Received: 6 May 2022 | Accepted: 16 August 2022

DOI: 10.1111/dmcn.15410

SYSTEMATIC REVIEW

Pain coping tools for children and young adults with a neurodevelopmental disability: A systematic review of measurement properties

Nadine L. Smith[1,2,3] | **Meredith G. Smith**[4,5] | **Noula Gibson**[1,2,6] | **Christine Imms**[7,8] | **Ashleigh l. Thornton**[1,3,6] | **Adrienne R. Harvey**[7,8]

[1]Kids Rehab WA, Perth Children's Hospital, Nedlands, WA, Australia

[2]Department of Physiotherapy, Perth Children's Hospital, Nedlands, WA, Australia

[3]Division of Paediatrics, Medical School, The University of Western Australia, WA, Australia

[4]School of Allied Health Science and Practice, The University of Adelaide, SA, Australia

[5]Novita Disability Services, Adelaide, SA, Australia

[6]Telethon Kids Institute, Perth, WA, Australia

[7]Department of Paediatrics, The University of Melbourne, VIC, Australia

[8]Murdoch Children's Research Institute, Melbourne, VIC, Australia

Correspondence
Nadine Lee Smith, Kids Rehab WA, Perth Children's Hospital, 15 Hospital Avenue, Nedlands, WA 6009, Australia.
Email: nadine.smith@health.wa.gov.au

Funding information
This study has received research support from the Centre of Research Excellence: CP-ACHIEVE funded by the NHMRC, Grant/Award Number: Grant and 1171758

Abstract

Aim: To systematically identify and evaluate the measurement properties of patient-reported outcome measures (PROMs) and observer-reported outcome measures (parent proxy report) of pain coping tools that have been used with children and young adults (aged 0–24 years) with a neurodevelopmental disability.

Method: A two-stage search using MEDLINE, Embase, CINAHL, Web of Science, and PsycInfo was conducted. Search 1 in August 2021 identified pain coping tools used in neurodevelopmental disability and search 2 in September 2021 located additional studies evaluating the measurement properties of these tools. Methodological quality was assessed using the COnsensus-based Standards for the Selection of Health Measurement INstruments (COSMIN) guidelines (PROSPERO protocol registration no. CRD42021273031).

Results: Sixteen studies identified seven pain coping tools, all PROMs and observer-reported outcome measures (parent proxy report) versions. The measurement properties of the seven tools were appraised in 44 studies. No tool had high-quality evidence for any measurement property or evidence for all nine measurement properties as outlined by COSMIN. Only one tool had content validity for individuals with neurodevelopmental disability: the Cerebral Palsy Quality of Life tool.

Interpretation: Pain coping assessment tools with self-report and parent proxy versions are available; however, measurement invariance has not been tested in young adults with a neurodevelopmental disability. This is an area for future research.

Abbreviations: BAPQ, Bath Adolescent Pain Questionnaire; COSMIN, COnsensus-based Standards for the Selection of Health Measurement INstruments; CP QoL, Cerebral Palsy Quality of Life; CSES, Child Self-Efficacy Scale; FOPQ, Fear of Pain Questionnaire; PCQ, Pain Coping Questionnaire; PCS-C, Pain Catastrophizing Scale for children; PPCI, Paediatric Pain Coping Inventory; PROM, patient-reported outcome measure.

Chronic pain is a common comorbidity for individuals with cerebral palsy (CP), with reported prevalence in children and adolescents of between 17% and 77%.[1,2] Chronic pain is defined as 'an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage'.[3] The revised International Association for the Study of Pain definition highlights that pain is always a personal experience and patient report of their pain experience, either by verbal description or behaviours, should always be respected.[3] Assessment using a biopsychosocial model is considered best practice for children with chronic pain since the development and persistence of chronic pain involves the interaction of neurosensory (nociceptive), emotional, sociocultural, behavioural, and cognitive factors.[4] The contribution of emotional, behavioural, and cognitive factors to chronic pain in children and adolescents has been further explained using the 'fear avoidance' model.[5,6] This model explains how three key, interrelated psychological factors—pain anxiety, pain catastrophizing, and fear of pain—drive pain-related physical disability and pain-related anxiety and depression. Pain catastrophizing, defined as exaggerated negative thoughts about pain,[7] is the psychosocial factor with the strongest and most consistent association with poor physical and emotional outcomes. Accurate and reliable assessment of these constructs is considered core in paediatric populations with chronic pain since they are a target for psychological interventions.[8,9]

Despite the high prevalence of chronic pain in young adults with CP, there is limited research into how they cope with their chronic pain. Recently, Chaleat-Valayer et al.[10] used the Paediatric Pain Coping Inventory (PPCI) to assess the pain coping strategies of 142 children with CP. Results demonstrated that children and adolescents with CP used less coping strategies than other paediatric populations and that coping strategies were influenced by Gross Motor Function Classification System (GMFCS) level, age, and previous surgery.[10] Children with CP used less independent coping strategies and they emerged later in age compared to children without CP.[10] In non-CP paediatric populations with chronic pain, teaching positive or adaptive coping strategies, such as distraction or cognitive self-instruction, and reducing maladaptive coping strategies and behaviours, such as catastrophizing and helplessness, have shown positive effects on quality of life and pain intensity.[8,10]

Children with severe cognitive impairment or inability to self-report were excluded from the study by Chaleat-Valayer et al.[10] despite the knowledge that pain prevalence in CP increases in non-ambulant children classified in GMFCS levels IV and V.[2,10,11] Pain coping assessment tools suitable for all individuals with CP or neurodevelopmental disability,[12] regardless of their communication, cognitive, or functional limitations have not been rigorously reviewed, leaving a significant gap in assessment of pain coping strategies for children and young adults with CP and their families. Thus, the need for and referral to multidisciplinary treatments, which may include physiotherapy, occupational therapy, and psychology are not consistently identified.

What this paper adds

- There are few valid tools available to assess pain coping in children and young adults with a neurodevelopmental disability.
- Three pain coping tools (Cerebral Palsy Quality of Life, Fear of Pain Questionnaire, and Bath Adolescent Pain Questionnaire) show promise.
- Pain coping tools that are feasible for children and young adults who require cognitive or communicative support are lacking.

Recent systematic reviews of pain coping measurement tools focused on children and adolescents with chronic pain but did not include populations with a disability.[7] This systematic review aimed to identify pain coping measures cited in the literature in children and young adults with neurodevelopmental disabilities (e.g. CP), and assess their psychometric properties.

We defined neurodevelopmental disability according to the consensus-based definition from Morris et al.[12] as 'a group of congenital or acquired long term conditions that are attributable to impairment of the brain and/or neuromuscular conditions and create functional limitations'. We identified pain coping patient-reported outcome measures (PROMs) and observer-reported outcome measures. Observer-reported outcome measures are defined as observations made, appraised, and recorded by an individual other than the patient, who does not require professional training (e.g. proxy measures).[13] The measurement properties of the identified tools were reported according to the criteria outlined in the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidelines.

