Chronic Pain Assessment Tools for Cerebral Palsy: A Systematic Review

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BACKGROUND AND OBJECTIVE: Chronic pain in children with cerebral palsy (CP) is underrecognized, leading to detriments in their physical, social, and mental well-being. Our objective was to identify, describe, and critique pediatric chronic pain assessment tools and make recommendations for clinical use for children with CP. Secondly, develop an evidence-informed toolbox to support clinicians in the assessment of chronic pain in children with disabilities.

abstract

METHODS: Ovid Medline, Cumulative Index to Nursing and Allied Health Literature, and Embase databases were systematically searched by using key terms "chronic pain" and "clinical assessment tool" between January 2012 and July 2014. Tools from multiple pediatric health conditions were explored contingent on inclusion criteria: (1) children 1 to 18 years; (2) assessment focus on chronic pain; (3) psychometric properties reported; (4) written in English between 1980 and 2014. Pediatric chronic pain assessment tools were extracted and corresponding validation articles were sought for review. Detailed tool descriptions were composed and each tool underwent a formal critique of psychometric properties and clinical utility.

RESULTS: Of the retrieved 2652 articles, 250 articles met eligibility, from which 52 chronic pain assessment tools were retrieved. A consensus among interprofessional working group members determined 7 chronic pain interference tools to be of importance. Not all tools have been validated with children with CP nor is there 1 tool to meet the needs of all children experiencing chronic pain.

CONCLUSIONS: This study has systematically reviewed and recommended, through expert consensus, valid and reliable chronic pain interference assessment tools for children with disabilities.



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Dr Kingsnorth conceptualized and designed the study, led study selection, tool critique, review and assessments of tools for inclusion, as well as substantial contributions to the draft manuscript; Ms Adler and Mr Ami participated in study selection, data acquisition, and tool critique; Ms Fay, Ms Gresley-Jones, Dr Hoffman, Mr Joachimides, Dr Mankad, and Dr Slonim participated in study selection, tool critique, review, and assessment of tools for inclusion; Dr Fehlings, Dr Hung, and Ms Provvidenza participated in the review and assessment of tools for inclusion; Ms Orava updated the search with respect to study selection, data acquisition, and drafted the initial manuscript; all authors helped shape execution of the study; and all authors approved the final manuscript as submitted.

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Chronic pain, defined as pain that persists longer than 3 months or that of the expected time to heal, is an increasingly common concern for children and adolescents with disabilities. Children with cognitive and physical impairments such as cerebral palsy (CP) are at risk for chronic pain rooted from gastrointestinal dysfunctions, musculoskeletal complications, therapeutic procedures, as well as other universal causes including trauma, infection, and common childhood pain. 2.3

CP is the most common physical disability among pediatric populations, with an incidence rate of 2 to 2.5 cases per 1000 births within the United States.⁴ It is classified as a group of permanent disorders caused by nonprogressive disturbances to the developing brain.⁵ Children with CP experience disturbances associated with behavior, cognition, communication, and perception, in addition to accompanying risk of epilepsy and musculoskeletal issues.^{5,6} The Gross Motor Function Classification System (GMFCS) is used with children with CP to classify physical function in a clinically significant manner.⁷ As the GMFCS scale moves from level I to V, a child becomes increasingly limited in their gross motor movement and more reliant on assistive equipment.7

Previous research has documented a correlation between GMFCS levels and the presence of chronic pain.8 Children with more severe motor impairments may experience pain stemming from musculoskeletal changes (eg, hip subluxation/ dislocation, fragility fractures secondary to a reduction in bone mass), neurologic issues (eg, hypertonia, spasticity, dystonia), gastrointestinal issues (eg, gastro esophageal reflux), and/or assistive equipment (eg, uncomfortable seating).^{6,9} This is not to say that children at lower levels of GMFCS do not experience chronic pain. Previous estimates suggest that pain is experienced by upwards of 60% of children with CP who can self-report, and as high as 73% of children when report is provided by a caregiver proxy.8,10 Within a Canadian context, 1 in 4 children with CP have moderate to severe pain and in some cases, report multiple sources of pain.9 The vast heterogeneity of the CP condition, as well as multiple potential sources of pain and varied communicative abilities hampers accurate assessment: this often leaves pain unrecognized and untreated.9,11,12

