Assessment Tools and Classification Systems Used For the Upper Extremity in Children With Cerebral Palsy

Lisa V. Wagner MHS, OTR/L, Jon R. Davids MD

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Abstract

Background Clinicians interested in assessment and outcome measurement of upper extremity (UE) function and performance in children with cerebral palsy (CP) must choose from a wide range of tools.

Questions/purposes We systematically reviewed the literature for UE assessment and classification tools for children with CP to compare instrument content, methodology, and clinical use.

Methods We searched Health and Psychosocial Instruments (HaPI), US National Library of Medicine (PubMed), and Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus) databases (1937 to the present) to identify UE assessment and outcomes tools. We identified 21 tools for further analysis and searched HaPI, PubMed, CINAHL Plus, and Google Scholar (<http://scholar.google.com/schhp?tab=ws>) databases to identify all validity and reliability studies, systematic reviews, and original references for each of the 21 tools.

Results The tools identified covered ages birth to adulthood. International Classification of Functioning, Disability and Health domains addressed by these tools included body function, body structure, activities and participation, and

environmental factors. Eleven of the tools were patient or family report, seven were clinician-based observations, and three tools could be used in either fashion. All of the tools had published evidence of validity. Nine of the tools were specifically designed for use in subjects with CP. Two of the tools required formal certification before use. Ten of the tools were provided free of charge by the investigators or institution who developed them.

Conclusions Familiarity with the psychometric and clinometric properties of assessment and classification tools for the UE in children with CP greatly enhances a clinician's ability to select and use these tools in daily clinical practice for both clinical decision-making and assessment of outcome.

Introduction

The paradigm of evidence-based medicine is built on the foundation of outcome assessment [43, 70]. Information on outcomes derived from assessment tools and classification systems may be used to guide treatment planning, measure the efficacy of an intervention, discriminate between subjects, and determine the natural history of a disease process. In pediatric orthopaedics, outcome assessment has historically focused on technical domain outcomes such as skeletal alignment as measured from plain radiographs. However, in the last 15 years, it has been recognized that outcome assessment in multiple domains (technical, functional, satisfaction, and cost) is essential [6].

The International Classification of Functioning, Disability and Health (ICF) provides a standard language and framework for the description of health and health-related states [68]. The ICF emphasizes the importance of measuring or addressing an individual's function not only in

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L. V. Wagner, J. R. Davids (✉)
Motion Analysis Laboratory, Shriners Hospital for Children,
950 West Faris Road, Greenville, SC 29605, USA
e-mail: jdavids@shrinernet.org

terms of body structure and function, but also in terms of activities, participation, and environmental factors. Optimal outcome assessment tools should therefore consider the multidimensional nature of function as described by the ICF and measure these multiple facets [14]. Clinicians interested in evaluation and treatment of the upper extremity in children with cerebral palsy (CP) must choose from a wide range of assessment tools and classification systems. Both types of instruments may be used for outcome assessment in multiple domains.

Choosing the correct instrument may be a complex undertaking and should be based on a variety of factors. This process is greatly facilitated by knowledge of instrument content, methodology, and clinical use [60].

The purposes of our review are to (1) identify the characteristics of the most commonly used assessment tools for the upper extremity (UE) in children with CP; and (2) provide a framework for determining which of these tools are appropriate for assessment, classification, and measurement of outcome for the UE in children with CP.

Search Strategy and Criteria

In May 2010, we conducted literature searches to identify all available UE outcome measures in children with CP. The following electronic databases were used for the literature searches: Health and Psychosocial Instruments (HaPI) database (1985 to April 2010), US National Library of Medicine (PubMed) database (1947 to the present), and Cumulative Index to Nursing and Allied Health Literature (CINAHL Plus) database (1937 to the present).

In the HaPI database, the phrase “cerebral palsy” was searched as a Measure Descriptor (.md), Sample Descriptor (.sd), and combined with the phrase “upper extremity” to search all fields (.af). In PubMed, the MeSH terms Upper Extremity, Cerebral Palsy, and Outcome Assessment (Health Care) were searched and combined using the Boolean operator “AND” in the search strategy. A keyword search was also conducted in PubMed to capture citations that were “in process” or “supplied by publisher” and had not yet been assigned MeSH terms. The keywords “outcome,” “measures,” “cerebral,” “palsy,” and “upper” were combined using the Boolean operator “AND” with the citation status subsets “publisher [sb]” and “in process [sb].” In CINAHL Plus, the CINAHL Headings Cerebral Palsy, Upper Extremity, and Outcome Assessment were searched and combined using the Boolean operator “AND” in the search strategy. Reference lists from key studies were also reviewed to identify any additional studies not included in the databases listed. Forty-seven UE, CP, assessment, and/or classification tools were identified (Fig. 1).

The 47 tools identified by the initial literature search were reviewed by the authors. Exclusion criteria included duplication, subject age, ICF domain, and subject diagnosis. Eighteen tools were selected for inclusion. In June 2010, e-mail communication was initiated with two occupational therapists (VC, WT); one was a certified hand therapist and both had years of clinical and research experience in the assessment and treatment of the UE in children with CP. Each therapist was asked to review the list of tools for approval as well as any suggestions for additional tests. Three additional tools were suggested. Twenty-one tools were ultimately selected for inclusion and review in the current study (Table 1).