The aims of this review were to: (1) identify PROMs and observer-reported outcome measures, for example, parent proxy versions, which have been used for assessing pain coping, including pain anxiety, pain catastrophizing, and fear of pain, suitable for children, adolescents, and young adults aged 0 to 24 years with chronic pain and a neurodevelopmental disability; and (2) determine the psychometric properties of the identified tools, including: (a) validity, (b) reliability, (c) responsiveness, and (d) interpretability.

METHOD

The details of the protocol for this systematic review were prospectively registered on PROSPERO, the international register of systematic reviews (and can be accessed at https://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42021273031).

In the published protocol, articles were excluded if they were in languages other than English or French; however, after further discussion, no restrictions on language were placed due to the ability to access and use translation software. The reporting of this systematic review followed the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines[14] and outcomes are reported in accordance with COSMIN.[15–17] Measurement properties from multiple studies were qualitatively summarized and the quality of each measurement property from pooled results were reported using a modified GRADE approach.[15–17]

Search strategy

A comprehensive two-search strategy was designed by the authors and a medical librarian. The first search was used to identify and select measurement tools (aim 1) and the second search identified any evidence, not previously identified in search 1, of the psychometric properties of those tools for appraisal (aim 2). Both searches were completed in five electronic databases: MEDLINE, Embase, PsycInfo, CINAHL, and Web of Science from database inception to the 30th September 2021 for search 2. Citation tracking of key articles and targeted reference scanning was used to minimize the chance of missing key studies. Relevant assessment manuals were sourced. The five search strategies for searches 1 and 2 are provided in Appendix S1. The electronic databases were searched by one reviewer (NS) and exported to Covidence (Covidence systematic review software; Veritas Health Innovation, Melbourne, Australia; www.covidence.org), an online systematic review management software.

Inclusion and exclusion criteria

Table 1 displays detailed inclusion and exclusion criteria. Search 1 identified all studies that assessed pain anxiety, pain catastrophizing, and fear of pain in children, adolescents, and young adults with chronic pain and a neurodevelopmental disability, such as CP. The search strategy was based on search terms used in a previous systematic review by Fisher et al.[9] with the addition of inclusion of young adults (19–24 years) and people with a neurodevelopmental disability or CP. We included conditions such as intellectual disability, spinal dysraphism, attention-deficit/hyperactivity disorder, and autism. Articles were included if a valid, reliable PROM was used to assess pain coping in children or young adults with chronic pain and a neurodevelopmental disability. Exclusion criteria included: (1) multidimensional quality of life tools that only assessed pain interference or intensity, or emotional difficulties not related to chronic pain (detailed in Table S1); and (2) conditions not considered a neurodevelopmental disability, such as acquired brain injury after the age of 2 years, spinal cord injury, neurodegenerative or neuromuscular conditions, and life-limiting conditions such as cancer and cystic fibrosis.

Any type of study, including systematic reviews, case studies, cross-sectional studies, or cohort studies that used or identified pain coping tools for children or young adults with a neurodevelopmental disability, aged between 0 years and 24 years, were included in search 1. The characteristics of the studies included in the review, including reference, study design, population, setting, and the tool used are outlined in Table S2.

Search 2 identified the reports of the psychometric properties of tools identified in search 1. The psychometric properties of the tools were reported according to the specific

TABLE 1 Eligibility criteria of the full-text studies: searches 1 and 2

	Inclusion criteria	Exclusion criteria
Search stage 1	Children and young adults aged 0–24 years	Results for those aged under 24 years cannot be separated
	Experiencing chronic pain (>3-month duration)	Acute pain, procedural pain, pain in life-limiting conditions
	Neurodevelopmental disability (e.g. Down syndrome, spinal dysraphism, intellectual disability, or cerebral palsy)	Acquired or progressive conditions (spinal cord injury, acquired brain injury after the age of 2 years)
	Tool measures pain coping or contains a subscale that includes pain anxiety, pain catastrophizing, or fear of pain limited to PROM including proxy (observer-reported outcome measures)	Tool did not measure pain coping as primary or secondary focus
Search stage 2	Examines psychometric properties of one of the tools identified in search 1: • CP Quality of Life teenager self or primary caregiver report • Child Self Efficacy Scale (parent or child version) • Pain Coping Questionnaire (parent or child version) • Fear of Pain Questionnaire (parent or child version) • Pediatric Pain Coping Inventory (parent or child version) • Pain Catastrophizing Scale (parent or child version) • Bath Adolescent Pain Questionnaire (parent or child version)	Tool is used in an intervention study only as an outcome measure, no evidence of psychometric testing

Abbreviations: CP, cerebral palsy; PROM, patient-reported outcome measure.

[Correction added on 28 September 2022 after first online publication: In Table 1, the word 'minute' was updated to 'month' in the sentence "Experiencing chronic pain (>3-month duration)" under Inclusion criteria]

criteria outlined in the COSMIN manual for evaluating the methodological quality of studies on measurement properties.[15–17] In accordance with COSMIN, studies were excluded if the PROM was used as an outcome measure for an intervention study.

Study selection

Titles and abstracts generated by the search were screened against the eligibility criteria by two authors (NS and MS) independently. Full texts of the articles were obtained for all included abstracts and further screened against the eligibility criteria by the same two independent reviewers. Any disagreements between authors were resolved by discussion and a third author (AH), if required. Reference lists of selected articles were manually searched for other articles that matched the eligibility criteria.

Data extraction and quality assessment

Data extraction was completed independently by two reviewers (NS and MS) and checked by a third reviewer (AH) using a customized template in Covidence. The template was customized by the three reviewers (NS, MS, and AH) and pilot tested to ensure consistency. Data were extracted and recorded under the following headings. Search 1: study details, author, study design, population, and outcome measure or scale/subscale used. Characteristics of the PROM(s), including construct(s), target population, mode of administration (e.g. self-report, observer-reported outcome measures [parent proxy report]), scales or subscales, number of items, response options, range of scores/scoring, time taken to complete, and available translations. Search 2: title, name of PROM/observer-reported outcome measure measurement properties assessed, population, and results. Where needed, authors were contacted to provide additional data to assess the PROM/observer-reported outcome measure.

