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Subjective measurement of physical activity and sedentary behaviour in children and adolescents with cerebral palsy: a scoping review

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ABSTRACT

Purpose: Physical activity is essential for maintaining overall health. Cost-effective and easily administered outcome instruments are valuable for clinical practice and large-scale population studies. The scoping review aimed to identify and map subjective instruments developed or validated to measure habitual physical activity and/or sedentary behaviour in children and adolescents with cerebral palsy aged 0–18 years across all levels of the GMFCS-E&R.

Materials and methods: This scoping review was conducted in accordance with the JBI methodology for scoping reviews and searched the databases PubMed, CINAHL, Web of Science, Cochrane Database of Systematic Reviews, JBI Database of Systematic Reviews and Implementation Reports, Embase and Pedro to identify articles.

Results: From 288 full-text references, 13 studies met the inclusion criteria. Nine instruments measured habitual physical activity and/or sedentary behaviour in children and adolescents with cerebral palsy aged 18 months to 18 years. Six subjective instruments were tested for ambulatory children, while three instruments were tested in children and adolescents at GMFCS-E&R level I–V.

Conclusion and implications: Reporting of the psychometric properties were found on reliability in three instruments, while data on validity were reported in all instruments. Further studies assessing the psychometric properties of subjective instruments in the target population are needed.

IMPLICATION FOR REHABILITATION

- Subjective instruments allow for monitoring of physical activity levels in children with cerebral palsy (CP).
- Personal perceptions of physical activity and/or sedentary behaviour can be assessed using subjective instruments.
- Caution should be exercised when using subjective instruments to measure physical activity and/or sedentary behaviour, as knowledge about their validity and reliability is limited.

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Cerebral palsy; children; outcome instruments; physical activity; sedentary

Introduction

Cerebral palsy (CP) is a group of permanent disorders of movement and/or posture and motor function caused by a non-progressive disturbance in the immature brain [1]. Movement- and neuro-musculoskeletal-related functions, comorbidities and personal and environmental factors might result in different limitations with regard to activity performance and participation in physical activities [2].

Children with CP experience barriers to participation in leisure and sport activities and are challenged to meet the recommended levels of physical activity and limit sedentary behaviour, which can impact their overall health and quality of life [3–5]

Physical activity and sedentary behaviour are critical factors influencing public health. Understanding the patterns and determinants of these behaviours is essential for developing effective interventions to promote health and prevent disease [6–8]. Habitual physical activity performance (HPA) and sedentary behaviour (SB) can be measured using objective methods (e.g., direct observation and use of motion sensors and heart rate monitors) as well as subjective instruments (e.g., self- or proxy self-report questionnaires, activity diaries, and structured interviews) [9]. Accurately measuring these behaviours is essential for developing targeted interventions to enhance HPA and reduce SB in this population. The reliability and validity of subjective measures in children with CP are critical for ensuring accurate assessments.

Systematic reviews on the instruments used for monitoring HPA for children with CP have been conducted with diverse eligibility criteria and findings [10–12]. Capio et al. included instruments used in field-based research with young people with CP and concluded that the Activity Scale for Kids-Performance (ASKp) and the Children's Assessment of Participation and Enjoyment/ Preferences for Activities of Children (CAPE/PAC) had established

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reliability and validity [10]. Two reviews included questionnaires with at least 60% of the items relating to the domain of physical activity performance [11,12]. Clanchy et al. included CAPE/PAC and the Physical Activity Questionnaire for Adolescents (PAQ-A) [11]. In contrast, Mitchell et al. considered the PAQ-A and Multimedia Activity Recall for Children and Adults (MARCA) and excluded ASKp, CAPE/PAC and the System for Observing Fitness Time (SOFIT) for not meeting their HPA-measuring inclusion criterion of at least 60% of items being related to physical activity [12]. Furthermore, a recent scoping review summarised how SB was measured in children with disabilities and found that MARCA, the International Physical Activity Questionnaire (IPAQ) and PAQ-A were used as subjective instruments in research with children and adolescents with CP [13]. Objective measures, such as accelerometers, heart rate monitors and pedometers, are often used to validate subjective measures. Comparative studies in children and adolescents with CP have indicated that subjective tools like the MARCA shows poor correlation with pedometer data and PAQ-A shows poor correlation with pedometer data as well as accelerometer data [12]

Moderate correlations and discrepancies between direct and indirect methods of assessing physical activity are seen in paediatric populations [14,15]. Self-report measures are useful for information on physical activity levels, but they risk over- or underestimating true physical activity level because of measurement bias such as recall bias or social desirability [16,17]. Objective devices, such as accelerometers, objectively estimates the frequency, duration and intensity and is considered an effective and feasible instrument to measure physical activity [14,18]. Nevertheless, it is cost intensive and time consuming to administer in clinical settings and in large-scale populations.

To include measures of HPA as well as SB in large epidemiologic studies and the data registries on CP, there is a need to identify instruments that can be employed for children with CP. Public health surveillance needs to be implemented in a valid and reliable manner to assess population-wide levels of HPA and SB. The focus of the current review is to provide a detailed overview of subjective instruments used for measuring HPA and/or SB, with an emphasis on the physiological impact of HPA. Subjective instruments that are potentially applicable in clinical practice and quality registers are needed when objective instruments are not available. They may serve as an adjunct to collecting objective data regarding treatment effects and support future research into the optimal patterns and intensities of physical activity as well as the dose–response relationship between physical activity and health outcomes in children and adolescents with CP.

The current scoping review aimed to identify and map subjective instruments that have been developed or validated to measure HPA and/or SB in any setting for 0–18-year-old children and adolescents with CP across all levels of the GMFCS-E&R [19].

Review questions

i. Which subjective instruments measure HPA for 0–18-year-old children and adolescents with CP across all levels of gross motor function according to the GMFCS-E&R (level I–V)?
ii. Which subjective instruments measure SB for 0–18-year-old children and adolescents with CP across all levels of gross motor function according to the GMFCS-E&R (level I–V)?
iii. What are the psychometric properties of these instruments, and in what contexts have they been tested?

Material and methods

This scoping review was conducted in accordance with the JBI methodology [20] and has been reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension statement for scoping reviews (PRISMA-ScR) [21]. The JBI methodology was chosen due to its rigorous and systematic approach to conducting scoping reviews. In agreement with the JBI methodology [20], the intend of this scoping review was to provide a comprehensive overview of existing subjective instruments and not to assess the quality of the literature. The objectives, inclusion criteria and methods for this scoping review were specified in advance and published in JBI Evidence Synthesis [22]. The deviations from the protocol are described in the section *Deviations from original protocol*.

Participants

This scoping review included studies with participants who were children and adolescents of 0–18 years old with CP across all five GMFCS-E&R levels.

Concept

This scoping review included studies that reported on subjective instruments (a) that measure HPA and/or SB, including classifications and questionnaires that were self-completed, administered by a parent or caregiver or professionally administered or reported; (b) were validated for children and adolescents with CP at all or specific GMFCS levels; and (c) that reported on the psychometric properties and documented validity, reliability or clinical utility with respect to measuring HPA and/or SB.

Physical activity is defined as any bodily movement using skeletal muscles that results in energy expenditure and, therefore, encompasses all gross and fine motor tasks, incidental movements and activities of daily life [23].

