

# Instruments that evaluate functional independence in children with Cerebral Palsy: a systematic review of observational studies

*Instrumentos que avaliam a independência funcional em crianças com paralisia cerebral: uma revisão sistemática de estudos observacionais*

*Instrumentos que evalúan la independencia funcional en niños con parálisis cerebral: revisión sistemática de estudios observacionales*

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**ABSTRACT** | This article aimed to do a systematic review of instruments that assess functional independence of children with cerebral palsy. We used MEDLINE/Pubmed, Scopus, and Web of Science for the search. Observational studies of the past five years, with full text available and without language restriction, were included in this review. We found 222 articles, of which 63 were analyzed and 24 were included in the study. The main instruments found were: PEDI, WeeFIM, ASK, PODCI, VABS-II, LIFE-H, and CAPE/PAC.

**Keywords** | Cerebral Palsy; Child; Disability Evaluation; Review.

**RESUMO** | Este artigo teve como objetivo fazer uma revisão sistemática de instrumentos que avaliam a independência funcional de crianças com paralisia cerebral. As bases eletrônicas da MEDLINE/PubMed, Scopus e Web of Science foram usadas para as buscas. Estudos observacionais dos últimos cinco anos, com texto completo disponível e sem restrição de idioma foram

incluídos nesta revisão. Foram encontrados 222 artigos, dos quais, 63 foram analisados e 24 foram incluídos no estudo. Os principais instrumentos encontrados foram: PEDI, WeeFIM, ASK, PODCI, VABS-II, LIFE-H e CAPE/PAC.

**Descritores** | Paralisia Cerebral; Criança; Avaliação da Deficiência; Revisão.

**RESUMEN** | En este texto se pretende llevar a cabo una revisión sistemática de instrumentos que evalúan la independencia funcional de niños con parálisis cerebral. Se emplearon las bases de datos electrónicas MEDLINE/PubMed, Scopus y Web of Science en las búsquedas. En esta revisión se incluyeron estudios observacionales de los últimos cinco años, con texto completo y disponible, sin restricción de idioma. De los 222 textos encontrados, 63 fueron evaluados y 24 incluidos. Los principales instrumentos encontrados fueron: PEDI, WeeFIM, ASK, PODCI, VABS-II, LIFE-H y CAPE/PAC.

**Palabras clave** | Parálisis Cerebral; Niño; Evaluación de la Discapacidad; Revisión.

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## INTRODUCTION

Cerebral palsy (CP) is a non-progressive injury that affects the central nervous system at immature and developing stages, causing postural deficits, motor dysfunctions, cognitive and mobility changes<sup>1-3</sup>. The set of disorders present in children with CP can limit their performance in functional activities and affect their daily life activities, such as feeding, clothing, locomotion, personal care, and social interaction<sup>1,4,5</sup>.

The functional evaluation of children with CP must be individualized and carried out by a multidisciplinary team. These evaluations aim to collect the maximum information on the functional activity of the child, to help determine the goals of the treatment<sup>6</sup>. Functionality evaluations are divided into two groups: assessment of body structure and function (musculoskeletal system, mobility, locomotion); and evaluation of activities (daily life skills: feeding, clothing, personal care) and participation (socialization, community life), according to a consensus of the World Health Organization (WHO) and International Classification of Functioning, Disability and Health (ICF)<sup>6-8</sup>.

The choice and use of instruments that assess functionality depend on the therapeutic objectives and goals to be achieved; therefore, the knowledge of the instruments favors the planning of therapeutic strategies<sup>6</sup>. Based on the above, this systematic review aimed to identify the instruments that assess functional independence of children with cerebral palsy through observational studies.

## METHODOLOGY

This systematic review was conducted between September and October 2014. The studies were searched in MEDLINE/Pubmed (Medical Literature Analysis and Retrieval System on-line), Web of Science, and Scopus. The descriptors used for the search, according to the Medical Subject Headings (MeSH)/Pubmed, are listed in Table 1. In addition to MeSH terms, we used keywords found in the previously obtained articles.

