into a randomized treatment block and received one of two interventions. Trained assessors collected data on the mobility and self-care domains of the PEDI FSS using parent report at baseline (T1), after 6 months of intervention (T2), and 3 months after the intervention was completed (T3). The results of the clinical trial revealed no difference in the scores of the mobility and self-care domains of the PEDI FSS between the two interventions; children in both groups had significant increases in PEDI scores from baseline to the end of intervention but no changes from the end of intervention to the 3 month follow-up. The authors concluded the two types of therapy provided over 6 months were equally effective,[13] and thus the data from the two groups were pooled for these secondary analyses. To be included in these secondary analyses a child needed to have PEDI FSS data for at least two adjacent assessments (T1 and T2 or T2 and T3). One hundred and twenty-eight children completed the original study and 115 children had data over at least one adjacent time period. Two children with greater than 5% of PEDI FSS items not scored by their parents at any assessment time were removed from the dataset and 12 children did not have T3 data. Thus T1-T2 analyses were completed with the scores of 113 children and T2-T3 analyses used the scores of 101 children.

Measurement

The mobility and self-care domain data of the PEDI FSS and demographic variables from the original study were evaluated. The self-care and mobility domains have 73 and 59 items respectively, describing skills necessary to complete complex activities (e.g. brushing teeth thoroughly, getting in and out of bed). A child is scored ‘capable’ if he or she has mastered the skill described by an item. The parent can give a score of ‘1’ (capable) for an item if the child can do the skill but no longer demonstrates the skill due to preference, compliance, or progression to more advanced skills. When a parent completes the scale independently, a trained examiner uses the scoring criteria in the manual to review any items scored “out of sequence” [4(p.81)] in a content area because items are presented in the order typically achieved developmentally.[4] The scoring criteria for the FSS provides specific guidelines for scoring individual items.

Procedure

In the original study, families received a PEDI FSS adapted scoresheet in the mail with written instructions to answer each item as ‘unable’ or ‘capable’. The mail-out included an instruction sheet with examples of how to score an item if their child no longer demonstrates a skill they have mastered and if the item is described in two separate parts connected by ‘and’ or ‘or’. A trained assessor (occupational therapist or physical therapist) went to each family’s home to complete other assessment measures and reviewed the parent’s scoring to ensure the questionnaire was scored completely.

For these secondary analyses, an item was classified as unstable if the item’s scoring decreased from ‘1’ (capable) to ‘0’ (unable) between baseline and the end of intervention (T1-T2), or between the end of intervention and 3 months post-intervention (T2-T3). Two new variables (Instability T1-T2 and Instability

T2-T3) were created for each item to document when a child’s item score changed from ‘1’ to ‘0’ over adjacent assessments. The variables were coded ‘1’ if the score decreased and ‘0’ if the score increased or did not change.

Scoring instability was evaluated by examining both individual child instability and individual item instability. To evaluate child instability two summary variables (Total Child Instability T1-T2 and Total Child Instability T2-T3) were calculated to count the total number of items scored unstable between T1-T2 and T2-T3 for each child. Then, to determine item instability, two new summary variables (Total Item Instability T1- T2 and Total Item Instability T2-T3) were computed by totaling the number of children who had an unstable score between T1-T2 and T2-T3 for each item.

To evaluate the effect of age and severity on scoring instability, children were divided into two age groups and into two groups indicating severity of cerebral palsy. The age groups were children less than 3 years and 6 months old and children 3 years and 6 months old and over. Children classified as GMFCS level I-III were grouped as children with less severe motor limitations and those identified as GMFCS level IV- V were in the more severe motor limitations group.

Analysis

Descriptive statistics summarized the children’s sex, age, and GMFCS classification. To examine the association of summary scores of two adjacent assessment intervals, Pearson correlation coefficients were calculated for domain (self-care and mobility) scaled scores between T1-T2 and between T2-T3. The frequency distributions of ‘Total Child Instability T1-T2’ and ‘Total Child Instability T2-T3’ were examined to evaluate if children’s scores were unstable by parent report. To determine whether specific items are more unstable than others, the frequency distributions of ‘Total Item Instability T1-T2’ and ‘Total Item Instability T2-T3’ were examined. In order to categorize the degree of instability at the child and item level, proportions were examined in two categories of instability (less than or equal to 5 and over 5) of the number of items per child and number of children per item respectively. Categories of "less stable" and "more stable” were determined at the child level, by the identification of up to 5 items that may be problematic for parents to score, and at the item level, based on an item having 5% of children scoring unstable.