In June and July 2010, further literature searches were conducted for each of the 21 selected outcome tools using the HaPI (1985 to April 2010), PubMed (1947 to the present), CINAHL Plus (1937 to the present), and Google Scholar (<http://scholar.google.com/schhp?tab=ws>) databases with the goal of identifying and retrieving all validity and reliability studies, systematic reviews, and original references for each tool. Keyword and phrase searching in all fields as well as the title and/or text word fields were used in all databases using the title of each tool and combining the terms in the titles using the Boolean operator “AND.” The Advanced Scholar Search was used in searches of the Google Scholar database. Reference lists from key studies were reviewed to identify any additional references not included in the databases listed. One hundred forty-two articles were ultimately selected for analysis. Abstracts and full text, when available, of all citations were reviewed to determine whether the studies should be classified as validity/reliability studies, original references, or systematic reviews. A reference list was then prepared listing each tool along with citations for the original reference, reliability/validity studies, and systematic reviews.

The literature for each tool was evaluated in a standardized fashion, and each instrument was characterized with respect to content, methodology, and clinical use [60]. Content assessment considered tool type (clinician-based outcome versus patient-reported outcome), target population (generic versus disease-specific), ICF domain (body function, body structure, or activity and participation), administration, and scoring. Methodology assessment considered content validity (how adequately the instrument reflects its purpose, usually based on review by a panel), construct validity (quantitative assessment of the extent to which practical tests developed from a theory actually measure what the theory says they do), criterion validity (correlation with a gold standard measure of the same topic or theme), and reliability (ability of a test to measure something the same way twice, eg, test-retest, intraobserver, and interobserver). Clinical utility assessment considered the ease of and time required for administration

Fig. 1 Results of search for upper extremity evaluation tools for patients with cerebral palsy. UE = upper extremity; CP = cerebral palsy; ICF = International Classification of Functioning, Disability and Health.

of the tool, the training required, and the cost of the tool. We categorized the 21 UE assessment and classification tools selected for review by ICF domain and tool type (Table 1).

Results

With respect to content, the tools identified covered ages birth to adulthood (Table 2; Appendix 1). The ICF domains addressed by these tools included body function, body structure, activities and participation, and environmental factors. Eleven of the tools were patient or family report, seven were clinician-based observations, and three tools could be used in either fashion.

With respect to method, all of the tools had published evidence of validity. However, validity for two of the tools (Jebson Taylor Hand Function Test and House Scale) had been challenged by subsequent investigators [7, 8, 22, 23, 31, 61].

With respect to clinical use, nine of the tools were specifically designed for use in subjects with CP (ABILHAND, AHA, CHEQ, CPQOL, House, MACS, MUUL, PedsQLCP, and SHUEE). The remaining 12 tools were designed for use in subjects with a range of diagnoses (including CP). Two of

the tools required formal certification before use (AHA and WeeFIM). The remaining 19 tools provided instructions or training materials for self-study. Nine of the tools were provided free of charge by the investigators or institution who developed them (ABILHAND, CHEQ, CPQOL, GAS, House, MACS, PODCI, QUEST, and SHUEE). The remaining 12 tools required payment before accessing the instrument and associated materials.

Discussion

Clinicians interested in evaluation and treatment of the UE in children with CP must choose from a wide range of assessment tools and classification systems. Both types of instruments may be used for outcome assessment in multiple domains. Selection of the proper or optimal instrument by clinicians can be a daunting task. Familiarity with the psychometric and clinometric properties of an assessment or classification tool greatly enhances a clinician's ability to select and use these tools in daily clinical practice for both clinical decision-making and assessment of outcome. The purposes of this review were to (1) identify the characteristics of the most commonly used assessment tools for the

Table 1. Tool types

<i>Functional performance tests; clinician-based</i>
Assisting Hand Assessment
Box and Block
House Scale
Jebsen Taylor Hand Function Test
Melbourne Assessment of Unilateral Upper Limb Function
Quality of Upper Extremity Skills Test
Shriners Hospitals Upper Extremity Evaluation
<i>Functional and/or perception of performance test; clinician- or patient-/caregiver-based</i>
Pediatric Evaluation of Disability Inventory
WeeFim
<i>Perception of performance test; patient-/caregiver-based</i>
ABILHAND-Kids
Activities Scale for Kids
Cerebral Palsy Quality of Life
Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children
Children's Hand-use Experience Questionnaire
Child Health Questionnaire
Life Habits Assessment
Manual Ability Classification System
Pediatric Outcomes Data Collection Instrument
Pediatric Quality of Life Inventory–Cerebral Palsy Module
<i>Patient goals; clinician- and patient-/caregiver-based</i>
Canadian Occupational Performance Measure
Goal Attainment Scaling

UE in children with CP; and (2) provide a framework for determining which of these tools are appropriate for assessment, classification, and measurement of outcome for the UE in children with CP.

There are a number of specific limitations related to the literature, some related to our review, and others related to the instruments themselves. Critical analysis of the multi-dimensional nature of the assessment and classification tools and their application as instruments for outcome assessment requires expertise across multiple medical and psychosocial fields. Review of the relevant literature requires access to multiple medical and professional journals. Comparing and contrasting studies is complicated by the variable clinical, methodological, and analytical parameters used by the various journals. Our specific study was limited to evaluating instruments found in the English literature. Although the 21 tools selected for inclusion in the review were all commonly used in the literature, there may have been a possible tool selection bias based on the authors and queried experts professional backgrounds and clinical experiences. Perhaps the area of greatest challenge to investigators is related to instrument responsiveness [19, 55]. There is little in the existing literature that addresses

the fundamental issue of what change in the score of a test after an intervention is clinically important. New data collection techniques such as computer adaptive testing will allow for more efficient and effective analysis in multiple ICF domains [17]. Future analysis of existing assessment tools and classification systems, and development of new instruments, will require the use of increasingly sophisticated psychometric techniques such as Rasch analysis [2, 17, 32].

