DEVELOPMENT AND VALIDATION OF AN OBSERVATIONAL TOOL TO EVALUATE UPPER EXTREMITY FUNCTIONING OR HAND-OBJECT INTERACTION IN CHILDREN DIAGNOSED WITH BILATERAL CEREBRAL PALSY GMFCS III, IV, AND V

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ABSTRACT

DEVELOPMENT AND VALIDATION OF AN OBSERVATIONAL TOOL
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Cerebral palsy is the most common physical disability among children. Children diagnosed with bilateral cerebral palsy (BCP) have limited mobility and hand use due to a neurological insult in utero or during the first year of life, resulting in hypertonicity or uncontrolled movements which impede upon optimal performance and participation in daily life. Although occupational therapists evaluate and provide interventions throughout a child's development, only two validated assessment tools exist for children with BCP: Melbourne Assessment 2 and Both Hands Assessment, and ABILHAND-Kids questionnaire. The purpose of this study was to (a) develop an observational tool to evaluate upper extremity functioning in children with BCP during everyday tasks, and (b) determine the tool's content validity, preliminary inter-rater reliability, and internal consistency.

The Hand-object Observation Tool (HOOT) was developed, standardized, and evaluated for content validity via expert review and feedback regarding relevance for children with BCP. Following pilot administration to three children and content validation by expert clinicians (n = 8), the HOOT was administered to six children diagnosed with BCP, GMFCS III, IV, and V. Three licensed occupational therapists and the primary investigator observed and scored video-recordings of the administration. Cohen's kappa was used to determine inter-rater reliability among three pairs of clinician raters and the gold standard. Internal consistency of items was analyzed using Cronbach's alpha coefficient.

The content of the HOOT is consistent with expert opinions and the Content Validity Index results met criteria for retaining items. This study further suggests that HOOT scores are reliable indicators of upper extremity functioning in children with BCP. Rater agreement between occupational therapy raters and the gold standard was almost perfect when scoring hand-object interaction (touch, grasp, transport, manipulate, place, and release). Rater agreement was substantial to almost perfect for hand use and poor to almost perfect for maintenance of posture during tasks. Further research is required to (a) gather additional data from trained clinicians administering the HOOT in community-based settings to more than 30 children with BCP, and (b) analyze scores and performance to determine internal consistency of HOOT items and complete tool refinement and dissemination.

DEDICATION

I dedicate this dissertation to my family

for their endless love, encouragement, guidance, and support.

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This work would not have been possible without the children, families and clinicians who participated in this study. I am grateful for their eagerness to spend time on this project and enthusiasm to support this research.

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TABLE OF CONTENTS

I—INTRODUCTION 1
Background 1
Research Problem 2
Research Purpose 3
Research Questions 4
Significance of Research 4

II—REVIEW OF THE LITERATURE 6
Motor Abilities and Functioning in Children and Youth With Cerebral Palsy 6
Upper Extremity Abilities in Children With and Without Cerebral Palsy 7
Existing Measures of Upper Extremity Functioning in Children 10
Assessment Design and Validation Methodology 13

III—THEORETICAL FRAMEWORK 19
Dynamical Systems Theory 19
Perception Action Framework 21
Frameworks Guiding Occupational Therapy for Children and Youth 23
Summary 24

IV—METHODS 26
Research Design 26
Instrument Development, Standardization Process, and Reliability Evaluation 26
Participants and Recruitment 29
Inclusion Criteria 30
Exclusion Criteria 30
Administration and Scoring Procedures 31
Assessment Administration and Video-recording 31
Scoring 33
Expert Consensus and Qualitative Feedback 34
Ethical Assurances 35
Data Analysis 35
Content Validity of the HOOT 35
Reliability Evaluation 36

V—RESULTS 38
Content Validity of the HOOT 38
Participant Characteristics 38
Content Validation Quantitative and Qualitative Results 39
Reliability Evaluation 40
Participant Characteristics 40
Inter-rater Reliability of Item and Task Scores 47
Internal Consistency 50

VI—DISCUSSION 51
Instrument Development and Standardization 51
Content Validity and Reliability of Assessment Scores 52
Upper Extremity Functioning in Children With BCP 54
Evaluation of Functioning in Natural Contexts 56
Limitations 56
Directions for Future Research 57
Conclusion 58

REFERENCES 59

APPENDICES
Appendix A Item Specification Table 66
Appendix B HOOT Manual 68
Appendix C HOOT Forms 81
Appendix D Pilot Study 90
Appendix E Informed Consent and Assent 106
Appendix F Activity Images 117

LIST OF TABLES

Table

1 Characteristics of Participants Diagnosed With Bilateral Cerebral Palsy 41

2 HOOT Administration Details 42

3 Task Completion Time of Each Participant 44

4 Characteristics of Licensed Occupational Therapy Participants 46

5 Distribution of Kappa Coefficient for the Item Scores 48

6 Distribution of Kappa Coefficient Scores for Task Scores 48

7 Distribution of Kappa Coefficient for the Hand-use Scores 49

8 Distribution of Kappa Coefficient for the Posture Scores 49

LIST OF FIGURES

Figure

1 HOOT validation process model 27

2 Upper extremity functioning of subjects at GMFCS Levels III, IV, and V......... 45

3 Upper extremity functioning of subjects at MACS Levels II, III, and V 45

I-INTRODUCTION

This dissertation is a report of a sequential mixed-method instrument design and validation study. A performance-based assessment tool for clinicians that measures upper extremity functioning levels and hand-object interaction abilities of children and youth with bilateral cerebral palsy (BCP), more specifically Gross Motor Function Classification (GMFCS) Levels III, IV, and V was developed, standardized, and evaluated for reliability. This study was carried out with children and youth diagnosed with BCP, in natural settings including an urban recreation center, an apartment, and private homes. The assessment tool was administered to the child or youth, evaluated for content validity by expert clinicians and scored by licensed occupational therapists.

Background

Cerebral palsy is a group of disorders that affect movement and posture and are the result of a non-progressive insult to the developing brain (Novak, 2014; Rosenbaum & Rosenbloom, 2012). Cerebral palsy is the most common physical disability in children. One in 2,000 newborns are diagnosed with cerebral palsy annually and the most common risk factor for cerebral palsy is encephalopathy of prematurity (EOP). This is followed by intrauterine asphyxia and/or infection (Stavsky et al., 2017). Cerebral palsy is characterized by subtype including spastic, ataxic (hypotonic ataxic or mixed), or dyskinetic (dyskinesia or athetosis), and by topography (hemiplegia, diplegia, triplegia, and tetraplegia) (Novak, 2014). Motor and sensory impairments result in difficulty with voluntary and controlled movements, balance, coordination, mobility, and hand use.

Although the motor and sensory impairments of cerebral palsy impede upon capacity and performance, the presence of comorbidities have a greater impact on function and daily life. Comorbidities include communication impairment, cortical vision impairment, dysphagia, hearing loss, seizure disorder, and intellectual disability (Stavsky et al., 2017).

Research Problem

Research on responsiveness of hand functioning measures for children and adolescents with cerebral palsy is limited (Steenbeck, Gorter, Keteelar, Galama, & Lindemn, 2011). Elvrum et al. (2016) conducted a systematic review of outcome measures of hand function in children with BCP. The authors concluded that there are only two assessments, the Melbourne Assessment-2 (MA2) (Randall, Carlin, Chondros, & Reddihough, 2001) and the ABILHAND-Kids scale (Arnould, Penta, Renders, & Thonnard, 2004; Université Catholique de Louvain, 2007), that are reliable and validated for use with children with BCP. The feasibility and clinical utility of the MA2 is limited because it requires specialized training and certification to administer, score, and interpret and financial resources to purchase. The MA2 is a criterion-referenced assessment of unilateral upper extremity movement qualities in children with congenital or acquired brain injuries, 2.5-15 years of age. The ABILHAND-Kids is a parent questionnaire that assesses level of difficulty with functional tasks as perceived by the parents of children 5-16 years of age. Although this questionnaire is available online and feasible for use in clinical practice when interviewing parents, it does not provide objective measurements of upper extremity performance or capacity in children. The Both Hands Assessment (BoHA) was recently developed, through adaptation of the AHA, to measure bimanual hand performance and asymmetrical hand use in children, 22 months to 13 years of age, with BCP (Elvrum, Zethraeus, Vik, & Krumlinde-Sundholm, 2018). Although the assessment showed internal construct validity for measuring bimanual performance in children with BCP, this study was limited to children at MACS levels I-III. Additionally, this assessment requires specialized training and certification to administer, score, and interpret and financial resources to purchase.

Therefore, the development of an assessment of upper extremity functioning or hand-object interaction with daily objects, sensitive to changes in a developing child with a movement disorder, is needed to gain an understanding of overall upper extremity functioning and to provide a valid and reliable outcome measure for studying the effectiveness of therapeutic interventions with children with BCP (Eliasson et al., 2013; Elvrum et al., 2106).

Research Purpose

The purpose of this study was to conceptualize a theory supported and evidence-based domain framework on upper extremity movement and functioning of the targeted client population and to design and validate an observational tool with standardized procedures to measure upper extremity functioning in children and adolescents with BCP, GMFCS III, IV, and V, aged 5-17 years. The long-term goal of this research is to provide clinicians with a tool that can systematically evaluate and reevaluate upper extremity functioning in children with BCP and guide clinical decisions and interventions systematically to facilitate improvement in hand-object interaction and upper extremity functioning for this population.

Research Questions

An examination of the extent to which the data produced by the Hand-Object Observation Tool (HOOT) provides valid and reliable information to support inferences and actions with BCP populations in therapeutic contexts was needed; therefore, the research questions guiding this study were:

1. To what extent are the domains, subdomains, and indicators of the HOOT consistent with the theoretical literature on the condition and expert opinions of levels of upper extremity functioning in children with BCP?
2. What is the level of agreement among raters in comparison to the "gold standard" examiner or primary investigator?
3. Do the assessment scores produced by inter-raters remain consistent irrespective of the rater and do the items consistently measure the same construct, upper extremity functioning in children with BCP, GMFCS III, IV, and V?

Significance of Research

Occupational therapy evaluation of children with CP, GMFCS III-V, typically includes caregiver interview, observations in natural and clinical environments, and evaluation of body functions and performance in daily occupations (Eliasson et al., 2013; Elvrum et al., 2016; Novak, 2014). There is a paucity of information in the literature on evaluation methodology and the use of the validated and reliable assessments including the MA2, BoHA, and ABILHAND-Kids in clinical practice. Additionally, there are limited assessments available to evaluate children with complex conditions or severe motor impairments and established measures currently being administered by clinicians were not developed for children with CP and have limited psychometrics (Elvrum et al., 2016).

II-REVIEW OF THE LITERATURE

This literature review addresses the topics of motor abilities and functioning in children and youth with cerebral palsy (CP), upper extremity abilities in children and youth with and without cerebral palsy; existing measures of upper extremity functioning; and assessment design and validation methodology.

Motor Abilities and Functioning in Children and Youth With Cerebral Palsy

There are four classifications of function which are utilized to better understand the abilities and functioning of children and youth with CP in their daily lives: the expanded and revised Gross Motor Classification System (GMFCS-E&R) (Palisano, Rosenbaum, Bartlett, & Livingston, 2008); the Manual Ability Classification System (MACS) (Eliasson et al., 2006); a communication function classification system of CFCS (Hidecker et al., 2011); and the Eating and Drinking Ability Classification System (EDACS) (Sellers, Mandy, Pennington, Hankins, & Morris, 2014). The most widely used classification is the GMFCS, which was developed by clinicians and physicians with expertise working with children with cerebral palsy. The GMFCS is a five-level classification system based on the child's walking, sitting, and transferring performance in daily life: Level I—walks without assistance; Level II—walks with assistance; Level III—walks with ambulatory device; Level IV—self-propels in a wheelchair; and Level V—is dependent for mobility in a wheelchair. This classification system is utilized throughout the literature and clinical practice to provide a universal method of identifying gross motor function in children with CP.

The MACS is a classification system utilized to identify a child's ability to handle objects in everyday life: Level I—handles objects without difficulty; Level II—handles objects with limited speed and accuracy; Level III—handles objects with adaptations or modifications; Level IV—handles objects with support; and Level V—requires complete assistance to handle objects. The MACS is a valid and reliable tool for classifying hand function in children with CP (Elvrum, Sæther, Riphagen, & Vik, 2016).

The CFCS and EDACS are valid and reliable methods for classifying communication and eating and drinking performance in individuals with cerebral palsy (Hidecker et al., 2011; Sellers et al., 2014). The five levels of the CFCS and EDACS were developed to reflect the GMFCS Levels. These classifications systems are appropriate clinical tools that provide uniform terminology and reference to guide evaluation, treatment planning, parent discussion, and equipment recommendations and order. For example, children diagnosed with CP, GMFCS III-V, require mobility devices, adaptive equipment, varied levels of physical assistance and environmental modifications to communicate; they also navigate the environment, perform self-care tasks, and participate in daily occupations.

Upper Extremity Abilities in Children With and Without Cerebral Palsy

Children with CP MACS III-V require support or varied levels of assistance to handle functional items (Eliasson et al., 2006). Combining information gathered from the literature on kinematic analysis of reach and grasp with observed functional abilities provides profiles of upper extremity capacity and performance in children with cerebral palsy (Butler et al., 2010a). Additionally, children with CP GMFCS III-V are positioned in wheelchairs or positioning devices (classroom chairs, beds, standers) throughout the day; therefore, prehension abilities are often dependent on passive positioning and assistance of others.

The quality and accuracy of hand use develops in childhood as children engage in meaningful activities for self-care, play, social interactions, and schoolwork. Schneiberg, Sveistrup, Mcfadyen, Mckinley, and Levin (2002) studied the reach and grasp patterns of children ages 3-12. They studied 37 children, ages 3-12, and 9 adults. The children were grouped according to age (3-4, 5-6, 7-8, 9-10, and 11-12 years old) to better understand how age-related reach and grasp patterns develop. Standardized seating position was established at a table. A wooden block was presented at three distances from midline. The block was used to simulate a drinking activity. The participant was instructed to reach, pick up the block, and bring it to the mouth (pretending to drink). A 3D motion capture system was used to measure speed, index of curvature, and smoothness (movement units). Results indicated that younger children require more time and have greater index of curvature and decreased trajectory smoothness (more movement units) than older children and adults. Therefore, inter-joint coordination and speed of movement increase with age. Schneiberg et al. (2002) repeated the aforementioned study with typically developing children (TDC) and children with CP (MACS I-IV). Results indicated that children with CP utilize compensatory movements at the trunk and shoulder and have decreased elbow excursion in comparison to TDC. Additionally, children with CP require more time and have greater index of curvature indicative of a less efficient motor pattern.

When compared to typically developing peers, children with CP utilize different movement patterns that require more body segments and may be inefficient to engage in a task. Butler et al. (2010a) developed the Reach & Grasp Cycle to objectively quantify upper limb motion in children via three-dimensional motion analysis. In the initial study, the authors assessed utility of this approach by comparing the Reach & Grasp Cycle results of typically developing children (TDC) with children with hemiplegic cerebral palsy (HCP). Results of this study demonstrated consistent movement patterns in typically developing children and significant differences in kinematic patterns between TDC and children with HCP. Therefore, they concluded that the quantitative analysis of motor difficulties during functional tasks can be quantitatively analyzed utilizing the Reach & Grasp Cycle. In a follow-up study by Butler, Ladd, LaMont, and Rose (2010b), temporal-spatial characteristics of TDC and children with CP were evaluated during the Reach & Grasp Cycle. Forty-two children participated in the study, 25 TDC and 12 children with HCP (mean ages 11.0 and 11.9, respectively). Participants were seated at a table and were instructed to complete a simulated drinking task by reaching and grasping a cylindrical cup, placed at 75% of maximum reaching distance, bringing it to the mouth and returning the cup to the start position. The Reach & Grasp Cycle phases were determined by the velocity of the light reflective marker located on the lateral wrist. Movement onset and offset were determined by velocity of the wrist marker and Spearman’s rank correlation coefficients were computed to determine: (a) the effect of age on movement speed, strategy, efficiency, and smoothness; and (b) the correlation between Manual Ability Classification System (MACS) score and duration of each phase and total time to complete the cycle. The index of curvature was used to determine efficiency of movement. The number of movement units in each phase was calculated to determine smoothness of motion. The results of the study indicated that children with

HCP demonstrated increased time to complete the Reach & Grasp Cycle, increased index of curvature during reach and return, and increased total number of movement units in comparison to TCD. Additionally, these results were strongly correlated with MACS scores. The authors concluded that the results supported the utility of the Reach & Grasp Cycle to measure differences in TDC and children with CP; therefore, this standardized protocol is recommended to measure upper limb function in children with and without CP.