Descriptive statistics (median and interquartile range) summarized the total child and item instability. The difference between time periods (6 months versus 3 months) on the stability of parents’ scoring was evaluated using the Wilcoxon signed rank test at both the child and item level. The impact of the severity of motor limitation and age was examined using the Mann-Whitney U test. Domain instability differences (mobility and self-care) were compared using the Wilcoxon signed rank at the child level and Mann-Whitney U test at the item level. Statistical Package for Social Sciences, Version 16.0.0[15] was used for all analyses. An alpha level of .05 was used to determine statistical significance.

RESULTS

The characteristics of the children in the study are presented in Table 3-1. The associations between the total scaled scores of T1 and T2 were r=0.96 (p<.001) for both the self-care and mobility domains. The relationships between total scaled scores of T2 and T3 were r=0.98 (p<.001) for self care and r=0.97(p<.001) for mobility.

Child Instability

Table 3-2 provides the frequency distributions of the child instability. Between T1-T2, 94 (83%) children scored 5 or less items unstable and 19 (17%) children scored more than 5 items unstable. Between T2-T3, 67 (66%) children scored 5 or less items unstable and 34 (34%) children scored more than 5 items unstable. Only 8 children scored more than 5 items unstable at both time periods (T1-T2 and T2-T3). Fewer children (9 compared to 24) between T2-T3 compared to T1-T2 had no items scored unstable. The degree of instability is greater between T2-T3 with a higher proportion of children (34% compared to 19%) in the ‘more unstable’ (over 5 items) category compared to between T1-T2. The results of non-parametric tests (Table 3-3) revealed children had significantly more scoring instability between T2-T3 compared to T1-T2 (T = -3.48, p<.001).

The frequency distribution of children’s scoring instability grouped by GMFCS level and age is presented in Table 3-4 and the results of the non-parametric tests are in Table 3-3. Children with GMFCS level I-III had significantly more scoring instability between T2-T3 (U=1224, p=.020). Age only impacted instability between T1-T2, with significantly more scoring instability in older children (U= 1106, p=.004).

The frequency distribution of child instability by domains is presented in Table 3-5 and the results of non-parametric tests in Table 3-3. There is no significant difference between the median scores of the self-care and mobility domains.

Item Instability

Table 3-6 provides the frequency distributions of the item instability. Between T1-T2, 119 (90%) items had 5 or less children scoring unstable and 13 (10%) items had more than 5 children scoring unstable. Between T2-T3, 110 (83%) items had 5 or less children scoring unstable and 22 (17%) items had more than 5 children scoring unstable. Similar to the child instability analyses, the results of non-parametric tests (Table 3-7) demonstrated items had significantly more instability between T2-T3 than T1-T2 (T = -3.46, p=.001). Table 3-8 presents the details of the 21 items (16%) with 10 or more children scoring unstable across both time periods (T1-T2 and T2-T3). Each domain has nearly equal number of items (10 items in self-care and 11 in mobility).

The distribution of item instability by domain is presented in Figure 3-1 for T1-T2 and Figure 3-2 for T2-T3. The non-parametric tests (Table 3-8) show there is no significant difference between the two domains.

DISCUSSION

The main objective of this study was to examine the instability in parents' scoring on individual items on the PEDI, specifically to look at the number of occurrences when a parent's score changed from a 1 to a 0 between adjacent assessments. This was evaluated first by examining individual child instability scoring patterns and then by examining individual items for the number of instances of unstable scoring. The effect of the two different time periods, functional domains, and child's age and severity of involvement on scoring instability was also examined.

Typically, stability of scores between time periods is examined using a measure of association, such as Pearson's correlation coefficient. Using this conventional approach, the PEDI total scaled scores obtained by parent report revealed strong significant relationships (r=0.96-0.98, p<.001) between adjacent assessment times, but examination of individual scoring patterns revealed many instances of scoring instability. This finding suggests that analyses at the individual child and item level provide different, more specific information than can be obtained with a measure of association between children's total scores.

Examination of parents' scoring from the perspective of both the individual child's scoring patterns and individual item scoring patterns suggest a modest degree of scoring instability. Most children (83% in T1-T2 and 66% in T2-T3) had 5 or less instances of item scoring instability. Children exhibiting unstable scoring patterns were not the same over the two adjacent assessment periods with only 8 out of a possible 103 children (8%) having more than 5 items unstable in both time periods. Item analysis also demonstrates the presence of instability. A broad distribution of items (90% in T1-T2 and 83% in T2-T3) had 5 or less children with unstable scoring. Only 21 out of 132 items (16%) had 10 or more children scoring unstable over both adjacent assessment periods. Just as specific children could not be identified with consistent instability patterns, no one item was consistently scored unstable. Both child and item analyses revealed significant differences when comparing the two time periods with T2-T3 scores demonstrating more child scoring instability and item scoring instability. The influence of child's age and severity of motor limitations on parental scoring instability were not consistent across time periods. Children with less severe motor limitations had more instability compared to the group with more severe limitations in T2-T3 and older children had more instability compared to younger children in T1-T2.