Unrecognized pain can have negative implications on health and quality of life, with the possibility that childhood pain will persist and progress into adulthood. 1,9,11,13-20 Chronic pain can significantly interfere with participation in daily living activities, both as a result of limited mobility resulting from the source of pain and fear-driven avoidance of specific activities.8,15,16,21-24 Childhood chronic pain has been associated with disturbances in sleep, increased fatigue, depression, and decreased physical functioning.¹¹ Unmanaged pain leads to social, functional, and behavioral consequences, increased stress on the family, and unnecessary prolonged suffering by the child.²⁵

To effectively manage chronic pain in children with CP, the source, site, and ways in which participation in daily living activities is limited must first be accurately identified. Recommendations have been gleaned from general pediatric pain research including the emphasis on using selfreport measures as much as possible to capture the subjectivity of pain interference.^{26–30} However, the heterogeneity of physical and cognitive impairments associated with CP makes it difficult to assess chronic pain using a single standardized tool.²⁶⁻³² Further. barriers to assessment stem from a lack of awareness among health

professionals of psychometrically sound tools and/or a lack of standardization within organizations for routine chronic pain assessment.32-34 Although previous reviews have identified measures to inform clinical practice, the application to children with disabilities is lacking.^{27–31,35,36} Therefore, the primary aim of this review was to identify, describe, and critique pediatric chronic pain assessment tools currently available and make recommendations for clinical use for children with CP. To address the gap between research and practice, a secondary aim was to select relevant assessment tools for inclusion in a clinical practice toolbox to support health care professionals in their efforts to accurately identify and assess chronic pain in children with physical disabilities.

METHODS

Interprofessional Working Group

From the outset, this project was undertaken with the goal of directly influencing clinical care. In keeping with an integrated knowledge translation approach,37 an interprofessional working group was created to guide and contribute to all stages of project development, data collection, analysis, and tool selection. The working group included representation from the following: developmental pediatrics, occupational therapy, psychology, nursing, research, knowledge translation, patient safety, senior management, as well as client and family representation.

Search Strategy

In developing the review search strategy, the working group took into account the following: the general lack of diagnostic-specific pediatric pain tools; the potential applicability of pediatric chronic pain tools addressing other physical disabilities and/or common childhood conditions; and the breadth of

cognitive, communicative, and functional impairments associated with a diagnosis of CP. Based on these considerations, the researchers opted to conduct a broad search to identify as many relevant pediatric chronic pain assessment tools as possible.

Consistent with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses statement and A Measurement Tool to Assess Systematic Review checklist, 38,39 the comprehensive search strategy was designed by clinicians, methodological experts, and a Health Sciences Librarian. Peerreviewed articles were searched within 3 scientific databases: Ovid Medline, Embase, and the Cumulative Index to Nursing and Allied Health Literature. Initial searches were conducted in January and February 2012 and subsequently updated in July 2014 by using terms outlined in the Supplemental Information. A hand search for additional titles was conducted by scanning reference lists of retrieved articles meeting eligibility criteria. This search strategy and systematic review were registered with PROSPERO: International Prospective Register of Systematic Reviews (CRD42014013255).

Inclusion/Exclusion Criteria

Articles were included if the eligibility criteria were met: (1) involved a pediatric population (1–18 years); (2) assessed chronic pain, detailed as pain lasting more than 3 months or lasting longer than expected; (3) reported tool psychometric properties; and (4) an English publication between 1980 and 2014. Articles were excluded based on: (1) the wrong age group (eg, neonates or adults); (2) a nonclinical population (eg, athletes, professionals); (3) nature of pain did not align with chronic pain as defined; (4) a pediatric population with diseases or disorders not habitual to a pediatric rehabilitation context: psychosomatic nerve pain, HIV/AIDS,

gynecologic/prostate pain or mental health concerns devoid of an underlying physical diagnosis; (5) tool did not measure pain as a primary or secondary focus; (6) psychometric properties were unreported; and/or (7) tool was not validated in English.