The methodological quality of the studies included in search 2 were assessed using the COSMIN Risk of Bias checklist, which has standards for PROM development and for nine measurement properties: content validity, structural validity, internal consistency, cross-cultural validity/measurement invariance, reliability, measurement error, criterion validity, hypothesis testing for construct validity, and responsiveness.[15–17] Two authors (NS and MS) independently performed quality assessments on each study using the COSMIN risk of bias checklists, followed by meetings to discuss the ratings with a third independent reviewer (AH). Disagreements on ratings were discussed until agreement was reached. The results were then qualitatively pooled and summarized for each PROM or observer-reported outcome measure as sufficient (+), insufficient (–), inconsistent (+/–), or undetermined (?) using the criteria for good measurement properties outlined by COSMIN. To rate a tool as sufficient at least 75% of the results met the criteria; if results were all undetermined, the overall rating was undetermined and for inconsistent studies that could not be pooled, such as for confirmatory factor analysis, the overall result was rated as 'inconsistent'.[15–17] Finally, the pooled results were graded for quality of evidence using the modified GRADE approach as high, moderate, low, or very low evidence.[15–17] The modified GRADE approach for PROMs and observer-reported outcome measures takes four factors into consideration: (1) risk of bias, (2) inconsistency, (3) imprecision, and (4) indirectness.

COSMIN identifies content validity as the most important measurement property for determining the quality of PROMs and recommends rating it first.[15–17] This step determines ease of understanding. Content validity, along with at least low-quality evidence for sufficient internal consistency, are key requirements for recommending tools for use in practice.[17] Recommendations about the most suitable measures for the assessment of pain coping for children and young adults with a neurodevelopmental disability were developed based on the overall quality of evidence[16] and feasibility of using the PROM or observer-reported outcome measure in clinical practice. Feasibility items included cost and accessibility of the PROM, time to complete the PROM, ease of understanding questions, ease of scoring, and ease of interpreting individual scores and changes in scores.[16,18,19]

RESULTS

Search 1

The combined searches retrieved 564 studies with 350 eligible studies for title and abstract screening after duplicate removal, resulting in 143 articles assessed for full-text eligibility. Of these, 127 publications were excluded after full-text review with a final 16 studies meeting eligibility for data extraction (Figure S1). These 16 studies reported on seven pain coping tools of which two have short forms and all have self-report and observer-reported outcome measure (parent proxy report) versions: the Bath Adolescent Pain Questionnaire (BAPQ) and Bath Adolescent Pain Questionnaire for Parents;[20,21] the Cerebral Palsy Quality of Life (CP QoL) teenager version, primary caregiver report, and self-report;[22] the Child Self-Efficacy Scale (CSES) self-report and parent report;[23] the Fear of Pain Questionnaire (FOPQ) parent and self-report and FOPQ short form self-report;[24,25] the PPCI parent and self-report;[26] the Pain Catastrophizing Scale for children (PCS-C), parent and self-report;[27] and the Pain Coping Questionnaire (PCQ) self-report and parent report and the PCQ short form self-report[28,29] (Table S3). The study populations included children and young adults with CP (11 studies),[10,30–39] intellectual disability (three studies),[40–42] spinal dysraphism (two studies),[32,43] and Down syndrome (two studies).[42,44]

Characteristics of the studies

Due to the volume of data, Tables S1 and S2 provide details about the tools excluded and the reason why as well as additional details about the studies included outlining the population the tool was used in, study design, setting, and country. The characteristics of the outcome measures included are detailed in Table S3. Two of the tools are multidimensional quality of life tools, the CP QoL teenager self-report and primary caregiver versions and the BAPQ and BAPQ for parents, which have subscales that measure pain-related anxiety. The PCS and FOPQ are scales based on the fear avoidance model[45] and measure the constructs of catastrophizing, fear of pain, and avoidance of activities. The PPCI has a 6-item subscale of catastrophizing/helplessness and the PCQ has a 5-item subscale of internalizing/catastrophizing. The CSES is based on social cognitive theory; although it does not contain catastrophizing or fear of pain responses, self-efficacy is related to coping with chronic pain.[23]

Search 2

Figure S2 outlines the results of the second search. Forty-four studies were included for the COSMIN risk of bias assessment.

Measurement properties

Table S4 reports the participant characteristics and sample size, study purpose, design, and measurement properties reported for each of the 44 studies included in the review. Figure 1 reports the pooled overall rating and quality of measurement evidence for each of the self- or parent-reported measures. All authors were contacted via e-mail regarding additional information; however, no further data were provided.

Bath Adolescent Pain Questionnaire

Three studies with a pooled sample of size of 333 children and adolescents reported on the BAPQ.[46–48] The studies by Eccleston et al.[20] and Cohen et al.[47,49] used the same sample of 222 adolescents with chronic pain. The BAPQ was the first assessment tool designed specifically for adolescents with chronic pain, developed from focus groups with adolescents with chronic pain and international experts. Overall content validity was graded as 'low' due to risk of bias (downgraded two points due to one study of doubtful quality). Three other measurement properties were reported for this tool: internal consistency, construct validity, and test–retest reliability. Despite all three studies reporting internal consistency, this was graded as 'very-low-quality' evidence since no evaluations of structural validity statistics were reported. There was moderate-quality evidence from two studies on construct validity, with the same two studies reporting reliability, which was graded as low quality due to risk of bias and inconsistency.

Measurement properties of the BAPQ for Parents (parent report), a direct translation of the BAPQ, were rated in two studies that used the same sample of 222 adolescents with chronic pain recruited from rheumatology-specific or chronic pain outpatient clinics.[21,49] There was 'low-grade' evidence for reliability, cross-cultural validity between adolescents and parents in the two chronic pain groups, and construct validity.

Cerebral Palsy Quality of Life

The CP QoL teenager version is the only outcome measure with content validity for individuals with a neurodevelopmental disability. It was developed by semi-structured interviews with 17 adolescents with CP and 33 parents.[50] Structural validity was implied in the paper by Davis et al.[22] and graded as 'low-quality' evidence since no statistics were reported. Internal consistency was reported in six studies, of which five were validity studies where the CP QoL teenager self-report was translated into other languages (Turkish, Persian, Finnish, Polish, and German). In three studies,[51–53] there was sufficient evidence of internal consistency and in the other three[54–56] there was insufficient or undetermined evidence. In summary, internal consistency was rated as 'low'. Four studies examined reliability; pooled summary of evidence was rated as undetermined and quality of evidence graded as 'low' due to imprecision, inconsistency, and risk of bias in the studies. Three studies reported Pearson's correlations with other established tools for evidence of construct validity. Due to inconsistency in results, evidence was downgraded to 'moderate'.