To determine the implications of the instability two questions are posed: What amount of scoring instability is expected, and is the amount observed clinically worrisome? Based on the hierarchical organization of PEDI items, both developmentally and statistically, and assuming that the majority of young children with cerebral palsy do not typically lose motor abilities, theoretically item instability is not expected. However, all measurement is subject to some degree of error or 'wobble'. The instability observed appears random rather than systematic as it is not always the same parents' scores or the same items associated with the unstable scoring patterns. Although the degree of instability revealed in these analyses is not high, it is important to speculate on some possible reasons for the instability in order to minimize its effect. Some explanations that are considered in this section are the scoring reference used by parents, the wording of items, and environmental context of items. Suggestions for therapists' consideration to support consistent parent scoring on the PEDI FSS are discussed.

The scoring reference used by parents to describe their child's function may have influenced scoring instability. Parents need to know if they score PEDI items in reference to their child's 'usual' performance or 'best' performance. PEDI FSS instructions to parents are to score their child 'capable' if: i) he or she can perform the skill in most situations, or ii) their child has previously mastered the skill or chooses not to do the skill but the parents know that they can do it. The ability to complete a skill in 'most situations' may align more closely with 'usual' performance,[16] but the instruction to score their child 'capable' if he or she can do the skill but chooses not to or has progressed beyond the skill may suggest 'best' performance. Parents' interpretation of the scoring reference (usual performance or best performance) may result in a change from 'capable' to 'unable' if a parent used 'best' reference to answer an item and then changed to 'usual' at the next assessment.

The PEDI manual states the FSS measures 'capability' which is described as the child's best performance, although this is not stated explicitly in the scoring instructions. Ostensjo et al.[16] suggested that clarification on the PEDI is needed between the scoring construct 'capability' and the scoring instructions. The effect of scoring instructions on the construct that is ultimately captured is demonstrated by investigations into self-report measures.[17] Responses are different between questions asking whether a person can do an activity or if they actually did an activity.[18-20] Asking "could you" do an activity resulted in higher ratings of ability than asking about actual performance for children and adults,[18-20] suggesting different constructs of function are being measured. Clarity in the construct being measured and the specific instructions may improve consistency in parent scoring.

Clinically, it is important for therapists to know that they need to provide guidance to parents about the scoring reference to use when scoring their child on PEDI FSS items. Considering that the concept of ‘capability’ suggests ‘best’ performance, therapists should encourage parents to consider what their child ‘could do’ for each item rather than what their child ‘usually’ does. This suggestion could reduce the instances of item instability. Specific items identified as more susceptible to unstable scoring (over 10 instances of unstable scoring between both time periods) were evaluated closely to identify some common characteristics that may have contributed to the unstable scoring.

Items that describe two or more abilities together may be challenging for parents to score consistently if their child only does one of the skills described. For example, the items “washes and dries face thoroughly” (SC#38) and “up and down curbs” (M#49) had higher frequencies of unstable parent scores. Parents may have even more difficulty when several parts are imbedded within an item such as “moves indoors 50 feet; opens and closes inside and outside doors” (M#32). Several skills are highlighted in this one item including the ability to move indoors 50 feet, opening indoor doors, closing indoor doors, opening outdoor doors and closing outdoor doors. In the original study, parents received specific instructions to score questions with two parts as ‘capable’ only if their child could complete both parts, but it appears that this type of item may still have been difficult to score. These are items that therapists need to specifically discuss the scoring instructions with parents at each assessment.

Subjective wording may contribute to parent report scoring instability. Several PEDI FSS items are described with the adverb “thoroughly” such as, “thoroughly brushes teeth” (SC #18) and “washes body thoroughly, not including face” (SC# 35). Parents may interpret the quality or thoroughness of these tasks differently at different assessment times. Descriptive adverbs require a reference system that may be influenced by parents’ expectations and value judgments. For example, parents may change their score to ‘unable’ if they expect more from their child because he or she is older than the previous assessment or if their child has not shown improvement on the described skill between two evaluations. Therapists need to encourage parents to try to retain the same value for subjective words such as ‘thoroughly’ and ‘securely’ across adjacent scoring times.