Study Selection

Each title, abstract, and full-text article was independently appraised by a minimum of 2 reviewers from the working group (Ms Adler, Ms Fay, Ms Gresley-Jones, Dr Hoffman, Mr Joachimides, Dr Kingsnorth, Dr Mankad, Ms Orava, Dr Slonim). The exclusion criteria were pilot-tested to ensure interrater reliability. Discrepancies during review were discussed between pairs of reviewers and resolved through consensus with a majority of working group members.

Tool Identification

From the full-text articles, a master list of unique tools used in each article was created. A total of 9 working group members (Ms Adler, Mr Ami, Ms Fay, Mr Joachimides, Dr Kingsnorth, Dr Mankad, Ms Nizigama, Ms Orava, Dr Slonim) were assigned groupings of these tools, which were then screened to ensure a pediatric and chronic pain focus. After identification of pediatric chronic pain assessment tools, a reverse mapping exercise was conducted, by which articles validating and/or using the chronic pain assessment tools were retrieved for data extraction. Copies of the original full versions of each tool were also obtained from published materials and/or by directly contacting the developers.

Data Extraction

Five working group members (Ms Adler, Mr Ami, Ms Hanlon, Dr Kingsnorth, Ms Nizigama) completed and cross-checked a predefined data extraction template by using Microsoft Excel. Extracted data from retrieved articles included the following: original

and secondary source information (article citation, origin of tool questions, pain condition of interest, sample size, mean age and SD, setting, and study design), tool accessibility (how to access a full copy of the tool), tool components (domains of pain, single versus multidimensional, validated age range, number of subscales, number of items/questions, and scoring metrics), and quality metrics (criterion and construct validity, responsiveness, and interrater and/or test-retest). Extracted data and full tool versions were shared with working group members as background materials to inform the tool critique procedures.

Tool Critique

Tools were critiqued on the merit of psychometric properties and clinical utility and selected for inclusion within the best practice toolbox by using processes hereafter described.

Psychometric Properties

The Society of Pediatric Psychology Assessment Task Force developed a schematic for the formal critique of measures to assist in the identification, selection, and intended use of evidence-informed assessment tools in standard practice.40 The criteria are based upon the use of the tool within peer-reviewed publications, sufficient level of detail within primary source validation articles for a well-informed critique to be developed, and demonstration of good reliability and validity with the target population.⁴⁰ Reviewers (Ms Adler, Mr Ami, Ms Hanlon, Dr Kingsnorth, Ms Nizigama) critiqued the psychometric properties by using extracted data from each article citing identified tools and provided an overall Society of Pediatric Psychology Assessment Task Force criteria rating: well-established, approaching well-established, or promising assessment.40 For example, based upon the cumulative data extracted from cited articles, a tool would be categorized as wellestablished if the tool had been used within published studies from 2 or more investigator teams, the details pertaining to tool use were presented in the validation article, allowing for replicability, and at least 1 of the articles had presented statistically significant reliability and validity for use with children with chronic pain.

Clinical Utility

Although a tool may be grounded in evidence and have endured rigorous psychometric testing, a measure may be underutilized if the tool does not meet the needs of the target population.41 Assignment of a clinical utility rating involved a 2-step process, by which results of step 1 informed that of step 2. During step 1, each tool was rated independently by 2 members of the working group with direct clinical experience (Ms Fay, Ms Gresley-Jones, Mr Joachimides, Dr Mankad, Dr Slonim) using criterion adapted from existing rating schemas developed to assess pain tools (Table 1).42,43 Select content was modified and included 3 sections: usability (ie, format, length, scoring, suitable for population; Q1-4), comprehensiveness (ie, impact of pain, consideration of varied gross

motor abilities, appropriate window; Q5–8) and other considerations (ie, additional measures, considerations of varied verbal abilities; Q9–10).^{42,43}

Working group members were asked to select a rating of clinical utility for each tool based upon the overall score (ie, weak, 0-5 points; moderate, 6-11 points; strong, 12-16 points) and strengths within usability, comprehensiveness, and other considerations. These ratings were used to facilitate group discussions with a majority of working group members in step 2. Members were asked to weigh the strengths and limitations of each tool, considering its real-world applicability within a tertiary rehabilitation setting and predicted value for assessing chronic pain in children with CP. A final rating (ie, weak, moderate, strong) was selected through group consensus.