HPA is the physical activity performed during the usual activities of daily life over a period of time (day, week, etc.), varying through periods of rest, work and leisure [24]. HPA studies examine the amount (dosage) of HPA, which consists of the factors frequency, intensity, time and type (FITT) [25]. Frequency refers to how often a person does an activity; intensity represents how hard a person works to do the activity; duration/time denotes how long the activity is performed for in any one session, and the type of activity the person performs refers to the mode of activity [25]. Studies that included instruments that measure HPA for one day or more were considered for inclusion, as they can be used for consecutive days or sessions.

SB is defined as waking behaviour characterised by an energy expenditure of less than 1.5 metabolic equivalents (METs) in a sitting, reclining or lying posture [23,26].

Studies were excluded if they used instruments that primarily assessed body structure, physical function, participation and capability. Studies that did not distinguish between HPA and physical activity capability were excluded. Furthermore, studies including instruments exploring the concept physical literacy were excluded. Physical literacy and HPA are related concepts but differ in scope and components as physical literacy is defined as the "motivation, confidence, physical competence, knowledge, and understanding to value and take responsibility for engagement in physical activities for life" [27].

Context

Studies sought for inclusion had to provide information about the instruments used in the systematic assessment of participants' HPA and/or SB in any context, such as at home, educational institutions and hospitals or other rehabilitation facilities.

Types of studies

This scoping review considered quantitative, qualitative and mixed-methods study designs for inclusion. Experimental and quasi-experimental study designs, including randomised and non-randomised controlled trials, before-and-after studies and interrupted time series analysis, were considered. In addition, analytical observational studies, including prospective and retrospective cohort, case-control and analytical cross-sectional studies, were considered for inclusion. Descriptive observational study designs, including case series, individual case reports and descriptive cross-sectional studies, were also considered. Examples of qualitative study designs that were considered for inclusion are phenomenology, grounded theory, ethnography and qualitative description. Finally, psychometric instrument development or evaluation studies and systematic reviews were also considered for inclusion.

Search strategy

The search strategy aimed to find published, in-press and unpublished studies. Databases were searched from their inception to February 2021 and the search results were updated on 12 October 2023.

A three-step search strategy was implemented. In step one, an initial search of PubMed (PubMed.gov) and CINAHL (Cumulative Index to Nursing and Allied Health Literature; EBSCOhost) was conducted to identify relevant articles on the topic. This was followed by an analysis of the words contained in the title and abstract and of the index terms used to describe the articles to develop the full search strategy.

In step two, the full search strategy was modified according to each information source and implemented for the following databases: PubMed (PubMed.gov), CINAHL (EBSCOhost), Web of Science (Clarivate), Cochrane Library (Wiley), Embase (Embase.com), JBI Evidence Synthesis (via OVID) and Pedro (pedro.org.au). In order to include grey literature, Paediatric Exercise Science and Journal for the Measurement of Physical Behaviour were searched, as they specialise in physical-activity-assessment methods. The latter not currently indexed in PubMed. Furthermore, reference lists of systematic reviews and included full text reports were searched for additional relevant references Authors were contacted if a psychometric study was stated as a reference but not localised through the databases search or if only abstract were localised. The searches included combinations and variations of the following keywords: children, adolescents, cerebral palsy, physical activity, sedentary, measurement and psychometrics. The search strategy is detailed in Supplementary Appendix A – online only. In step three, the reference lists of the studies included in the review were examined to identify additional relevant studies.

No restriction regarding language was applied. A research librarian assisted with all steps of the research strategy to ensure the quality of the search.

Source of evidence selection

Following the search, all identified publications were uploaded into EndNote X20 (Clarivate Analytics, PA, USA), and all duplicates were removed. The systematic review software program Covidence (https://app.covidence.org/, Covidence, Melbourne, Australia) was used to facilitate the source selection process. To increase consistency among reviewers, the entire team screened a random sample of 25 titles/abstracts using the eligibility criteria, discussed the results and amended the eligibility criteria and definitions before the screening was conducted.

All titles and abstracts were screened by two independent reviewers (MJ, HMR, BL, JK or KL), and those that did not meet the inclusion criteria were excluded. The full content of potentially relevant studies was assessed in relation to the inclusion criteria by MJ and HMR, and reasons for exclusion were recorded. Disagreements were resolved through discussion and further adjudication by BL and KL.

In accordance with PRISMA [28] the results of the search are presented in a PRISMA flow diagram (Figure 1).