Child Self-Efficacy Scale

Two studies reported on the measurement properties for the self-report version of the CSES with a combined sample size of 1797. The original scale[23] was not developed with patient input; however, there was a pilot test of the Portuguese version in 10 adolescents with chronic pain.[57] Content validity of the CSES was graded as 'low' due to risk of bias (inadequate rating) and inconsistency. Structural validity was undetermined since no statistics were reported and overall quality was graded as 'low'. Therefore, in accordance with COSMIN, internal consistency was also graded as 'low-quality' evidence. Test–retest reliability was reported in one study (sample size $n = 63$ of adolescents with one painful body site).[57] The measurement properties reported were sufficient; however, overall quality was graded as 'moderate', downgraded due to indirectness and imprecision ($n < 100$). Construct validity was reported in both studies with the pooled result rated as sufficient and the overall grade as 'moderate'. Internal consistency for the CSES

	Content validity[a]				Structural validity[b]				Internal consistency[c]				Reliability[d]				Construct validity[e]				Cross-cultural validity/measurement invariance[f]			
Outcome measure	ROB score	No. studies	Rating	Quality	ROB score	No. studies	Rating	Quality	ROB score	No. studies	Rating	Quality	ROB score	No. studies	Rating	Quality	ROB score	No. studies	Rating	Quality	ROB score	No. studies	Rating	Quality
BAPQ	D	1	?	L	I	3	?	VL	I	3	?	VL	D	2	?	L	D	2	+	M				
BAPQ-P	D	1	?	L	I	2	?	VL	I	2	+	VL	D	2	?	L	A	1	?	L	A	1	?	L
CP QoL teenager self-report	A	1	+	M	D	1	?	L	D	6	?	L	D	4	-	L	A	3	+	M				
CP QoL teenager primary caregiver	A	1	+	M	D	1	?	L	D	3	?	L	D	3	?	M	A	2	+	M				
CSES child self-report	I	1	+/-	L	D	2	?	L	D	2	+	L	A	1	+	M	V	2	+	M				
CSES parent report	I	1	+/-	L	I	1	?	VL	I	1	+	VL												
FOPQ-C	D	1	+	M	A	2	?	L	V	2	+	L					A	2	?	L				
FOPQ-P	D	1	+	M	A	1	+	L	V	1	+	L					A	1	?	L				
FOPQ-SF					V	1	+	M	V	1	+	M	I	1	?	L	V	1	+	M				
PCS-C	I	1	+	VL	A	7	?	M	D	9	?	L	I	2	?	L	A	5	+	M	A	1	+	L
PCS-P	I	1	+	VL	V	2	+/-	M	V	3	+	M	D	2	?	L	A	1	?	L	A	1	+	L
PCQ	D	1	+/-	L	A	8	?	L	V	8	+	L	D	4	?	L	V	4	?	L	D	2	?	L
PCQ parent report					A	1	?	L	V															
PCQ-SF	I	1		L	I	1	-	L	D	1	-	L					A	1	+	M				
PPCI self-report	I	1	?	L	D	5	?	L	V	5	?	L	D	1	?	L	I	2	?	L	I	1	-	VL
PPCI parent report	I	1	?	L	D	2	?	L	D	2	?	L	D	1	?	L	I	1	?	L				

FIGURE 1 Overall quality of the evidence. There was no evidence for responsiveness, criterion validity, or measurement error for any of the tools, hence only six measurement properties were graded for overall quality. COSMIN Risk of Bias score: V, very good; A, adequate; D, doubtful; I, inadequate. Criteria for content validity rating: [a]Overall content validity is sufficient (+), insufficient (–), inconsistent (±), undetermined (?). (+) The relevance rating is (+), the comprehensiveness rating is (+), and the comprehensibility rating is (+). (–) The relevance rating is (–), the comprehensiveness rating is (–), and the comprehensibility rating is (–). (±) At least one of the ratings is (+) and at least one of the ratings is (–). (?) Two or more of the ratings are rated (?). Criteria for 'other measurement properties' rating: measurement property rating: (+) sufficient; (–) insufficient; (?) undetermined. [b](+) Confirmatory factor analysis: comparative fit index or Tucker–Lewis index or comparable measure >0.95 or RMSEA <0.06 or SRMR <0.08; (?) not all information for + reported; (–) criteria for + not met. [c](+) At least low evidence for structural validity and Cronbach's alpha ≥0.70 for each unidimensional scale of subscale; (?) criteria for at least low evidence for structural validity not met; (–) at least low evidence for structural validity and Cronbach's alpha <0.70 for each unidimensional scale or subscale. [d](+) Intraclass correlation coefficient (ICC) ≥ 0.70; (?) ICC not recorded; (–) ICC <0.70. [e](+) The result is in accordance with the hypothesis; (?) no hypothesis defined (by the review team); (–) the result is not in accordance with the hypothesis. [f](+) No important differences were found between group factors (such as age, sex, language) in multiple group factor analysis or no important differential for group factors (McFadden's $R^2 < 0.02$); (?) no multiple group factor analysis or differential analysis performed; (–) important differences between group factors or differential analysis was found. Modified GRADE (quality grade): H, high; M, moderate; L, low; VL, very low. Abbreviations: BAPQ, Bath Adolescent Pain Questionnaire; BAPQ-P, Bath Adolescent Pain Questionnaire for Parents; COSMIN, COnsensus-based standards for the Selection of Health Measurement Instruments; CP QoL, Cerebral Palsy Quality of Life; CSES, Child Self-Efficacy Scale (self-report); CSES-P, Child Self-Efficacy Scale (parent report); FOPQ, Fear of Pain Questionnaire; FOPQ-C, Fear of Pain Questionnaire for children; FOPQ-P Fear of Pain Questionnaire for parents; FOPQ-SF, Fear of Pain Questionnaire Short Form; PCS-C Pain Catastrophizing Scale for children; PCS-P, Pain Catastrophizing Scale for parents; PCQ, Pain Coping Questionnaire; PCQ-SF, Pain Coping Questionnaire Short Form; PPCI, Paediatric Pain Coping Inventory; PROM, patient-reported outcome measure; RMSEA, root mean square error of approximation; SRMR, standardized root mean square residual.

parent report, a direct adaptation of the child self-report version, was reported. This was 'very good';[23] however, it was downgraded due to the structural validity rating of the original tool.

Fear of Pain Questionnaire for children

The FOPQ for children was one of only three tools that were pilot tested in the population of interest: those experiencing chronic pain. This measure has also been translated into German.[58] The FOPQ for children was rated as having sufficient content validity with the quality of the relevance and comprehensibility graded as 'moderate' and comprehensiveness graded as 'high'. The overall quality of content validity was downgraded to 'moderate' due to risk of bias. Two studies with a combined sample size of 532 reported on structural validity, which had an overall grade of 'low-quality' evidence; therefore, internal consistency was also graded as 'low'. Construct validity for the FOPQ for children was also graded as 'low' due to risk of bias and inconsistency in two available studies. The FOPQ for parents was reported using the same sample of 299 adolescents and parents of adolescents from the study by Simons et al.[24] and was graded as for the FOPQ for children. The short form of the FOPQ developed by Heathcote et al.[25] was tested in a sample size of 526 adolescents with chronic pain and demonstrated 'moderate' evidence for structural validity, internal consistency, measurement error, and construct validity. It was graded as 'low' for reliability due to the sample size and risk of bias.