With respect to content, the tools evaluated in the current review covered a wide range of ages. The tools addressed multiple ICF domains that included body function, body structure, activities and participation, and environmental factors. The majority of the tools were patient or family reports, others were clinician-based observations, and a few could be used in either fashion.

With respect to method, all of the tools had published evidence of validity. However, the quality of validity and reliability analyses varied greatly. Some of the instruments had been extensively analyzed and established as valid and reliable, whereas others will require further testing to confirm their psychometric properties and applicability to children with CP.

With respect to clinical use, over half of the tools were designed for use in subjects with a range of diagnoses (including CP). The majority of the tools provided instructions or training materials for self-study. Just over half of the tools required payment before accessing the instrument and associated materials.

During the past 40 years many pediatric UE assessment tools and classification systems have been developed. Four important trends have been identified in the development of these instruments [26]. The first, best reflected by the ICF, is the recognition of the importance of measuring an individual's function not just in terms of body functions, but also with respect to activities and participation [68]. The second trend recognizes the importance of the caregivers in a child's life and the value of their perceptions of the child's routine functional abilities. The third trend consists of the application of increasingly sophisticated psychometric techniques to the development and interpretation of assessment and outcome measures. The final recent trend emphasizes issues related to the transition from childhood to adulthood.

Instruments should be chosen for a specific purpose and population. Clinicians may consider the following nine questions when selecting an assessment or classification tool: Content: (1) Does the tool address the question that is being considered? (2) Does the scoring algorithm provide the information that is desired? Methodology: (3) Has the instrument been validated for the target population? (4) Is the tool reliable? (5) Does the instrument have the ability to demonstrate substantial clinical changes after an

Table 2. Descriptions and assessment of tools

Tool	Age	Purpose	CB/PR	Validity	Reliability	Training	Cost	Applicability
ABILHANDS-KIDS	6–15 years	Parent describes ease or difficulty with bimanual activity performance	PR	+	+	Self-study	No charge	Designed for children with CP
AHA	18 months–12 years	Use of assisting hand in bilateral hand use activities	CB	++	++	Requires a certification process	Payment required	Designed for children with CP + BPP
ASK	5–15 years	Measures child/parent perception of actual performance of activity and potential capability of performance of activity	PR	++	+	Self-study	Payment required	Not diagnosis-specific; has been used with children with CP
B + B	6 years and older	Assesses unilateral gross manual dexterity	CB	++	++	Self-study	Payment required	Designed for any hand impairment; has limited published research with CP
CAPE/PAC	6–21 years	Measures five domains of participation and desire to participate	PR	+	+	Self-study	Payment required	Not diagnosis-specific; has been validated with CP population
CHEQ	6–17 years	Describes use of assisting hand during bimanual activities	PR	+	No	Self-study	No charge	Designed for functional limitations with one hand; original cohort designed for children with CP
CHQ	5–18 years	HRQOL as it relates to physical and psychosocial function of children	PR	++	++	Self-study	Payment required	Not diagnosis-specific; has been used with children with CP
COPM	Not age-specific	Patients identify and record perception of occupational performance	PR	++	++	Self-study	Payment required	Not diagnosis-specific; has been used with children with CP
CPQOL-Child	4–12 years	QOL in the domains of social well-being, emotional function, pain, impact of disability	PR	+	+	Self-study	No charge	Designed for children with CP
WEE FIM/FIM	0–7 years/adult	Performance of activity with respect to self-care, mobility, cognition	PR/CB	++	++	Formal training required	Payment required	Not diagnosis-specific; has been used with children with CP
GAS	Not age-specific	Patient identifies patient goals and measurement criteria	PR	++	+	Self-study	No charge	Not diagnosis-specific
HOUSE	2–20 years	Classification of spontaneous use of involved UE	CB	+	++	Self-study	No charge	Designed for children with CP
JTHFT	5 years and older	Timed test of effective hand use in everyday activities	CB	++	++	Self-study	Payment required	Not diagnosis-specific; has been used with children with CP
LIFE-H	0–13 years	Describes child's accomplishments in daily life habits	CB/PR	++	++	Self-study	Payment required	Designed for children with disabilities; has been used with children with CP

Table 2. continued

Tool	Age	Purpose	CB/PR	Validity	Reliability	Training	Cost	Applicability
MACS	4–18 years	Classification system of hand use in everyday life	PR	++	++	Self-study	No charge	Designed for children with CP
MUUL	5–15 years	Describes upper limb movement patterns	CB	++	++	Self-study	Payment required	Designed for children with CP
PEDI	6 months–7 years	Describes the patient functional level, the amount of caregiver assistance, and the modifications required to perform self-care, mobility, and social function tasks.	CB/PR	++	++	Self-study	Payment required	Designed for children who are chronically ill or disabled
PEDSQLCP	2–18 years	Measures HRQOL with respect to daily activities, school activities, movement and balance, fatigue, eating, speech	PR	+	+	Self-study	Payment required	Designed for children with CP
PODCI	2–18 years	Assesses UE function, transfers, mobility, physical function, sports, happiness, satisfaction, and expectation for treatment	PR	++	+	Self-study	No charge	Designed for children with musculoskeletal problems (including but not limited to CP)
QUEST	18 months–8 years	Describe quality of movement of the UE based on NDT theory	CB	+	++	Self-study	No charge	Designed for children with neuromotor dysfunction with spasticity (including but not limited to CP)
SHUEE	3–18 years	Assesses spontaneous functional use and segmental dynamic alignment of the involved UE	CB	+	+	Self-study	No charge	Designed for children with CP

CB = clinician-based; PR = patient report; HRQOL = health-related quality of life; QOL = quality of life; UE = upper extremity; NDT = neurodevelopmental treatment; CP = cerebral palsy; BPP = birth plexus palsy; ++ = multiple studies; + = single study.

intervention? Clinical Use: (6) Will the patients in the target population, or their caregivers, be able to complete the instrument? (7) Does the study staff have the time to administer the tool? (8) Is the training required to administer and score the instrument feasible? (9) Is the cost of the tool acceptable?