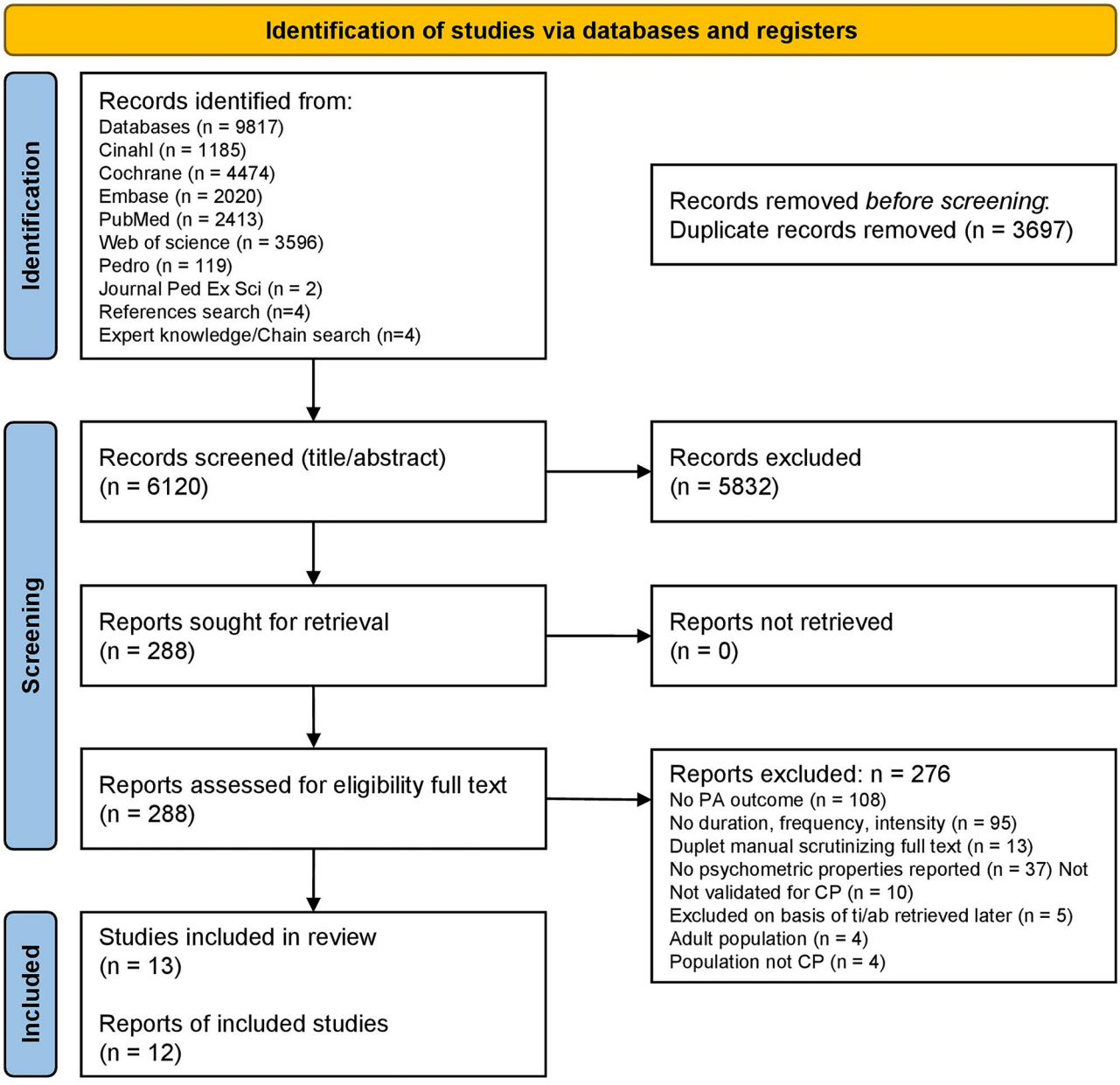
Deviations from the original protocol

The initial aim of the scoping review protocol was to identify and map subjective instruments developed to measure HPA and/or SB in children and adolescents with cerebral palsy. However, most of the identified studies reported on instruments that were developed for a broad population and subsequently tested in the study population. Therefore, the aim was specified to include instruments which were either developed or validated in the study population.

The protocol prespecified the duration/time of HPA measured as more than one day in daily life. In the review, we included outcome instruments that measure HPA for less than one day or more since these tools can be used for consecutive days or sessions. The protocol specified administration as self-, or parent reported. In the review outcome instruments with professional reporting were also included, as they can be used in clinical practice.

In an attempt to identify all relevant studies, search filters developed by *Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) – for use in systematic reviews of studies on measurement properties* [29] were considered and tested for application in the search strategy. Using the COSMIN filters in the initial searches revealed a large number of irrelevant studies, e.g., the initial search in PubMed revealed 4,630 references with a high number of irrelevant studies compared to the modified filter, which revealed 2,160 references. Therefore, the subsequent searches were modified to involve only the most sensitive and precise terms [29].

The data extraction tool was modified during the pilot test, and the measurement units were not extracted because the outcome measurements and scoring details were not always accessible in the identified studies. Domains were initially defined according to the International Classification of Functioning, Disability and Health (ICF) but redefined according to FITT due to the variation in terms of participation and HPA. In addition, the protocol stated that psychometric properties would be presented according to the COSMIN taxonomy of measurement properties. However, some of the included studies used different terminology. Therefore, data were extracted to comply with the studies' terminology.



From: 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. doi: 10.1136/bmj.n71
For more information, visit: http://www.prisma-statement.org/

Figure 1. The PRISMA flow diagram.

Data extraction

Data were extracted from the included studies by two reviewers independently using a data extraction tool developed by all team members. The tool included details about the study populations, concepts, contexts, methods, and findings relevant to the review questions. If an included study had multiple aims, only details related to psychometric properties were extracted. The terms of reliability and validity are extracted as stated in the original studies. The extraction tool was pilot tested by two reviewers (MJ and HMR) on two study sources to ensure its relevance and to reduce potential errors and disagreements. The two reviewers independently extracted the data, discussed the results with the team and updated the data extraction form following an iterative process. Any disagreements between the reviewers were resolved through discussion or by a third reviewer. The authors of the included studies were contacted to request missing or additional data where required.

Results

Study selection

The literature search identified 9,817 references, of which 6,120 were retained after the removal of duplicates. The titles and abstracts were screened based on the inclusion criteria and a total of 5,832 records were eliminated accordingly, leaving 288

reports that were to be subjected to a full-text assessment. References were scrutinised to localise psychometric studies that met the inclusion criteria. Authors were contacted if a psychometric study was stated as a reference but not localised through the databases search or if only abstract were localised. In this process, psychometric data on four outcome instruments were identified in four studies [30–33]. In addition, three more studies were located: three through expert contact [34–36], and one through chain search [37]. After the full-text assessments, 276 reports were excluded, and 12 reports containing 13 studies were retained (flow chart Figure 1).

Included instruments

Table 1 'Included outcome instruments' presents the outcome instruments and summarises the types of study design, concepts and population characteristics of the studies in which the instruments were identified. In total, 13 studies, which included nine subjective HPA outcome instruments, were considered eligible for this review. The studies were located as an abstract ($n = 1$), a PhD thesis containing two studies ($n = 2$), and 10 were research studies published from 2008 to 2023. They were conducted in North America and Canada ($n = 4$), Canada ($n = 1$), Korea ($n = 1$), England ($n = 1$), Australia ($n = 2$), China ($n = 2$), Turkey ($n = 1$) and Brazil ($n = 1$).

The included outcome instruments in Table 1 are the Early Activity Scale for Endurance (EASE, two versions), the Habitual Activity Estimation Scale (HAES), the International Physical Activity Questionnaire (IPAQ, two versions), the Multimedia Activity Recall for Children and Adults (MARCA), the Physical Activity Questionnaire for Adolescents (PAQ-A), the Behaviours of Eating and Activity for Children's Health Evaluation System (BEACHES) and the System for Observing Fitness Time (SOFIT)

The EASE [33,38–42] is a parent-completed measure for children with CP designed to estimate endurance for activity via reports of the frequency, intensity, and duration of PA of young children within their typical environments. It comes in two versions, 11 items and four items, developed for children with CP aged 1.5–5 years with GMFCS level I–V. The HAES [30] is a tool for measuring levels of HPA in clinical research and is validated in children GMFCS I with a mean age 11.3 years. The IPAQ long form (LF) and short form (SF) is a questionnaire evaluating HPA and SB and validated in youth GMFCS I–III from 10 years of age [43,44]. The IPAQ-LF consists of 25 questions assessing PA and two questions assessing sedentary behaviour grouped into four domains: work activities, travel activities, household and yard-work activities, and recreational activities [43]. The short version (IPAQ-SF) consists of six questions assessing PA and one question assessing sedentary behaviour [44]. MARCA is a time-use tool relying on accurate recall in 5-min intervals and validated in youth aged 11–17 years GMFCS I–V [32]. Software is required to use the MARCA, and allows one to report activities undertaken on the previous day from wake-up to bedtime, using a segmented-day format with self-determined anchor points (e.g., meals, school bells). Activities from a list of about 250 activities grouped under seven main rubrics (inactivity, transport, sport and play, school, self-care, chores, and other) are chosen. Each activity in the MARCA is associated with an energy expenditure, which allows calculation of daily minutes of moderate to vigorous physical activity, and daily physical activity level [32]. PAQ-A is an eight-item tool to examine HPA at different times throughout the day in the preceding seven days validated in youth below 17 years at functional level GMFCS I–V [32]. Each item contains five response options, which are scored based on the frequency or intensity with which physical activity was undertaken (where 1 = minimal activity, and 5 = high level of activity). An overall physical activity score is calculated from the average of all items, with a higher overall score indicating a greater level of physical activity. Two measures use observations, BEACHES [37] and the SOFIT [45], and are validated in children 6–12 years old with a functional level GMFCS I and 6–14 years old with a functional level GMFCS I–III, respectively.