Information gathered from objective measures of upper limb movement patterns provides critical information regarding the quality of upper limb movements in goal-directed tasks (Butler et al., 2010). In order to train or retrain reach and grasp patterns in children with neurologic pathology, clinicians must have knowledge regarding the development and measurement of upper limb coordination. Researchers in movement sciences and biomechanics provide evidence for the utilization of kinematic analysis to objectively measure temporal-spatial characteristics of upper limb motion. Research or analysis of movement in children is more complex and variable because children are developing and maturing at individual rates.

Existing Measures of Upper Extremity Functioning in Children

Therapists need to be able to evaluate hand use in children with CP as it is important for children’s function and participation in daily tasks. Evaluation protocols should be able to provide qualitative and quantitative characteristics of hand use. They should also be sensitive to changes in hand use and function to document effectiveness of intervention strategies and support the development of meaningful goals.

Elvrum et al. (2016) completed a systematic review of hand measures for children with bilateral CP. Eight assessments were identified; however, the Melbourne Upper Limb Assessment, 2nd edition (MA2; Randall et al., 2001) and the ABILHAND-Kids (Arnould et al., 2004) scale were the only assessments that were valid and reliable measures of bimanual hand function in children with bilateral cerebral palsy (BCP).

The ABILHAND-Kids is a parent questionnaire of hand use (including bimanual tasks) that assesses level of difficulty with functional tasks as perceived by the parents of children 5-16 years of age. Arnaud et al. (2004) developed the questionnaire based on existing scales of manual ability and expert advice. A Rash-measurement model was utilized to develop the tool. The development and validation process of the tool consisted of authors submitting the questionnaire to 113 children with cerebral palsy, GMFCS I-V, and their parents at an initial session and 1-month follow-up for test-retest reliability. Results indicated that the ABILHAND-Kids is a reliable measure of parent-reported manual ability in children with cerebral palsy (R = 0.94) and has good reproducibility over time (R = 0.91). According to de Jong, van Meeteren, Emmelot, Land, and Dijkstra (2018), the ABILHAND-Kids questionnaire is a reliable rating method of upper extremity capacity and performance in children with spastic cerebral palsy across observers. Although this questionnaire is available online and is feasible for use in clinical practice when interviewing parents, it does not provide objective measurements of upper extremity performance or capacity.

The MA2 is a performance-based assessment of upper extremity movement for children diagnosed with neurological conditions, ages 2.5-16 years of age. The quality of upper extremity movement is measured while children perform simulated functional tasks such as feeding and brushing hair. Movements required for each task include reach, grasp, manipulation, and object release. Each upper extremity is measured separately by scoring range of movement, accuracy, fluency, and level of grasp and release (Randall, Imms, & Carey, 2008). Randall et al. (2001) examined the reliability of the initial Melbourne Assessment of Unilateral Upper Limb Function by administering the assessment to 20 children, 5-16 years of age, diagnosed with various types and severity of cerebral palsy. Each administration was videotaped so that consequently 15 occupational therapists could score the performance. Scores were analyzed and results indicated that the assessment was a valid and reliable objective measure of the quality of unilateral upper extremity function in children with cerebral palsy. In 2014, Randall, Imms, Carey, and Pallant further tested the psychometrics of the Melbourne Assessment of Unilateral Upper Limb Function in order to investigate and refine the psychometric properties of the assessment using Rasch analysis. Results indicated that the test required modifications to improve unidimensionality. The revised version, the MA2, resulted from this study to include 14 tasks and 30 upper extremity movement scores. The MA2 was determined to be a valid and reliable measure of unilateral upper limb function in children with congenital or acquired neurological conditions (Randall et al., 2014); however, further testing of responsiveness of the MA2 was indicated. It is important to also recognize that the feasibility and clinical utility of the MA2 is limited because it requires specialized training and certification to administer, score, and interpret; moreover, extensive time is required to complete the assessment.

Assessment Design and Validation Methodology

Construct measures for therapeutic evaluation purposes are typically developed to measure performance, abilities, and response of patients/clients to particular interventions and to guide treatment planning (Wagner & Davids, 2012). Instrument development and validation efforts in such contexts require in-depth study of: the standard evaluation processes; research evidence on, and knowledge of, the population to be tested; an understanding of measurement and psychometrics; coursework or training in instrument development; and experience in the administration of the type of assessment being developed.

The initial step in the instrument development process is to identify the construct that is being measured (Chatterji, 2003). Once operationalized and measured, the construct is manifested along a continuum of ability. The construct can be operationalized by observing behaviors of the target population, or through review of the scientific literature on the disorder (here, a neurological disability), and by gathering information from the population that will be tested with the assessment.

Krumlinde-Sundholm and Eliasson (2003) identified the construct of assisting hand function in children with hemiplegic cerebral palsy (HCP) by observing subjects in different and specific conditions. At the time of development, there were no assessment tools that measured hand function in children with HCP and more specifically bimanual hand function. The authors developed a behavior-based assessment, the Assisting Hand Assessment (AHA) (Krumlinde-Sundholm & Eliasson, 2003), to evaluate hand use in children with hemiplegic cerebral palsy (HCP). The construct was fully operationalized by describing levels of upper extremity performance and hand use in children with and without HCP. Recognizing the paucity of literature and evaluation tools for measuring bimanual hand use in children with CP, the authors developed the BoHA by observing children with BCP playing with the AHA objects or toys. The AHA was then adapted and new test-items were developed based on observed hand and arm actions on objects. Based on the internal validation study of the tool, the authors concluded that the BoHA is recommended to evaluate bimanual performance in children with BCP (Elvrum et al., 2018).

The second step in the assessment development process is to describe the purpose of the assessment tool in clinical evaluation, research, or other practice contexts (Chatterji, 2003). In the American Occupational Therapy Association (AOTA) Centennial vision paper, Brown and Bourke-Taylor (2014) outlined the four purposes of evaluations in occupational therapy: descriptive, discriminative, predictive, and evaluative.

A descriptive assessment provides information regarding a child's current level of functioning, strengths, and problem areas to address in treatment. The *Child Occupational Self-Assessment* or COSA (Keller, Kafkes, & Kielhofner, 2005) is an example of a descriptive assessment tool in which a child completes self-rating scales regarding his/her occupational performance and perceived importance of daily activities. Results provided information regarding the child's self-reported functional performance and participation, rather than a "score" to measure in comparison to peers or prior performance.

Discriminative assessments, however, are typically norm-referenced and therefore are utilized to identify children who are not performing compared to their age-matched peers (Brown & Bourke-Taylor, 2014). The *Peabody Developmental Motor Scales* (2nd edition) (Folio, 2000) is an assessment tool utilized to compare a child's motor skill performance to a normative sample of age-matched children. The results of norm-referenced assessments are often utilized to determine eligibility for occupational therapy services in early intervention and preschool programs.

Predictive assessment tools are utilized to classify children into specified categories, based on behavior or performance, that indicate functional performance in other environments or future situations. For example, the Functional Independence Measure for Children (WEEFIM II; Uniform Data System for Medical Rehabilitation, 2011) is a functional independence questionnaire used to measure severity of disability and level of assistance required during activities of daily living. This assessment tool is utilized to predict the level of assistance the child will require upon discharge from a hospitalization or in a different environment.

Evaluative assessments, or outcome measures, are utilized to measure change over time in an individual child or group of children as therapeutic interventions are administered. Multiple administrations are required to detect change following an intervention or event. For example, the Box and Block Test (Mathiowetz, Federman, & Wiemer, 1985) is an evaluative assessment tool utilized to measure manual dexterity in children with unilateral cerebral palsy before, immediately following, and then at 6 months after upper extremity intensive therapy programs (Arnould, Bleyenheuft, & Thonnard, 2014).

The purpose of an assessment tool in evaluation contexts, including CP-related inferences to be drawn about members of the population based on scores, should be clearly operationalized and supported by established frameworks (Coster & Khetani, 2008). The international classification of functioning for children and youth (ICF-CY) (WHO, 2007) and the Occupational Therapy Practice Framework (OTPF-3, AOTA, 2014) guide and support the evaluation process and selection of assessment tools in occupational therapy practice. This includes identifying the strengths and problem areas related to body function, activity performance, and participation in occupations in natural and clinical environments.

The third step is to identify the population for whom the assessment is intended (Chatterji, 2003). This includes age, gender, clinical condition, inclusion criteria, and exclusion criteria. Specificity of the population may limit use; however, it improves the psychometric properties and leads to a stronger outcome from the measurement tool for the identified population. The populations identified during the initial development of the AHA, for example, were children, ages 18 months-5 years, diagnosed with hemiplegic cerebral palsy or birth-related brachial plexus injury. Therefore, assessment items were generated that reflected skills and activities of children 18 months-5 years with and without cerebral palsy.

The construct is the overarching area to be captured via the assessment tool. In order to develop a tool that measures the identified construct, the domains, subdomains, and items to match must also be clearly specified (Chatterji, 2003). According to the American Educational Research Association, American Psychological Association, and National Council on Measurement in Education (AERA, APA, & NCME, 2014), the validation processes should follow the design, as required, to show that the tool is measuring the construct, the items are representative of the construct being measured, and the scores are valid and reliable in psychometric terms.

The first action in the overall validation process should be content validation by experts in the field of study or evaluation—in this case, clinicians knowledgeable about evaluations of children with CP (Chatterji, 2003). Experts include clinicians and researchers with expertise in cerebral palsy and upper extremity evaluation and performance. Expertise in the area of assessment is required in order to provide feedback regarding item relevancy and qualitative characteristics of the assessment. This may include alternative activities, positions, or environmental modifications. This feedback is invaluable for developing a tool that is clinically relevant and valid. An item relevance checklist can be developed and distributed to experts to evaluate content validity (Polit & Beck, 2006).

A content validity index (CVI), upon review of the assessment, is an index produced based on data collected from the experts' or clinicians' item Relevance Rating Form (Polit & Beck, 2006). Additional qualitative feedback is important to gather as well. Data from the item Relevance Rating Form provide information regarding which items are (and not) representative of the construct. When developing the tool, it is imperative to have more items than are needed in order to allow for the removal of items based on the CVI.

When an assessment is behavior-based and direct observations are required by clinicians, it is also necessary to establish inter-rater reliability (Chatterji, 2003). Inter-rater reliability is evaluated by asking at least two or more clinicians (or caregivers for parent questionnaires) to complete the assessment. Pairs of assessment scores evaluated for level of agreement. Further reliability testing includes intra-rater reliability, test-retest reliability, and internal consistency reliability evaluation.

Additional steps for assessment development include describing the design, standardization methodology and set-up, and materials. Finalizing the scoring procedure and developing a training protocol for administrators are necessary for the instrument to be applied appropriately by others following the design (Chatterji, 2003).

III-THEORETICAL FRAMEWORK

The following theory and approach provided the foundation for assessment development and guided this study.

Dynamical Systems Theory

Nicolai Bernstein was a Russian neurophysiologist in the early and mid-1900s who proposed systems theory to explain how the nervous system controls motor performance. Bernstein's approach and proposed systems theory have been further developed and expanded by researchers and are known today as dynamical systems theory. His work continues to guide clinicians and researchers in understanding how complex movements are coordinated and tasks are performed in a controlled manner. Additionally, Bernstein's descriptions of the role of repetition, practice, and problem solving in the learning process have influenced motor control theory and practice today.

According to Bernstein (1967), the motor control system is responsible for controlling the complex independent physiological components, or degrees of freedom, that are required to perform coordinated movements. He described this as the "degrees of freedom problem" and hypothesized that humans develop synergistic movement patterns to solve this problem (Davids, Glazier, Araujo, & Bartlett, 2003; Thelen, Kelso, & Fogel, 1987). Additionally, he proposed that new learners control inter-limb movements by using a joint locking strategy to control the degrees of freedom. For example, while learning a novel reach task, an individual will initially lock multiple joints to control the distal movement and then release the control or "locking" as the skill is refined. Through practice and the search for optimal motor solutions, the individual develops refined skills as evidence by mastery of the degrees of freedom and task performance (Newell & van Emmerik, 1989).

The human body is a system that is influenced by external forces and interaction between subsystems. Movement patterns emerge from the interaction between the child, the task, and the environment. Controlling the degrees of freedom of body segments or freezing is further evident when a child is learning a motor skill. Upper extremity coordination patterns ultimately self-organize in response to control parameters and environmental conditions. Mastery of the skill is then evidenced by isolated control and efficiency of movement to handle objects for use (Magill & Anderson, 2014; Shumway-Cook & Woollacott, 2017).

The traditional medical model has interpreted variability in movement systems as noise or error; however, dynamical systems theory interprets variability in movement systems as an adaptive response to personal, task, and environmental constraints (Davids et al., 2003). Constraints are features or boundaries that shape motor behavior and task performance or functioning of a system (Newell, 1986). Functional variability, adequate adaptation to changes in the environment, and coordinated voluntary goal-directed movements emerge to optimize function and performance in daily life. Furthermore, observation during functional activities allows clinicians to examine the dynamic structure of motor behaviors and evaluate self-organization of the system to coordinate and control movements for skilled function and handling of objects during daily tasks.

In the context of the dynamical systems theory, hand use is the dynamic process of interacting with meaningful objects in the world. When approaching an object with the intention to touch, lift, manipulate, and carry, a variety of motor patterns are available.

This variety allows for adaptation and flexibility when executing a task. Specific task constraints such as the shape of the object, its distance from the body, its stability or mobility, the weight, and many more help the person select from the plethora of motor options and use those that best serve their intent. Coordination and control of movements are indicators of the quality of this dynamic process. In addition, specific parameters of the movement and their presence or absence determines the efficacy of motor actions. These parameters include reaching, touching, grasping, lifting, carrying, manipulating, and releasing. For the purposes of this study and assessment, upper extremity functioning is defined as the use of the arm and hand to interact effectively with objects. This is evidenced by the ability to complete the movement parameters to touch, activate, propel, grasp, lift, place, open, remove, and release an everyday object for use within 1 minute.

Perception Action Framework

Perceptual learning (Gibson, 1988) begins in early infancy with exploratory, sensory, and motor behaviors. Auditory, haptic, and proprioceptive information is perceived during spontaneous and reflexive movements. As the infant develops, voluntary controlled movements become goal-directed and the child further refines the perceptual experiences through specification and differentiation for task performance. Goal-directed movements (Gentile, 2000) consist of movement patterns characterized by orienting responses, or movement patterns focused on the stimulus or task, and adaptive responses which are movement patterns generated to stabilize or maintain posture or positioning in response to a perturbation or change in the environment. This perceptual learning and motor skill development results from the successful interaction of the child’s abilities or motor development, interaction with the environment, and the goal of the task or interaction (Zwicker & Harris, 2009).

Successful interaction with the environment, as measured by perceptual learning and motor performance, is often dependent on the affordances or function and action-based information in the environment (J. J. Gibson, 1979; Hétu & Mercier, 2012). According to J. J. Gibson, an affordance links a person's perception to action during functional tasks. This may include object characteristics, contextual or environmental information, task relevance, and an indicator of the purposefulness of an activity. This ecological approach proposes that there is a reciprocal relationship between a child's perception of the environmental and contextual demands of the task and the action required to achieve a specific goal or behavior. The basic concepts of the perception-action framework guide clinicians to evaluate and provide interventions, attending to affordances while facilitating adaptive motor actions or movements in various contexts.

The concept of affordances helps us understand movements from an interaction perspective. That is, instead of thinking of hand use as a collection of movements that an individual decides to use in the context of a task, we expand this process to include specific characteristics of the tasks that can provoke and facilitate certain movement patterns. For example, the shape and size of an object can assist the person to generate movements that may not have been part of their repertoire, or they can assist the person to constrain the variability of existing ones. The distance of the object from the body can alter the strategies to be used in the same way.

Frameworks Guiding Occupational Therapy Practice With Children and Youth

The Occupational Therapy Practice Framework: Domain and Process, 3rd Edition (OTPF-3) (AOTA, 2014) outlines and describes the scope of knowledge and expertise of occupational therapists and actions that are taken to complete comprehensive evaluations and provide client-centered care. Occupational therapy practice is guided by the uniform terminology, domain specification, and occupational therapy process outlined and described within the framework. The domain aspects are occupations (subdomains: education, play, and activities of daily living or ADL); client factors (movement-related functions); performance skills (motor and process skills); and physical environments (natural environment of community, home, and school). Occupational therapy with children includes comprehensive evaluation of client factors, performance skills and physical environments; activity-based interventions; assistive-technology provision; child and family education; and advocacy and outcome evaluations to determine the effectiveness of interventions.