No single assessment tool or classification system instrument for the UE of children with CP comprehensively addresses all domains of the ICF. Clinicians and other investigators should recognize that a range or combination of measures may be required to evaluate UE function and perception of performance in children with CP. Instrument selection must account for the needs of the population being treated and the interventions under consideration. It is hoped that this review will facilitate the selection and use of assessment tools and classification systems in daily clinical practice, promote the critical assessment of study design in professional journal articles, and encourage the development of new and improved outcome instruments for the UE in children with CP.

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Appendix 1

ABILHAND-kids

The ABILHAND-kids is a parent questionnaire in which the parent describes the child's ease or difficulty in performing bimanual activities [55]. The ABILHAND-Kids was designed for children with CP between the ages of 6 and 15 years of age. Twenty-one items relate to everyday activities of daily living such as taking off a T-shirt, filling a glass of water, or putting on a backpack. The parent records whether the item is impossible, difficult, or easy to complete. The item is scored on the completion of the task regardless of how the item is completed. After the questionnaire has been completed, the raw score can be entered into the Web site for an online analysis. The online analysis will convert the raw scores into a linear measure of manual ability. There are 10 different score sheets with random orders of the same 21 items.

Psychometric properties of the ABILHAND-Kids have been assessed with analysis of content, criterion, construct validity, and reliability [1].

The ABILHAND-Kids is available for download at www.rehab-scales.org/evaluation-scales-in-rehabilitation.html. The online site contains information on administration, questionnaire forms as well as entry portals for raw scores.

To access the ABILHAND-Kids, a free registration process must be completed. The test packages are available in three languages.

Assisting Hand Assessment

The Assisting Hand Assessment (AHA) is a videotaped evaluation tool that describes the use of the assisting hand in activities requiring bilateral hand use [14, 15]. The AHA was designed for children with a unilateral disability between the ages 18 months and 12 years of age. The evaluation has a specific test kit comprised of standardized toys. Children between 18 months and 5 years of age participate in a play session, whereas those children between 6 and 12 years of age participate in a board game. The therapist leads the play session/game while the session is video-recorded so it can be scored later. Twenty-two components of assisting hand use are described. These items range from general use, arm use, grasp-release, fine motor adjustment, coordination, and pace of the performance. Each of these items has a four-point scale (1 = does not do; 2 = ineffective; 3 = somewhat effective; 4 = effective). These 22 item scores cumulate in a raw score that can be converted into a percentage score. The AHA has been calibrated in logits, a unit of measure from the Rasch Measurement Model [2]. A score of 22 means the hand is not used at all and a maximum score of 88 means that the hand is used effectively as a typical nondominant hand.

The AHA is a reliable and validated tool [20, 21, 32, 33]. Publications include evidence of content and construct validity; intrarater and interrater reliability; and test-retest reliability.

The AHA can be performed in a 10- to 15-minute timeframe depending on the play session of the child. The AHA is a video-based evaluation that requires additional scoring time aside from administration. The time required for scoring depends on the experience of the therapist scoring. There is a certification process to administer the AHA, which is described at www.ahanetwork.se/. This process requires attending a 3-day workshop and followup assignments for certification. The cost of the training is \$260.00 to \$320.00. The cost of a test kit is \$350.00 (\$1 US = 1.27 Euro, xrates.com August 26, 2010). The AHA manual, scoring criteria, and board game have been translated into numerous languages.

Activities Scale for Kids

The Activities Scale for Kids (ASK) is a child self-report measure of physical performance [19, 41]. The ASK was

originally designed for children between 5 and 15 years of age with musculoskeletal disorders but without major cognitive impairment. The questionnaire includes 30 items relating to personal care, dressing, other skills, locomotion, play, transfers, and standing skills. There are two versions of the ASK. The ASKp (performance measure) asks what the child “did do” in the last week. The ASKc (capability measure) asks what the child “could do” during the last week. Each item is rated on a five-point ordinal scale. For performance, the ordinal scale ranges from 4 (performs all of the time) to 0 (performs none of the time). For capability, the ordinal scale ranges from 4 (could do with no problem) to 0 (I could not). An aggregate score is achieved by summing the item ratings. Children younger than age 9 years often require someone to read the questions to them.

Psychometric properties of the ASK have been assessed with analysis of content, criterion, construct validity, and reliability [69, 70].

There is a comprehensive manual available to describe requirements for training, which can be found at www.activityscalesforkids.com. The manual states that it takes approximately 30 minutes to complete the ASK the first time and as little as 10 minutes on subsequent administrations. A license is required to use this tool, and the cost for the license varies depending on the projected use of the ASK.

Box and Blocks Test

The Box and Block is a timed test that is used to assess unilateral gross manual dexterity [37]. The Box and Block was designed for clients 6 years of age through adulthood who may or may not have any hand impairments. The Box and Block test has a standardized kit. Beginning with the dominant hand, the client has 1 minute to quickly move blocks from one side of the box, over a center divider, and place on the other side of the box. The amount of blocks that were placed on the opposite side of the box is recorded. The nondominant hand repeats the same process. There are normative data for both the impaired and non-impaired populations.