Psychometric properties and context of included instruments

The psychometric data were reported in 12 cross-sectional studies and a randomised controlled trial. Details about the outcome instruments, reported psychometric properties, contexts, and key findings are reported in Table 2. An overview of reported psychometric properties is shown in Table 3.

The EASE (11 items) is a parent-reported measure developed for children with CP [39]. It was designed to estimate their endurance with regard to activity, reporting the frequency, intensity and duration of the HPA of young children with CP within their typical environments. The EASE (11 items) was tested for test-retest reliability, internal consistency and measurement error in children who were 18 months to five years old. Construct validity is reported as well as convergent validity tested against the Six Minute Walk Test (6MWT), and criterion validity against Paediatric Outcomes Data Collection Instrument (PODCI) [39,41]. The EASE (four items) was derived from EASE (11 items) and tested with children who were 3–12 years old. Construct validity and hypothesis-testing are reported [40,42]. Convergent validity is tested against 6MWT [33,40] and concurrent validity against an activity monitor is reported for the four-item EASE [38]. Both versions are parentally reported instruments.

The IPAQ (IPAQ-SF and IPAQ-LF) is a self- or parent-reported questionnaire used to provide information regarding children's HPA at different times and intensities throughout the day in the preceding seven days. It was validated for concurrent and criterion validity in two studies against the Paediatric Outcomes Data Collection Instrument (PODCI) and accelerometers [43,44].

The MARCA is a self- or parent-reported questionnaire and is a time-use tool that relies on accurate recall at five-minute intervals and the ability to subjectively grade the intensity of physical activity as low, medium, and hard. The concurrent validity of the MARCA against step counts (activity monitor) is reported for 11–17-year-old children and adolescents with CP in an RCT evaluating the effectiveness of an intervention in improving physical activity behaviours in adolescents with CP [32].

The PAQ-A is a self-reported instrument that examines HPA at different times and intensities throughout the day in the preceding seven days, and its test-retest reliability and convergent validity against pedometer and accelerometer was tested for adolescents below 17 years of age [32].

Three of the included instruments are designed to measure physical activity for an interval of one day or less. The HAES is a self-report scale that measures intensity, duration of activity and category of movement as type [46]. Its criterion validity has been tested using an accelerometer [30]. The BEACHES and SOFIT involve professional interviews or assessments. The BEACHES is a measurement system that documents children's physical activity and eating behaviour as well as the associated environmental characteristics and events in their homes and schools. Its criterion validity has been tested against an accelerometer [37]. The SOFIT is designed to record a child's activity levels and the amount of time the child spends engaged in moderate to vigorous physical activity during the defined sessions of structured play and free

Table 1. Included outcome instruments.

Study ID	Instrument	Study title	Study design	Age group	GMFCS	Participants *n*= (*N* =)	Substudy *n*=	Substudy 2 *n*=	Software	Domains and dimensions	HPA/SB (%)	Funding
McCoy 2012 [39] (United States and Canada)	EASE (11-item)	Development of the early activity scale for endurance for children with cerebral palsy	Cross sec	1.5–5 y	I–V	520 414 CP 106 TD	28 14 CP 14 TD	32		Frequency; intensity; time; type	100/–	Canadian Institutes of Health Research, the US Department of Education, National Institutes of Disability and Rehabilitation Research. No conflicts of interest to declare
Dere 2023 [41] (Turkey)	EASE (11-item)	Validity and reliability of the Turkish version of the early activity scale for endurance in pre-school children with cerebral palsy	Cross sec	2–5 y	I–V	55				Frequency; intensity; time; type	100/–	The author(s) reported there is no funding associated with the work featured in the article. No conflicts of interest to declare
Jeffries 2016 [33] (United States and Canada)	EASE (4-item)	Description of primary and secondary impairments in young children with cerebral palsy	Cross sec	1.5–5 y	I–V	429	32	35		Frequency; intensity; time; type	100/–	Canadian Institutes of Health Research, the US Department of Education, National Institutes of Disability and Rehabilitation Research. No conflicts of interest to declare
Fiss 2019 [40] (United States and Canada)	EASE (4-item)	Validity of the Early Activity Scale for endurance and the 6-minute walk test for children with cerebral palsy	Cross sec	1.5–12 y/3–12 y	I–V	708	376			Frequency; intensity; time; type	100/–	Canadian Institutes of Health Research, The Patient-Centered Outcomes Research Institute. No conflicts of interest to declare
Wentz 2020 [38] (United States and Canada)	EASE (4-item)	Walking performance, physical activity, and validity of the early activity scale for endurance in young children with cerebral palsy	Cross sec	3–11 y	I–V	79	50			Frequency; intensity; time; type	100/–	Canadian Institutes of Health Research, The Patient-Centered Outcomes Research Institute. No conflicts of interest to declare
Romeros 2023 [42] (Brazil)	EASE (4-item)	Translation, reliability, and validity of the Brazilian–Portuguese version of the Early Activity Scale for Endurance (EASE)	Cross sec	1.5–11 y	I–V	194 100 CP 94 TD	50 CP 46 TD	50 CP 48 TD		Frequency; intensity; time; type	100/–	Programa de pesquisa para o sus: gestão compartilhada em saúde-ppsus – fapemig and Conselho Nacional de Pesquisa No conflicts of interest to declare
Dufour 2015 [30] (Canada)	HAES	The physical activity-related perceptions of youth with cerebral palsy are associated with their physical activity performance and fitness	Cross sec, abstract	11.3 ± 3.3 y	I	15				Intensity; time	50/50 [53]	Funding not stated Conflict of interest not stated
Kwon 2020 [43] (Korea)	IPAQ-LF and IPAQ-SF	Correlation between accelerometer and questionnaire-based assessment of physical activity in patients with cerebral palsy	Cross sec	10–33 y CP 18–38 y TD	I–III	103 19 CP 84 TD				Frequency; intensity; time; type	93/7 (IPAQ-LF) 86/14 (IPAQ-SF)	Funding not stated. No conflicts of interest to declare
Lavelle 2020 [44] (England)	IPAQ-SF	Validity of the International Physical Activity Questionnaire Short Form (IPAQ-SF) as a measure of physical activity (PA) in young people with cerebral palsy: Across-sectional study	Cross sec	10–19 y	I–III	58				Frequency; intensity; time; type	86/14	Action Medical Research, Chartered Society of Physiotherapy Charitable Trust, The he Henry Smith Charity. No conflicts of interest to declare
Maher 2008 [32] (Australia)	MARCA	Using the internet to increase physical activity in adolescents with cerebral palsy are you kidding??!!	RCT, PhD-thesis	11–17 y	I–III				Yes	Frequency; intensity; time; type	–/–	The Australian Cerebral Palsy Foundation. No conflicts of interest to declare

(*Continued*)

Table 1. Continued.