The multidisciplinary approach to rehabilitation is guided internationally by the *International Classification of Functioning, Disability and Health-Children and Youth Version* (ICF-CY), which was designed by the World Health Organization (WHO, 2007) to provide a universal language and terminology as it relates to childhood development and the surrounding environment. This common language is intended for clinicians and researchers in clinical, research, and public health applications. The functioning domain includes body functions, activities, and participation, while the disability domain includes body impairments, activity limitations, and participation limitations. Additionally, detailed classifications and definitions for body functions and activities are provided.

Individuals with CP receive therapeutic interventions from infancy through adulthood to promote performance and participation in daily life. Activity-based interventions promote posture, mobility, coordination, and strength, including upper extremity reaching, grasping, transporting, and manipulating objects for use. Current evidence-based interventions that promote motor and functional outcomes in children with CP include family-centered care, goal directed training, home programs, and context-focused interventions (Novak & Honan, 2019). Despite therapeutic interventions being provided from infancy through adulthood for individuals with cerebral palsy, there is limited evidence regarding efficacy of upper extremity interventions for children with quadriplegic cerebral palsy (Elvrum et al., 2016).

Summary

In summary, reach and grasp patterns appear throughout infant and child development, emerging from variable and reflexive patterns to goal-directed, voluntarily controlled, and isolated movements. As the child matures, reach and grasp abilities and upper extremity functioning develop from the interaction with objects in the environment and therefore are dependent on affordances in the environment. Infants, children, and youth with CP often require external supports and assisted changes in position to explore the environment and develop reach and grasp patterns. External supports, interventions, and limited access to explore objects and environments may impede upon development, object manipulation and participation in play, learning, and self-care. Therefore, a valid and reliable method of objectively measuring the reciprocal interaction between children with movement disorders, more specifically BCP, and objects used in daily life is needed to systematically determine upper extremity functioning abilities when the activity is structured and environmental conditions are controlled. This assessment was designed to provide not just a global understanding of hand use, but also a description of the components of hand use (such as reach and manipulate or the need to use one or both hands) under different task and environmental conditions (middle, left, and right side of table-top surface). Clinicians can develop a profile of abilities as well as limitations and create meaningful and systematic goals for the development of new skills in this population.

IV-METHODS

Research Design

A mixed-method research design (qualitative and quantitative) was utilized to examine the extent to which the data produced by the newly developed Hand-Object Observation Tool (HOOT) provides valid and reliable information to support inferences and actions with BCP populations in therapeutic contexts. This study consisted of four steps: (I) instrument development; (II) standardization of administration procedures; (III) content validation; (IV) tool administration and scoring; and (V) preliminary reliability evaluation.

Instrument Development, Standardization Process, and Reliability Evaluation

A theory-based domain framework on upper extremity movement and functioning was developed to design and validate a formal observational tool of hand-object interaction during daily activities in children with BCP—more specifically, the population of children and youth between the ages of 5 and 17, classified as GMFCS Levels III, IV, and V. Informed by the dynamical systems theoretical principles and the process of perceiving affordances as well as relevant literature on instrument development, a Process Model was developed and utilized to describe the decisions made regarding tool design and evaluation of the validity and reliability of the HOOT (Chatterji, 2003) (see Figure 1).

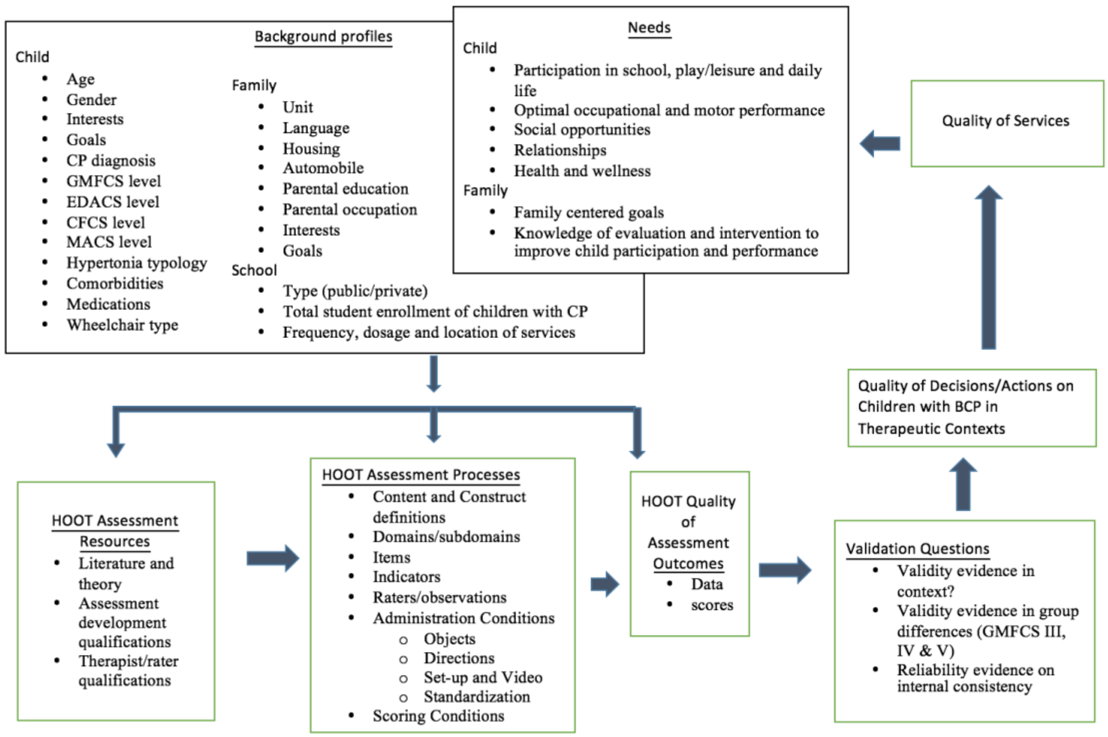


Figure 1. HOOT validation process model

The first step was to describe the population, construct, and purpose (Chatterji, 2003). The construct of upper extremity functioning is the overarching area to be captured via the assessment tool. Conceptually, upper extremity functioning is defined as the use of the arm and hand to interact effectively with objects in daily tasks. The construct was operationalized by observing behaviors of the target population, reviewing the scientific literature on the disorder, and gathering information from the population being tested with the assessment. The HOOT measures a single construct, upper extremity functioning or hand-object interaction, in children and youth with BCP by measuring: observed performance or completion (yes/no) of task components (reach to touch object, grasp to lift object, placement or use of object); hand use (right hand, left hand, or both hands interaction with object); frequency of errors (missed target or drop); and maintaining posture (head, neck, and trunk remaining upright and midline orientation during task presentation at each location). Movement time (MT) (the interval of time between initiation and completion of the task component or total task) can also be observed via the recording if task is completed within 1 minute (Magill & Anderson, 2014).

Two classification systems guided the development of the HOOT. These systems guided the operational definition of the construct, the identification of the domains, item specifications, and behavioral indicators that supported the development of this instrument. The International Classification of Functioning, Disability, and Health-Child and Youth Version (ICF-CY) was utilized to describe the HOOT assessment domains: (a) activity as measured by an individual's actions during task execution; and (b) body function as measured by the individual's capacity, or ability, to execute actions and perform within the natural or given environment (WHO, 2007). The uniform terminology, domain specification, and occupational therapy evaluation process descriptions in the OTPF-3 (AOTA, 2014) were utilized for item generation and specification. Items were generated from occupation subdomains, and related objects were identified from the literature and established standardized assessment tools. Occupation subdomains and related objects were identified as: education (writing utensil or marker and tablet computer); play (ball and board game); and ADL (food, drink, napkin, hairbrush, container, and drawstring bag). Alternate items for eating and drinking were selected based on movement parameters required for the task (lip-balm instead of food and echo-microphone instead of a drink) and included for children with eating and drinking difficulties or precautions (see Appendix F).

The second step included the standardization process. Materials, set-up, administration procedures, instructions, and score form (see Appendix C) were identified and designed from review of established standardized measures and literature review. The HOOT Manual was developed for clinician education and standardization of administration, scoring, and interpretation (see Appendix B).

The third step, the pilot study, consisted of an evaluation of content validity and tool refinement. The content validation process of the tool was completed to determine to what extent the domains, subdomains, and indicators of the HOOT are consistent with expert opinions of levels of upper extremity functioning in children with BCP. The fourth step consisted of HOOT administration and scoring by the primary investigator, while the fifth step consisted of HOOT scoring by occupational therapists and analysis of participant characteristics, HOOT scores, and inter-rater reliability of clinician scores and the gold standard.

Participants and Recruitment

Child participants in Step III, the pilot study, were recruited from a community adaptive fitness center via flyer. Purposive sampling was utilized in order to have each GMFCS level (III, IV and V) represented and recorded. Experts were identified from professional organizations (American Academy of Cerebral Palsy and Developmental Medicine [AACPDM]) and private schools and were recruited via email communication. Participants in Step IV were recruited from the community, via flyers and email communication, using purposive sampling to recruit children with bilateral cerebral palsy, representing all three levels of gross motor ability. Occupational therapists working with children and youth were recruited via email communication.

Inclusion Criteria

The following criteria were used to determine child and youth participation in Steps III and IV:

1. age 5-17 years;
2. diagnosed with quadriplegic or bilateral cerebral palsy; and
3. classified as level III, IV, or V on the Gross Motor Function Classification System (GMFCS).

The following inclusion criteria were used to determine expert clinician participant selection for Step III and occupational therapist participant selection for Step IV:

1. clinician (occupational or physical therapist), researcher, or physician with at least 5 years of experience evaluating and providing interventions to children diagnosed with BCP;
2. licensed occupational therapist practicing in school or home environments with children; and
3. at least 5 years of clinical experience working with children and youth.

Exclusion Criteria

There were no exclusion criteria.

Children with cerebral palsy were initially screened via caregiver communication regarding: date of birth; diagnosis; medical history or concerns related to the study;

precautions; seating and mobility; durable medical equipment, adaptive equipment, communication device and orthotic provisions and use; and classifications of function including the GMFCS, MACS, CFCS, and EDACS. The evaluating occupational therapist (primary investigator) measured the child's active or available reach distance to edge of tray and range of motion of both upper extremities. Additionally, hypertonicity was evaluated utilizing the Hypertonia Assessment Tool (HAT) (Jethwa et al., 2010) to determine if the child exhibited spasticity, dystonia, rigidity, or mixed tone.

Administration and Scoring Procedures

Assessment Administration and Video-recording

During Step III, the HOOT was administered by the principal investigator (PI) to three children diagnosed with bilateral cerebral palsy (1 triplegia and 2 quadriplegia). During Step V, the HOOT was administered by the PI to six children diagnosed with bilateral cerebral palsy (3 triplegia and 3 quadriplegia) (see Table 1), as instructed in the manual, in a natural setting, selected by the caregiver or clinician familiar with the child. The PI provided education and instruction regarding the video recording and assessment activities and then interviewed the caregiver regarding background information, diagnosis, classification of function (gross motor, fine motor, communication, and feeding), and precautions. The caregiver was consulted regarding standardizing the initial seated positioning of the child with adjusted seat angle, postural supports and positioning accessories that are typically used during daily activities.

A paper template (poster board 22 x 28 inches), trimmed to the size of the tray if needed, was placed on the child's tray or table, at midline, to standardize placement of objects and for video observation of reaching range and movements. Hypertonicity was evaluated utilizing the Hypertonia Assessment Tool (HAT) (Jethwa et al., 2010) to determine if the child exhibits spasticity, rigidity, dystonia, or mixed tone. Active and passive range of motion of both upper extremities was measured to determine available reaching distance on table or tray and to calculate 75% of available reaching at midline, left, and right sides of the table-top surface for object placement (Butler et al., 2010a, 2010b).

The assessment was recorded via a videorecorder positioned on a tripod at approximately 2-4 feet away, at midline, with the camera elevated to approximately five feet to provide downward viewing of the child's reaching space. Recording began once the child was positioned, with tray and object placement location labeled. Video recording was terminated once the last item or activity was completed.

The assessment consists of 10 tasks that require interactions with: touch-screen tablet; 6-10-inch ball; cup or toy microphone; finger food or lip balm; napkin or tissue; hair brush or personal grooming tool; marker or writing utensil; container with lid; drawstring bag and game board with pieces (i.e., tic-tac-toe). The objects were selected prior to administration and utilized during each administration with the child for standardization. Each task was presented in three locations on the tray to observe reach and hand use when objects are placed in the middle of the tray aligned with the child's navel, right side of the tray aligned with the child's right shoulder or acromion process, and left side of the tray aligned with the child's left shoulder or acromion process. The child was given standardized instructions to engage in the tasks: (a) *make a mark on the iPad*; (b) *roll the ball*; (c) *drink from the cup* or *sing into the microphone*; (d) *eat the food* or *put on lip balm*; (e) *wipe your mouth*; (f) *brush your hair*; (g) *color with the marker*; (h) *open the bag*; (i) *open the container*; and (j) *let's play, put a game piece on the board* (see Appendix C).

The child was not required to participate for any length of time, but rather interact with the object within 1 minute. If the child did not interact with the object within 1 minute, the PI assisted the child with completing the activity if the child exhibited interest or was persisting with the task. The drinking and eating items required use of personal food and cup with drink. Alternate items were presented during the eating and drinking tasks if the child: did not eat finger foods and/or drink from a cup; was classified as EDACS III, IV, or V; refused to eat or drink; or the caregiver preferred that the child refrain from eating and/or drinking during the assessment.

The interview and assessment administration were approximately 30-60 minutes in duration.

Scoring

Video-recorded administration was scored by the PI using the HOOT Score Form (see Appendix C). The pilot study score forms were utilized for tool review by experts in order to complete the content validation process. In Step IV, three occupational therapists received education and training for the tool via written instructions regarding HOOT purpose, administration, and scoring procedures. Each occupational therapist viewed the video recordings and completed the score forms for all six children. Therefore, each administration or recording of a child was scored by the PI and three occupational therapists.

Object interaction or task component completion (87 items) was scored as yes or no. Tasks (tablet, ball, drink, food, napkin, brush, marker, container, and game) were scored one or zero points, at each location (middle, right, and left location on table or tray), if completed within 1 minute. Hand use (hand interaction with object at each location on table or tray) was scored as right, left, or both hands. Posture (upright positioning of head, neck, and shoulders in alignment during each object presentation, at each location) was scored as yes or no. Errors (hand missing target or dropping object prior to placement or completion of task) were tallied during each task, at each location, and summed for total scale error scores.

Expert Consensus and Qualitative Feedback

Expert clinicians in the field of rehabilitation medicine or research and CP completed the content validation process as follows. Each expert received an email containing a consent form, confidentiality agreement, HOOT description and instructions, score forms, and Relevance Rating Form. Upon receipt of the participation confirmation and signed documents, the PI emailed a password for video/flash drive access. The encrypted and password-protected flash drive, along with paper copies of the manual, completed score forms, and Relevance Rating Form were mailed to each expert without video-identifying information included; a postage-paid return envelope addressed to the PI was included. The clinicians reviewed the instructions and manual, viewed the three recorded administrations, reviewed the completed score forms for each child, and completed the Relevance Rating Form. Experts then completed the item relevance feedback form (Polit & Beck, 2006) and provided qualitative feedback regarding item relevance and the tool (alternative activities, position, environment and scoring). The experts returned the completed feedback form and flash drive via mail to the PI.

Ethical Assurances

Participants were identified by a number and data were stored on a password-protected and encrypted computer flash drive in a locked file cabinet in the PI's home.

Caregivers/guardians and children were educated regarding the purpose, procedures, risk, benefit, and option to refuse or stop the study at any time. This included verbal explanations, images, discussion, and answering questions following the education. The PI reviewed the Parental/Guardian permission form, parental/guardian consent, and child assent. In order to ensure that the children had an understanding of the study and what was involved, an image-based questionnaire (faces) was utilized to determine like/dislike paired with yes/no cards for children. Caregivers were asked to read and sign the consent forms.

Occupational therapists were educated on the purpose of the study, procedures, tool development, and administration instructions and scoring procedures. Occupational therapists completed an informed consent and confidentiality form (see Appendix E).

Data Analysis

Content Validity of the HOOT

The content validity index (CVI) was calculated for single items (I-CVI) and overall scale index (S-CVI). The CVI is a value that can be computed for a single item on a scale (I-CVI) or overall scale (S-CVI). The scale most commonly used and applied to this study is the 4-point relevance rating: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = highly relevant. The proportion of agreement was then calculated as the number of experts who rated a 3 or 4 divided by the total number of experts.