Psychometric properties of the Box and Blocks test have been assessed with analysis of content, criterion, construct validity, and reliability [37, 51].

The Box and Block can be administered in less than 10 minutes. There is no specific training required for administering this test. The Box and Block test kit comes with specific directions and verbiage for administration. The Box and Block kit can be purchased for approximately \$200.00 from various vendors.

Children’s Assessment of Participation and Enjoyment and Preferences for Activities of Children

The Children’s Assessment of Participation and Enjoyment (CAPE) is a child self-report measure of physical performance; the Preferences for Activities of Children (PAC) records the child’s desire to participate in those same activities [55]. The CAPE, a 55-item questionnaire, records various dimensions of participation and enjoyment in a wide array of child-friendly everyday activities. The CAPE and the PAC are contained in the same questionnaire booklet but can be used in isolation. The CAPE and PAC were designed for children and youth between 6 and 21 years of age. The 55 items are divided into five types of activity: Recreational, Active Physical, Social, Skill-based, and Self-improvement/Educational. The CAPE measures five dimensions of participation: have you done the activity in the past 4 months, how often, with whom, where, and how much do you like to do the activity? The PAC records if the child would not like to, sort of like to, or would really like to participate. Each dimension of participation is given an overall score. These scores can be plotted on a scale that describes aspects of participation such as if the child participates more socially versus solitary or participates in community-based versus home-based activities. The PAC has a single overall score.

Psychometric properties of the CAPE/PAC have been assessed with analysis of content, criterion, construct validity, and reliability [27, 28].

Information on the CAPE/PAC can be found online at www.canchild.ca. The CAPE/PAC can be self-administered or interview-assisted. When self-administered, the CAPE requires 30 to 45 minutes and the PAC requires 15 to 20 minutes. The interview-assisted method requires 45 to 60 minutes to complete the CAPE. The manual provides comprehensive details on how to administer the questionnaire with no formal training required [28]. The complete kit, which contains the manual, cards describing activities, and score forms, can be purchased for \$118.00. Additional score sheets can be purchased in sets of 25 forms for \$31.00.

Children’s Hand-use Experience Questionnaire

The Children’s Hand-use Experience Questionnaire (CHEQ) is a questionnaire designed for children between 6 and 17 years of age with functional limitations in one hand. The CHEQ describes the use of the assisting hand during various activities that are typically completed with two hands. The CHEQ records if a client performs the task; if yes, do they use two hands to complete the task? If two hands are incorporated in performance, then the

questionnaire uses a four-point scale to describe three components of use: how effective is grip or support of the assisting hand, how does the time to completion compare with your peers, and how bothered are you by the use of the affected hand? This questionnaire can be completed by a parent or child. The questionnaire can be completed on the Internet or printed and given to the family to complete. The Internet version is interactive and adapts the amount of questions to the response given. When the questionnaire is completed on the Internet, a report is automatically generated with responses listed per activity and charts describing the participation, the hand use, and the three components of hand use.

The CHEQ is a recently developed tool and has undergone Rasch analysis [56, 57]. There is evidence to support validity of test content and validity based on internal structure.

The CHEQ is available for download at www.chcq.se. This online site contains the interactive questionnaire and comprehensive information regarding the CHEQ. The CHEQ is available in four languages.

Child Health Questionnaire

The Child Health Questionnaire (CHQ) is a questionnaire that attempts to describe multiple aspects of health-related quality of life as it relates to the physical and psychosocial functioning of children [19, 41]. The CHQ was designed for children between 5 and 18 years of age regardless of their diagnoses. Components of the CHQ describe areas such as physical function, general health perceptions, bodily pain, self-esteem, and mental health. The CHQ has multiple versions of parent- and child-reported questionnaires. The parent or child is asked to answer items based on experiences in the last 4 weeks. The preference is for the questionnaires to be completed independently without the use of an interviewer. All questions are answered on a four-point scale.

The CHQ has been validated and established as reliable [38, 40, 52]. The literature includes evidence of content and construct validity, interrater reliability, and test-retest reliability. However, a systematic review of the literature cautioned on the use and interpretation of the CHQ with children with CP [40].

There are multiple versions of the CHQ, and the time to complete the questionnaire can take from 10 minutes to 45 minutes. There is a comprehensive manual available with purchase of the instrument [34]. The manual provides information regarding each of the versions of the instrument and includes instructions for administration. There is a fee for the CHQ. Registration at www.healthact.com is

required to obtain pricing. The CHQ has been translated into almost 70 languages.

The Canadian Occupational Performance Measure

The Canadian Occupational Performance Measure (COPM) records the patient's or caregiver's perception of the subject's occupational performance. The COPM is a semistructured, patient- and caregiver-directed interview that guides the subject in identifying problem areas in the domains of self-care, productivity, and leisure [55]. Together, the patient, caregiver, and the therapist identify a problem list. Once the problem list is created, the tasks are ordered in accordance to importance of the task for the subject. The top five tasks are then rated on two scales. First, on a scale of 1 to 10, the subject rates how well he or she completes the task. Second, on a scale of 1 to 10, the subject rates how satisfied they are with their performance of the task. After the intervention, the COPM list is reviewed and the patient or caregiver rates the same items once again on performance and satisfaction with performance. The scores are recorded and are only used to compare with the individual's scores over time. The COPM is not age-specific or diagnoses-specific.