Study ID	Instrument	Study title	Study design	Age group	GMFCS	Participants *n*= (*N* =)	Substudy *n*=	Substudy 2 *n*=	Software	Domains and dimensions	HPA/SB (%)	Funding
Maher 2008 [32] (Australia)	PAQ-A	Using the internet to increase physical activity in adolescents with cerebral palsy are you kidding?!!	Cross sec, PhD-thesis	Adolescents <17 y	I–V	20	14			Frequency; intensity; time; type	100/–	The Australian Cerebral Palsy Foundation. No conflicts of interest to declare
Sit 2013 [37] (China)	BEACHES	Assessment of measures of physical activity of children with cerebral palsy at home and school: a pilot study	Cross sec	6–12 y	I	5				Intensity; time	60/40	Seed Funding for Basic Research, The University of Hong Kong Conflict of interest not stated
Capio 2010 [45] (China)	SOFIT	Physical activity measurement using MTI (Actigraph) among children with cerebral palsy	Cross sec	6–14 y	I–III	31			Yes	Intensity; time	60/40	Funding not stated no conflicts of interest to declare

Abbreviations: CP: cerebral palsy; GMFCS: Gross Motor Function Classificaton System; RCT: randomised controlled trial; Cross sec: cross-sectional study; PA: physical activity; TD: typically developing; EASE: Early Activity Scale for Endurance; HAES: Habitual Activity Estimation Scale; IPAQ-LF: International Physical Activity Questionnaire Long Form; IPAQ-SF: International Physical Activity Questionnaire Short Form; MARCA: Multimedia Activity Recall for Children and Adolescents; PAC-A: Physical Activity Questionnaire for Adolescents; BEACHES: The Behaviours of Eating and Activity for Children's Health Evaluation System; SOFIT: System for Observing Fitness Instruction; Time; Y: years; Mins.: minutes.

play activity. Its criterion validity has been validated using an accelerometer (MTI) and heart rate monitor [45].

Excluded instruments

In all, 11 outcome instruments were identified and excluded, as they did not meet the inclusion criteria. The 11 outcome instruments identified and excluded was: Patient-Reported Outcomes Measurement Information System Paediatric Physical Activity (PROMIS PA) [35,36], 24-h checklist [47], The Canadian Assessment of Physical Literacy (CAPL-2) [48], the Exercise Questionnaire [31,49], the Activity Questionnaire for Adults and Adolescents (AquAA) [50–54], the Physical Activity Scale for Individuals with Physical Disabilities (PASIPD) [55–58], Canada fitness survey [10,59] the Compendium of Physical Activity [10,60,61], A Youth Compendium of Physical Activities [34], the Physical Activity Record [62] and the Physical Activity Questionnaire for Children (PAQ-C) [12,63,64]. The excluded outcome measurements are listed along with the reasons for exclusion in Table 4 – online only.

The review team discussed four of these instruments from five studies in detail during the full-text assessments [31,35,36,47,48], which led to the exclusion of PROMIS PA, The 24-h checklist, CAPL-2 and Exercise Questionnaire, that collect data on HPA and SB. The PROMIS PA instrument was developed to collect data on children's lived experiences of short bouts of moderate to rigorous physical activity [35,36]. The concurrent validity of the PROMIS PA was explored for a broad population of both healthy and chronically ill children but excluded because no specific diagnosis was stated in the study [35]. The 24-h checklist was co-created from interviews with parents of children with CP and health care professionals as a checklist to access physical activity, SB as well as sleep and nutrition, and it is, according to the authors, not an outcome instrument [47]. The Canadian Assessment of Physical Literacy (CAPL-2) was developed to assess physical literacy in children and designed to be inclusive for children with and without disabilities [48]. Finally, the Exercise Questionnaire was developed through expert consultation, and its items were confirmed through pilot-testing with youth with CP [31]. However, the aim of these two studies was not to report on psychometric properties.

Discussion

This scoping review identified and mapped nine subjective outcome instruments developed to measure HPA and/or SB for children with CP. Some of the included outcome instruments have been validated for both ambulatory and non-ambulatory children, while others have been validated for ambulatory children and adolescents with CP. None of the identified subjective outcome measures cover the entire age span of 0–18 years of age, implying that different outcome instruments must be used for different ages. The following key areas of importance were identified.

If considered reliable and valid, subjective outcome instruments are suitable for use in clinical settings or for data collection in larger populations when objective measurement methods are not available or viable. The aim was to identify subjective outcome instruments that measure an individual's HPA to monitor whether the individual meets the HPA recommendations, to monitor change in HPA over time, or to measure an intervention effect in a clinical setting. When implementing interventions that target HPA, we need to measure HPA. We excluded outcome instruments that measured activity and participation in physical activities, such as the ASKp, which has been validated as a measure of physical

Table 2. Measurement properties of included outcome instruments.

Study ID	Instrument	Aim of study	Context	Reliability	Validity	Reference comparison	Responsiveness	Study conclusion
McCoy 2012 [39]	EASE (11-item)	Examine the validity and reliability of the EASE with respect to its use with children with CP.	Parentally reported	Test-retest (GMFCS I–V) Internal consistency Measurement error	Construct – hypothesis testing (GMFCS I–V); convergent (GMFCS I–II)	GMFCS, age, sex 6MWT		Test-retest: (GMFCS I–V) Test-retest reliability was high, intraclass correlation (2,1) =0.95, 95% CI: 0.90–0.98). The mean difference was small (mean total score difference = 0.8, SD = 3.7). The Cronbach alpha was 0.93, indicating good internal consistency among the items. The standard error of the measurement was 2.9, indicating that, for a 68% confidence interval, the true EASE score for an individual child is within 3 points of the reported score. The MDD was 8.0, indicating that, for a 95% confidence interval, a change of 8 points or less could be attributed to measurement error. Construct: (GMFCS I–V) EASE scores differed significantly by GMFCS, but not by age or gender. Convergent: (GMFCS I–II) The EASE correlated moderately (rs = 0.57) with the 6-minute walk test.
Dere 2023 [41]	EASE (11-item)	Determine the validity and reliability of the Turkish version of EASE as well as to demonstrate whether EASE show significant difference at different GMFCS levels in a Turkish pre-school CP population.	Parentally reported	Test-retest (GMFCS I–V) Internal consistency	Construct Criterion	Confirmatory factor analysis PODCI, GMFCS		The ICC ranged between 0.923 and 0.996 for each of the items and was 0.996 for the total score. The Cronbachs' alpha (α) value was above 0.70 (α=0.903) which indicated that the internal consistency of the items created for the scale was sufficient. Construct: According to the model obtained (χ^2=44,510, df = 32), T-EASE was determined to be a one-dimensional measurement tool. The fit indices of the T-EASE showed that the model was acceptably fit. Model regression weights showed the effects of 10 items prepared for T-EASE on the model. Accordingly, the effects of 10 items used in the model ranged from 0.365 to 0.963, and all items were significant for the model. Criterion: T-EASE had positive, significant correlations ranged from weak-to-strong with PODCI-upper extremity (r=0.602 p=.001), PODCI-transfer and basic mobility (r=0.816, p=.001), PODCI-sport and physical functions (r=0.813, p=.001), PODCI-happiness (r=0.274, p=.043) and PODCI- global functioning (r=0.766, p=.001), while no correlation was found between T-EASE and PODCI-pain (r=0.111, p=.420). T-EASE was also determined to be strongly correlated with GMFCS (r=−0.832 p<.001).
Jeffries 2016 [33]	EASE (4-item)	Describe primary and secondary impairments in young children with CP and determine whether difference exist in impairments on the basis of GMFCS, age or sex.	Parentally reported	Test-retest (GMFCS I–V)	Convergent (GMFCS I–II)	GMFCS, age, sex 6MWT		The 4-item EASE was determined through confirmatory factor analysis of the original 11-item questionnaire. The 4-item EASE was found to report appropriately on endurance foractivity (χ^2=2.8, p>.05; comparative fit index = 0.998; Tucker–Lewis index = 0.993; root mean square error of approximation = 0.03). The shorter version correlates well with the full-length version (Pearson r=0.88; p<.001). Validity of the EASE 4-item scale is also supported by moderate correlations (Spearman r=0.41; p=.01) with the 6-MinuteWalk Test in a group of 35 children aged 3–6 years composed of 21 children without CP and 14 with CP at GMFCS levels I or II. Test-retest reliability for 32 children was found to be acceptable, ICC (2,1) = 0.79 (95% CI = 0.62–0.89).
Fiss 2019 [40]	EASE (4-item)	Describe the EASE and 6MWT scores by GMFCS level, sex and age and test the hypothesis that EASE scores would be higher in children with higher motor function and age by not differ by sex. Examine the convergent validity of the EASE with the 6MWT scores to examine the association between these 2 measures.	Parentally reported		Hypothesis testing (GMFCS I–V); convergent (GMFCS I–III)	GFMCS, age, sex, 6MWT		Hypothesis testing: Mean EASE scores differed based on participants' GMFCS levels (p<.001) except between levels II and III (p=.09). Higher EASE scores, representing greater perceived endurance for activity, were reported for participants with higher gross motor function. Participants aged 1.5–3 years and 3–6 years had significantly lower EASE scores than participants aged 9–12 years (p=.01 and p<.001, respectively). No differences were found between other age groups. EASE scores were not significantly different between boys and girls (p = .11) Convergent: The EASE and the 6MWT had a statistically significant but low, positive correlation (r=0.30; p<.001) across GMFCS levels I–III, indicating that the EASE and the 6MWT appear to measure different constructs.