Expert Consensus

Based upon ratings of psychometric properties and clinical utility, consideration of tools in their entirety (ie, relevance of all subscales) and all supporting materials (ie, results of data extraction, cited articles, full tools), triads of working group member (Ms Chin, Ms Fay, Dr Fehlings,

Mr Geremia, Ms Gresley-Jones,
Dr Hoffman, Dr Hung, Dr Kingsnorth,
Dr Mankad, Ms Provvidenza, Dr Slonim)
made independent recommendations
to include or exclude each tool
within the best practice toolbox.
Tools receiving unanimous agreement
for inclusion from working group
members were included in the
toolbox. Tools receiving conflicting
recommendations were then
presented to the full working
group, with inclusion based on a
majority vote.

Tool Description

Upon selection, a formative description of each tool was developed incorporating: (1) assessment tool type; (2) reporting type; and (3) clinical populations each tool had previously been used with.

Tool Assessment Type

Each tool was further categorized as discriminative or evaluative.⁴⁴ The purpose of a discriminative assessment is to compare 2 or more individuals or groups at a given point in time in the absence of a gold standard measure.⁴⁵ For the purpose of this review, discriminative tools were used to identify the presence or

TABLE 1 Rating Schema for Assessing Clinical Utility of Chronic Pain Tools Within a Tertiary Rehabilitation Setting

Factor	ltem	Applicable for Children With CP ^a	Can Be Used for Children With CP, but With Caveats ^b	Not Applicable for Children With CP ^c
Usability	1. Have questions that are easy to understand.			
	2. Is easy to score and interpret.			
	3. Is not too time consuming.			
	4. Is appropriate for use with			
	children and adolescents with CP.			
Comprehensiveness	5. Gives me useful information			
	about how pain affects function			
	or quality of life.			
	6. Tells me if the client does			
	or does not have pain.			
	7. Can be used with a client of any GMFCS			
	8. Assesses chronic pain/pain	≥14 d	1–13 d	≤1 d
	behavior over number of days			
Other considerations	9. Measures outcomes other		Yes/no	
	than pain (ie, depression, anxiety).		If yes, what does it measure?	
	10. A child with CP with verbal		Yes/no	
	skills would be able to self-report pain using this tool.			

^a Two points = the tool is effective in this situation

^b One point = the tool can be used in this situation but with caution.

^c Zero points = the tool is not effective in this situation.

absence of chronic pain. Evaluative assessment tools, on the other hand, are intended to track the progress of the dimension of interest (ie, chronic pain) of a person or a group over time.⁴⁵

Tool Reporting Type

The reporting type of each tool was identified as self-report, observational, or combination. Selfreport measures are considered to be the gold standard in pain assessment3,46 and require an individual to reflect upon his or her unique pain experience. Observational measurements call upon a health care professional, parent, or caregiver as a proxy to report signs and symptoms of chronic pain on the child's behalf. Observational tools are highly valuable and frequently used for individuals with cognitive or communicative impairments.^{47–49} Some tools provide different versions, such that either a self-report and/or observational version can be selected depending on the specific needs of the child. When appropriate, both versions may be completed to gain information on the experience of chronic pain from multiple perspectives. 50,51

Tool Use With Clinical Populations

Based upon information collected from original source articles identified through the review, a list of pediatric clinical populations previously having used each tool was generated. The list aimed to record both physical disabilities and other medical conditions for which chronic pain is prevalent. As few tools exist for children with CP, the working group considered the capacity of each tool to be used with children with physical limitations associated with weight bearing and mobility. Four members with practical experience delivering assessment tools to children across the spectrum of GMFCS (Ms Fay, Ms Gresley-Jones, Dr Hoffman, Dr Mankad) used

extracted data and tool descriptions, alongside professional judgment, to make recommendations for use for GMFCS levels I to III (independent/some assistance) and/or GMFCS levels IV to V (full assistance).

RESULTS

Identification of Assessment Tools

The results of the comprehensive search strategy are outlined in Fig 1. In total, 2652 records were retrieved from Medline (n = 1356), Embase (n = 873), and the Cumulative Index to Nursing and Allied Health Literature (n = 423; as of July 2014). As shown in Fig 1, screening of titles, abstracts, and articles yielded 240 studies for tool identification.