Certain functional areas may be more prone to scoring instability, because many of the items identified as more susceptible to unstable scoring were from the same content areas. Nine of the 21 items were from five content areas (“washing body and face”, “fasteners”, “pants”, “indoor locomotion/distance/ speed” and “indoor locomotion-pulls/carries objects”) previously reported to have poorer parent test-retest reliability.[8] Therapists need to pay particular attention to these five content areas when providing scoring instructions to parents. The 12 other items came from areas with acceptable parent test-retest reliability. There were three items from outdoor mobility and one item each from other content areas.

Environmental context of the activity may influence scoring instability over time, as indicated by the following outdoor mobility items: “Moves 100-150 feet (35-50 yards)” (M #42); “Moves 150 feet or longer, but with difficulty (stumbles, slow for age)” (M#43); “Moves 150 feet and longer with no difficulty” (M#44); and “Up and down curbs” (M#49). Parents may change their score and report that their child is ‘unable’ to do an item if they no longer see their child perform the skill or the child has lost the ability in a new weather environment. For example, if the first assessment was completed in the summer, a child may be able to walk outdoors for 150 feet. For the next assessment, 6 months later in the winter, the child may no longer be able to walk outdoors due to increased balance challenges. It may also be that parents no longer see their child perform a skill with a change in seasons even though the child is still capable of the item. For instance, a parent may not observe their child going up and down curbs during the winter because they no longer walk outside and have the opportunity to manage curbs. Lastly, over time children may decide to change their mode of mobility for longer distances, for example using a wheelchair instead of walking so that they are able to meet social expectations. Parents may interpret this as no longer being able to complete the skill the same way and change their scoring to ‘unable’.

The impact of the environment on function has been described previously.[21-24] Children with cerebral palsy used different methods of mobility in their home, school, and outdoor or community. In the outdoors or community environment children used mobility methods requiring the least amount of gross motor control[21] and required more adult assistance compared to the home and school setting.[24] For PEDI items that may be affected by environmental context, therapists need to remind parents if their child was able to do the skill previously (in a different season or using a different mobility method) they can score their child ‘capable’.

The item challenges discussed highlight the importance of therapists providing clear instructions to parents at each assessment, especially when evaluating change over time. The instructions need to be consistent across evaluations and among therapists. It might be worthwhile for therapy departments or institutions to have a common set of instructions to review with parents before they complete the items by parent report. The scoring instabilities identified also confirm the importance of therapists checking parents’ scores after completion of the PEDI FSS independently to determine if the scoring pattern is developmentally appropriate. If there are instances when more developmentally advanced skills are receiving a score of ‘1’ and less challenging skills are receiving a score of ‘0’, therapists need to be confident that parents understood the scoring guidelines and help parents rescore any items that may be scored incorrectly upon review with the scoring criteria. Assessors in the study did not have access to the previous scoring, but this check of developmentally appropriate patterns performed at consecutive assessments may minimize the number of items with unstable scoring.

In addition to the potential scoring difficulties already discussed, therapists may also improve the accuracy of parent report by discussing the remainder of the items susceptible to unstable scoring that did not appear to have any of the common characteristics discussed above: “Indicates when wet in diapers or training pants” (SC#64); “Sits unsupported by equipment or caregiver” (M#1); “Sits unsupported on chair or bench” (M#7); “Gets in and out of own bed, not needing arms” (M#19); and “Walks up entire flight of stairs with no difficulty” (M#54). The criteria for scoring the FSS from the manual could specifically be used for these particular items and the potentially problematic content areas described earlier. Although examiners are directed in the manual to use the criteria for the items that are scored “out of sequence,” they would not necessarily use it for these problematic items as the intent is not to review all items. Highlighting problematic items is very important so that the efficiency of completing the PEDI FSS as a questionnaire is not lost by having the examiner review all the items, essentially repeating the assessment.

Beyond item specific challenges, other factors may have influenced the instances of instability including the time period and characteristics of the child. The functional domain did not significantly affect parental scoring instability. The results differed from previous evaluation of the test-retest reliability of parents on the PEDI, which reported increased instability in the self-care domain compared to the mobility domain.[8] Evidence that parents are more accurate when reporting on motor function compared to cognitive, emotional, or social function[25-27] relate to the results of this research project because the area of motor function impacts both the PEDI FSS self-care and mobility domains. Parents may be more accurate when reporting on motor function because physical skills are concrete and easier to observe.[25-27]

The T2-T3 time period had more instances of scoring instability. The phase of the study may be a factor; during T1-T2 children received the treatment protocol which for many children was more frequent than their regular therapy and during T2-T3 they reverted to regular therapy. Parents may have expected their children to decline in skill level between T2-T3 because their child’s therapy decreased in frequency. Differences in the actual amount of time, 6 versus 3 months, would likely not have decreased the parents scoring between T2-T3 since stability of test results are typically better over shorter periods compared to longer.[28] This is also demonstrated in the PEDI with greater test-retest reliability over a one week period compared to a three week period.[8,9] It may also be possible that children have actually decreased in function with the change in therapy. Due to the exploratory nature of this research, conclusions regarding the cause of instability are limited as it is not possible to know if a child actually lost a skill.