Psychometric properties of the COPM have been assessed with analysis of content, criterion, construct validity, and reliability [35, 39].

Administration of the COPM is an interview process that can vary from 20 to 40 minutes depending on the engagement of the client in the interview process. The COPM is a standardized test and requires the purchase of a manual, which is available online at www.caot.ca/copm. The manual is comprehensive and formal training is not required. The Web site offers videos of sample administrations with different age groups. The cost of the tool is approximately \$55.50 (\$1 US = .945 CAD, xrates.com August 26, 2010). The manual can be obtained in a paper format as well as an electronic version. The COPM has been translated into over 20 languages.

Cerebral Palsy Quality of Life Questionnaire for Children

The Cerebral Palsy Quality of Life Questionnaire for Children (CPQOL-child) is a quality-of-life questionnaire that addresses the domains of social well-being, emotional well-being, participation, function, pain, and impact of disability [65]. The CPQOL-child was designed for children with CP between 4 and 12 years of age. There are two versions, a 53-question child self-report version for children between 9 and 12 years of age and a 66-question parent proxy report for children between 4 and 12 years of

age. The additional questions in the parent proxy report refer to access to services and the family's health. The questionnaires can be completed through an interview process or through paper-and-pencil report. Scoring is accomplished when data are entered into an established database as described on the Web site (www.cpqol.org). The developers are currently working on a CPQOL-teen for the adolescent population.

Psychometric properties of the CPQOL-child have been assessed with analysis of content, criterion, construct validity, and reliability [65, 66].

The CPQOL-child is available free at www.cpqol.org. The developers ask that users register and provide information concerning the purpose of the intended use and the version of the tool to be used. There is a comprehensive manual online that gives direction for administration and data entry for scoring. Currently the CPQOL-child has been translated into eight languages.

Functional Independence Measure and Functional Independence Measure for Children

The Functional Independence Measure (FIM) and the Functional Independence Measure for Children (WeeFIM) are functional and/or perception of performance measures that may be clinician- or caregiver-based [19, 25]. The FIM is for adult populations. The WeeFIM system includes modules designed to assess children birth to 7 years of age. The WeeFim is a checklist that rates the child's performance of activities with respect to the amount of assistance required to perform the tasks. There are 18 items relating to self-care, mobility, and cognition. Each of the items has specific rating guidelines that use a seven-point scale. The range of the scale is from a score of 7, being independent, to a score of 1 being totally dependent. The cumulative score ranges from 18 to 126. The WeeFIM system also includes a 0 to 3 module that rates precursors to function in children from birth to 3 years of age.

The WeeFIM system has been validated and established as reliable [45, 47, 71]. Publications include evidence of content, construct, and criterion validity; intrarater and interrater reliability; and test-retest reliability.

Use of the WeeFIM requires a contract, which may be purchased at www.udsmr.org/. Comprehensive education and training along with a credentialing process must be completed before use of the WeeFIM.

Goal Attainment Scaling

The Goal Attainment Scaling (GAS) is a patient-focused tool used to help the subject develop goals and

measurement criteria for those goals [29]. The GAS defines observable repeatable goals and definitions for meeting those goals within a specific timeframe based on a semi-structured interview between the subject and a healthcare professional. After the intervention, the therapist and subject meet to review the GAS and score the outcome. The original scoring system was based on a five-point scale. A score of 0 means the expected outcome was met, +2 the outcome exceeds expectations, and -2 the outcome is less than expected. Several authors have attempted to use the GAS process with varying scales between 3 and 7 points [59]. The GAS is not age-specific or diagnoses-specific.

The GAS has been validated and established as reliable [4, 48, 59]. Publications include evidence of content and criterion validity and interrater reliability.

Initial administration of the GAS, to identify goals and set outcomes, can take approximately 45 minutes. Retest to assess status of goal attainment can be completed in less than 10 minutes. Guidelines for the construction, administration, and scoring of the GAS are available in the literature [29].

House Scale

The House Scale is a classification of the spontaneous use of the involved UE. The House Scale was first described in a study evaluating hand function of children with a thumb in palm deformity [22]. The House Scale is designed for children with CP between 2 and 20 years of age. The House Scale uses a nine-point scale (0 to 8) of descriptors that range from does not use (0), to passive use, to active spontaneous use (8). It can be completed through observation by the patient, parent, therapist, or physician. There are no specific tasks for administration. There is no manual. A Modified House Classification (MHC) that incorporates 32 additional descriptors to the nine-point rating scale has been developed [31].

The original House Scale and the proposed MHC are reliable and valid classification tools [31, 67]. Publications include evidence of criterion validity and interrater and intrarater reliability. Psychometric testing the original House Scale suggests increased reliability when the classification system is condensed versus the complete nine categories [7].

The House Scale is a classification system and does not require any specific tasks that must be performed for assessment. There are no specific time requirements. The original article describing and using the House Scale has the classification written in a table format [22].

Jebsen-Taylor Hand Function Test

The Jebsen-Taylor Hand Function Test (JTHFT) is a timed test of effective hand use in everyday activities [23, 61].

The JTHFT was designed for children and adults 5 years of age and older. This tool is a norm-referenced test with respect to age and gender. There are seven standardized subtests that are each timed for completion with the non-dominant and dominant hand. The subject is asked to perform tasks such as turn cards over, pick up small items, and pick up large items. Each of these items has specific verbiage to use during administration. Item scores and total scores can be compared with normative tables or on reassessment can be compared with clients' own scores to measure effectiveness of change.