Qualitative feedback regarding item relevance to upper extremity functioning in children with BCP was analyzed utilizing Classical Content Analysis (Miles, Huberman, & Saldaña, 2014; Nowell, Norris, White, & Moules, 2017). Written feedback from experts was transcribed into a Word document and organized according to item. The document was uploaded into *NVivo* (QSR International Pty. Ltd., Version 12, 2018) and a word frequency count and word cloud were generated (see Table 2; Figure 2). The qualitative data were read and reread to identify themes. Sentence coding was used to identify themes within sentence units of text and representative quotes were provided for each theme within each item (see Table 4).

Reliability Evaluation

Data gathered from completed score forms were examined using visual graphics and descriptive analyses. Inter-rater reliability was evaluated to determine the level of agreement among three occupational therapists in comparison with the “gold standard” examiner or PI using inter-rater reliability coefficient or Cohen’s kappa statistics (Mor et al., 2003; Nowell et al., 2017). Kappa statistics were generated for the nominal data (object interaction, posture, and hand use). In order to determine if assessment scores produced by inter-raters remained consistent irrespective of the rater, preliminary internal consistency reliability or Cronbach’s alpha (*Kuder-Richardson 20*) was used to evaluate reliability of total scale scores (sum of task scores) and error scores (sum of error scores). SPSS 26 software was utilized.

V-RESULTS

As mentioned in Chapter I, this study consisted of instrument development and an examination of content validity, preliminary inter-rater reliability, and preliminary internal consistency reliability of HOOT scores. Further, this research analyzed level of clinician rater agreement regarding subject's hand use, errors, and maintenance of posture. In the beginning of the Methods section, a detailed description of the conceptual definition and process of operationalization of the main construct for this assessment tool was provided. This was based on theoretical foundations and existing classification systems guiding clinical practice. Steps I-III were followed to develop the items, the scoring system, and a manualized and standardized administration process, as detailed in the HOOT manual (Appendix B). The following section of the results presents data gathered for the content and preliminary inter-rater reliability and internal consistency of the HOOT.

Content Validity of the HOOT

Participant Characteristics

Expert clinicians (n = 8; mean years of clinical experience working with children with cerebral palsy = 19.75 years; 2 physical therapists and 6 occupational therapists) participated in the study by reviewing the HOOT manual; observing videos of HOOT administration to child participants and reviewing completed score forms; and completing the expert relevance form (see Appendix D, Table D-1). The HOOT was administered to children (n = 3; mean age = 12 years) diagnosed with BCP, GMFCS III (triplegia), IV, and V (quadriplegia) in their home. Caregivers (n = 3) were present during the administration and completed the caregiver feedback form.

Content Validation Quantitative and Qualitative Results

Question number 1: To what extent are the domains, subdomains, and indicators of the HOOT consistent with the theoretical literature on the condition and expert opinions of levels of upper extremity functioning in children with BCP?

The HOOT is a performance-based individual assessment developed for use in clinical and research settings. The International Classification of Functioning, Disability and Health-Children and Youth Version (ICF-CY) was utilized to describe the assessment domains: (a) activity as measured by the *execution of a task or action by an individual* (WHO, 2007, p. 9); and (b) body function as measured by capacity (ability to execute actions) and performance (what the child does within the natural or given environment). The uniform terminology, domain specification, and occupational therapy evaluation process descriptions in the Occupational Therapy Practice Framework (OTPF-3) (AOTA, 2014) were then utilized for HOOT item generation and specification. Items were generated from occupational subdomains and related objects were identified from the literature and standardized assessment tools (Coster & Khetani, 2008). Expert review of the HOOT manual (Appendix B) and score forms (Appendix C) was included in the content validation process and results.

The content validity index (CVI) or proportion of agreement was calculated as the number of experts rating individual item relevance a 3 or 4, divided by the total number of experts. As can be seen in Appendix D, Table D-2, all items met the criteria for excellent content validity index for single items (I-CVI) within .75-1.0 and overall scale index (S-CVI/Ave) .90 or higher (Polit & Beck, 2006).

A word frequency chart (see Appendix D, Table D-3) and word cloud (see Appendix D, Figure D-1) were generated from transcribed expert feedback regarding item relevance, representativeness and recommendations.

Content and Thematic Analysis (Miles et al., 2014, Nowell et al., 2017) resulted in five themes (positive comments, task content, utility, considerations, and recommendations) (see Appendix D, Table D-4) which were coded within sentence units of text. Representative quotes were identified for each theme per item.

Reliability Evaluation

Participant Characteristics

As summarized in Table 1, the six children and youth who participated in this study ranged in age from 8-17 years, with a mean age of 12.55 years. The sample was divided equally between males and females and GMFCS Levels. The majority of the subjects (4) were evaluated in a home environment. HOOT administration time ranged from 11-55 minutes (see Table 2). All tasks (30 tasks x 6 participants) were administered with the exception of three tasks (task 7 at left location and task 7 at right location with subject 3; and task 3 at left location with subject 6) due to facial grimacing and eye closure upon presentation. These tasks were recorded as not administered (NA). These participants are nonverbal; therefore, the PI made a clinical decision to remove the items from the tray due to nonverbal communication and facial expressions. Two task

Table 1. *Characteristics of Participants Diagnosed With Bilateral Cerebral Palsy*

Subject	Age (year)	Dx	Sex	GMFCS	CFCS	EDACS	MACS	HAT	Mobility Device	Medical History
1	11.9	TCP	F	IV	I	I	II	Dystonia; spasticity	Power WC	None reported
2	12.8	QCP	F	IV	III	III	III	Dystonia; spasticity	WC	Seizure disorder; glasses; orthopedic
3	15.5	QCP	F	V	IV	IV	V	Spasticity	WC	Seizure disorder; cortical vision impairment
4	9.7	TCP	M	III	III	II	II	Spasticity	Walker	Hydrocephalus; infantile spasms; legally blind; glasses; asthma; orthopedic
5	8.9	TCP	M	III	II	II	II	Spasticity	Walker	Seizure disorder; strabismus; glasses; orthopedic
6	16.5	QCP	M	V	V	V	V	Spasticity; rigidity	WC	Seizure disorder; cortical vision impairment; respiratory; orthopedic

Abbreviations: Communication Function Classification System (CFCS); Diagnosis (Dx); Eating and Drinking Ability Classification Systems (EDACS); Gross Motor Function Classification System (GMFCS); Hypertonicity Assessment Tool (HAT); Manual Ability Classification System (MACS); Quadriplegic Cerebral Palsy (QCP); Triplegic Cerebral Palsy (TCP); Wheelchair (WC)

Table 2. *HOOT Administration Details*

GMFCS Level	Age Range	MACS	Location of Administration	Time to Complete Administration (range in minutes)	Total Score Range	Error Score Range
III	8.9-9.7	II, II	Recreation center	11-21	81-84	0
IV	11.9-12.8	II, III	Home	16-18	78-86	3-5
V	15.5-16.5	V, V	Home; apartment	33-55	24-34	45-67

Note. The total and error score ranges were scored by the primary investigator (gold standard).

administration errors occurred across six participants and were recorded as an administration error (AE). During administration of the two tasks, the PI placed the objects in the wrong location (right side location on the tray instead of the left location).

Time to complete each task, task not administered, and administration errors for each participant are summarized in Table 3.

Item (N = 87) performance by subjects is presented in Figure 2 and Figure 3. Item scores were summed across task components or movement parameters (touch, activate, place, open, remove, release) to determine upper extremity functioning levels of subjects according to GMFCS Levels III, IV, or V (Figure 2) and MACS Levels II, III or V (Figure 3). The results indicated that subjects at all GMFCS levels had the ability to touch and activate or propel objects. Both subjects at GMFCS Level III and GMFCS Level IV had the ability to grasp, place, and release objects. Bimanual performance or the ability to open the drawstring bag or remove the top from a container and remove item from bag were only completed by subjects at GMFCS Level III and one subject at GMFCS Level IV. Results according to MACS Levels indicate that children at MACS Level II have the ability to perform all task components, the child at Level III is unable to perform the bimanual tasks and the children at Level V have the ability to touch and activate or propel objects.

Occupational therapists (n = 3) who participated in this study ranged in years of practice working with children from 5-27 years. All therapists have experience working in school-based practice. Time to complete HOOT scoring form, via video observation, per child reportedly ranged from 15-30 minutes (see Table 4).

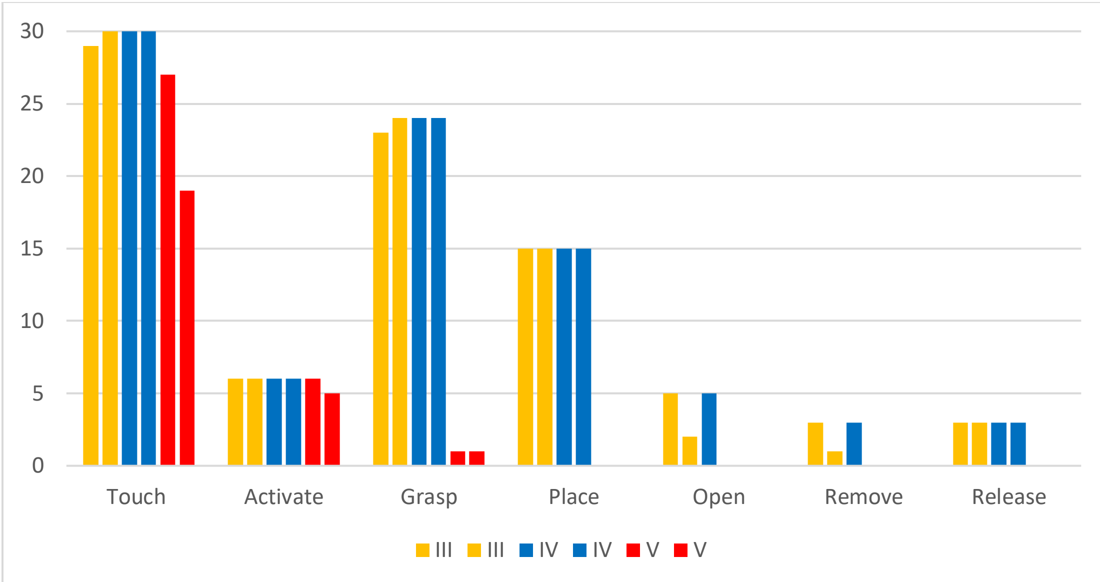
Table 3. *Task Completion Time of Each Participant*

Subject (GMFCS)	Tablet			Ball			Cup or Microphone			Food or Lip Balm			Napkin			Hair-brush			Marker			Bag			Container			Game		
	M	R	L	M	R	L	M	R	L	M	R	L	M	R	L	M	R	L	M	R	L	M	R	L	M	R	L	M	R	L
1 (IV)	3	3	2	3	2	1	2	3	3	4	3	2	3	1	2	2	2	2	2	2	3	24	29	27	11	X	40	2	2	17
2 (IV)	2	2	2	3	2	2	3	8	4	3	3	3	2	3	1	3	5	5	3	3	3	X	X	X	X	X	X	3	2	2
3 (V)	9	7	13	5	10	12	X	X	X	X	X	X	X	X	X	X	X	X	X	NA	NA	X	X	X	X	X	X	X	X	AE
4 (III)	3	2	1	1	1	1	3	2	2	1	2	3	2	2	1	2	2	2	3	3	3	6	7	6	11	3	AE	3	2	2
5 (III)	2	7	2	5	2	2	2	1	1	2	2	1	1	1	1	2	2	2	3	4	5	59	X	X	28	X	X	2	2	2
6 (V)	51	4	16	X	X	X	X	X	NA	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Notes. Time (seconds) to complete the task at each location (middle, right, left); "X" if the child did not complete the task within one-minute

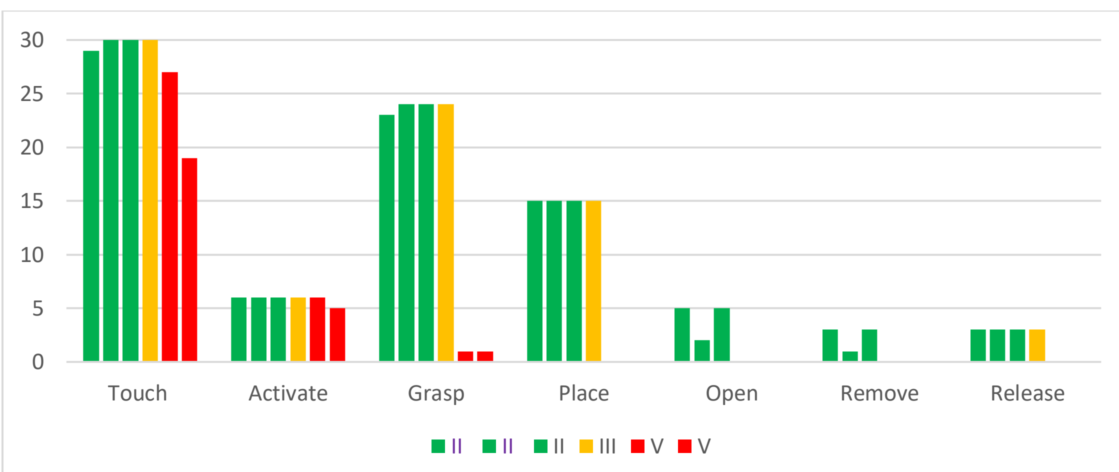
Abbreviations: Administrator Error (AE); Not Administered (NA)

Figure 2. Upper extremity functioning of subjects at GMFCS Levels III, IV, and V



Notes: Successful interaction with objects was measured by the ability (yes or no) to complete items (N = 87) within one minute. Items were summed according to movement parameters: touch (N = 30); activate or propel (N = 6); grasp (N = 24); place (N = 15); open bag or container (N = 6); remove container (N = 3); and release (N = 3) objects. Abbreviations: Gross Motor Function Classification System (GMFCS)

Figure 3. Upper extremity functioning of subjects at MACS Levels II, III, and V



Notes: Successful interaction with objects was measured by the ability (yes or no) to complete items (N = 87) within one minute. Items were summed according to movement parameters: touch (N = 30); activate or propel (N = 6); grasp (N = 24); place (N = 15); open bag or container (N = 6); remove container (N = 3); and release (N = 3) objects. Abbreviations: Manual Ability Classification System (MACS)

Table 4. *Characteristics of Licensed Occupational Therapy Participants*

Participant	Years of OT Experience Working With Children	Area of Practice	Certifications	Place of Practice	Reported Time to Complete Scoring of One Administration (minutes)
1	27	School; early intervention	SIPT	New York City; New Jersey	20-30
2	5	School		New York	15-20
3	10	School	CHT	Pennsylvania	15-20

Abbreviations: Certified Hand Therapist (CHT); Occupational Therapy (OT); Sensory and Integration Praxis Test (SIPT)

Inter-rater Reliability of Item and Task Scores

Question number 2: What is the level of agreement among raters in comparison to the "gold standard" examiner or primary investigator?

In order to determine the degree of agreement among two raters, assessment of inter-rater reliability of the nominal HOOT variables or scores was evaluated using Cohen's (1960) Kappa Coefficient. Scores from each occupational therapist rater were assessed in comparison to scores from the primary investigator or "gold standard" rater, across all child participants (n = 6). Item scores (87) were generated from receiving a yes or no for completing the task component within 1 minute at each location (see Table 5). For example, in each task location, the child receives a point for touching the object, grasping to lift the object, placing the object on self or surface, opening the object, removing the object or the top off of the object, and releasing the object. Because some of the item scores had perfect agreement between the rater and gold standard, the SPSS 26 package was unable to compute Cohen's Kappa Coefficient. In these cases, the following formula was used to complete the computations:

$$\kappa = 1 - \frac{1 - P_o}{1 - P_e}$$

$P_o =$ the relative observed agreement among raters.
$P_e =$ the hypothetical probability of chance agreement

Task scores (30) were generated from receiving a point for completing the whole task, within 1 minute at each location (Table 6). As in the case of the item scores, for perfect agreement scores that SPSS 26 could not compute, the formula above was used

Table 5. *Distribution of Kappa Coefficient for the Item Scores*

Kappa	Strength of Agreement (Landis & Koch, 1977)	Count (N = 87 items)		
		R1*GS	R2*GS	R3*GS
<0	Poor agreement	0	0	0
0.0-.20	Slight agreement	0	0	0
.21-.40	Fair agreement	0	0	0
.41-.60	Moderate agreement	2	3	1
.61-.80	Substantial agreement	3	3	3
.81-1.0	Almost perfect	82	81	83

Notes: Inter-rater reliability of item scores across six subjects was evaluated using Cohen's Kappa Coefficient.
Abbreviations: gold standard (GS); rater 1 (R1); rater 2 (R2); rater 3 (R3)

Table 6. *Distribution of Kappa Coefficient Scores for Task Scores*

Kappa	Strength of Agreement (Landis & Koch, 1977)	Count (N = 87 items)		
		R1*GS	R2*GS	R3*GS
<0	Poor agreement			
0.0-.20	Slight agreement			
.21-.40	Fair agreement			
.41-.60	Moderate agreement			
.61-.80	Substantial agreement			
.81-1.0	Almost perfect	30	30	30

Notes: Inter-rater reliability of task scores across six subjects was evaluated using Cohen's Kappa Coefficient.
Abbreviations: gold standard (GS); rater 1 (R1); rater 2 (R2); rater 3 (R3)

for the calculations. Hand-use scores (right, left, or both) were generated from raters identifying which hand(s) interacted with the objects during the task (see Table 7). As in the case of the item scores, for perfect agreement scores that SPSS 26 could not compute, the formula above was used. Moreover, posture scores were generated from raters scoring a yes or no for maintaining posture during the task (see Table 8).