Children’s age may have influenced parental scoring instability on the PEDI. The impact of age on the accuracy of parent report has been consistent in the literature with parents of children 2 years old and younger rating their children higher than professionals when compared to older groups of young children.[29,30] In contrast, our analysis revealed that older children had more instability in parent scoring compared to the younger children in the T1-T2 period. Children in the older group may have had more instances of unstable scoring because younger children may have fewer items scored as ‘capable’ on their baseline assessments (T1) and thus less items to decrease scoring at T2. At T2, children in the younger group may have scored ‘capable’ more often, increasing the probability of having a similar frequency of unstable scoring between T2-T3 as the older children.

Similar to age, the impact of severity of motor limitations on parental scoring instability was only found in one time period. Children with GMFCS level I-III had significantly more instability between T2-T3 compared to children with GMFCS level IV-V. In previous parent report literature, effect of severity of disability was equivocal with children with more or less severity related to better parental accuracy, although the method of classifying severity was not consistent across studies.[25,31,32] Using GMFCS level to classify severity of motor limitations, Morris et al.[33] found that parents of children with less limitations were less congruent with professionals tending to classify their children’s motor abilities lower than professionals. Similarly, the results of these secondary analyses demonstrated children with less severe motor limitations had less consistency with parental scoring. The skills of children with more severe impairments may change less making it easier for parents to score consistently. Therefore, these parents may not be as affected by the scoring issues previously discussed as children with less severe limitations.

Limitations

The results of this study can only be interpreted with the implementation of the PEDI in the identical manner to the original study. Although the implementation closely resembled the PEDI manual’s instructions, it is not known if parents read the instructions for scoring items at each assessment. It is difficult to determine if the decrease in scoring is due to parental interpretation of the

PEDI items or due to parents not reading the instructions. It is also not known if the assessors checked the questionnaire for items scored in a developmentally appropriate pattern across all assessments which may have reduced the amount of scoring instability. Another potential limitation is that we do not know if the same parent completed the assessment at each assessment time. Even though assessors were advised in the training session to confirm the same parent filled out the questionnaire, this was not tracked systematically. Conclusions could relate to different parents rating their children over time instead of the consistency of one parent reporter over time. The applicability of this study is limited to parents of young children with cerebral palsy.

CONCLUSIONS

The results of the study suggest that instability of items is present, but its magnitude is low. There appears to be no systematic instability, but some items are more problematic than others. Clinically, these results are relevant to pediatric therapists using parent report on the PEDI for functional change over time for young children with cerebral palsy. Because the PEDI FSS by parent report is a popular tool for this population, the results of this study have many clinical and research applications. The stability of parent report for individual items on the PEDI was not previously investigated and overall the results support the use of parent report on the PEDI FSS as a questionnaire. Evaluating PEDI FSS items scored by therapists in the same manner would be interesting as it would give a general sense of the difference in scoring instability between parents and therapists. It would be difficult to compare directly to this study with data from a clinical trial as many factors would likely not be duplicated, so a prospective study comparing the child's actual change in function over time as recorded by a therapist to parent reported change in functional skills would be valuable.

Table 3-1. Descriptives of the Children in the Item Analysis of the PEDI

Characteristics		**Children from T1-T2 (N=113)**	**Children from T2-T3 (N=101)**
Male, n (%)		70 (62)	65 (64)
Age at baseline assessment			
	mean (SD), y	3.61 (1.42)	3.58 (1.39)
	range, y, mo	9m - 6y 5m	1y 1m – 6y 2m
Age groups, n (%)			
	< 3y 6mo	55 (49)	51 (51)
	≥3y 6mo	58 (51)	50 (49)
GMFCS level groups, n (%)			
	I-III	71 (63)	64 (63)
	IV-V	42 (37)	37 (37)

Abbreviations: PEDI, Pediatric Evaluation of Disability Inventory; T1-T2, time period between baseline and six months of intervention; T2-T3, time period between six months of intervention and 3 months after intervention; N, sample size; n, number; SD, standard deviation; y, year; mo, month; GMFCS, Gross Motor Function Classification System

Table 3-2. Overview of Child Instability on Items from the PEDI (132 items)

Total Child Instability (number of items scored unstable per child)	Number of Children, n (%)	
	T1-T2 (N=113)	**T2-T3 (N=101)**
0	24 (21)	9 (8)
1	14 (12)	15 (15)
2	23 (20)	6 (6)
3	16 (14)	16 (16)
4	10 (9)	13 (13)
5	7 (6)	8 (8)
6	7 (6)	8 (8)
7	2 (2)	10 (10)
8	5 (5)	5 (5)
9	1 (1)	3 (3)
10	1 (1)	3 (3)
11	2 (2)	4 (4)
16	0	1 (1)
18	1 (1)	0

Abbreviations: explained in footnotes to Table 3-1.