The Pain Catastrophizing Scale for Children

The PCS-C is a direct adaptation of the adult measure.[23] The PCS-C was the first paediatric tool to measure catastrophizing as a separate and distinct construct that was not a subset of a broader pain coping tool and has been widely used and translated.[27]

The original tool was not developed with patient input and therefore was rated 'inadequate' indicating high risk of bias; 'insufficient' for comprehensiveness, relevance, and comprehensibility; and content validity was graded as 'very low'. Despite this, reviewer ratings were 'sufficient' with eight studies reporting measurement properties for the child version and four studies reporting on the parent-reported version. This tool has been translated into Swedish, Catalan, German, and French, with a total sample size of more than 4000. Measurement properties were graded as 'moderate' for structural validity and construct validity and as 'low' for internal consistency. The parent-reported version, in addition to 'moderate' structural validity and internal consistency, demonstrated low-grade evidence for reliability and construct validity.

Pediatric Pain Coping Inventory

Five studies evaluated the PPCI, which was developed by Varni et al.[26] in 1996 from existing literature and consultation with paediatric pain experts. Content validity from this study was inadequate and graded overall as 'low'. Structural validity and internal consistency were reported in all five studies with a total sample size of 800 and were graded as 'very low' due to inconsistency and risk of bias. Test–retest reliability was reported in one study, with a sample size of 166, and graded as 'low-quality' evidence due to risk of bias and overall indeterminate rating. Two studies reported on construct validity for the self-report version, one which reported construct validity for the parent-reported version, which were graded as 'low'.

Pain Coping Questionnaire

Eight studies with a total of 9518 participants were identified and reported in English (one study), Spanish (three studies), German (one study), Dutch (one study), Danish (one study), and Finnish (one study). Based on these studies, the PCQ had evidence of structural validity, internal consistency, cross-cultural validity, and construct validity. Six studies reported on construct validity; however, due to inconsistency, risk of bias, and a pooled rating of 'undetermined', the evidence was downgraded two points to 'low'. Cross-cultural validity and reliability were also graded as 'low-quality' evidence. Although all the studies reported on internal consistency, none reported on structural validity. In the original article by Reid et al.,[28] a parent-reported version was directly adapted from the child version and showed a moderate relationship with the self-report version for both the Distraction and Emotional Focused Avoidance subscales; however, a weak relationship was reported for information seeking and cognitive distraction. In 2022, Kohut et al.[29] published a short form of the PCQ, developed in a sample of 1225 children and adolescents. The short form demonstrates moderate evidence for construct validity. There was no evidence for responsiveness, criterion validity, or measurement error for any of the tools, hence only six measurement properties were graded for overall quality (Figure 1).

All self-report and observer-reported outcome measure (parent proxy report) versions of the seven pain coping tools were feasible for use in clinical practice. Time to complete ranged from 5 minutes for the subscales to 15 minutes for the complete tool. All tools had clear instructions for scoring and used ordinal scales, which were easy to understand. All tools were freely available for clinical use; however, the Pediatric Quality of Life PPCI has a cost for funded academic use. No equipment is required for any of the tools. This is summarized in Table S3.

DISCUSSION

There were two purposes to this systematic review. First, we wanted to identify PROMs or observer-reported outcome measures that have been used to assess the construct of pain coping in children with a neurodevelopmental disability who have chronic pain. Second, we wanted to evaluate the measurement properties of the tools identified using the criteria for good measurement properties outlined by COSMIN.[15–17] Our goal was to identify tools that are valid and reliable for those individuals with neurodevelopmental disabilities, where self-report may be impacted by the need for cognitive or communicative support. From 16 eligible studies retrieved in search 1, we identified seven PROMs used in a range of populations with neurodevelopmental disability: most (11 studies) included young adults with CP. All seven tools had observer-reported outcome measure (parent proxy report) and self-report versions, with additional short forms for the PCQ and FOPQ for children, and variable evidence in support of their measurement properties.

Clinical utility for children and young adults with cognitive impairment or communication difficulties

There were three studies where presence of an intellectual disability was an exclusion criterion;[10,33,43] however, five studies included young adults with an intellectual disability. In these five studies, observer-reported outcome measure (parent proxy report) versions of the tools were used. This is an important consideration for clinical utility in a population with neurodevelopmental disability, such as CP, where approximately 46% of children[59] have cognitive impairment. Although young adults with an intellectual disability may

require ongoing support from caregivers to interpret behavioural cues and provide information on the impact of their pain and their pain coping strategies, wherever possible they have a right to self-report. This means instrument developers have a responsibility to consider the cognitive accessibility of their measures to maximize the potential for valid self-report. We identified eight PROM development and content validity studies for the seven tools included in this review. In all eight studies, participants needed the cognitive abilities of a 7- to 8-year-old, at a minimum, to read, understand, and complete the questionnaires. There are currently no PROM or observer-reported outcome measure versions of pain coping tools that are validated for children and young adults with cognitive and communication support needs apart from the CP QoL. The CP QoL primary caregiver version was specifically designed for parent use with children who cannot self-report; the other six tools were not developed with the intention of using the parent proxy version for children with an intellectual disability, rather to assess the parents' perspective and understanding of their child's chronic pain.[21]

None of the seven identified pain coping outcome tools had evidence of high overall quality for any measurement property and none had reported evidence about all nine measurement properties. For the tools to be useful in clinical practice, they need to be able to discriminate between adaptive and maladaptive pain coping strategies, reliable, with low measurement error, and if they are to be used as evaluative outcome measures, be responsive to change in pain coping. There was only low-grade evidence for reliability for each tool except for the CSES, which had moderate evidence. No tool had reported evidence of responsiveness and four of the tools did not have evidence in support of their content validity for the population with chronic pain.

Content validity

Content validity is the most important measurement property because it ensures that the PROM is meaningful and understandable to the target population.[17] The lack of input in tool development from young adults with neurodevelopmental disability and their parents is a limitation when using these tools for this population. It is important to note that all the tools have been used extensively in young adults with chronic pain and have good face validity.

Until recently, research about the measurement properties of PROMs had not been supported by guidelines for study conduct or reporting the outcomes. Some of the studies in this systematic review did not report on each criterion considered in the comprehensive methodological guidelines developed by COSMIN; therefore, many of the tools could only be rated as doubtful or inadequate. Thus, many of the tools were downgraded, potentially due to lack of published information. The absence of standardized reporting guidelines being available before COSMIN was published in 2018 has been reported as a limitation when using COSMIN guidelines to retrospectively evaluate the measurement properties of PROMs.[60] In our review, only the CP QoL teenager self-report and primary caregiver versions[33] had acceptable content validity for use with young adults who have a neurodevelopmental disability.

Two tools had evidence of content validity for adolescents with chronic pain, the FOPQ for children and the BAPQ. The FOPQ for children is appropriate for use with populations with chronic pain while the BAPQ has only provisional evidence due to the lack of structural validity reported in the paper by Eccleston et al.[46] These two tools and the CP QoL Pain and Bother subscales are provisionally recommended as the most appropriate to use, until further psychometric testing is completed. Each are clinically feasible to administer (Table S3). Although four of the pain coping tools (PCS-C, PCQ, PPCI, and CSES) did not meet the criteria for content validity, these tools had some promising measurement properties (Figure 1). We also note that these tools were developed before the COSMIN guidelines were published.