Inclusion criteria were as follows: observational studies (cross-sectional, cohort, and case control), published in the last five years, with full text available, which evaluated functionality and had as sample children with cerebral palsy of both sexes. We excluded articles that evaluated other populations (adolescents,

adults, and older adults) or children with other types of disabilities; semiexperimental or experimental studies; articles not assessing functionality or using instruments that did not meet the main areas of functional independence (mobility, self-care, and participation); and studies in duplicate, as shown in Figure 1.

Table 1. Keywords used for the search, according to the Medical Subject Headings (MeSH)/Pubmed

Main themes	Keywords used
Assessment tools	"Patient Outcome Assessment"[Mesh] OR "Assessment, Patient Outcome" OR "Outcome Assessment, Patient" OR "Assessments, Patient Outcome" OR "Outcome Assessments, Patient" OR "Patient Outcome Assessments" OR "Assessment, Patient Outcomes" OR "Patient Outcomes Assessment" OR "Outcomes Assessments, Patient" OR "Disability Evaluation"[Mesh] OR "Disability Evaluations" OR "Evaluation, Disability" OR "Evaluations, Disability" OR "Outcome Assessment (Health Care)"[Mesh] OR "Assessment, Outcomes" OR "Assessments, Outcomes" OR "Outcomes Assessments" OR "Instruments" OR "Inventory" OR "Questionnaires"[Mesh] OR "Evaluation instruments" OR "functional outcome" OR "Scales" OR "Form"
Functional independence	"Disability Evaluation"[Mesh] OR "Disability Evaluations" OR "Evaluation, Disability" OR "Evaluations, Disability" OR "Functional independence" OR "Functional Independence Measure" OR "Functional Assessment" OR "Disability measures" OR "Functional status measures" OR "Performance evaluation" OR "Disability evaluation" OR "Functional capacity" OR "Functional performance"
Cerebral palsy	"Cerebral Palsy"[Mesh] OR "CP (Cerebral Palsy)"
Children	"Children" OR "Child" OR "Preschool" OR "Disabled children"
Type of study	"Epidemiologic studies" OR "Exp case control studies" OR "Exp cohort studies" OR "Case control" OR "Cohort adj" (study or studies) OR "Cohort analys" OR "Follow up adj" (study or studies) OR "Observational adj" (study or studies) OR "Longitudinal" OR "Retrospective" OR "Cross sectional" OR "Cross-sectional studies"

The search was conducted by three independent reviewers, who first read the titles, then the abstracts, and, finally, the full articles. In cases of differences of the selected articles, the reviewers repeated the procedures until the discrepancies were corrected.

After the selection of 24 articles for qualitative and quantitative analysis, we collected the following information: author(s) and year of publication, place of study, type of study, research aim and follow up time, sample number, average age, sex of participants, instrument used to classify the severity of cerebral palsy, classification of CP's functional level and instrument used to evaluate children's functional independence, and aspects related to the choice of the instrument, as shown in Table 2.