Table 3-3. Number of PEDI Items (132 items) Scored Unstable per Child by Time Periods, Child Factors, and Domains (self-care 73 items; mobility 59 items)

		Median (IQR) in number of items	
		T1-T2	**T2-T3**
Total children		2 (3)	4 (5)
P value[a]		<.001[d]	
GMFCS level groups			
	I-III	3 (4)	4.5 (4)
	IV-V	2 (3.25)	3 (4)
P value[b]		.108	.020[d]
Age group			
	< 3y 6mo	2 (3)	4 (4)
	≥3y 6mo	3 (3.25)	4 (6)
P value[b]		.004[d]	.566
Total children by domain			
	Self-Care	1 (2)	2 (2)
	Mobility	1 (2)	2 (3)
P value[a]		.085	.380

Abbreviations: IQR, interquartile range; other abbreviations explained in footnotes to Table 3-1.

[a] Wilcoxon signed rank test

[b] Mann Whitney U test

[d] Statistically significant difference, alpha ≤ .05, using non-parametric test

Table 3-4. Overview of Child Instability on items from the PEDI (132 items) by GMFCS level and Age

Total Child Instability (number of items scored unstable per child)	**Number of Children, n (%)**			
	T1-T2		**T2-T3**	
	GMFCS Level I-III (N=71)	**GMFCS Level IV-V (N=42)**	**GMFCS Level I-III (N=64)**	**GMFCS Level IV-V (N=37)**
0	13 (18)	11 (26)	5 (8)	4 (11)
1 to 5	42 (60)	28 (67)	33 (42)	25 (68)
5 to18	16 (22)	3 (7)	26 (41)	8 (21)
	Age <3y 6mo (N=55)	**Age ≥3y 6mo (N=58)**	**Age <3y 6mo (N=51)**	**Age ≥3y 6mo (N=50)**
0	16 (29)	8 (14)	3 (6)	6 (12)
1 to 5	34 (62)	32 (62)	30 (59)	28 (56)
5 to 18	5 (9)	14 (24)	26 (35)	16 (32)

Abbreviations: Explained in footnotes to Table 3-1

Table 3-5. Child Instability for Self Care (73 items) and Mobility (59 Items)

Total Child Instability (number of items scored unstable per child)	Number of Children, n (%)	
	Self- Care	Mobility
	T1-T2 (N=113)	
0	30 (27)	52 (46)
1 to 5	79 (69)	55 (49)
5 to 18	4 (4)	6 (5)
	T2-T3 (N=101)	
0	20 (20)	30 (30)
1 to 5	73 (72)	63 (62)
5 to 18	8 (8)	8 (8)

Abbreviations: Explained in footnotes to Table 3-1

Table 3-6. Overview of PEDI Item Instability

Total Item Instability (number of children scored unstable per item)	Number of Items (N=132), n (%)	
	T1-T2	**T2-T3**
0	14 (11)	12 (9)
1	31 (23)	14 (11)
2	31 (23)	27 (20)
3	22 (17)	27 (20)
4	17 (13)	14 (11)
5	4 (3)	16 (12)
6	5 (4)	9 (7)
7	4 (3)	7 (5)
8	3 (2)	3 (2)
9	1 (1)	1 (1)
10	0	1 (1)
11	0	1 (1)

Abbreviations: Explained in footnotes to Table 3-1

Table 3-7. Number of Children Scored Unstable per Item by Time Periods and Domains

		Median (IQR) in number of children	
		T1-T2 (N=113)	**T2-T3 (N=101)**
Total items		2 (3)	3 (3)
P value[a]		.001[d]	
Items by domain			
	Self-Care	2 (2)	3 (3)
	Mobility	2 (3)	3 (3)
P value[b]		.832	.368

Abbreviations: Explained in footnotes to Table 3-1 and 3-3

[a] Wilcoxon signed rank test

[b] Mann-Whitney U test

[d] Statistically significant difference, alpha ≤ .05, using non-parametric test

Table 3-8. Details of Individual Item instability [a]