(*Continued*)

Table 2. Continued.

Study ID	Instrument	Aim of study	Context	Reliability	Validity	Reference comparison	Responsiveness	Study conclusion
Wentz 2020 [38]	EASE (4-item)	Describe the walking performance and physical activity of children with CP by GMFCS, age, sex, and geographical location; and, to examine the concurrent validity of the 4-item Early Activity Scale for Endurance (EASE) to walking performance and physical activity scores.	Parentally reported		Concurrent	GMFCS I–V: StepWatch Monitor (modus health IIc) GMFCS I–III: Accelerometer (MTI, Actigraph)		The 4-item EASE findings were moderately correlated (0.61) with average PA counts per minute (0.61, $p<.001$) and minutes per day spent in moderate to vigorous physical activity (0.62, $p<.001$) as determined by the MTI. The 4-item EASE scores were weakly correlated with average strides per day (one leg) (0.35) and average strides per day faster than 30 strides per minute (0.29) as determined by the StepWatch. Using the 4-item EASE in conjunction with parental participation shows promise for estimating the daily PA of both ambulatory and non-ambulatory children diagnosed with CP.
Romeros 2023 [42]	EASE (4-item)	(1) Translate the 4-item EASE into Brazilian-Portuguese; (2) Evaluate internal consistency and test–retest reliability; (3) Analyse floor and ceiling effect size; (4) evaluate construct validity	Parentally reported	Test-retest (GMFCS I–V) internal consistency	Cross-cultural Construct	Age, GMFCS, CP/TD		No cross-cultural adaptations were required. The EASE version showed good reliability for children with CP aged 18-months to 5-years (ICC = 0.80; CI [95%]: 0.68–0.88) and excellent reliability for children with CP from 6- to 11-years age (ICC = 0.93; CI [95%] = 0.87–0.96). The internal consistency analysis of the EASE items showed a good internal consistency with Cronbach's alpha of 0.76 and 0.89 for the young and older group, respectively. The SEM found for the group of young children was 0.42 and for the older children group was 0.33. In addition, EASE showed no ceiling or floor effects. Participants with CP in the young children group showed lower EASE scores when compared to the children with CP in the older group ($p<0.05$). Children in GMFCS levels I–III had significantly higher scores than children in levels IV–V ($p<0.05$). Children with CP had lower levels of physical activity endurance when compared to participants with typically developing in the same age group ($p<0.05$)
Dufour 2015 [30]	HAES	Quantify associations between perceived PA and PA performance.	Self-reported; parentally reported		Criterion	Accelerometer		The perceived time spent being active and accelerometer-derived time spent in VPA were moderately and significantly correlated ($r=0.59$, $p=0.02$). All other relationships between different levels of perceived and accelerometer-derived PA were weak and not significant. The perceived time spent being active, however, was significantly greater than accelerometer-derived time spent in VPA (perceived PA = 99.582.2 min/d; accelerometer-derived VPA = 26.19.5 min/d, $p=0.002$). Youth functioning in GMFCS level? Associate how active they are only with the time they spend in VPA although they overestimate this time.
Kwon 2020 [43]	IPAQ-LF and IPAQ-SF	Evaluate PA in patients with CP by assessing the correlation between the accelerometer- and questionnaires-derived data and by comparing it with the PA of normally developed participants.	Self-reported; parentally reported		Concurrent	Accelerometer (Fitbit One) PODCI		In the accelerometer-based assessment, time spend in PA was significantly shorter at every intensity level in CP patients than in TD participants ($p<0.001$). However, PA assessed by IPAQ was significantly higher in the patients with CP than in TD participants (short-IPAQ, $p=0.001$; long IPAQ, $p=0.019$). The subscales of PODCI were not significantly correlated with PA assessed by IPAQ. The results suggest that patients with CP tend to exaggerate their participation in PA in self-report questionnaires.
Lavelle 2020 [44]	IPAQ-SF	Examine the validity of the International IPAQ-SF as a measure of physical activity (PA) in young people with CP.	Self-reported		Criterion	Accelerometer wGT3X-BT triaxial accelerometer (MTI)		The IPAQ-SF is not a valid method of measuring total PA or sedentary behaviour in young people with CP. Additionally, poor agreement between measures was observed for moderate to vigorous PA. Time spent in sedentary and total PA was underestimated.

(*Continued*)

Table 2. Continued.