Table 7. *Distribution of Kappa Coefficient for the Hand-use Scores*

Kappa	Strength of Agreement (Landis & Koch, 1977)	Count (N=87 items)		
		R1*GS	R2*GS	R3*GS
<0	Poor agreement	0	0	0
0.0-.20	Slight agreement	0	0	0
.21-.40	Fair agreement	0	0	0
.41-.60	Moderate agreement	3	2	2
.61-.80	Substantial agreement	11	12	12
.81-1.0	Almost perfect	16	16	16

Notes: Inter-rater reliability of scoring hand-use scores (right, left or both) across six subjects was evaluated using Cohen's Kappa Coefficient.
Abbreviations: gold standard (GS); rater 1 (R1); rater 2 (R2); rater 3 (R3)

Table 8. *Distribution of Kappa Coefficient for the Posture Scores*

Kappa	Strength of Agreement (Landis & Koch, 1977)	Count (N = 87 items)		
		R1*GS	R2*GS	R3*GS
<0	Poor agreement	0	3	0
0.0-.20	Slight agreement	3	0	0
.21-.40	Fair agreement	8	6	4
.41-.60	Moderate agreement	2	4	8
.61-.80	Substantial agreement	10	1	1
.81-1.0	Almost perfect	7	16	17

Notes: Inter-rater reliability of posture scores (yes or no) across 6 subjects was evaluated using Cohen's Kappa Coefficient.
Abbreviations: gold standard (GS); rater 1 (R1); rater 2 (R2); rater 3 (R3)

Internal Consistency

Question number 3: To what extent are the items in the tool intercorrelated or measuring behaviors from the same construct, upper extremity functioning in children with BCP, GMFCS III, IV, and V?

Reliability across assessment items was evaluated by measuring the internal consistency of the HOOT scores, using Cronbach's alpha correlation coefficient. Although this interpretation is preliminary, based on six subjects and four raters, an analysis was completed to provide some evidence to continue research and reliability evaluation of HOOT scores. The Cronbach's alpha coefficient for the scale score (sum score) was 1.0, and sum error score was .920. These alpha values were greater than the accepted score of at least .70 (Crocker & Algina, 1986). Since reliability estimates are dependent on true score variance, there is limited interpretation of the results due to small sample size and dichotomous data (limited variability in true scores).

VI-DISCUSSION

This study dealt with the development and validation of a pediatric assessment tool for clinicians (occupational therapists, physical therapists, and researchers) that measures upper extremity functioning levels and hand-object interaction abilities of children with bilateral cerebral palsy (BCP). This tool can be utilized during evaluation and re-evaluation of children during therapy or in research settings. This final chapter of the dissertation summarizes the reliability findings, upper extremity functioning in children with BCP, and assessment administration in natural contexts. Study limitations and directions for future research are also discussed.

Instrument Development and Standardization

Assessment instruments should have established procedures for administration, scoring, documentation, and interpretation of score results (AERA, APA, & NCME, 2014, p. 114). In this study, HOOT procedures were carefully designed and standardized through a sequential-multistep process. As summarized in Chapter II, an in-depth study of cerebral palsy, movement science, and assessment development literature was completed in order to operationalize the construct; identify the domains and subdomains; complete the item specification, including selection of relevant tasks, objects, and performance indicators; determine the optimal positioning of the child and objects; and specify the instructions for administration (Steps I-II).

The content validation process, Step III, was completed in order to determine if the HOOT tasks and indicators were relevant and representative of upper extremity functioning in children and youth with BCP. The expert clinicians in this study provided extensive qualitative information, which further guided the standardization of the tool.

Content Validation and Reliability of Assessment Scores

This study aimed to answer three questions regarding the reliability of scores generated from the administration of the HOOT.

The first question was related to content validation of the HOOT. Question 1: *To what extent are the domains, subdomains, and indicators of the HOOT consistent with the theoretical literature on the condition and expert opinions of levels of upper extremity functioning in children with BCP?* Based on this study, the content of the HOOT is consistent with expert opinions of upper extremity functioning in children with BCP GMFCS III, IV, and V. Additionally, the results of Step IV suggested that item and scale CVI results met the criteria for retaining items and proceeding with further evaluation of reliability and internal consistency. Based on clinician review of video administration and qualitative feedback, the HOOT description and instructions were edited to further standardize object placement, script or child instructions, scoring, and reporting. Standardization of object placement and instructions was established for Step V of the study. This included editing of the instruction form and score form.

The second question was related to inter-rater reliability. Question 2: *What is the level of agreement among raters in comparison to the "gold standard" examiner or primary investigator?* Agreement among raters when scoring item performance showed moderate to almost perfect agreement and almost perfect agreement when scoring task performance on the HOOT. This indicated greater agreement when scoring completion of the total task within 1 minute than when scoring individual item performance (or movement parameters) within 1 minute. Moderate and substantial agreement occurred across raters when they scored: grasp napkin and lift off of table (n = 3); touch marker (n = 2); touch container (n = 1); and grasp container and lift off of table (n = 9). When developing HOOT items, the primary investigator included “lifting off of table” as an observable indicator of grasping. Upon review of scoring and videos, it was evident that the bimanual task of grasping a container, to remove a lid, did not require the child to lift the container off of table, which may be why there was disagreement in this scoring. Additionally, it is important to consider that using a supportive surface may facilitate or support manipulation of the container. This should be further evaluated via video coding and qualitative evaluation of reaching and grasping during everyday tasks, especially bimanual activities. HOOT scores provide information regarding ability to perform the task component (i.e., touch), but further information on how the child performs the task component (i.e., touch with finger, thumb or fist) is needed.

Inter-rater reliability of recording which hand (right, left or both) was used to interact with the object (hand-use score) and postural observations (maintenance of posture during the task) were analyzed as well. There was moderate to almost perfect agreement across participants. Moderate agreement results were unexpected, considering that hand-object interaction is observable via video observation. One rater, however, asked the primary investigator, “Does it matter if they used tone to touch the object?” Raters were directed to the instruction and scoring form (Appendix C) in order to standardize training across raters. Variability in movement patterns exhibited when interacting with objects may lead clinicians to interpret reaching and grasping abilities rather than record the objective observation of movement parameters. Further explanation regarding objective indicators and development of a training protocol are needed, despite reliability results. Video camera distance and angle and lighting in the natural environment should be considered during administration as well.

The third question was related to internal consistency of assessment items. Question 3: *To what extent are the items in the tool intercorrelated or measuring behaviors from the same construct, upper extremity functioning in children with BCP, GMFCS III, IV, and V?* Reliability estimates were dependent on true score variance in assessment scores. Preliminary item analysis showed internal consistency of HOOT test items, which indicated that further evaluation is warranted. An evaluation of internal consistency, using Cronbach's alpha correlation coefficient, with a larger sample size of at least 30 children and youth with BCP is also needed. Additional data from clinical populations would provide the opportunity to analyze internal consistency and correlation of items, and then complete a factor analysis to explain the factors contributing to the variance.

Upper Extremity Functioning in Children With BCP

Children with BCP have varying levels of ability to perform functional tasks (Rosenbaum & Rosenbloom, 2012). They often require extended time and physical assistance to perform daily activities due to limited postural control, hypertonicity, and/or difficulties executing controlled and isolated movements (Schneiberg et al., 2002). The Manual Ability Classification System (MACS) has been used throughout research and clinical practice to describe a child's overall ability to handle everyday objects (Wagner

& Davids, 2012). More specifically, the tool is utilized to determine eligibility and to develop individualized interventions and group programs for children with cerebral palsy (CP). During the intake process for this study, caregivers were asked to describe the child's manual ability and identify the current MACS level. Although the MACS is valid and reliable in classifying overall ability (Eliasson et al., 2006), administration of the HOOT provides the opportunity to further evaluate the unique reaching and handling abilities among children with BCP and, therefore, levels of functioning within the classification levels.

All children (n = 6) in this study demonstrated the ability to touch, activate, and propel an object. The child at MACS Levels II and III (n = 4) demonstrated the ability to grasp, transport, place, and release objects and the children (n = 3) at MACS Level II demonstrated the ability to open and remove objects. Therefore, the performance indicators in the HOOT were consistent with manual ability classifications according to the MACS. Convergent validity is pursued to establish overall construct validity of an assessment tool in research contexts (AERA, APA, & NCME, 2014; Chatterji, 2013). These results are early evidence of convergent validity, indicating that the HOOT and MACS are tapping into the same construct, upper extremity functioning or hand-object interaction. Further evaluation with a larger sample size will allow the primary investigator to further evaluate convergent and concurrent validity with established measures of upper extremity functioning.

Evaluation of Functioning in Natural Contexts

In order to understand the functioning capacity or abilities of an individual, we must observe them within the natural environment. The HOOT was therefore developed to provide clinicians with a tool that standardizes tasks and child positioning in order to evaluate and reevaluate upper extremity performance. The environment in which the HOOT is administered is selected by the caregiver or adult familiar with the child. This includes the room, chair, table-top surface, and objects as needed (i.e., cup with liquid and food). Although the child's position and presentation are standardized for this assessment, some environmental features and interruptions were unavoidable in this study. Video observations and field notes revealed common interruptions, including animals or pets, family members or nurses entering the room, television or technology in adjacent rooms, and limited control over lighting and space for camera positioning. Further refinement of the tool is recommended to account for these interruptions.

Limitations

There were several limitations in this study. First, there was a small purposive sampling size and, therefore, generalizability of this study is limited. This study depended on having access to students with disabilities in a nonprofit private school; however, due to IRB policy changes within the organization during the development of this study, approval to access students was not provided. The supervising therapist reported that administration of the tool by therapists within the organization, rather than the primary investigator may be considered in future studies.

Second, administration errors and clinical decision making regarding nonverbal communication occurred during this study. Alternative plans and method for scoring is needed as this population presents with a variety of comorbidities or difficulties including communication disorders. Third, training of clinician raters included education and review of the manual and instructions for scoring via written instructions and answering clinician questions upon review of one video. Further development of an administration and scoring training protocol is needed.

Directions for Future Research

This study suggests that the HOOT is a promising performance-based measure of upper extremity functioning in children with BCP, GMFCS Levels III, IV, and V. Future research should include a larger sample size and further examination is needed to refine the training protocol, scoring instructions, and documentation of object characteristics and environmental features observed during administration. In order to validate the HOOT further, community-based occupational therapists will be recruited to administer the tool in school, camp, or home environments to at least 30 children and youth diagnosed with BCP. Data retrieved from clinician administration and scoring of the HOOT will be utilized to determine inter-rater reliability and complete an item and internal consistency reliability analysis. Additional qualitative data will be gathered regarding clinician experiences and narrative documentation or summary regarding performance in order to further describe the upper extremity functioning levels of children with BCP.

Conclusion

Design and validation of a performance-based instrument require extensive research and collaboration with multiple disciplines. The ICF-CY affirmed the importance of measuring a child's function not only through body structure, but also through observation of participation, activity engagement, and environmental factors (Wagner & Davids, 2012). Functional classifications are effectively being utilized by clinicians internationally to classify levels of functioning and abilities (Rosenbaum, Eliasson, Hidecker & Palisano, 2014). Although these classification systems provide a systematic approach to evaluation of individuals with cerebral palsy, further understanding and specification of functioning abilities within each classification are needed for clinicians to identify abilities in order to develop individualized treatment plans that effectively improve performance and functioning in the individual. The pediatric upper extremity functioning assessment, presented in the dissertation, fills a gap in the literature regarding the quality of reaching and grasping abilities in children with BCP, GMFCS III-V and provides the unique opportunity for clinicians to better understand and systematically measure upper extremity performance and levels of functioning in children with bilateral cerebral palsy.

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Appendix A

Item Specification Table

Outcome: **following set-up and instruction, the child will:**	**Indicator:** **within 1 minute, the child can:**
1. Activate cause-and-effect toy or touch screen device technology via direct selection	1.1 Reach to touch tablet/iPad (overshoot, undershoot) 1.2 Activate device/sound
2. Propel 7” ball in any direction	2.1 Reach to touch ball (overshoot, undershoot) 2.2 Propel ball 6-10” ball in any direction with elbow extension or shoulder flexion
3. Pick up a cup, from tray, and bring to mouth to drink	3.1 Reach to touch cup (overshoot, undershoot) 3.2 Secure cup in hand or sustain/orient cup to lift off of table (drop) 3.3 Transport cup to mouth (overshoot, undershoot, drop)
4. Pick up finger food from the tray and place on mouth to eat	4.1 Reach to touch food (undershoot, overshoot) 4.2 Secure food or sustain grasp to lift food off of the table (drop) 4.3 Transport cracker to mouth (overshoot, undershoot)
5. Wipe face with a napkin	5.1 Reach to touch napkin (undershoot, overshoot) 5.2 Secure napkin in hand (drop) 5.3 Transport napkin to mouth (overshoot, undershoot, drop)
6. Brush hair	6.1 Reach to touch brush (overshoot, undershoot) 6.2 Secure brush in hand (drop) 6.3 Transport brush to head (overshoot, undershoot, drop)
7. Color or write with marker on paper	7.1 Reach to grasp marker (overshoot, undershoot) 7.2 Sustain grasp on marker to lift off the table and orient (drop) 7.3 Make instructed mark on paper (overshoot, undershoot, drop)
8. Retrieve personal item from bag	8.1 Reach to touch bag (overshoot, undershoot) 8.2 Sustain grasp on bag to open (drop) 8.3 Reach into bag to retrieve item (overshoot, undershoot, drop) 8.4 Sustain grasp to remove item from bag (drop)

Outcome: **following set-up and instruction, the child will:**	**Indicator:** **within 1 minute, the child can:**
9. Open a container with a lid to retrieve a game piece	9.1 Reach to touch container (overshoot, undershoot, drop) 9.2 Stabilize container with ipsilateral hand and grasp lid with other hand to open (drop) 9.3 Remove top of container (drop)
10. Play board game	10.1 Reach into container to touch game piece (overshoot, undershoot) 10.2 Sustain grasp on game piece to remove piece from container (drop) 10.3 Transport game piece to board (overshoot, undershoot, drop)

Appendix B

HOOT Manual

Hand-object Observation Tool (HOOT)

User Manual
April 2019

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TABLE OF CONTENTS

HAND-OBJECT OBSERVATION DESCRIPTION…………………………...3

DEVELOPMENT OF THE HOOT………………………………………......4

HOOT ADMINISTRATION……………………………………….……...7

SCORING OF THE HOOT……………………………………………………11

REFERENCES…………………………………………………………....13

FORMS

1. Caregiver Intake
2. Classifications of functioning
3. Upper Extremity Reach and Range of Motion Chart
4. HOOT Description and Instructions
5. HOOT Systematic Observation Score Form

THE HAND-OBJECT OBSERVATION TOOL (HOOT) DESCRIPTION

The HOOT is a performance-based measure of upper extremity functioning in children with bilateral cerebral palsy (BCP), Gross Motor Function Classification System (GMFCS) III, IV, and V (Rosenbaum et al., 2008). The current version of the HOOT is a 10-item tool that has been developed for children and youth between the ages of 5 and 14. The assessment is composed of 10 items in which the child reaches, manipulates, and places objects to engage in play, educational, and self-care activities. Total task completion time and errors are measured during the activities, when presented in three locations on a table or tray. Administration is video-recorded and scored via video observation and score form. The HOOT can be utilized by occupational therapists, physical therapists, and/or researchers in movement science to measure upper extremity performance. This assessment will additionally provide clinicians with a clinical tool to systematically observe hand-object interaction and may be used as an outcome measure to evaluate upper extremity functioning and object placement during daily activities.