From these studies, 308 assessment tools were identified and screened, from which 254 tools were excluded due to varied reasons (as described in Supplemental Table 3). Ultimately, 54 chronic pain assessment tools underwent a formal critique of psychometric properties, clinical utility, and expert consensus from which 15 chronic pain assessment tools were selected for inclusion in the best practice toolbox.

Selection of Tools

The 15 tools were divided into 1 of 2 categories focused on how chronic pain interferes with daily activities or how children cope with chronic pain. Based on the weight of the evidence, the in-depth overview provided herein focuses solely on the formal critique of chronic pain interference tools, alongside expert recommendations made by the working group in regards to tool applicability. In contrast to the chronic pain coping tools, the chronic pain interference tools had a stronger evidence base pertaining to children with disabilities and held higher ratings of clinical utility. Thus the working group prioritized this category of tool as the first step in identifying the site, source, and ways

in which chronic pain affects a child with CP. Although the working group additionally recognized the importance of assessing strategies used to cope with chronic pain, there was no empirical evidence validating the identified tools for use among children with CP. Focusing on chronic pain interference tools as the priority was also supported by the justification that chronic pain cannot be effectively managed if it is not accurately identified.

Selected Chronic Pain Interference Tools

Table 2 summarizes the characteristics of the 7 pediatric chronic pain interference tools selected through working group consensus. The tools were intended to determine if a child had chronic pain (Body Diagram, Noncommunicating Children's Pain Checklist-Revised [NCCPC-R], Pediatric Pain Questionnaire [PPQ]), track pain over time (Bath Adolescent Pain Questionnaire [BAPQ], Child Activity Limitations Interview [CALI], Pediatric Pain Interference Scale [PPIS]), or both (Pediatric Pain Profile [PPP]). They relied on observational (NCCPC-R, PPP), self-report (Body Diagram), or combination reporting styles (BAPQ, CALI, PPIS, PPQ). All tools had been validated with a pediatric population and a broad range of medical conditions; of note, the NCCPC-R, PPIS, PPP, and PPQ have been used specifically to assess pain in children with CP. Ratings of psychometric properties, clinical utility, and recommendations for tool use according to GMFCS levels are presented.

Bath Adolescent Pain Questionnaire

The BAPQ is an evaluative tool used to assess chronic pain in adolescents from the perspective of the adolescent⁵² or parent (BAPQ-P).⁵³ The 61-item questionnaire has broad applicability because it covers multiple domains related to chronic pain, including development and

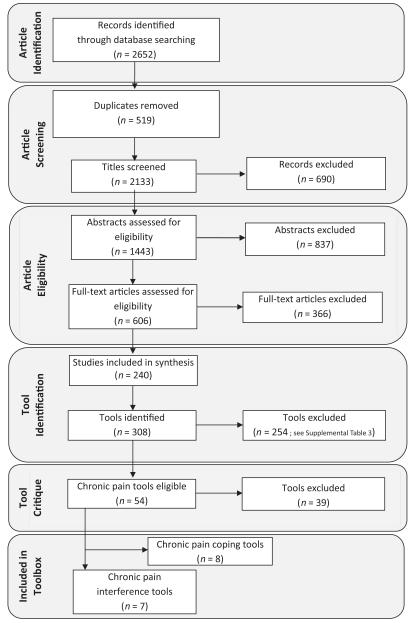


FIGURE 1
Results of the systematic review.

family functioning, which are unique attributes of adolescence.⁵² The BAPQ has not been used with children with CP but has been validated with children who experience chronic musculoskeletal pain conditions (Table 2).^{52–59} The working group deemed the BAPQ and BAPQ-P as well-established with weak clinical utility. The working group suggests this tool to be of potential value for children with GMFCS levels I to III because it inquires about impact of

pain on mobility. However, reviewers critiqued its lengthy format and felt it may be a challenge to embed within clinic workflow.

Body Diagram

The Body Diagram was originally developed, validated, and used with an adult population to assess the location, distribution, and intensity of acute and chronic pain. 60,61 This discriminative tool has been validated with children with chronic

pain conditions (Table 2).62-67 The working group deemed the Body Diagram to be approaching wellestablished in psychometric properties with strong clinical utility. As a standalone tool, the Body Diagram would not provide as much detailed information related to chronic pain interference and thereby, is recommended by current reviewers to be paired with another tool. A benefit of this tool is the absence of weight bearing or mobility-specific questions, and is recommended for use with children of all GMFCS levels.