Domain	Item Description	Item Instability (number of children with unstable scoring)		
		T1-T2	T2-T3	Total
Self Care	SC 13 Lifts open cup securely with one hand	4	8	12
	SC 18 Thoroughly brushes teeth	6	5	11
	SC 22 Brushes and combs hair	3	8	11
	SC 35 Washes body thoroughly, not including face	8	7	15
	SC 36 Obtains soap (and soaps washcloth if used)	7	5	12
	SC 38 Washes and dries face thoroughly	4	7	11
	SC 45 Zips and unzips, doesn't separate or hook zipper	7	3	10
	SC 46 Snaps and unsnaps	5	5	10
	SC 52 Removes pants, including fasteners	9	2	11
	SC 64 Indicates when wet in diapers or training pants	4	7	11
Mobility	M 1 Sits if supported by equipment or caregiver	8	2	10
	M 7 Sits unsupported on chair or bench	8	6	14
	M 19 Gets in and out of own bed, not needing arms	2	8	10
	M 32 Moves indoors 50 feet; opens and closes inside and outside doors	5	7	12
	M 35 Carries objects small enough to be held in one hand	4	6	10
	M 36 Carries objects large enough to require two hands	3	9	12
	M 42 Moves 100-150 feet (35-50 yards)	7	5	12
	M 43 Moves 150 feet or longer, but with difficulty (stumbles, slow for age)	6	6	12
	M 44 Moves 150 feet and longer with no difficulty	2	11	13
	M 49 Up and down curbs	4	10	14
	M 54 Walks up entire flight with no difficulty	7	5	12

Abbreviations: SC, self care; M, Mobility; other abbreviations explained in footnotes to Table 3-1

[a] 16% of items are showing total instability of more than 10 children with unstable scoring across the two time periods

Figure 3-1. Item Instability for Domains between T1-T2

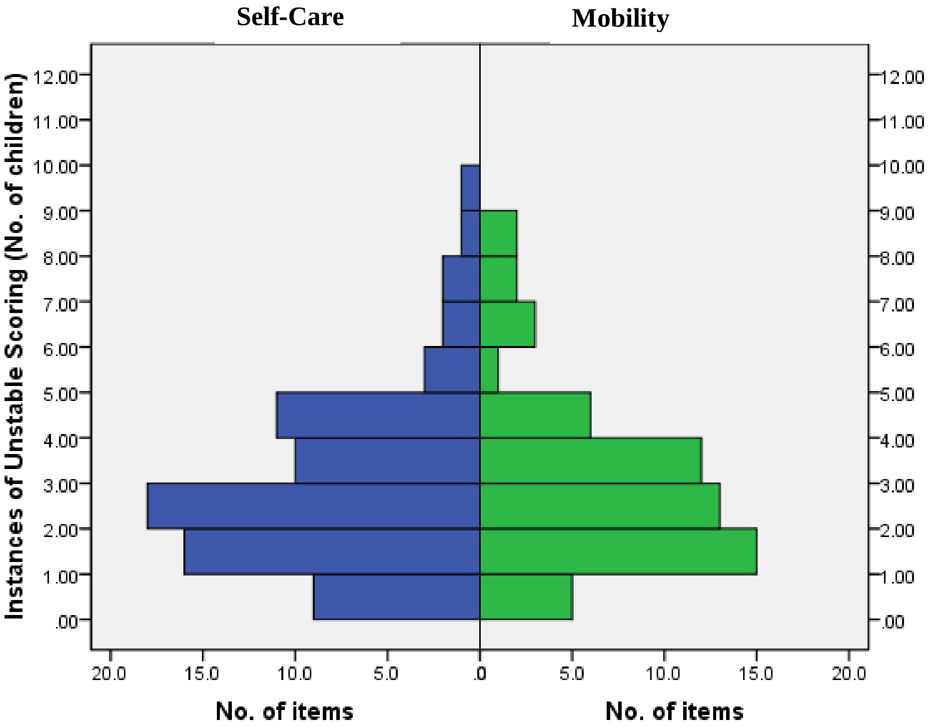
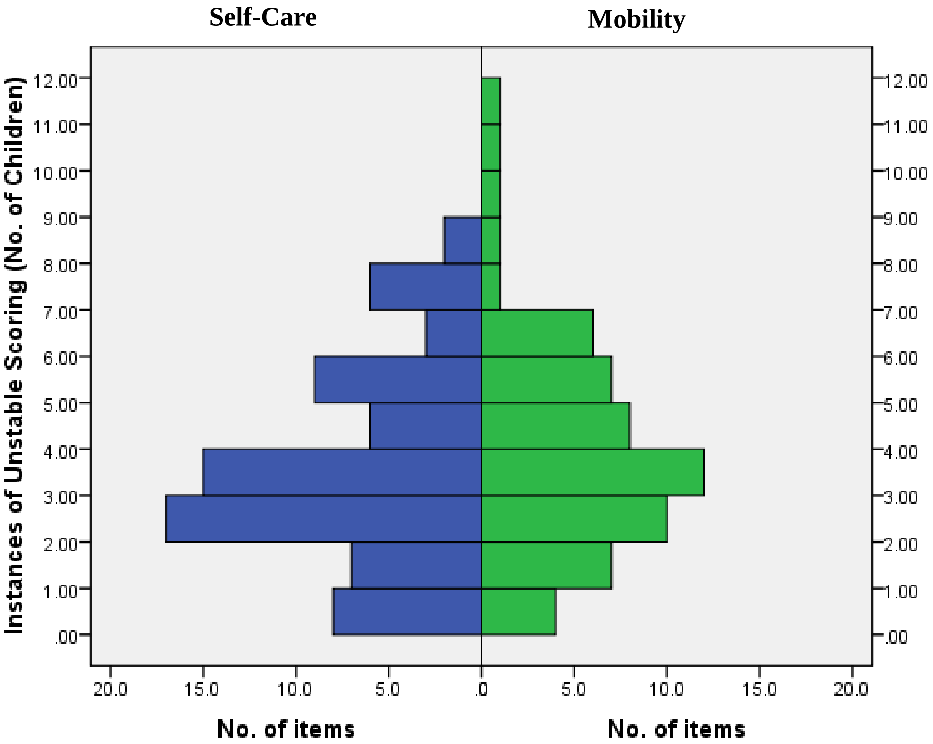