Measurement invariance and cross-cultural validity

Establishing validity of a measure for each population in which it is intended to be used is necessary to ensure it is interpreted in the same way by different groups. For example, participants who are different to the ones in which the PROM was initially validated may react differently to the wording or content of a measure; therefore, the PROM will not be equivalent for these individuals. Measurement invariance compares the responses to items in PROMs from two groups that are similar in population characteristics apart from one group variable, such as age, sex, disability type, or language.[14–16] Measurement invariance was not reported for any of the PROMs in a population with a neurodevelopmental disability. Without evidence of measurement invariance for individuals with neurodevelopmental disability, the PROM may be susceptible to measurement errors. It would have been beneficial to understand any measurement invariance in items in pain coping tools in children with neurodevelopmental disability compared with the population for whom the tool had initially been developed. Establishing measurement invariance of the observer-reported outcome measure (parent proxy report) versions for parents of children with intellectual disabilities or communication challenges is also needed.

Neurodevelopmental disability comprises a heterogeneous group of disorders. Increasingly, research in chronic pain in disability is global.[38] Therefore, there is a need to adapt these measures for use in other languages to ensure the tool is culturally relevant and understandable while maintaining the meaning of the original items. Cross-cultural validation consists of two steps: translation of the original PROM into another language and testing equivalence, then validation of the translated PROM. There was no reported evidence of cross-cultural validation of the CP QoL for teenagers, CSES, FOPQ, PPCI, or PCQ, despite these tools being translated into several other languages.

Construct validity

Hypothesis testing for construct validity was reported for all tools, supporting their validity to measure pain coping. Six tools were graded as 'moderate-quality' evidence for construct validity including the CSES, FOPQ short form, PCQ short form, BAPQ, CP QoL, and the PCS-C. The FOPQ short form, PCQ short form, and PCS-C measure the constructs of fear and avoidance of pain and catastrophizing or helplessness, which are important for predicting positive pain outcomes.[7] Based on the overall rating and quality of measurement evidence, the CP QoL 'Pain and Bother' subscales could be considered the most relevant tool to use for people with a neurodevelopmental disability; however, we do not recommend it as a stand-alone tool to assess pain coping. The CP QoL is a multidimensional quality of life tool and does not specifically capture the aspects of catastrophizing that are needed to inform suitability for therapies that are considered best practice in other populations with chronic pain. We suggest high scores in the Pain and Bother subscales could be a flag to further assess pain coping using an additional tool. Tools such as the FOPQ, BAPQ, PCQ, and PCS will identify suboptimal pain coping styles and help support referral for therapies where needed. We recommend using the FOPQ or BAPQ, the two tools with content validity in populations with chronic pain; however, we acknowledge that all the tools identified, apart from the CP QoL, require further validation for individuals with a neurodevelopmental disability.

Feasibility

COSMIN defines feasibility as the ease of application of the PROM that considers the cost of the instrument, length of time to complete the instrument, and type and ease of administration.[15–17] All self-report and observer-reported outcome measure (parent proxy report) versions of the pain coping tools included in this review have good feasibility for use in the community and hospital settings (Table S3). They are freely available for clinical use (the PPCI has a fee for funded academic use), easy to administer and score, no equipment is required, and the subscales take approximately 5 to 10 minutes to complete, which is not overly burdensome for families or clinicians. However, the feasibility of using these PROMs with people who have cognitive and/or communication impairments has not been reported and is likely to be limited.

Strengths and limitations

A strength of this review is the use of COSMIN to rate the risk of bias and the modified GRADE approach that assisted in determining recommendations for PROM or observer-reported outcome measure use based on the overall quality of evidence from a synthesis of studies. The inclusion of all languages ensured comprehensiveness of the review, particularly when determining if any tool had cross-cultural validity.

There are several limitations noted. We only rated tools that had already been used to assess pain coping in neurodevelopmental disability, which may mean we missed potentially useful tools that are available. There were other quality of life tools that were excluded (Table S1) because they do not directly measure pain coping. However, these tools provide some information on pain intensity and interference, which could impact emotional well-being, such as anxiety and depression.

Future research

Further testing of many measurement properties for children and young adults with a neurodevelopmental disability is needed to ensure appropriate decisions are made for monitoring and treating young adults with a neurodevelopmental disability and chronic pain. Significant gaps were noted in content validity, measurement invariance, cross-cultural validity, measurement error, and responsiveness. Observer-reported outcome measures (parent proxy report and self-report versions) are available for all seven PROMs; however, these versions have been developed with parents and children who have cognitive abilities of approximately 7 to 8 years and therefore may not reflect what is important to measure for people who have cognitive impairments. Measurement invariance in populations with neurodevelopmental disability is recommended as a focus for future research to ensure that these tools adequately capture pain coping for individuals with a neurodevelopmental disability who cannot self-report. It is important to determine what adaptations are needed to support young adults to self-report despite cognitive or communicative support needs, given that pain is a subjective experience. There is also a gap in understanding how asking parents to report on their child's experience of pain is reflective of the child's actual experience of pain coping versus any influence from the parent's own difficulties managing their child's chronic pain. Both perspectives are needed given that studies in other populations with chronic pain demonstrated that parental catastrophizing of their child's pain symptoms are linked to greater functional disability and poor emotional outcomes for the parent–child dyad.[61]

Conclusion

This systematic review highlighted that while seven PROMs, all which have observer-reported outcome measures (parent proxy report and self-report versions), were identified that had been used to measure pain coping in young adults with neurodevelopmental disability, they all require further psychometric evaluation and validation. We recommend the CP QoL as a screening tool for chronic pain. The BAPQ and FOPQ show promise for use in this population; however,

they cannot be used with confidence without further psychometric testing.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article

ACKNOWLEDGEMENT

Open access publishing facilitated by The University of Western Australia, as part of the Wiley - The University of Western Australia agreement via the Council of Australian University Librarians.