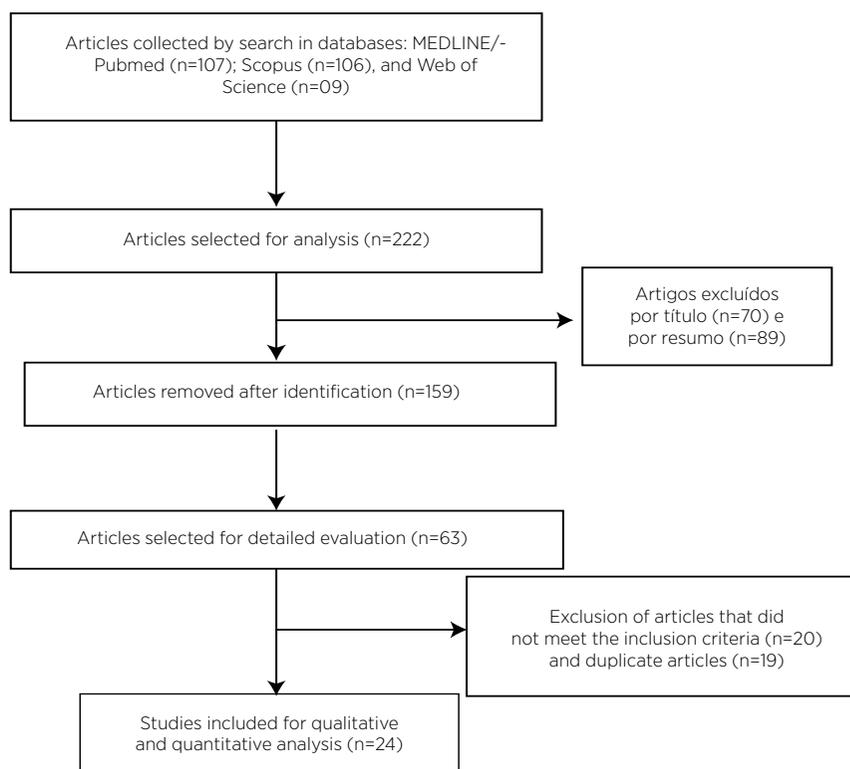


Figure 1. Flowchart of the studies included in the review

Table 2. Instruments used to evaluate functional independence of children with CP

Author/year	Place/Type of study:	Objectives	Average age and standard deviation (years)	Sample (n) Sex (n)	Classification of PC severity	Classification level n (%)	Instrument used	Justification for using the instrument
HOLSBEEKE et al. (2009) <sup>9</sup>	Netherlands/ Transversal study	Analyze the relationship between motor skills (what the children are able to do in a standardized and controlled environment, and what they can do in their daily environment), and among the performance of motor skills of children with CP.	1.5 (± NI)***	n = 85 Male= 47 Female = 38	GMFCS	I = 27(32.0) II = 10(12.0) III = 23(27.0) IV = 17(20.0) V = 8(9.0)	PEDI	PEDI features good psychometric properties.
GUNEL et al. (2009) <sup>10</sup>	Turkey/Transversal study	To investigate the relationship between the functional classification systems: MACS (Manual Ability Classification System), GMFCS (Motor Function Classification System) and WeeFim in children with spastic CP.	7.0 (± NI)***	n = 185 Male= 101 Female = 84	GMFCS	I = 64(34.5) II = 27(14.5) III = 38(20.5) IV = 35(18.9) V = 21(11.6)	WeeFIM	Is one of the most used methods for pediatric functional evaluation; studies have demonstrated its reliability and validity, both for disabled and healthy children.
SMITS et al. (2010) <sup>11</sup>	Netherlands/ Cohort	To analyze the relationship between gross motor function and daily mobility in children with CP; and to explore the moderation of this relationship with the PC severity.	6.2 (±1.0)	n = 116 Male= 76 Female = 40	GMFCS	I = 56(48.0) II = 20(17.0) III = 17(15.0) IV = 9(8.0) V = 14(12)	PEDI	The PEDI (Dutch version) was used because it has good psychometric properties.

(continues)