DEVELOPMENT OF THE HOOT

A literature-supported domain framework on upper extremity movement and functioning was conceptualized to design and validate a formal observational tool hand-object interaction during daily activities, in children with BCP. More specifically, children and youth between the ages of 5 and 14, classified as GMFCS levels III, IV, and V.

Construct

The initial step in the instrument development process is to identify the construct that is being measured (Chatterji, 2003). The construct is the overarching area to be captured via the assessment tool. Once operationalized and measured, the construct is manifested as the variable along a continuum of ability. The construct can be operationalized by observing behaviors of the target population, or through a review of the scientific literature on the disorder, and by gathering information from the population that will be tested with the assessment.

The HOOT measures a single construct, upper extremity functioning or hand-object interaction, in children and youth with BCP by measuring: performance (yes/no) of task components (reach to touch object, grasp to lift object, placement, or use of object); movement time (MT) (the interval of time between initiation and completion of the task) (Magill & Anderson, 2014); and frequency of errors (drop, overshoot, and undershoot).

Purpose

The HOOT is a performance-based individual assessment developed for use in clinical or research settings. This occupation-centered assessment of upper extremity functioning is supported by established frameworks including the International Classification of Functioning for Children and Youth (ICF-CY, 2007) and the Occupational Therapy Practice Framework- third edition (OTPF-3; AOTA, 2014).

Domain and Item Specification

The *International Classification of Functioning, Disability and Health-Children and Youth Version* (ICF-CY) was designed by the World Health Organization (WHO, 2007) to provide universal language and terminology related to childhood development and the surrounding environment. This common language is intended for clinicians and researchers in clinical, research, and public health applications. The functioning domain includes body functions, activities, and participation, while the disability domain includes body impairments, activity limitations, and participation limitations. Additionally, detailed classifications and definitions for body functions and activities are provided. This framework was utilized to describe the assessment domains: (a) activity as measured by *the execution of a task or action by an individual* (WHO, 2007, p. 9); and (b) body function as measured capacity (ability to execute actions) and performance (what the child does within the natural or given environment).

The Occupational Therapy Practice Framework (OTPF-3) (AOTA, 2014) describes the domain aspects and process of occupational therapy for both occupational therapists and audiences other than clinicians. The uniform terminology, domain specification, and occupational therapy evaluation process descriptions were utilized for item generation and specification. The domain aspects are occupations (subdomains: education, play, and activities of daily living or ADL), client factors (movement-related functions), performance skills (motor and process skills), and physical environments (natural environment of community/home/school). Items were generated from occupation subdomains and related objects were identified from the literature and established standardized assessment tools: education (writing/coloring and use of technology); play (ball and board game); and ADL (feeding, drinking, hygiene/wiping face, brushing hair and managing personal care items/bag/container).

Current Version and Ongoing Instrument Development

The HOOT has been developed in partial fulfillment of the requirements for the degree of Doctor of Education at Teachers College, Columbia University. The purpose of the pilot study (IRB#18-160) was to complete the content validation process of the tool, thereby determining to what extent the domains, subdomains and indicators of the HOOT are consistent with expert opinions of levels of upper extremity functioning in children with BCP. Proportion of agreement or a content validity index (CVI) (Polit et al., 2006) was calculated and qualitative data were analyzed for word frequency, themes, and representative quotes. Inter-rater reliability and internal consistency will be further evaluated in the full study (IRB#19-095) to include tool administration in the community, scoring by the principal investigator and occupational therapists and data analysis of inter-rater reliability and internal consistency.

HOOT ADMINISTRATION

Materials

HOOT materials include: (a) video camera with SD card; (b) tripod; (c) documents (caregiver interview form, classification intake forms, instruction form, observation score forms and video release or consent form); (d) wheelchair tray/table graphed paper template; (e) tape measure; (f) stop watch; and (g) task items (personal and clinician). Task items include: touch screen tablet with coloring app; 7-inch ball; personal cup with liquid (provided by caregiver) or Echo Microphone; personal finger food (provided by caregiver) or lip-balm; napkin or tissue; personal hairbrush or comb; marker and paper; drawstring bag; three plastic containers (identical) with lid (peel); and game with at least three pieces and a board (tic-tac-toe).

Prior to Administration

1. Complete caregiver interview.
2. Determine classification levels (GMFCS, CFCS, EDACS, and MACS).
3. The child should be between 5 and 17 years of age and GMFCS level III, IV, or V.
4. Determine feeding and drinking ability, based on EDACS level, for object/task selection in items 3 and 4.
5. Evaluation of upper extremity hypertonicity, range of motion, and reach distance.
    a. *Hypertonia Assessment Tool* (HAT) (Jethwa et al., 2010)
    b. Range of motion

i. Measure bilateral upper extremity active and passive or available range of motion (shoulder, elbow, forearm, wrist and hand)

c. Reach distance

i. Measure bilateral upper extremity available reaching distance by asking the child to reach "with both hands as far as you can" to the distal end of the tray or "with both hands to the sticker." The clinician will make marks on graphed paper to designate distance, calculate and mark 75% of the available reaching range on the paper on the right and left side aligned with the acromion process. The middle location is aligned with the sternum at a middle distance of right and left locations (see Figure 1).

Figure 1. Reaching range and object placement

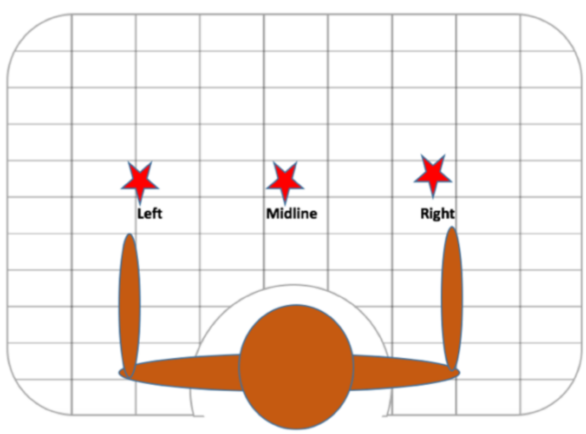

Table mat with grid: Stickers to identify object placement locations at: midline (at distance of 75% of max reach or available ROM (Butler et al., 2010); right (parallel to midline location aligned with right acromion process); and left (parallel to midline location aligned with left acromion process.

Set-up

1. The clinician will utilize a video camera on a tripod, positioned in front of the child elevated and at midline approximately 4 feet from the wheelchair, to record the performance with viewing of child head and reaching range on tray and extended at least 4 inches beyond tray or template border. The recording will begin once the camera is positioned.
2. The child will be seated, upright, in his or her wheelchair or adaptive chair, with a tray or table directly in front him/her, within the natural environment. Wheelchair tilt-angle, seat-belt, chest harness, neck and chin support, and foot straps will be utilized to standardize upright position and comfort as per caregiver or clinician familiar with the child. Positioning devices and measurements are recorded on the score form to standardize position for multiple/repeated testing.
3. A graphed wheelchair template will be placed directly in front of the child on the wheelchair tray or table. Each task is limited to one minute.
4. All task items should be placed within reach of the clinician.

Assessment Administration

Setting

Administration will take place within the child's natural environment (home, school or community environment) with caregiver, or clinician familiar with the child, present.

Instructions

Clinicians are seated or standing in front of the child (without obscuring camera view). The HOOT instruction form is utilized to adhere to item progression/standardization of item presentation and verbal instructions/prompts. Each activity begins with object placement and verbal instructions are provided as stated on the form. Clinicians utilize a timer to adhere to a 1-minute total task time limit. The child is provided with the opportunity to participate in all items. If the child does not complete the task within 1 minute, the therapist provides assistance to complete as needed.

HOOT SCORING

The HOOT is scored by utilizing a systematic observational strategy to document performance. Scoring of task performance (within 1 minute) can be documented and calculated on the instruction form. Further scoring requires video administration observation. The clinician observes the video recording of tool administration and scores task performance on the HOOT Score Form. Object presentation at each location is observed and task component performance is scored. Task components are scored as *yes* or *no*. If the child does not complete the item within 1 minute, the child receives a score of 0. Hand use is documented and errors (missed target or drop) during each task are tallied. The total score indicates a percentage of completion of total task components. Item scores can also be calculated to determine percentage of individual task completion. Total errors per item and scale are calculated and frequency of hand use (right, left, and both) per item and scale are calculated.

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Appendix C

HOOT Forms

HOOT Description and Instruction Form

HOOT Administration Instruction Form

HOOT Score Form

The Hand-object Observation Tool (HOOT): Description and Instructions for Administration and Scoring

Amanda Sarafian, MS, OTR/L

Description

The Hand-object Observation Tool is a performance-based measure of upper extremity functioning in children with bilateral cerebral palsy, Gross Motor Function Classification System (GMFCS) (Rosenbaum et al., 2008) III, IV, and V. The assessment is composed of 10 items in which the child reaches, transports, manipulates, and places objects to engage in play or self-care activities. Task component, total task completion, handedness and errors are measured during the activities, when presented in three locations on a table or tray. The HOOT can be utilized by occupational therapists, physical therapists, and/or researchers in movement science to measure upper extremity performance. The procedures for administering, scoring, and interpreting are as follows.

Instructions

Prior to set-up and administration of the HOOT, complete the following: (1) interview a caregiver or a clinician who is familiar with the child in order to establish a standardized seated position with try or at table-top and (2) determine gross motor function utilizing the GMFCS and eating and drinking ability utilizing the Eating and Drinking Ability Classification System (EDACS) (Sellers et al., 2014).

Procedures

<u>Part I: Set-up and Measurement</u>

- Standardize child position, table-top environment, and video camera position.
- Stabilize paper template on table or tray at midline location.
- Set-up tripod with camera, elevated above child's head at midline, in order to record the child's head and face, tray or table-top and reaching range.
- Evaluate active available upper extremity reaching range by instructing the child to reach to distal edge of tray, aligned with acromion process, with both upper extremities.
    - Evaluate passive range of motion or reaching range if the child does not actively reach across tray when instructed.
- Determine object placement locations, by calculating 75% of available reaching range at midline, right and left. Label locations with marker or stickers.

<u>Part II: Administration</u>

- Administer the items sequentially (1-10).
- Follow instructions regarding verbal prompts and document task completion and comments (if needed).
- Place object in (1) middle, (2) right, and (3) left locations for each item, allowing for one minute at each location, using timer.
    - Food (cracker/cookie) and drink are to be provided by parent/caregiver.
        *Children with EDACS III, IV, or V: administer alternate objects (Echo microphone and lip balm) instead of drink and food.

- Place object in designated location.
- If not completed within one minute, provide assistance to complete as needed or preferred.

Part III: Scoring via video recording observation

- Complete child information on score form.
- Observe video recording, pause, and re-play as needed to record scores and information, completing score form as follows.
- Score form documentation for each item.
    a. Time: utilize the time/counter on the video toolbar to determine if the total task was completed within one minute. Time is measured as follows:
        - *Onset* or beginning of task time: when the child lifts his/her hand off of the starting point (handprint necklace or identified location). If the child does not position hand on starting point, onset of movement is when the therapist instructs the child
        - *Offset* or end of task time: placement of object on self or surface or as per score form
        - If the child does not complete the task within one minute, document "no"
    b. Handedness: indicate which hand was used right (R), left (L), or both (B) for each location (middle, right, and left) per item. Document if handedness was not observed or if an item is not administered by writing an (X).
    c. Errors: tally each time the child
        - Misses the target or object as evidenced by touching the table or tray in front, beyond or to the side of the object
        - Drops the object prior to placement or completion of the task
    d. Points: record one point (1) for each task component performed and total task completion or no points (0) if the task component is not performed and if the task is not completed within one minute
    e. Posture: record "yes," if the child maintains upright posture (head, neck and shoulders in alignment) during task performance and "no" if lateral or anterior/posterior posture occurs during task performance
    f. Calculate total scores.
        - Total task component points (out of 87 available points).
        - Total task points (out of 30 available points).
        - If an item is not administered or there is an administrative error, no points (0) are recorded for the task components and total task.
    g. Signature and date.
        - Therapist signature and date of scoring

Item#	**Object**	**Instruction**	**Completed within 1 minute: write Yes or No. (Assist to complete after 1 minute)**			**Child Feedback: Did you like the activity?**		
			Middle	**Right**	**Left**	**Yes**	**It's ok**	**No**
1	Tablet	*Touch the tablet to make a color or sound*						
2	Ball	*Roll the ball*						
3	Cup or *microphone	*Drink your drink* or *Talk into the microphone*						
4	Food or *lip balm	*Eat your snack* or *Put on lip balm*						
5	Napkin	*Wipe your mouth*						
6	Brush	*Brush your hair*						
7	Marker and paper	*Make a mark on the paper*						
8	Drawstring bag (with container and game pieces inside)	*Open the bag and get the container*						
9	Container with game pieces	*Open the container*						
10	Container with game pieces and board	*Let's play*__________________. *Put a piece on the board*						

Comments:

Item	Object Location	**Task Component Points** (Yes=1; No=0) *Did the child complete the task component, within one minute, at the designated location?*							**Hand use:** right (R) left (L) both (B)	**Errors with arm targeting object:** tally		**Total task completed within one minute?** Yes=1 No=0	**Maintain Posture:** *yes* or *no*
		Touch object	Activate (A) or propel (P)	Grasp object and lift off of table	Place object on self or make mark on paper	Open bag or remove top from container	Remove item from bag	Release object on game board		Miss target	Drop		
1.Tablet	Middle	I-1.	I-2.										
	Right	I-3.	I-4.										
	Left	I-5.	I-6.										
2.Ball	Middle	I-7.	I-8.										
	Right	I-9.	I-10.										
	Left	I-11.	I-12.										
3.Cup*	Middle	I-13.		I-14.	I-15.								
	Right	I-16.		I-17.	I-18.								
	Left	I-19.		I-20.	I-21.								
4.Food*	Middle	I-22.		I-23.	I-24.								
	Right	1-25.		I-26.	I-27.								
	Left	I-28.		I-29.	I-30.								
5.Napkin	Middle	I-31.		I-32.	I-33.								
	Right	I-34.		I-35.	I-36.								
	Left	I-37.		I-38.	I-39.								
6.Hair-brush	Middle	I-40.		I-41.	I-42.								
	Right	I-43.		I-44.	I-45.								
	Left	I-46.		I-47.	I-48.								
7.Marker	Middle	I-49.		I-50.	I-51.								
	Right	I-52.		I-53.	I-54.								
	Left	I-55.		I-56.	I-57.								

8.Bag	Middle	I-58.		I-59.		I-60.	I-61.						
	Right	I-62.		I-63.		I-64.	I-65.						
	Left	I-66.		I-67.		I-68.	I-69.						
9.Container	Middle	I-70.		I-71.		I-72.							
	Right	I-73.		I-74.		I-75.							
	Left	I-76.		I-77.		I-78.							
10.Game	Middle	I-79.		I-80.				I-81.					
	Right	I-82.		I-83.				I-84.					
	Left	I-85.		I-86.				I-87.					
TOTAL SCORE									R: L: B:				

Appendix D

Pilot Study

Table D-1. *Relevance Rating Form*

1. Please watch the video recordings and review the completed score forms for child participants P1, P2, and P3.
2. Please read the item description and rate the relevance of the item to assess upper extremity function in children with bilateral cerebral palsy.
3. Rate: 1 = not relevant, 2 = somewhat relevant, 3 = quite relevant, and 4 = highly relevant.