The assessment of JTHFT validity and reliability is controversial [8, 23, 61, 62]. Publications include evidence of content, construct, and criterion validity; interrater reliability; and test-retest reliability. However, one study concluded that the JTHFT should not be used as an outcome measure after surgical intervention as a result of poor validity and correlation studies [8].

Administration of the JTHFT requires approximately 15 to 30 minutes. There is no specific training manual. The original article describes how to fabricate the test kit [23]. Currently a standardized kit can be purchased for approximately \$320.00 through various vendors. There is controversy regarding variations in some of the test components and the effect that has on the psychometric properties (eg, the use of wooden checkers versus plastic checkers).

Assessment of Life Habits

The Assessment of Life Habits (LIFE-H) is a questionnaire that focuses on the child's accomplishments of daily life habits such as nutrition, fitness, and personal care [41, 55]. It was designed for children with disabilities from birth to 13 years of age. For each daily life habit, the subject is asked to rate both the level of difficulty when performing the life habit and the type of assistance required to perform the life habit. The respondent is also asked to rate the satisfaction with the level of accomplishment of the life habit. The scores from these subscales are combined to form a score between 0 and 9. A score of 0 means total impairment and a score of 9 means optimal social participation. There are three versions of the LIFE-H. The LIFE-H for children birth to 4 years of age consists of 71 questions distributed among 11 categories of life habits and social roles. The LIFE-H is for children from 5 to 13 years of age, long version, consisting of 198 questions distributed among 12 categories of life habits and social roles. A short version consists of 64 questions distributed among 12 categories of life habits and social roles. This questionnaire can be self-administered or completed in an interview

format. The respondent of the questionnaire can be the client, a parent, or a professional.

The LIFE-H has been validated and established as reliable [13, 36, 46]. Publications include evidence of content, construct, and criterion validity; intrarater and interrater reliability; and test-retest reliability.

This tool may be purchased from International Network on the Disability Creation Process at www.ripph.qc.ca. A user fee is required. The starter kit includes the assessment tool, 25 record forms, and initial users' rights for first 25 forms at a cost of \$160.00 (\$1US = .945 CAD, xrates.com August 26, 2010). Fees vary for subsequent forms and membership. This tool is available in French and English.

Manual Ability Classification System

The Manual Ability Classification System (MACS) is a caregiver report classification system that describes how children with CP use their hands to handle objects in everyday living activities [11]. The MACS was designed for children 4 to 18 years of age. The caregiver reports a score from Level 1 (handles objects easily and successfully) to Level 5 (does not handle objects and has severely limited ability to perform even simple actions). The levels are based on ease of manipulation of objects and the amount of assistance required to manipulate the objects. The score is designed to reflect the child's typical performance in everyday life situations.

Psychometric properties of the MACS have been assessed with analysis of content, criterion, construct validity, and reliability [11, 42, 50, 63].

The MACS can be performed in approximately 2 minutes. There is no formal training required. The MACS can be downloaded at no cost from www.macs.nu. The MACS has been translated into 19 different languages.

Melbourne Assessment of Unilateral Upper Limb Function

The Melbourne Assessment of Unilateral Upper Limb Function (MUUL) is a video-based measurement that describes unilateral upper limb movements based on activities such as reach, grasp, release and manipulation [14, 24]. The MUUL was designed for children with CP or neurologic impairment 5 to 15 years of age. There are 16 items that are administered in a standardized format. Each item has its own scoring system, which may include numerous subskills and a three-, four-, or five-point scoring system for each subskill. Within each subskill, various characteristics of movement are described such as ROM, target accuracy, and fluency. The total score that can be

obtained is 122. The score is converted to a percentage. The higher the percentage score, the greater the quality of upper limb movement.

The MUUL has been validated and established as reliable [3, 5, 30, 53, 54]. Publications include evidence of content, construct, and criterion validity; intrarater and interrater reliability; and test-retest reliability.

The MUUL can be administered in 30 minutes. The MUUL is a video-based evaluation that requires an additional scoring time of 30 minutes after administration. A training guidelines and standardized kit may be purchased at www.rch.org.au.ot.resource. The cost of the manual and kit is approximately \$708.00 (\$1 US = .887 AUD, xrates.com August 26, 2010).

Pediatric Evaluation of Disability Inventory

The Pediatric Evaluation of Disability Inventory (PEDI) is a functional and/or perception of performance assessment tool that may be completed by a caregiver or professional provider [19, 25]. The PEDI is best completed through a structured interview but can be completed through professional observation. The PEDI was designed for children between 6 months and 7.5 years of age (or older if their functional development is substantially delayed) who are chronically ill or disabled. The PEDI addresses self-care, mobility, and social function of the client by describing the functional level of the skill, the amount of caregiver assistance required, and the modifications or adaptive equipment used to complete the task. The function level of the skill is recorded as “capable” or “not capable.” The caregiver assistance needed for the skill is rated on a six-item scale that ranges from total assistance to independence. The modification scale considers the frequency that modifications are used to complete the skills. Higher functional level score and caregiver assistance score describe increased levels of independence and performance. Higher modification score describes the use of more extensive modifications to complete the task. There are normative scores that indicate the child’s performance with respect to age. In addition, there are scaled scores that indicate the child’s performance in regard to ease or difficulty of the item.

The PEDI has been validated and established as reliable [12, 18, 38, 44]. Publications include evidence of content, construct, and criterion validity; intrarater and interrater reliability; and test-retest reliability.

The PEDI takes 45 to 60 minutes to complete the instrument by interviewing parents or 20 to 30 minutes if a professional is completing it based on observations of the child. There is a comprehensive manual that describes administration with various case studies for training [18].