Study ID	Instrument	Aim of study	Context	Reliability	Validity	Reference comparison	Responsiveness	Study conclusion
Maher 2008 [32]	MARCA	Test the efficacy of the online intervention.	Self-reported; parentally reported Telephone 15–25 mins., face to face 16–33 mins.		Concurrent	Step counts (activity monitor)		Comparing the daily step counts (activity monitor) with the daily PA (MARCA), for the 342 matched days on which MARCA and pedometer data were available resulted in a Spearman's rho of 0.31 ($p < 0.01$). Comparing the daily step counts (activity monitor) with the daily MVPA minutes (MARCA) produced a Spearman's rho of 0.24 ($p < 0.01$). Thus, there was a "weak to fair" level of correlation between objectively and subjectively measured PA variables in the study population
Maher 2008 [32]	PAQ-A	Examine the test-retest reliability and convergent validity of the PAQ-A for measuring physical activity in adolescents with cerebral palsy.	Self-reported; parentally reported 25–50 mins.	Test-retest	Convergent validity	Pedometer (Digi-walker SW-700) and a uniaxial accelerometer (Computer Science and Applications (CSA), Inc.)		Test-retest reliability of overall PAQ-A score was excellent (ICC = 0.90), with the test-retest reliability of individual PAQ-A items ranging from 0.51 to 0.99 ("moderate to excellent") The correlation between the pedometer counts per minute and the PAQ-A overall score was $r = 0.24$, indicating no-to-little relationship. With the pedometer data from two participants excluded (leaving $n = 14$ datasets), the correlation between weekly pedometer counts per minute and PAQ-A score was $r = 0.44$ ($p = 0.12$), suggesting a fair relationship. The correlation between accelerometer counts per minute and the PAQ-A score was $r = -0.21$, suggesting no relationship between objective PA as recorded by the accelerometers and self-reported PA, as recorded by the PAQ-A.
Sit 2013 [37]	BEACHES	Examine the suitability of BEACHES for assessing PA and related variables among children with CP.	Professional observation		Criterion	Uniaxial accelerometer (MTI)		Analysis indicated high agreement between estimates derived from the two measures for both the sedentary (ICC = 0.78, $p<.001$) and active (ICC = 0.85, $p<.001$) categories. Bland-Altman plots showed high agreement between BEACHES and MTI in estimating the number of minutes being sedentary and active (MVPA for MTI). Specifically for active time, the Bland-Altman plots showed a mean difference of 1.1 min between the estimates of the MTI and BEACHES. Furthermore, the ± 1.96 SD value showed that overestimation did not go beyond 5.7 min, while underestimation did not go beyond 7.8 min. Consistent with the intra-class correlation coefficients, the Bland-Altman plots suggest that BEACHES is comparable to the MTI in estimating time spent being active. This study suggests that BEACHES be considered as a valid measure of PA in school and residential settings for children with CP, especially by researchers interested in assessing contextual factors.
Capio 2010 [45]	SOFIT	Investigate the validity of Uniaxial accelerometer (MTI) as a physical activity (PA) measurement instrument for children with CP.	Professional video observation		Criterion	(a) Uniaxial accelerometer (MTI) (b) HRM (Polar)		In structured activities there is (a) strong relationship between MTI and SOFIT ($r = 0.75$; $R^2 = 0.56$; $p < 0.001$). (b) Strong relationship between HRM and SOFIT ($r = 0.65$; $R^2 = 0.43$; $p < 0.001$). In free play activities; (a) MTI and SOFIT ($r = 0.67$; $R^2 = 0.45$; $p < 0.001$). (b) HRM ($r = 0.14$; $R^2 = 0.02$; $p < 0.001$). Bland–Altman plots showed better agreement between observed SOFIT and MTI-predicted SOFIT data than observed SOFIT and –predicted SOFIT data from the linear regression analysis.

Abbreviations: CP: cerebral palsy; GMFCS: Gross Motor Function Classification System; RCT. Randomised controlled trial; Cross sec: cross-sectional study; EASE: Early Activity Scale for Endurance; HAES: Habitual Activity Estimation Scale; VPA: vigorous physical activity; IPAQ-LF: International Physical Activity Questionnaire Long Form; IPAQ-SF: International Physical Activity Questionnaire Short Form; PODCI: Paediatric Outcomes Data Collection Instrument: MARCA: Multimedia Activity Recall for Children and Adolescents; PAC-A: Physical Activity Questionnaire for Adolescents; BEACHES: The Behaviours of Eating and Activity for Children's Health Evaluation System; SOFIT: System for Observing Fitness Instruction Time; MVPA: moderate to vigorous activity; P;p: *p*-value; *r*: reliability quotient; ICC: interclass correlation; HRM: heart rate monitor; 6MWT: six minute walk test.

Table 3. Reported psychometric properties of included outcome instruments.

Instrument	Reliability	Validity	Responsiveness	References
Ease 11	Yes	Yes	No	McCoy 2012 [39], Dere 2023 [41]
Ease 4	Yes	Yes	No	Jeffries 2016 [33], Fiss 2019 [40], Wentz 2020 [38], Romeros 2023 [42]
HAES	No	Yes	No	Dufour 2015 [30]
IPAQ SF	No	Yes	No	Kwon 2020 [43], Lavelle 2020 [44]
IPAQ LF	No	Yes	No	Kwon 2020 [43]
MARCA	No	Yes	No	Maher 2008 [32]
PAQ-A	Yes	Yes	No	Maher 2008 [32]
BEACHES	No	Yes	No	Sit 2013 [37]
SOFIT	No	Yes	No	Capio 2010 [45]

Table 4. Excluded outcome instruments.

Outcome instrument	Reported/ used in	Reason for exclusion
Patient-Reported Outcomes Measurement Information System Paediatric Physical Activity – PROMIS PA	[35,36]	Population not defined as CP but ambulatory and chronically ill, not specified
24-Hour Checklist	[47]	Check list not an outcome instrument
The Canadian Assessment of Physical Literacy – CAPL-2	[48]	Psychometric properties not stated
Exercise Questionnaire	[48]	Psychometric properties not stated
The Physical Activity Record	[62]	Not validated for children and adolescents with CP
The Physical Activity Questionnaire for Children – PAQ-C	[12,63,64]	Not validated for children and adolescents with CP
The Activity Questionnaire for Adults and Adolescents – AquAA	[50–54]	Not validated for children and adolescents with CP
The Physical Activity Scale for Individuals with Physical Disabilities – PASIPD	[55–58]	Not validated for children and adolescents with CP
Canada fitness survey	[10,59]	Source not located or population not CP
Compendium of physical activity [61]	[10,60]	A code book of MET intensities. Not validated for children and adolescents with CP
A youth compendium of physical activities	[34]	A code book of MET intensities. Not validated for children and adolescents with CP

disability or physical function [65], and CAPE/PAC, which has been designed and validated as a measure of children's participation in everyday activities outside of school [66]. Although these outcome instruments evaluate various physical activities, their items are used to assess participation in physical activities and not the physical activity – according to the FITT definition.

Three out of nine subjective outcome instruments included in this scoping review (the EASE (11-item), EASE (4-item) and PAQ-A) were tested for test-retest reliability and the ICC ranged from good to excellent (0.79–0.99) for the EASE [33,39,41] and good or excellent (0.90) for the PAQ-A [32]. Internal consistency were tested only for the EASE (11-item) and EASE (4-item) and showed good internal consistency [39,41]. Seven outcome instruments (the EASE (4-item), HAES, IPAQ-LF, IPAQ-SF, PAQ-A, BEACHES and SOFIT) were tested against accelerometry, while the MARCA was compared to daily step counts (activity monitor) indicating weak to fair or moderate correlation with objectively measured HPA (Table 2). However, criterion validity of the BEACHES and SOFIT compared to accelometry indicated higher agreement between estimates derived from the two measures. Both outcome measures collected data from professional observation. The EASE (11-item) and EASE (4-item) are compared to 6 MWT showing low to moderate correlation [33,38,40]. In addition, the EASE (11-item) showed weak to strong correlations compared with the PODCI [41], whereas the subscales of PODCI were not correlated with HPA assessed with the IPAQ [43]. When comparing the correlation between the subjective outcome instruments and established HPA measures it is important that the measures align conceptually to ensure that outcome measures are validated against other outcome measure representing the same construct. Accelerometers capture continuous movement data, while 6 MWT assesses functional walking capacity over a fixed period of time.