ORCID

Nadine L. Smith https://orcid.org/0000-0002-3882-4713
Noula Gibson https://orcid.org/0000-0003-0183-9214
Christine Imms https://orcid.org/0000-0001-9055-3554

REFERENCES

1. Eriksson E, Hegglund G, Alriksson-Schmidt AI. Pain in children and adolescents with cerebral palsy - a cross-sectional register study of 3545 individuals. BMC Neurology. 2020;20(1):15.
2. McKinnon C, Morgan P, Meehan E, Harvey A, Antolovich G. The prevalence and characteristics of pain in children with cerebral palsy. Dev Med Child Neurol. 2018;60(Supplement 1):28.
3. Raja SN, Carr DB, Cohen M, Finnerup NB, Flor H, Gibson S, et al. The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises. Pain. 2020;161(9):1976–82.
4. Liossi C, Howard RF. Pediatric Chronic Pain: Biopsychosocial Assessment and Formulation. Pediatrics. 2016;138(5):e2016-0331.
5. Asmundson GJG, Noel M, Petter M, Parkerson HA. Pediatric fear-avoidance model of chronic pain: Foundation, application and future directions. Pain Research Manag. 2012;17(6):397–405.
6. Simons LE, Kaczynski KJ. The Fear Avoidance model of chronic pain: examination for pediatric application. J Pain. 2012;13(9):827–35.
7. Fisher E, Heathcote LC, Eccleston C, Simons LE, Palermo TM. Assessment of Pain Anxiety, Pain Catastrophizing, and Fear of Pain in Children and Adolescents With Chronic Pain: A Systematic Review and Meta-Analysis. J Pediatr Psychol. 2018;43(3):314–25.
8. Fisher E, Law E, Dudeney J, Palermo TM, Stewart G, Eccleston C. Psychological therapies for the management of chronic and recurrent pain in children and adolescents. Cochrane Database Syst Rev. 2018;9(9):CD003968. https://doi.org/10.1002/14651858.CD003968.pub5
9. Miller MM, Meints SM, Hirsh AT. Catastrophizing, pain, and functional outcomes for children with chronic pain: a meta-analytic review. Pain. 2018;159(12):2442–60.
10. Chaleat-Valayer E, Roumenoff F, Bard-Pondarre R, Bernard J-C, Ganne C, Verdun S, et al. Pain coping strategies in children with cerebral palsy. Dev Med Child Neurol. 2019;61(11):1329–35.
11. Fairhurst C, Shortland A, Chandler S, Will E, Scrutton D, Simonoff E, et al. Factors associated with pain in adolescents with bilateral cerebral palsy. Dev Med Child Neurol. 2019;61(8):929–36.
12. Morris C, Janssens A, Tomlinson R, Williams J, Logan S. Towards a definition of neurodisability: a Delphi survey. Dev Med Child Neurol. 2013;55(12):1103–8.
13. Mokkink LB, Boers M, Van Der Vleuten C, Bouter LM, Alonso J, Patrick DL, et al. COSMIN Risk of Bias tool to assess the quality of studies on reliability or measurement error of outcome measurement instruments: a Delphi study. BMC Med Res Method. 2020;20(1):1–13.
14. Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021;372:n71.
15. Mokkink LB, de Vet HCW, Prinsen CAC, Patrick DL, Alonso J, Bouter LM, et al. COSMIN Risk of Bias checklist for systematic reviews of Patient-Reported Outcome Measures. Qual Life Res. 2018;27(5):1171–9.
16. Prinsen CAC, Mokkink LB, Bouter LM, Alonso J, Patrick DL, de Vet HCW, et al. COSMIN guideline for systematic reviews of patient-reported outcome measures. Qual Life Res. 2018;27(5):1147–57.
17. Terwee CB, Prinsen CAC, Chiarotto A, Westerman MJ, Patrick DL, Alonso J, et al. COSMIN methodology for evaluating the content validity of patient-reported outcome measures: a Delphi study. Qual Life Res. 2018;27(5):1159–70.
18. Smart A. A multi-dimensional model of clinical utility. Int J Qual Health Care. 2006;18(5):377–82.
19. Voepel-Lewis T, Malviya S, Tait AR, Merkel S, Foster R, Krane EJ, et al. A comparison of the clinical utility of pain assessment tools for children with cognitive impairment. Anesth Analg. 2008;106(1):72–8.
20. Eccleston C, Jordan A, McCracken LM, Sleed M, Connell H, Clinch J. The Bath Adolescent Pain Questionnaire (BAPQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. Pain. 2005;118(1–2):263–70.
21. Eccleston C, McCracken LM, Jordan A, Sleed M. Development and preliminary psychometric evaluation of the parent report version of the Bath Adolescent Pain Questionnaire (BAPQ-P): A multidimensional parent report instrument to assess the impact of chronic pain on adolescents. Pain. 2007;131(1–2):48–56.
22. Davis E, Mackinnon A, Davern M, Boyd R, Bohanna I, Waters E, et al. Description and psychometric properties of the CP QOL-Teen: A quality of life questionnaire for adolescents with cerebral palsy. Res Dev Disabil. 2013;34(1):344–52.
23. Bursch B, Tsao JCI, Meldrum M, Zeltzer LK. Preliminary validation of a self-efficacy scale for child functioning despite chronic pain (child and parent versions). Pain. 2006;125(1–2):35–42.
24. Simons LE, Sieberg CB, Carpino E, Logan D, Berde C. The Fear of Pain Questionnaire (FOPQ): assessment of pain-related fear among children and adolescents with chronic pain. J Pain. 2011;12(6):677–86.
25. Heathcote LC, Bhandari RP, Timmers I, Harrison LE, Simons LE. Rapid identification and clinical indices of fear-avoidance in youth with chronic pain. Pain. 2020;161(3):565–73.
26. Varni JW, Waldron SA, Gragg RA, Rapoff MA, Bernstein BH, Lindsley CB, et al. Development of the Waldron/Varni Pediatric Pain Coping Inventory. Pain. 1996;67(1):141–50.
27. Crombez G, Bijttebier P, Eccleston C, Mascagni T, Mertens G, Goubert L, et al. The child version of the pain catastrophizing scale (PCS-C): a preliminary validation. Pain. 2003;104(3):639–46.
28. Reid GJ, Gilbert CA, McGrath PJ. The Pain Coping Questionnaire: preliminary validation. PAIN. 1998;76(1–2):83–96.
29. Kohut SA, Stinson J, Chambers CT, Reid GJ, Pillai Riddell RR. The Pain Coping Questionnaire short-form: preliminary reliability and validity. Pain Rep. 2022;7(1):e982.
30. Yamaguchi R, Nicholson Perry K, Hines M. Pain, pain anxiety and emotional and behavioural problems in children with cerebral palsy. Dis Rehab. 2014;36(2):125–30.
31. Ostojic K, Paget S, Morrow A. Biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy. Dev Med Child Neurol. 2019;61(Supplement 3):138–9.
32. Stout J, Novacheck T, Barney C. Use of a pain coping assessment to enhance understanding of pain in individuals with physical disabilities. Gait Posture. 2017;57 (Supplement 1):92–3.
33. Ostojic K, Sharp N, Paget S, Morrow A, Khut G. BrightHearts: A pilot study of biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy. Dev Med Child Neurol. 2020;62(Supplement 4):38–9.
34. Engel JM, Wilson S, Tran ST, Jensen MP, Ciol MA. Pain catastrophizing in youths with physical disabilities and chronic pain. J Ped Psych. 2013;38(2):192–201.
35. Davis E, Davern M, Waters E, Mackinnon A, Reddihough D, Boyd R, et al. Psychometric properties of the Cerebral Palsy Quality of