Figure 3-2. Item Instability for Domains between T2-T3



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Chapter 4: Conclusion

SUMMARY OF RESULTS

Parent report of functional skills appears to be a valid and useful tool for pediatric rehabilitation, but further verification of the validity of parent report is needed. Previous literature on parent report is predominately for the purposes of identification and investigation of overall relationships between summary test scores.[1,2] This item analysis provided a greater understanding of the use of parent report for the evaluation of functional skills. Evaluating summary test scores over time did not demonstrate the changes in scoring found in the evaluation of individual functional skills. Parameters were identified that can improve the use of parent report on the PEDI FSS in a clinical and research setting. The use of parent report on other outcome measures or in the development of new measures may also be strengthened from these findings. Many challenges in the current literature were highlighted especially the limitation in the number of parent report measures of functional skills and in the number of investigations into the use of parent report to evaluate a child's function. One of the major challenges is to determine the gold standard to compare parent report to when assessing its validity.[3,4]

CLINICAL IMPLICATIONS

Pediatric therapists can improve the accuracy of parent report by clearly providing a scoring reference, giving a time reference, defining the aspect of function being measured, and clarifying any potential confusion in the wording of questions. Parents may be more consistent in scoring over time if they are clearly asked to report on their child’s abilities (“can do”) or typical performance (“does do”), but it may be confusing for parents without reflecting on a specific time frame or knowing whether to consider the amount of assistance their child receives to complete a task. It can also be helpful to have specific guidelines on how to interpret subjective or multi-pronged questions. Overall, based on this item analysis, the use of the PEDI FSS by parent report is recommended for clinical use. Clinicians should consider using parent report as part of their practice for children receiving ongoing intervention.

DISSEMINATION OF RESULTS

Chapter 2 will be submitted to the Physical and Occupational Therapy in Pediatrics journal under the topic theory/perspectives. The results of the secondary analyses, Chapter 3, will be submitted to Pediatric Physical Therapy journal as a research report. The results of the study will shared in presentations for interested staff members from the Glenrose Rehabilitation Hospital and from the Preschool Rehabilitation Service. Poster presentations will be submitted to the 2013 meeting of the Academy of Cerebral Palsy and Developmental Medicine and the 2013 Canadian Association of Paediatric Health Centres Annual Conference.

IMPLICATIONS FOR FURTHER RESEARCH

Challenges in the current literature may be avoided by comparing parent report measures to the same measure using another form of administration and by using a method of analysis that demonstrates more than an association between measures. The major challenge of establishing the criterion method of administration for evaluating parent report may be addressed by new approaches such as comparing parent report to child report or to parent direct observation of child performance. It has been suggested that determining whether parents or professionals are more accurate is not possible because they simply represent different perspectives. Regardless, an important area for further research is examining the role of parent report in pediatric rehabilitation and the effects parent report has on family centered care in pediatric rehabilitation. It is also important to know how parent report over time relates to overall function in the future, as it would be clinically valuable if parent report of a child's function has predictive value. This could assist therapists with treatment planning and parental education.

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