Child Activity Limitations Interview

The CALI was designed to assess the impact of functional impairment from pain on a child's ability to participate in his or her activities of daily living.66 This evaluative chronic pain-specific tool has been validated both as an interview for parent and child and a self-report, paper-pencil tool.66,68 The CALI has been used with children with a number of chronic pain conditions (Table 2).67-70 Reviewers found value in the meaningful content of the CALI, because the individual is asked to select and rate 8 of 21 activities that are difficult because of pain.66 The child and/or caregiver are able to select the activities, which have the most personal meaning.71 This tool has been classified as having wellestablished psychometric properties and moderate clinical utility. Although the CALI rated high in usability, this questionnaire does contain weight bearing and mobility-based questions. Although a child may choose other activities, the reviewers have recommended the CALI for use for children with GMFCS levels I to III.

Noncommunicating Children's Pain Checklist—Revised

The NCCPC was developed through semistructured interviews with primary caregivers of children who are nonverbal⁷² and later validated with caregivers of children with a broad array of cognitive and motor

Tool Name	Assessment Type	Reportir	ing Style	Examples of Tool Use With	Rating of Psychometric	Rating of	Considerations for Use
		Self-Report	0b servation	Pediatric Medical Conditions	Properties	Clinical Utility	tor Children With CP
ВАРО	Evaluative	,	>	 Complex regional pain syndrome Juvenile idiopathic arthritis Juvenile widespread idiopathic musculoskeletal pain Low back pain 	Well-established	Weak	GMFCS I-III
Body Diagram	Discriminative	>		Chronic headache Complex regional syndrome Cystic fibrosis Functional abdominal pain Juvenile idiopathic arthritis Musculoskeletal pain Myofascial pain Sickle real disease	Approaching well-established	Strong	GMFGS I-V
CALI	Evaluative	>	>	Abdominal pain Back pain Cancer Duchene and Becker muscular dystrophy Juvenile chronic arthritis Neuropathic pain Migraine Musculoskeletal pain Myofascial pain Obesity Sickle cell disease	Well-established	Moderate	GMFOS I-III
NGGPG-R	Discriminative		>	 Autism spectrum disorder CP Congenital hydrocephalus Epilepsy Down syndrome Lennox-Gastaut syndrome Motor disabilities Rett syndrome Severe cognitive impairment 	Well-estab lished	Strong	GMFCS I-V

TABLE 2 Continued							
Tool Name	Assessment Type	Reporti	Reporting Style	Examples of Tool Use With	Rating of Psychometric	Rating of	Considerations for Use
		Self-Report	Observation	Pediatric Medical Conditions	Properties	Clinical Utility	for Children With CP
PPIS PPP Varni-Thompson PPQ	Evaluative Discriminative/ evaluative	,	,	Attention deficit disorder; attention-deficit/hyperactivity disorder Allergies Arthritis Asthma CP Chronic foot pain Chronic low back pain Chronic low back pain Complex regional pain syndrome Diabetes Fibromyalgia Gastrointestinal disorders Immune disorders Migraines Musculoskeletal pain Progressive pseudorheumatoid chondrodysplasia Spinal cord injury Cerebral malformations CP Congenital and chromosomal disorders Spastic quadriplegia Spastic quadriplegia Abdominal pain CP Fibromyalgia Abdominal pain CP Musculoskeletal pain CP Fibromyalgia Abdominal pain CP Musculoskeletal pain Mygrasoial pain Mygrasoial pain Recurrent abdominal pain Recurrent abdominal pain Regional pain syndrome Mygrasoial pain Regional pain syndrome Conic co	Approaching well-established Well-established	Moderate Moderate	GMFCS I-III GMFCS I-V

impairments, including CP (Table 2).73-77 This observational, discriminative tool can be used to assess past chronic pain, pain as it occurs, or postoperative pain. 73,74 The revised version requires a 2-hour observational period followed by the completion of the 30-item questionnaire.75 The NCCPC-R hosts strong external validity as psychometric testing has taken place within natural and clinical settings.74 Researchers have affirmed the NCCPC-R accurately captures pain behaviors across various levels of a child's development.⁷⁸ The working group recommended the NCCPC-R for children with GMFCS levels I to V because of its well-established psychometric properties and strong clinical utility. One consideration, however, is the 2-hour time frame required for completion, which limits its appropriateness for clinical application.