Life Questionnaire for Adolescents (CP QOL-Teen). Dev Med Child Neurol. 2010;52(Supplement 2):24–5.
36. McKinnon CT, White JH, Morgan PE, Antolovich GC, Clancy CH, Fahey MC, et al. The lived experience of chronic pain and dyskinesia in children and adolescents with cerebral palsy. BMC Pediatr. 2020;20(1):125.
37. Badia M, Orgaz B, Riquelme I, Go mez-Vela M. Are the domains of the CPQOL adequate for exploring quality of life in children with cerebral palsy associated with intellectual disabilities in Spain? Dev Med Child Neurol. 2019;61(Supplement 3):80–1.
38. Andersen RD, Genik L, Alriksson-Schmidt AI, Anderzen-Carlsson A, Burkitt C, Symons FJ, et al. Pain burden in children with cerebral palsy (CPPain) survey: Study protocol. Paediatr Neonatal Pain. 2021;4(1):12–22.
39. Schiariti V, Oberlander TF. Evaluating pain in cerebral palsy: Comparing assessment tools using the International Classification of Functioning, Disability and Health. Disability and Rehabilitation: An International, Multidisciplinary Journal. 2019;41(22):2622–9.
40. Zabalia M. Pain self-report and pain coping in children and adolescent with mild to moderate intellectual disabilities. Expression de la douleur et strategies de faire-face des enfants et adolescents atteints de deficience intellectuelle legere ou moyenne. 2013;26(1):24–9.
41. Burkitt CC, Breau LM, Zabalia M. Parental assessment of pain coping in individuals with intellectual and developmental disabilities. Res Dev Disabil. 2011;32(5):1564–71.
42. Mprah KW, Owusu I, Acheampong E, Ansa OEO, Moses MO. Effect of Community-Based Functional Aerobic Training on Motor Performance and Quality of Life of Children with Spastic Cerebral Palsy. Ethiop J Health Sci. 2021;31(2):381–92.
43. Engel JM, Wilson S, Tran ST, Jensen MP, Ciol MA. Pain catastrophizing in youths with physical disabilities and chronic pain. J Pediatr Psychol. 2013;38(2):192–201.
44. Valkenburg AJ, Tibboel D, van Dijk M. Pain sensitivity of children with down syndrome and their siblings: Quantitative sensory testing versus parental reports. Dev Med Child Neurol. 2015;57(11):1049–55.
45. Turk DC, Wilson HD. Fear of pain as a prognostic factor in chronic pain: conceptual models, assessment, and treatment implications. Curr Pain Headache Rep. 2010;14(2):88–95.
46. Eccleston C, Jordan A, McCracken LM, Sleed M, Connell H, Clinch J. The Bath Adolescent Pain Questionnaire (BAPQ): development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. Pain. 2005;118(1–2):263–70.
47. Cohen LL, Vowles KE, Eccleston C. The impact of adolescent chronic pain on functioning: Disentangling the complex role of anxiety. J Pain. 2010;11:1039–46.
48. Gagnon C, Amstutz D, Revivo G. Psychometric evaluation of the Bath Adolescent Pain Questionnaire (BAPQ) in a US-based clinical population. J Pain. 2011;12(4):17.
49. Cohen LL, Vowles KE, Eccleston C. Adolescent chronic pain-related functioning: Concordance and discordance of mother-proxy and self-report ratings. Eur J Pain. 2010;14(8):882–6.
50. Davis E, Davern M, Waters E, Mackinnon A, Reddihough D, Boyd R, et al. Psychometric properties of the Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL-Teen). Developmental Medicine and Child Neurology. 2010;(2):24–5.
51. Yarmohammadi N, Rassafiani M, Joveini G, Rostami HR, Mahani MK, Behnia F, et al. Validation of Persian Caregivers' Report of Quality of Life questionnaire for adolescents with cerebral palsy. Int J Ther Rehab. 2018;25(5):234–9.
52. Boling S, Varho T, Haataja L. Longitudinal study showed that the quality of life of Finnish adolescents with cerebral palsy continued to be relatively good. Acta Paediatrica. 2018;107(3):469–76.
53. Wolinska O, Snela S, Guzik A, Druzbicki M. Validation of the Polish version of the CP QOL-Teen scale. Dev Med Child Neurol. 2021;63(Supplement 2):78.
54. Davis E, Mackinnon A, Davern M, Boyd R, Bohanna I, Waters E, et al. Description and psychometric properties of the CP QOL-Teen: a quality of life questionnaire for adolescents with cerebral palsy. Research in Developmental Disabilities. 2013;34(1):344–52.
55. Celik S, Calis FA, Durmaz B. Validating the cerebral palsy quality of life for teen (CPQOL-teen) questionnaire for use in turkish population. Turkiye Fiziksel Tip ve Rehabilitasyon Dergisi. 2013;1:448.
56. Maier M, Stoltenburg C, Sarpong-Bengelsdorf A, Lebek S. Validity and Reliability of the German Version of the CP QOL-Child and CP QOL-Teen Questionnaire. Neuropediatrics. 2022;53(2):102–8.
57. Andias R, Silva AG. European Portuguese version of the Child Self-Efficacy Scale: A contribution to cultural adaptation, validity and reliability testing in adolescents with chronic musculoskeletal pain. Musculoskelet Sci Pract. 2020;49:102176.
58. Flack F, Gerlach AL, Simons LE, Zernikow B, Hechler T. Validation of the German fear of pain questionnaire in a sample of children with mixed chronic pain conditions. Eur J Pain. 2017;21(7):1224–33.
59. Smithers-Sheedy H, McIntyre S, Badawi N, Goldsmith S, Balde I, Gibson C, et al. Australian Cerebral Palsy Register Report, 20182018.
60. Bull C, Byrnes J, Hettiarachchi R, Downes M. A systematic review of the validity and reliability of patient-reported experience measures. Health Serv Res. 2019;54(5):1023–35.
61. Law E, Fisher E, Eccleston C, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. Cochrane Database Syst Rev. 2019;3(3):CD009660-CD.

SUPPORTING INFORMATION

The following additional material may be found online:

Table S1 List of excluded tools from search stage 1

Table S2 Characteristics of the studies from search stage 1

Table S3 Characteristics of pain coping measurement tools used in neurodevelopmental disability identified in search 1

Table S4 Characteristics of the included studies from search 2

Figure S1 PRISMA flow chart indicating results and screening process for search stage 1

Figure S2 PRISMA flow chart indicating results and screening process for search stage 2

Appendix S1 Search strategies: pain coping tools stage 1

How to cite this article: Smith NL, Smith MG, Gibson N, Imms C, Thornton Al, Harvey AR. Pain coping tools for children and young adults with a neurodevelopmental disability: A systematic review of measurement properties. Dev Med Child Neurol. 2022;00:1–11. https://doi.org/10.1111/dmcn.15410