#	**Purpose and Task:** Each object is placed in three locations (middle, right and left) on the tray.	**Rating (circle)**	**Qualitative Feedback** regarding rating. Please state why you rated the item accordingly, how you would modify the item/task and comment on task and item representation.
1	Purpose: To evaluate task component performance and completion time to activate a **tablet** or touch screen technology *The child will activate a single switch or tablet to make a sound.*	1 2 3 4	
2	Purpose: To evaluate task component performance and completion time to propel a **ball** from three locations on table *The child will roll or throw a ball at least 1 foot away from starting point.*	1 2 3 4	
3	Purpose: To evaluate task component performance and completion time to transport a **cup** or microphone to his/her mouth from three locations on table *The child will hold a cup and bring it to his/her mouth.* **Alternate item for children EDACS III-V:* To evaluate task component performance and completion time to transport a microphone to his/her mouth from three locations on table. *The child will hold a microphone and bring it to his/her mouth.*	1 2 3 4	

4	Purpose: To evaluate task component performance and completion time to self-feed finger food or apply lip balm to lips *The child will pick up a finger-food and place it in his/her mouth or pick up lip-balm and place it on his/her lips.* **Alternate item for EDACS III-V.* To evaluate task component performance and completion time to apply lip balm to lips *The child will pick up lip balm and place it on his/her mouth*	1 2 3 4	
5	Purpose: To evaluate hygiene task component performance and completion time *The child will pick up a napkin and place the napkin on his or her face*	1 2 3 4	
6	Purpose: To evaluate grooming task component performance and completion time *The child will pick up a brush and place the brush on his or her head.*	1 2 3 4	
7	Purpose: To evaluate coloring task component performance and completion time *The child will pick up a marker and make a mark on paper.*	1 2 3 4	
8	Purpose: To evaluate task component performance and completion time to grasp, open, and retrieve object from drawstring bag *The child will pick up a drawstring bag, sustain grasp, reach into bag and remove a small container from bag.*	1 2 3 4	

9	Purpose: To evaluate task component performance and completion time to open a container *The child will hold or stabilize container with one hand while opening the container with the contralateral hand.*	1 2 3 4	
10	Purpose: To evaluate game task component performance and completion time *The child will remove a game piece from the container and place it on the game board.*	1 2 3 4	
Please describe additional tasks to evaluate upper extremity function in individuals with bilateral cerebral palsy.			

Thank you so much for participating in the development of the assessment. Your feedback is imperative to validating the content of this assessment.

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Table D-2. *Content Validity Index*

Task	E-1	E-2	E-3	E-4	E-5	E-6	E-7	E-8	TA	I-CVI
1. Tablet	4	4	4	4	4	4	4	4	**8**	**1**
2. Ball	4	4	3		4	2	2	3	**6**	**0.75**
3. Cup	3	4	4	4	4	4	4	4	**8**	**1**
4. Food	3	4	4	4	3	4	4	4	**8**	**1**
5. Napkin	4	3	4	4	4	3	2	3	**7**	**0.875**
6. Brush	2	3	4	4	4	3	4	3	**7**	**0.875**
7. Marker	4	4	4	4	4	3	3	3	**8**	**1**
8. Bag	4	4	4	4	4	3	2	3	**7**	**0.875**
9. Container	4	4	2	3	3	3	4	4	**7**	**0.875**
10. Game	4	4	4	4	4	3	4	4	**8**	**1**
									S-CVI/AVE	**0.925**

Abbreviations: Average (AVE); Expert (E); Item Content Validity Index (I-CVI); Scale Content Validity Index (S-CVI); Total Agreement (TA)

Table D-3. *Word Frequency Table*

Word	Count	Similar Words
task	49	task, tasks
item	38	item, itemized, items
relevant	33	relevance, relevant
component	26	component, components
movement	24	movement, movements
functional	24	function, functional,
hands	24	hand, hands
grasp	21	grasp, grasping
Use	20	use, used, useful, using
children	18	children
May	17	may
reach	17	reach, reached, reaching
ability	17	abilities, ability
objects	17	object, objects

Figure D-1. Word cloud of frequently used words

Table D-4. *Thematic Data*

Item and Total Number of Sentences	Theme	Number of Sentences per Item	Representative Quotes
1. Tablet (17)	Positive comment	11	• A motivating and interesting task • This item is very relevant • Highly relevant • This is an excellent • This component is essential • This is a very important component • This is very relevant for all children's lives • I think this activity is important for participation and peer interaction • Tablets are so useful for augmentative communication and learning • I like how this item provides a simple observation
	Task Content	6	• Requires less dexterity • Assess UE function b • Testing right, middle left helps to determine best placement to encourage success with an assistive tech device • Has the ability to use upper extremity to interact with them • It should be a motivating task for most kids and can therefore maximize their performance. • Reach pattern simply gross upper extremity movement pattern
	Utility	13	• Very functional information • Because the children will rely on some form technology like an iPad for either leisure or as communicating device for many aspects of life. • Testing right, middle left helps to determine best placement to encourage success with an assistive tech device.

			• Task to evaluate the ability to activate a touch screen especially for individuals who lack grasp control • His component is essential to determining access for communication and leisure. • Everyone within the united states especially familiar with either an iPad or something similar or switches • Due to the prominence of technology • For participation and peer interaction • Tablets are so useful for augmentative communication and learning. • The ability to use upper extremity to interact with them • Is an important clinical observation to make, can therefore maximize their performance. • All kids could to some level.
	Consideration	4	• Timing may be different for a switch verses making a mark on the tablet. • Since the video only demonstrated the tablet are these items going to be interchangeable according to whom you are testing. • Wording is very important. • It was a little hard to hear on the video verses live so this maybe great as well.
	Recommendation	1	• It may be good to add or have a simple cause and effect thing happen in colors or sounds for motivation.

2. Ball (19)	Positive comment	8	• Another excellent, simple reach task • I liked the ball size. • I think this is very motivating and relevant. • The size and color of the ball are motivating. • It is nice to encourage both hands. • The placements are wonderful. • Provides increased information
	Task content	4	• Simple reach task • It gave the children a bigger target. • Does not require fine motor for this task • Or middle, left and right
	Utility	5	• For children of all ages and abilities • Assesses child's ability to move an object on wheelchair tray, acquire utensil, etc. • This is quite relevant to assess ability to push an object. • The variability of how the ball moved from the start position (especially wheelchair trays) pulled different aspects of hand/eye coordination into different trial. • Provides increased information on extension patterns and reach to target
	Consideration	6	• One of the videos had you giving the instruction "roll the ball to me." • Much more difficult than roll the ball off the table which does not include a directionality. • In case child is not motivated by a ball. • The distance of the ball's movement may not be time dependent but also strength if initiation of movement to touch is time based if not.

			• I am trying to think of other activities that this would generalize to. • It is more relevant for the younger kids.
	Recommendation	5	• Could possibly provide an alternate item. • Suggested modification: size of objects and object that doesn't roll. • if initiation of movement to touch is time based if not, require minimal distance requirement. • It may be beneficial to use a smaller ball. • Perhaps completing several trials with varying sized balls to observe reach accuracy.
3. Cup (18)	Positive comment	7	• Highly relevant • The microphone alternative is a clever modification for children EDACS III-V. • Very relevant. • The choice of either is very meaningful for children of all ages. • This activity is good. • Very relevant task to everyday life. • Very functional
	Task content	6	• I thought the reach to grasp portion of the task. • The grasp to mouth portion of the task. • Reach face for hygiene or leisure (microphone). • These movement pattern requires both upper extremity strength, coordination, and grading of movement amplitude. • Provides information on the hand to mouth patterns as well as a gross grasp of a larger item.

	Utility	6	• Very relevant to many ADLs-eating. • Essential functional task. • Ability to drink independently and from a task component perspective-ability to bring hand to mouth. • Hand to mouth movement patterns are essential in participation and development. • This activity is good to determine functional level with ADLs. • Provides information on the hand to mouth patterns as well as a gross grasp of a larger item
	Consideration	6	• The task is more variable as there is head/neck movement as compensation. • Is this universally understood? • Could modify this item to prevent need to complete both flexion (to mouth) and extension (reach) in the same item, as well as grasp (cup/microphone). • Combining all these degrees of movement increases the complexity of the task. • Regarding the task components, touching cup to lips is considered the endpoint of the task? • It makes it more comparable to microphone but is really only part way to the title "drink."
	Recommendation	2	• Could modify this item to prevent need to complete both flexion (to mouth) and extension (reach) in the same item, as well as grasp (cup/microphone). • The size of the microphone may be easier if it was smaller in diameter.

	Alternate item	3	• The microphone alternative is a clever modification for children EDACS III-V. • The microphone is a nice item for children EDACS III-V. • The microphone is great because it makes a sound.
4. Food (23)	Positive comment	11	• Love the grasp portion. • Loved watching P03S do this. • Likes how you assisted. • It is beneficial that an alternative task is given. • Highly relevant. • Great alternate items. • The food is a 4 definitely. • The lip balm is a nice exception to food. • This activity is highly relevant. • This is a critical upper extremity function for many people. • I like that it's family-provided.
	Task content	10	• Alternative task is given to self-feeding, with similar movement components. • Breaking down components of task like this helps to show what child/student can do even if they can't fully complete full functional task. • Feeding is an essential task. • Still relates to bringing something to the child's mouth. • I think this is the closest to food other than a spoon. • Is related to ADLs (feeding). • To account for individual preferences, allergies, etc. • I noticed in the video that some people pulled from a bowl and other directly from a tray. • The inclusion of increased fine motor control to finger feed.

	Utility	5	• The assessment of time to complete can show progress over time for therapy reassessment. • Helps show progress in more involved individuals (GMFCS IV, V). • Hand to mouth movement patterns are essential. • Timing and accuracy are important for functional movement. • Provides more conclusive information about functional abilities for self-help/feeding skills.
	Consideration	3	• The last patient the more significantly involved boy might not have that much intrinsic value to "lip balm" as the other children for food. • Individuals and inter-rater reliability. • I noticed in the video that some people pulled from a bowl and other directly from a tray.
	Recommendation	2	• Then a toothbrush, even a small one, may have more relevance. • Again. if possible perhaps trialing with varied foods to observe movement patterns, and ability to maintain grasp or grasp several food items at once.
	Alternate item	3	• Great alternate items. • The lip balm is a nice exception to food. • I think this is the closest to food other than a spoon.
5. Napkin (10)	Positive comment	5	• Particularly relevant to this population. • I think that this is an excellent one. • I think wiping the face is excellent. • This activity is highly relevant. • This item I like. • In a way, I prefer this because it can be more standardized.

	Task content	2	• Personal care task. • Relevant as related to ADLs.
	Utility	4	• A universal, functional task. • Personal care task that can be directly affected with repetition and measured through timing without complexity. • Even for lower upper extremity function abilities. • Many individuals can still attempt to grossly wipe their face.
	Consideration	2	• Task components are redundant with items 3 and 4 (bringing hand to face). • Different, the practical aspects of task completion for this item is the same as #4 if including food going into mouth is not part of #4.
	Recommendation	4	• Would add swiping napkin side to side. • Consider replacing with a task that involves asymmetrical independent use of both hands. • Noted by the second girl wiping the face or even her lap tray might be another place which would work well. • Children are asked to wipe their tray or a table to help out.
6. Brush (12)	Positive comment	4	• This is a nice functional task. • This activity is highly relevant. • This is relevant to daily life. • Very good.
	Task content	3	• This component also incorporates shoulder flexion, abduction and external rotation which is not found in any other component. • The size of the brush handle involved greater range of motion for the arm relative to other tasks which is nice to evaluate.
	Utility	1	• This item allows observation of increased gross upper extremity reach coordination.

	Consideration	6	• In my experience, so many children dislike this task so there is less motivation and lots of compensatory head/neck movement. • Since just bringing the brush to the head is not fully functional. • Pulling the brush through the hair is the more important and unique feature of hair-brushing. • On this test, other items measure item to head/face. • Limited to individuals that have hair that requires brushing. • Should there be any component of the correct orientation of the brush or is that the same as secure in hand?
	Recommendation	2	• Would like to see added component of pulling brush through hair. • Consider modifying with comb for short hair or task that simulates washing head and scalp.
7. Marker (16)	Positive comment	7	• A universally accepted and motivating task. • Highly relevant. • This component is purposeful. • This was very good and easy for children. • This activity is relevant for the age group evaluated. • However, the value of this skill for creative/recreation pursuits is relevant. • Very functional.
	Task content	4	• Requires more refined grasp and motor planning. • Coloring and drawing is essential functional task. • Doesn't require completion of specific written letter or words. • I feel it shows an increased level of manipulation of object.

	Utility	2	• This item addressed all necessary components of making a mark on paper. • Can be important for first stage/step to movement quality for grasp and tool use.
	Consideration	3	• I was just curious how you came up with the size of the marker for coloring. • Especially with #1 and prevalence of technology, the necessity of coloring on paper seems limited for everyday life. • Should starting position of marker be standardized?
	Recommendation	1	• Consider modifying by using wider markers for individuals that have difficulty grasping narrow objects.
8. Draw-string bag (14)	Positive comment	6	• Excellent bimanual assessment. • This is highly relevant. • The bag is also interesting. • This is great to have them open this up. • This would be great for bilateral assistance from the more involved upper extremity.
	Task content	5	• This is the first mandatory bilateral item tested. • It incorporates multiple movements and varied movements unilaterally in a bilateral task completion. • Has a lot of intrinsic value for a child to want to open. • I think this is the one the participant will need help. • Some of the strategies (shaking) were successful without the last 2 components on the score sheet.

	Utility	2	• The ability of the child to adapt if the child is not able to do bilateral tasks. • Shows if attempts at bimanual and bilateral coordination skills are attempted.
	Consideration	9	• Removing the object can be a separate item. • This is the first mandatory bilateral item tested. • The items could be clarified, for example, sustain grasp on bag vs. sustain grasp on the item they are retrieving. • Removing the container from the drawstring bag appears awkward and difficult for children with higher hand function (#1). • This task is complex and requires multi-step completion. • It incorporates multiple movements and varied movements unilaterally in a bilateral task completion. • This activity was less relevant in relation to the others. • I think this is the one the participant will need help or “cheat” using the chest or anchoring. • It didn’t seem like everyone reached into the bag for retrieval- some of the strategies (shaking) were successful without the last 2 components on the score sheet.
	Recommendation	4	• Maybe just “pick up the bag and open it”? • Removing the object can be a separate item. • Sustain grasp on bag vs. sustain grasp on the item they are retrieving. • Consider easier to remove objects (ball or cube).

9. Container (16)	Positive comment	6	• Another excellent bimanual. • Opening containers is quite relevant. • So it important to be assessed. • Motivating and functionally relevant. • The activity itself is relevant. • Of key importance when describing upper extremity function.
	Task content	3	• If it is a twist to open, there would likely be an additional component: example: 1. Reach; 2. Stabilize and grasp with opposite; 3. Twist; 4. Pull top off. • May be directly impacted by vision but does directly test pinch strength and bilateral coordination. • The ability to stabilize with one arm and mobilize with another.
	Utility	1	• This activity is also very motivating for most children.
	Consideration	8	• Requires an additional visual component in finding the tab to pull. • These are separate movements even if almost simultaneous. • However, these particular containers may be challenging for many individuals in this cohort. • The fine motor movements required may limit success for all participants GMFCS I-V. • This is not an easy task to complete due to the smallness of the container opening. • How would this be differentially scored if it is opened by using one hand such as one of the children in the video who squeezed it open. • This item and the next may be frustrating for MACS level IV/V. • Why does the score sheet specify reaching with both hands?

	Recommendation	3	• I would clarify more about the container: is it a pull to open? Or a twist. • Consider modifying to items with removable lids (bamboo storage/ salt box, bed and bath or magnets. • By varying containers and lids will also show varying distal upper extremity skill.
10. Game (15)	Positive comment	6	• Great motor skill information from this task. • Highly relevant. • I like how you switched the directions to place the game piece on the board or play the game. • I think its relevance would be very high for playing a game. • The activity itself is relevant. • I like the recreation aspect of this construct.
	Task content	4	• Sshows bimanual coordination as well as showing manipulation skills and strength. • Requires two targeted upper extremity movements within a single item. • The directions would have to include play the game or place the piece on the board which may change the "time factor." • Refined grasp patterns.
	Utility	1	• Shows in-hand manipulation skills and grading.
	Consideration	6	• Another one that may break down from cognitive or visual impairment. • I think it's ok to have some items with three and some with four components? • Consider modifying components for individuals who lack ability to grasp small objects. • The directions may need to be the same for all students no matter. • This item and the next may be frustrating for MACS level IV/V.

			• The score sheet states they should reach into the container but not all participants did.
	Recommendation	3	• I would add a step to place/release the game piece. • I think it should also include a release component. • Possibly like TGMD-2?

Appendix E

Informed Consent and Assent

Teachers College, Columbia University
525 West 120th Street
New York NY 10027
212 678 3000

PARENTAL PERMISSION FORM

Protocol Title: Reliability evaluation of the Hand-object Observation Tool (HOOT)
Principal Investigator: Amanda Sarafian, MS, OTR/L, Teachers College, aje6@tc.columbia.edu

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INTRODUCTION
Your child is being invited to participate in this research study called “Development and validation of an observation based assessment of upper extremity function or hand-object interaction during daily activities, in children diagnosed with bilateral cerebral palsy Gross Motor Function Classification System (GMFCS III, IV, and V)”. Your child may qualify to take part in this research study because they are diagnosed with quadriplegic or bilateral cerebral palsy and between the ages of 5 and 14 years old. Approximately ten children will participate in this study and it will take approximately one hour of your child’s time to complete. Occupational therapists, who have expertise working with individuals with cerebral palsy, will participate in scoring the video in order to evaluate the reliability of the assessment tool.