Pediatric Pain Interference Scale

The PPIS was developed by the National Institutes of Health Patient Reported Outcomes Measurement Information System initiative.⁷⁹ The National Institutes of Health Patient Reported Outcomes Measurement Information System hosts an item bank, which has been developed by using Item Response Theory and allows for customization of items to meet clinical needs.⁷⁹ This evaluative scale was initially developed for an adult population to assess painrelated behaviors across 5 domains (pain, fatigue, physical functioning, social health, and emotional health).79 The tool has since been validated with pediatric populations (5-18 years) representing a variety of chronic health conditions, including CP (Table 2).80-83 A parental proxy item bank can also be used when child self-report is not feasible.82,84 The working group categorized the PPIS as approaching well-established, with moderate clinical utility. The paper-based, observational tool was found to be easy to administer;

however, items related to mobility and weight bearing restricts the use to children with GMFCS levels between I and III.

Pediatric Pain Profile

The PPP was specifically developed to assess pain in children with neurologic impairments, including CP (levels I-V; Table 2).3,85-87 The foundation for the 20-item questionnaire stemmed from qualitative interviews with health care professionals and caregivers of children with significant neurologic impairments.3 The clinical utility of this dual purpose scale (evaluative and discriminative) scored high within usability; however, reviewers felt the information provided would not fully capture the impact of pain on function or quality of life. Therefore, the PPP was classified as having well-established psychometric properties and moderate clinical utility for recommended use for children with GMFCS levels I to V.

Varni/Thompson PPO

Varni and Thompson (1987)88 developed the PPQ to assess chronic pain from the perspective of the child and the parent. This tool, which was based upon the McGill Pain Questionnaire for adults,89 was validated with children with chronic pain conditions, and more recently, has been adapted for use with children with CP (Table 2).90,91 Within this modified version, parents were instructed to use verbal and nonverbal cues to indicate the presence and quality of their child's pain.91 Although all GMFCS levels were represented within this research, the reviewers have categorized the psychometric properties as well-established, yet, with moderate clinical utility. Children within GMFCS levels I to III may be able to self-report by using the PPQ; however, more research is needed to validate the modified version of the PPQ for use with children with GMFCS levels IV to V.

DISCUSSION

Previously published systematic reviews regarding pediatric chronic pain assessment have focused on typically developing children who are high functioning, with a single diagnosis causing chronic pain, who possess the ability to selfreport.^{27,29-31,36} Authors of these reviews suggest further research is needed for applicability of findings to meet the needs of children with cognitive impairments and physical disabilities.35,92 Against these reviews, we sought to address this gap by systematically reviewing and critiquing pediatric assessment tools to be used to evaluate chronic pain interference in children with CP across a broad range of physical and developmental function.

An exhaustive search of 3 scientific databases retrieved 2652 records from which 54 pediatric chronic pain assessment tools were identified and met eligibility criteria. A consensus strategy conducted with an interprofessional working group considered the psychometric properties and clinical utility of all tools, electing 15 chronic pain tools to be nominated for inclusion. These were further divided into tools focused on pain interference with daily activities and tools focused on coping with chronic pain. This review provided in-depth details of chronic pain interference tools, which were mainly classified as well-established with moderate clinical utility. They were found to be the most relevant to children with CP in so far that chronic pain cannot be managed if it has not been assessed.

The working group made recommendations for clinical use according to GFMCS levels. Four interference tools had been developed and/or used with children with CP, with all tools recommended for use with children with GMFCS

levels I to III. Only the NCCPC-R and PPP were developed to be used with children with GMFCS levels IV and V, which addresses a gap in chronic pain assessment for children with severe cognitive, motor, and physical impairments. The PPIS and PPQ were not initially designed for children with CP, but have since been adapted and validated for use in children with GMFCS levels I to III.91,93 Authors of the remaining tools (ie, BAPQ, CALI) could follow suit in extending the reach of their tools to include all GMFCS levels. For example, through its design the CALI offers great flexibility in allowing children and their parents to select from a list of activities that have personal meaning. It also allows for the identification of a child's own series of activities, including both ambulatory and nonambulatory events. Further work could be undertaken to generate a prescribed list of nonambulatory activities targeted at children in GMFCS levels IV and V. Likewise, opportunities to expand tool reach across the GMFCS continuum were also noted with respect to their assessment approach. The majority of tools recommended solely for GMFCS levels I to III were evaluative, drawing attention to the need for future validation of discriminative tools to assist with the determination of presence or absence of pain for this subpopulation.