None of the included outcome instruments were assessed for responsiveness (Table 3) Responsiveness is an aspect of validity and defined by the COSMIN as "the ability of an instrument to detect change over time in the construct to be measured" [67]. Evaluating whether an outcome instrument can detect changes is crucial for determining if a patient has improved following an intervention.

Seven studies compared subjective outcome instruments with accelometry [30,32,37,38,43–45]. Three studies conclude that the subjective outcome instruments overestimate the time spent engaged in vigorous physical activity [30,43,44] and underestimate the time spent being sedentary [32] when compared to objective accelerometery. Subjective outcome instruments may overestimate moderate to vigorous physical activity (MVPA) relative to objective measures since accelerometers are not suitable for water activities, which may be a common physical activity for children and adolescents with ambulatory activity limitations [68,69]. In addition, cycling may not be registered accurately depending on accelerometer placement [70]

Seven out of nine outcome instruments included SB as a part of HPA evaluation (HAES, IPAQ-SF, IPAQ-LF, PAQ-A, MARCA, SOFIT and BEACHES). The common definition of SB as any waking behaviour characterised by an energy expenditure of less than 1.5 METs while in a sitting, reclining, or lying posture [36] requires further examination and new measures within this group of children. This definition does not capture the muscle activity required, for instance, to maintain postural control when sitting for children challenged by their postural ability, to manually propel a wheelchair or to make arm/leg movements [71,72]. Movements that are typically low intensity, such as sitting unsupported, may require increased energy for children with spasticity and impaired selective motor control. However, Verschuren et al. found that energy expenditure was lower than 1.5 METs during sitting with and without support in children and adolescents with spastic CP, while they expended more energy (over 1.5 METs) when standing. This finding suggests that changing positions from sitting to standing may contribute to the accumulation of light activity and reduction of SB in children with CP [73].

Strengths and limitations

To ensure a systematic and transparent approach, this scoping review adhered to the JBI scoping review methodology and applied the PRISMA-ScR checklist [21]. The quality of the review was strengthened by publishing *a priori* peer-reviewed protocol and due to the fact that at least two authors selected and reviewed the studies at each stage of the scoping review process. Our aim was to map outcome instruments developed or validated for children and adolescents with CP. Since the scoping review

methodology allows for the inclusion of various study designs, a comprehensive literature search and screening of reference lists for all study types was conducted to address the research questions.

Despite the focus on the systematic approach to conducting a scoping review, limitations exist. Although the literature search was comprehensive, only 13 studies containing psychometric data of reliability and validity were located. Grey literature produced outside of the traditional peer-review processes that characterise academic publishing was sought and included; however, it can be difficult to locate. Furthermore, these sources of literature include a variety of forms, such as research reports and conference abstracts, with limited data reporting, making data management and extraction a challenge.

This scoping review applied a set of search terms with the aim of locating psychometric data; but in most of the cases, the psychometric data were located in other study types or publications and a thorough scrutinising of full text article references were needed to locate psychometric data on subjective instruments used to measure HPA and/or SB in children and adolescents with CP. It is also possible that the search terms used may not have captured all the relevant studies. We used a sensitive search filter, which yielded a large body of evidence. Despite the comprehensive search strategy, we located additional studies through a chain search.

Implications for research

This scoping review describes the psychometric properties of subjective HPA outcome instruments in research focusing on children and adolescents with CP. The methodological and practical challenges identified areas for further research to address the level of HPA evaluation studies on interventions for children with CP. First, a better understanding of the psychometric properties of HPA instruments used for CP is needed. Six outcome measures (AquAA, Exercise Questionnaire, PAQ-C, PASIPD, Physical Activity Record and CAPL-2) were used in past research but lacked validation for a population of children and adolescents with CP. Evaluation of the psychometric properties of these outcome instruments e.g., by using the Consensus-based Standards for the selection of health Measurements Instruments (COSMIN) checklist in larger-scale studies is needed.

Second, seven outcome measures were self- or parent-reported, while two involved being professionally interviewed or assessed (BEACHES and SOFIT). Proxy reporting may yield biased responses since the proxy responder cannot truly know the child's perception of intensity. Considerable disagreement between self-report and proxy-report have been seen regarding health-related behaviour in children 9-12-year-old [74]. It is important to acknowledge that proxy respondents for evaluating HPA are sometimes needed involving children with CP, as children with CP may have difficulties in understanding abstract concepts of health and well-being used in subjective HPA instruments. Children and adolescents with CP may have visual perceptual problems or lack cognitive and communication skills, limiting their ability to comprehend and complete self-reported outcome instruments. Developing instruments that make use of visual aids may help children with CP understand the intended meaning of the items and effectively draw upon life experiences during self-evaluations [75,76].

Finally, further research should explore the reliability and validity of two more recently developed outcome instruments related to the HPA of children and adolescents with CP. The Patient-Reported Outcomes Measurement Information System (PROMIS) is described as a set of person-centred measures that evaluates and monitors physical, mental and social health [39] and can be used for children. The PROMIS PA outcome measure is not yet specifically validated for children with CP [31,31]. The CAPL-2 is a measure of physical literacy, with items for measuring physical competence, daily behaviour, knowledge/understanding and motivation/confidence. The CAPL-2 was designed to be inclusive and can be used for a group of children with disabilities and medical conditions to describe physical literacy, but further data on its psychometric properties for children and adolescents with CP were not identified [48].

Conclusion

This scoping review identified nine subjective outcome instruments that measure HPA and/or SB in children and adolescents with CP who are 18 months to 18 years old. Seven out of nine subjective outcome instruments were designed for typically developed children and their psychometric properties were tested for the target population and various age ranges.

Six subjective outcome instruments were tested for ambulatory children and adolescents at GMFCS-E&R level I–III, while three instruments were validated for both ambulatory and non-ambulatory children and adolescents at GMFCS-E&R level I–V.

Psychometric data on validity were reported for nine outcome instruments, while test-retest reliability was tested in only three instruments in children with CP according to the guidelines and criteria established by the COSMIN checklist. Attention must be paid to the lack of reporting of the psychometric properties of some instruments as well as the limited correlation to objective measures of HPA. Novel subjective outcome instruments have been developed for children and adolescents but need psychometric testing for children and adolescents with CP.

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Ethical approval

This is a scoping review. No ethical approval required.

Author contributions

All authors contributed to the study conception and design. Material preparation, data collection, screening and data extraction were performed by Mette Johansen, Britt Laugesen, Katarina Lauruschkus and Helle M Rasmussen. The first draft of the manuscript was written by Mette Johansen and all authors commented on previous versions of the manuscript. All authors read and improved the final manuscript.

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Data availability statement

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

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