The cost for the manual is \$123.00; additional scoring forms are \$43.00 for a package of 25 scoring forms. The PEDI has been translated into five languages.

Currently, a computer-adapted testing version of the PEDI (PEDI-CAT) is under development [17]. The PEDI-CAT addresses the same domain areas but has enhanced the questions to create a broader and more culturally diverse assessment tool. The rating scales have been changed to a four-point functional level scale and a new responsibility scale.

Pediatric Quality of Life Inventory-Cerebral Palsy Module

The Pediatric Quality of Life Inventory-Cerebral Palsy Module (PedsQLCP) was designed to measure health-related quality of life for children 2 to 18 years of age with CP. The PedsQLCP consists of seven scales: Daily Activities, School Activities, Movement and Balance, Pain and Hurt, Fatigue, Eating Activities, and Speech and Communication. The PedsQLCP asks the respondent how much of a problem a task has been in the last month. There is a five-point response scale with a score of 0 meaning never to a score of 4 meaning almost always. Scaled scores are computed as the sum of items divided by the number of items answered. The higher the score, the higher the health-related quality of life. There are three child report versions (ages 5–7, 8–12, and 13–18 years) and four parent report versions (ages 2–4, 5–7, 8–12, and 13–18 years). The PedsQLCP is a diagnoses-specific module within the Pediatric Quality of Life Inventory (PedsQL).

Psychometric properties of the PedsQLCP have been assessed with analysis of content, criterion, construct validity, and reliability [64].

The PedsQLCP requires 10 to 15 minutes to complete. Tool materials and licensure information may be found at www.mapi-trust.org/services/questionnairelicensing/cataloguequestionnaires/84-pedql. There is a variable cost structure for the use of the PedsQL instruments. The cost varies according to the type of research in which the PedsQL is used such as academic versus commercial research and funded versus nonfunded research. Costs may include annual fees, license fees, and module fees.

Pediatric Outcomes Data Collection Instrument

The Pediatric Outcomes Data Collection Instrument (PODCI) is a perception of performance patient-reported outcome measure [19]. The PODCI consists of a norm-referenced, 108-item questionnaire that assesses upper extremity function; transfers and mobility; physical

function and sports; comfort happiness and satisfaction; and expectations for treatment. The PODCI was designed for children between 2 and 18 years of age with musculoskeletal problems. There are three formats: parent report for children (2–10 years of age), parent report for adolescents (11–18 years of age), and adolescent report (11–18 years of age). The results from the PODCI can be entered into an online score sheet that converts the results into standardized and normative scores. The PODCI was designed by orthopaedic surgeons to assess the functional health and efficacy of treatment of their patients at baseline and at followup [6].

The PODCI has been validated and established as reliable [6, 38, 49]. Publications include evidence of criterion and construct validity; intrarater and interrater reliability; and test-retest reliability.

The PODCI is available at no charge at www.aaos.org. There is no formal training required. A manual is not available. The PODCI can be administered in 10 to 20 minutes.

Quality of Upper Extremity Skills Test

The Quality of Upper Extremity Skills Test (QUEST) describes the quality of movement of the UE based on neurodevelopmental theories [14]. The validity of these theories remains controversial. The QUEST was developed for children with neuromotor dysfunction with spasticity between 18 months and 8 years of age. The QUEST concentrates on four domains: dissociated movements, grasp, protective extension, and weightbearing. The QUEST describes the child's ability to move out of pathologic patterns while performing various activities. A score of "yes" or "no" is given for completion of the movement or task within the domain. The four domain scores are summed to create a total score. The raw scores are converted to percentage scores for analysis. Higher scores represent better quality of movement. The QUEST is administered in a play context.

The QUEST has been validated and established as reliable [9, 10, 16, 58]. Publications include evidence of content, construct, and criterion validity; intrarater and interrater reliability; and test-retest reliability.

The QUEST takes approximately 45 minutes to administer. There is a manual that describes administration and scoring. The manual is available for free at www.canchild.ca/en/measure/quest.asp. There is no specific test kit. Items used for testing are typical items found in a therapy department.

Shriners Hospitals for Children Upper Extremity Evaluation

The Shriners Hospitals for Children Upper Extremity Evaluation (SHUEE) is a video-based evaluation that assesses the spontaneous functional use and the segmental dynamic alignment of the involved UE while performing 16 functional tasks [14]. The SHUEE was designed for children with CP between 3 and 18 years of age and is administered in a standardized sequence. The SHUEE is comprised of two sections. The first section records active and passive ROM in upper limbs, tone, activities of daily living performance, and the family's goals. The second section documents the scores from the video-recorded segment. The evaluator scores UE use in three components based on video analysis: the spontaneous functional analysis, dynamic positional analyses, and the grasp and release. A score is given to each subscale and converted to a percentage. The percentage is only to be used for comparison with the subject's own scores over time (ie, not for between-subject comparisons).

The SHUEE has been validated and established as reliable [7]. Publication includes evidence of construct and criterion validity and intrarater and interrater reliability.

The SHUEE can be performed in approximately 15 minutes. The SHUEE is a video-based evaluation that requires additional scoring time aside from administration. The time required for scoring ranges between 10 and 30 minutes and depends on the experience of the individual performing the scoring. There is a manual that offers training and case studies to become proficient in use of the tool. There are 1-day workshops available for approximately \$75.00, but they are not required. The SHUEE is available for free and can be obtained through the electronic supplement to the original article or by contacting the authors [7]. The SHUEE has been translated into three languages.

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