Due to the heterogeneous nature of CP, selecting appropriate tools to meet the assessment needs of a specific child (ie, self-report, observational, or combination tools) can be challenging in clinical practice. A 1-size fits all approach is not realistic; not all children with CP are able to self-report and not all children with CP require observational measures. The current review brings to light gaps in the assessment of chronic pain. However, simply calling for developers to respond may not be

viable because tool development takes years to accomplish. Therefore, the authors advocate for the validation of existing chronic pain assessment tools with children of all GMFCS levels to advance understanding of best practice recommendations.

Previous research highlights the importance of a "toolbox" to assist clinicians in selecting rigorous and clinically significant measurement tools for a range of clientele with CP.94 Furthermore, by forming an evidence-based toolbox, health care professionals from around the globe can use the same set of standardized measures, bettering universal approaches to care.94 Thus, an output of this work is the Chronic Pain Assessment Toolbox for Children with Disabilities (Available at www.hollandbloorview.ca/ toolbox). Included in the toolbox are the 15 chronic pain assessment tools identified through this systematic review and a compendium of evidence-informed best practice products intended to assist health care professionals in the assessment of chronic pain in children with disabilities. The toolbox includes the 7 interference tools discussed herein and 8 chronic pain coping tools, which have yet to be validated with a CP population and require further research to be generalized to meet the needs of children with physical disabilities. Since 2013, the Toolbox has been implemented in eight outpatient clinics at Holland Bloorview Kids Rehabilitation Hospital (Toronto, Ontario, Canada). The utility of the toolbox is currently undergoing a formative evaluation, with emphasis on developing a standard of practice for chronic pain interference assessment for children with CP.

A few considerations exist for application of the toolbox and future development. The included tools focus on general chronic pain, as symptom-specific chronic pain tools (eg, headache, abdominal pain) were excluded during the tool selection process. This was done on the basis that the toolbox in its current form encompasses a holistic approach to chronic pain assessment with many possible sources and/or sites of pain. Future work may broaden the scope as evidence validating the use of single-scale tools (eg, the Numerical Rating Scale) for chronic pain assessment is emerging⁹⁵; it may also consider the inclusion of non-English assessment tools, such as the Pain Evaluation Scale for Clients With Cerebral Palsy.96

The strengths of this review included the comprehensive search strategy, which spanned articles published over 3 decades to identify tools with few restrictions on special medical conditions, broadening the scope of retrieved articles beyond those that may have been selected if a strict CP-focus was taken. Moreover, a major strength was the evaluation of the clinical utility of tools by a group of clinicians actively involved in services and care for children with CP. Although authors were not able to shorten or rank the list of included tools on the basis of psychometric properties and clinical utility, the provision of 7 chronic pain interference tools ensures that all health care professionals have access to a valuable resource to meet the broad needs of their clients with CP, accounting for client-specific communication and gross motor abilities.

Moving forward, it is hoped this research will foster conversations with both tool-developers and endusers and help strengthen chronic pain assessment approaches for children across all GMFCS levels. With the growing emphasis on toolbox development, it is also hoped that considerations of the applicability of this toolbox or similarly developed resources might be extended to other populations of children who may also have restrictions to cognition,

communication, and/or physical functioning. This will help ensure all children with disabilities will have accurate chronic pain assessments and attempts are made to limit pain that interferes with their activities of daily living.

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ABBREVIATIONS

BAPQ: Bath Adolescent Pain Questionnaire

CALI: Child Activity Limitations Interview

CP: cerebral palsy

GMFCS: Gross Motor Function Classification System

NCCPC-R: Noncommunicating Children's Pain Checklist-Revised

PPIS: Pediatric Pain Interference

Scale

PPP: Pediatric Pain Profile

PPQ: Pediatric Pain Questionnaire

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