WHY IS THIS STUDY BEING DONE? The purpose of this study is to (1) administer the Hand-object observation tool (HOOT) to 10 children with cerebral palsy and (2) to evaluate the reliability of the scores generated by three clinician raters.

WHAT WILL MY CHILD BE ASKED TO DO IF I AGREE THAT MY CHILD CAN TAKE PART IN THIS STUDY?
If you decide to allow your child to take part in this study, your child will participate in 10 daily activities, while seated in his/her wheelchair at a table or with wheelchair tray. The principal investigator, participant, caregiver and/or clinician who is familiar with the child will be present throughout Phase I of the study. The initial observation of the participant and gathering information, from a caregiver and/or clinician familiar with the child will take approximately 10 minutes. Set-up of the participant, video camera and objects will take approximately 5-10 minutes. Administration of the tool will take 10-30 minutes, depending upon the participants’ level of upper extremity function. The assessment consists of 10 items with a three-minute time limit each. Clean-up will take approximately 5-10 minutes. Therefore, the total study duration for each child participant is 45-60 minutes.

Prior to administration of the assessment, an initial interview will be completed with you and/or your child's occupational therapist. The principal investigator will provide education and instruction regarding the assessment activities and video. Additionally, the PI will interview you and your child regarding background information, diagnosis, classification of function (gross motor, fine motor, communication and feeding) and precautions. The PI will then evaluate muscle tone and arm movements (reaching and passive movement) and positioning in a preferred chair or wheelchair.
Your child will be video-recorded. A videorecorder will be positioned in front of your child to provide downward viewing of your child's reaching space. Recording will begin once your child is positioned, with tray and object placement location determined. Video recording will be terminated once the last item or activity is completed. If you do not wish your child to be video-recorded, your child will not be able to participate in the study.
You will be asked to assist with positioning your child at the seat angle and with positioning accessories that are typically used during daily activities. A paper template will be placed on your child's tray or table to standardize placement of objects and for video observation of reaching range and movements.
The assessment consists of ten items or activities. Each activity is presented in three locations on the tray to observe hand use and reach when objects are placed in the middle, right and left. Your child will be given a standardized instruction (as follows) to engage in the task. They are not required to participate for any length of time, but rather interact with the object within one minute. If your child does not interact with the object, the PI will assist your child with completing the activity, if he/she indicate interest. The eating and drinking task require use of personal food and cup with drink. If your child does not eat crackers and/or drink from a cup, or you would prefer that he/she refrain from eating and/or drinking, there are alternate activities for your child to participate in. The items are (1) *touch the iPad to make a sound*; (2) *roll the ball to me*; (3) *drink from the cup* or *sing into the microphone*; (4) *eat a cracker* or *put on lip balm*; (5) *wipe your mouth*; (6) *brush your hair*; (7) *color with the marker*; (8) *open the bag*; (9) *take the game out of the bag*; (10) Let's play tic-tac-toe, *put a piece on the board*.

WHAT POSSIBLE RISKS OR DISCOMFORTS CAN MY CHILD EXPECT FROM TAKING PART IN THIS STUDY?

This is a minimal risk study, which means the harms or discomforts that your child may experience are not greater than what your child would ordinarily encounter in daily life while taking routine physical or psychological examinations or tests. Your child might want to continue engaging in an activity rather than proceeding to the next item or become bored. Your child does not have to complete each item or participate in each activity if they don't want to. Participation in this study is voluntary and therefore, your child can stop participating in the study at any time without penalty. The principal investigator is taking precautions to keep your child's information confidential and prevent anyone from discovering their identity, such as using a pseudonym (or code) instead of their name and keeping all information on an encrypted and password protected computer or server and locked in a file drawer.

WHAT POSSIBLE BENEFITS CAN MY CHILD EXPECT FROM TAKING PART IN THIS STUDY?

There is no direct benefit to your child for participating in this study.

WILL MY CHILD BE PAID FOR BEING IN THIS STUDY?

Your child will not be paid to participate but they will receive a small toy or game such as ball toy or playing cards (approximately $5.00 value). There are no costs to you for your child taking part in this study.

CAN MY CHILD LEAVE THE STUDY BEFORE IT ENDS?

The study is over when your child has completed the 10 activities and provides feedback regarding like/dislike. Your child can leave or terminate the study at any time even if they haven't finished. They will still receive the toy or game.

PROTECTION OF YOUR CHILD'S CONFIDENTIALITY

The investigator will keep all written materials locked in a desk drawer in a locked office. Any electronic or digital information (including video recordings) will be stored on a computer and flash-drive that is encrypted and password protected. There will be no record matching your child's real name with their pseudonym or code. Research data concerning children will be kept for five years.

HOW WILL THE RESULTS BE USED?

The results of this study will be published in journals and presented at academic conferences. Your child's name or any identifying information about your child will not be published. This pilot study is being conducted as part of the dissertation of the principal investigator.

CONSENT FOR AUDIO AND VIDEO RECORDING

Audio and video recording is part of this research study. You can choose whether to give permission for your child to be recorded. If you decide that you don't wish your child be recorded, they will not be able to participate in this research study.

______I give my consent for my child to be recorded ___________________________

Signature

______I **do not** consent for my child to be recorded ____________________________

Signature

WHO MAY VIEW MY CHILD'S PARTICIPATION IN THIS STUDY

____I consent to allow my child's written, video and/or audio taped materials viewed at an educational setting or at a conference outside of Teachers College.

____
Signature

_____I **do not** consent to allow my child's written, video and/or audiotaped materials viewed outside of Teachers College Columbia University.

____
Signature

OPTIONAL CONSENT FOR FUTURE CONTACT
The investigator may wish to contact you in the future. Please initial the appropriate statements to indicate whether or not you give permission for future contact.

I give permission to be contacted in the future for research purposes:

Yes _________________________ No________________________
Initial Initial

I give permission to be contacted in the future for information relating to this study:

Yes _________________________ No________________________
Initial Initial

WHO CAN ANSWER MY QUESTIONS ABOUT THIS STUDY?
If you have any questions about the study or your child's taking part in this research study, you should contact the principal investigator, Amanda Sarafian at aje6@tc.columbia.edu.
If you have questions or concerns about your child's rights as a research subject, you should contact the **Institutional Review Board** (IRB) at 212-678-4105 or email IRB@tc.edu. Or you can write to the IRB at Teachers College, Columbia University, 525 W. 120th Street, New York, NY 10027, box 151. The IRB is the committee that oversees human research protection at Teachers College, Columbia University.

PARTICIPANT'S RIGHTS

- I have read and discussed the informed consent with the investigator. I have had ample opportunity to ask questions about the purposes, procedures, risks and benefits regarding this research study.
- I understand that my child's participation is voluntary. I may refuse to allow my child to participate or withdraw participation at any time without penalty to future services that my child would otherwise receive. I understand that my child may refuse to participate without penalty.
- The investigator may withdraw my child from the research if the child refuses to be videotaped or exhibits signs of discomfort or distress.
- If, during the course of the study, significant new information that has been developed becomes available which may relate to my willingness to allow my child to continue participation, the investigator will provide this information to me.
- Any information derived from the research study that personally identifies my child will not be voluntarily released or disclosed without my separate consent, except as specifically required by law.
- I should receive a copy of the Informed Consent document.

My signature means that I agree to allow my child participate in this study

Child's name: **____**

Print Parent or guardian's name: **______________________________________**

Parent or guardian's signature: ____

Date: **____________________**

Teachers College, Columbia University
525 West 120th Street
New York NY 10027
212 678 3000

Assent Form for Minors

Protocol Title: Reliability evaluation of the Hand-object Observation Tool (HOOT)
Principal Investigator: Amanda Sarafian, MS, OTR/L, Teachers College, aje6@tc.columbia.edu

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You will be participating in research so that we can understand how you reach and pick up objects on your tray or table. I am going to measure how far you can reach across your tray or table and then we will do the activities in these pictures (iPad, ball, cup or microphone, cracker or lip balm, wipe face, brush hair, open bag, play tic-tac-toe). I will also have a video-camera recording what we are doing. It will take about 10 minutes to set up the camera and activities and about 3 minutes for each activity. Therefore, you will be participating in this research for about 45 minutes.

I________________________ (child's name) agree to be in this study, titled Reliability evaluation of the Hand-Object Observation Tool (HOOT). What I am being asked to do has been explained to me by Amanda Sarafian. I understand what I am being asked to do and I know that if I have any questions, I can ask Amanda Sarafian at any time. I know that I can quit this study whenever I want to and it is perfectly OK to do so. It won't be a problem for anyone if I decide to quit.

Name: ____
Signature: ____
Witness: ____
Date: _______________

Investigator's Verification of Explanation

I certify that I have carefully explained the purpose and nature of this research to _______________________________ in age-appropriate language. He/she has the opportunity to discuss it with me and knows that they can stop participating at any time. I have answered all of their questions and this minor child has provided the affirmative agreement (assent) to participate in this research study.

Investigator's Signature ________________________________Date _______________

Teachers College, Columbia University
525 West 120th Street
New York NY 10027
212 678 3000

INFORMED CONSENT

Protocol Title: Reliability of the Hand-object Observation Tool (HOOT)
Principal Investigator: Amanda Sarafian, MS, OTR/L, Teachers College, aje6@tc.columbia.edu

---

INTRODUCTION

You are being invited to participate in this research study called "Reliability of the Hand-object Observation Tool (HOOT)." You may qualify to take part in this research study because you are an occupational therapist currently working with children ages 5 to 17 years old. Approximately five occupational therapists will participate in this study and it will take approximately two hours of your time to complete.

WHY IS THIS STUDY BEING DONE?

This study is being done to complete the validation process of tool development. Scoring of via recorded tool administration, by occupational therapists, is needed to determine if the assessment scores produced by inter-raters remain consistent irrespective of the rater and if the items consistently measure the same construct, upper extremity functioning.

WHAT WILL I BE ASKED TO DO IF I AGREE TO TAKE PART IN THIS STUDY?

If you decide to participate, you will receive education regarding the assessment tool and be asked to do the following: receive education regarding the assessment tool; read the manual and score forms; watch video-recordings of tool administration and complete a score form for each child observed. You will be given a de-identified code in order to keep your identity confidential. This will take place via email, phone discussion and video observation and survey completion on an encrypted and password protected server.

WHAT POSSIBLE RISKS OR DISCOMFORTS CAN I EXPECT FROM TAKING PART IN THIS STUDY?

This is a minimal risk study, which means the harms or discomforts that you may experience are not greater than you would ordinarily encounter in while completing survey research. You **do not have to answer any questions that you do not want to and you can stop participating in the study at any time without penalty.** The principal investigator is taking precautions to keep your information confidential and prevent anyone from discovering or guessing your identity, such as using a de-identified code-explain instead of your name and keeping all information on a password protected computer and locked in a file drawer.

WHAT POSSIBLE BENEFITS CAN I EXPECT FROM TAKING PART IN THIS STUDY?

There is no direct benefit to you for participating in this study. Participation may benefit the field of evaluation and measurement of performance and participation in daily activity performance and functional object use in children with quadriplegic cerebral palsy.

WILL I BE PAID FOR BEING IN THIS STUDY?

You will not receive payment for participating in this study. You will be offered a newly published occupational therapy textbook. There are no costs to you for taking part in this study.

WHEN IS THE STUDY OVER? CAN I LEAVE THE STUDY BEFORE IT ENDS?

The study is over when you have completed and submitted the HOOT score forms. However, you can terminate the study at any time even if you haven't finished.

PROTECTION OF YOUR CONFIDENTIALITY

The investigator will store electronic or digital information on a computer and server that is encrypted and password protected. There will be no record matching your real name with your de-identified code. The master list identifying the subject is kept locked and separate from the list of codes.

HOW WILL THE RESULTS BE USED?

The results of this study will be published in journals and presented at academic conferences. Your name or any identifying information about you will not be published. This study is being conducted as part of the dissertation of the principal investigator. Data will be analyzed to evaluate inter-rater reliability and internal consistency of the HOOT.

WHO MAY VIEW MY PARTICIPATION IN THIS STUDY?

___I consent to allow written materials viewed at an educational setting or at a conference outside of Teachers College.

____

Signature

___I **do not** consent to allow written materials viewed outside of Teachers College Columbia University.

____

Signature

OPTIONAL CONSENT FOR FUTURE CONTACT

The investigator may wish to contact you in the future. Please initial the appropriate statements to indicate whether or not you give permission for future contact.

I give permission to be contacted in the future for research purposes:

Yes ______________________ No______________________
Initial Initial

I give permission to be contacted in the future for information relating to this study:

Yes ______________________ No______________________
Initial Initial

WHO CAN ANSWER MY QUESTIONS ABOUT THIS STUDY?

If you have any questions about taking part in this research study, you should contact the principal investigator, Amanda Sarafian at aje6@tc.columbia.edu or 212-305-1652. You can also contact the faculty advisor, Dr. Dimitropoulou at kd2524@cumc.columbia.edu If you have questions or concerns about your rights as a research subject, you should contact the Institutional Review Board (IRB) (the human research ethics committee) at 212-678-4105 or email IRB@tc.edu. Or you can write to the IRB at Teachers College, Columbia University, 525 W. 120th Street, New York, NY 1002. The IRB is the committee that oversees human research protection for Teachers College, Columbia University.

PARTICIPANT'S RIGHTS

- I have read and discussed the informed consent with the researcher. I have had ample opportunity to ask questions about the purposes, procedures, risks and benefits regarding this research study.
- I understand that my participation is voluntary. I may refuse to participate or withdraw participation at any time without penalty.
- The researcher may withdraw me from the research at his or her professional discretion.
- If, during the course of the study, significant new information that has been developed becomes available which may relate to my willingness to continue my participation, the investigator will provide this information to me.
- Any information derived from the research study that personally identifies me will not be voluntarily released or disclosed without my separate consent, except as specifically required by law.
- I should receive a copy of the Informed Consent document.

My signature means that I agree to participate in this study

Print name: ____ **Date**: _______________

Signature:
____

Teachers College, Columbia University
525 West 120th Street
New York NY 10027
212 678 3000

VERBAL ASSENT SCRIPT
For minors 5 to 10-years old

My name is Amanda Sarafian and I am a student at Teachers College at Columbia University. I am doing a study to learn about how you use your arms and hands while playing, learning, and taking care of yourself. I am asking you to take part in the study because you have cerebral palsy. I'm going to show you pictures and explain what you will do.

If you want to be in this study, you will do the 10 activities in the pictures. You will sit in your wheelchair comfortably with your tray or at the table. There will also be a video-camera recording what we are doing. You do not have to do any activity that you don't want to or you can stop at any time. It will take about 10 minutes to set up the camera and activities and about 3 minutes for each activity. Therefore, you will be participating in this research for about 45 minutes.

I talked to your parents and therapist about these activities and they said you can do them if you want to. But you can say "No" if you don't want to be in the study. It's ok to start and then stop, if you don't want to do it. We will not be mad at you.

Thank you for listening to me.

Do you want to be in the study? (utilize communication device or present yes/no cards if expressive communication difficulty)
Do you have any questions about what I just said? (utilize communication device or present yes/no cards if expressive communication difficulty)

Appendix F

Activity Images

<table>
<tr><td>1.</td><td>I-pad or touch screen device</td><td colspan="2">Insert image of touch-screen tablet</td></tr>
<tr><td>2.</td><td>Roll the ball</td><td colspan="2">Insert image of ball</td></tr>
<tr><td>3.</td><td>Drink
*Personal cup provided by caregiver
*Alternate item:
Echo Microphone</td><td>Insert image of a cup</td><td>Insert image of a toy microphone</td></tr>
<tr><td>4.</td><td>Eat
*Preferred finger food prepared by caregiver
*Alternate item:
lip Balm</td><td>Insert image of finger food</td><td>Insert image of lip-balm</td></tr>
<tr><td>5.</td><td>Clean mouth</td><td colspan="2">Insert image of napkin</td></tr>
<tr><td>6.</td><td>Brush hair</td><td colspan="2">Insert image of brush or comb</td></tr>
<tr><td>7.</td><td>Color with the marker</td><td colspan="2">Insert image of marker</td></tr>
<tr><td>8.</td><td>Open a string bag</td><td colspan="2">Insert image of drawstring bag</td></tr>
<tr><td>9.</td><td>Take game pieces out of container</td><td colspan="2">Insert image of plastic container with lid</td></tr>
<tr><td>10.</td><td>Board game</td><td colspan="2">Insert image of board game</td></tr>
</table>

COMMUNICATION CARDS

YES	NO

LIKE

DON'T

LIKE