Table 2. Continuation

Author/year	Place/Type of study:	Objectives	Average age and standard deviation (years)	Sample (n) Sex (n)	Classification of PC severity	Classification level n (%)	Instrument used	Justification for using the instrument
MEESTER-DELVER et al. (2009) <sup>12</sup>	Netherlands/ Transversal study	To validate CAP and verify the association between the CAP and PEDI domains of the (Caregiver's Assistance), as well as the independent contribution for each domain of the CAP to PEDI (Functional Skills)	2.6 (± NI) <sup>***</sup>	n = 72 Male= 56 Female = 16	GMFCS	I = 24(33.3) II = 8(11.1) III = 18(25.0) IV = 14(19.5) V = 8(11.1)	PEDI	CAP classifies the need of additional care for children.
HALEY et al. (2009) <sup>13</sup>	Canada and United States/ Transversal	To analyze psychometric properties of a new database and simulate an adapted test to assess the abilities of children with CP.	10,7 (± 4.0)	n = 308 Male= 169 Female = 139	GMFCS	I = 75(24.3) II = 91(29.6) III = 79(25.6) IV = 37(12.0) V = 26(8.5)	PODCI WeeFIM	PODCI is commonly used in clinical environments and in research to measure abilities of children with CP. WeeFim is a standard measure used in many hospitals and its scores include a motor function score.
MOREAU et al. (2010) <sup>14</sup>	United States/ Case Control	To develop a predictive regression model of the maximum knee extensor strength; and to quantify the relation between structural muscle parameters and muscle activity and participation measures of children and adolescents with and without PC.	12.0 (± 3.2) 12.3 (± 3.9)	n = 18 CP* 12 DT ** Male = 9 CP Female = 9 CP Male = 2 DT Female = 10DT	GMFCS	I = 4(22.2) II = 2(11.1) III = 9(50.0) IV = 3(16.6) V = 0(0.0)	PODCI ASKp	PODCI has been widely used in children with CP. It has high internal consistency, test-retest reliability, excellent concurrent validity in relation to GMFCS and is sensitive to changes after orthopedic surgeries. ASKp is able to discriminate GMFCS levels in individuals with PC in all subdomains; it has excellent reliability test-retest and good validity (content, concurrent and construct) in children with musculoskeletal disorders.
ÖHRVALL et al. (2010) <sup>15</sup>	Sweden/ Transversal study	To investigate the acquisition of self-care and mobility skills in children with CP regarding their manual ability and gross motor function.	8.1 (± 3.9)	n = 195 Male= 122 Female = 73	GMFCS	I = 90(46.0) II = 32(16.0) III = 29(15.0) IV = 21(11.0) V = 23(12.0)	PEDI	Not informed.
PARKES; MCGULLOUGH; MADDEN (2010) <sup>16</sup>	Northern Ireland (UK)/ transversal study	To describe the participation of children with CP in daily life situations; to investigate the relationship between the participation of children with paternal characteristics; to compare the frequency of participation of children with CP with children with or without disabilities.	9.81 (± NI) <sup>***</sup>	n = 102 Male= 63 Female = 39	GMFCS	I = 17(17.0) II = 32(31.0) III = 17(17.0) IV = 14(14.0) V = 22(22.0)	LIFE-H	LIFE-H has been used previously in populations with PC; it is validated and shows evidence of satisfactory reliability.

Table 2. Continuation

Author/year	Place/Type of study:	Objectives	Average age and standard deviation (years)	Sample (n) Sex (n)	Classification of PC severity	Classification level n (%)	Instru- ment used	Justification for us- ing the instrument
KERR et al. (2011) <sup>17</sup>	Ireland/Prospective Longitudinal study	To describe the relationship between age and energetic efficiency during the gait, activity and participation of children with CP.	10.8 ± 3.6	n = 184 Male= 112 Fe- male = 72	GMFCS	I = 57(31.0) II = 91(49.5) III = 22(12) IV = 14(7.5) V = 0(0.0)	PEDI	PEDI was developed to evaluate the functionality of children aged between 6 months to 7 years, but can be used for older children, since they present functional abilities inferior to the expected for children with typical development (aged between 6 months and 7 years).
TSENG et al. (2011) <sup>18</sup>	Twain/Transversal study	To identify the determinants of daily function in a sample of children with CP.	8.2 (± 3.4)	n = 216 Male= 124 Female = 92	GMFCS	I = 44(20.4) II = 51(23.6) III = 52(24.1) IV = 30(13.9) V = 39(18.1)	PEDI	When used in children with CP, PEDI show excellent internal consistency, test-retest reliability, concurrent validity and discriminative validity.
KIM; PARK (2011) <sup>19</sup>	Korea/Transversal study	To examine the causal relationship between spasticity, weakness, motor function, and functional outcome in children with CP and tested models of functional measures mediated by the gross motor function.	10.3 (±1.7)	n = 81 Male= 50 Female = 31	GMFCS	I = 14(17.3) II = 9(11.1) III = 13(16.0) IV = 5(6.2) V = 40(49.4)	PEDI	Not informed.
MOREAU; FALVO; DAMIANO (2012) <sup>20</sup>	United States/ Case Control	To analyze the rate of strength development and the characteristics of the knee extensor impulse in children with CP and those with typical development, and determine predictive parameters of muscle strength and impulse.	11.9 (± 2.9) .3 G911,3 (± 3.0)	n = 12 CP* 11 DT** Men = NI*** Fem = NI***	GMFCS	I = 4(33.3) II = 2(16.7) III = 6(50.0) IV = 0(0.0) V = 0(0.0)	PODCI ASKp	PODCI measures the self-reported physical function and psychosocial aspects of the health status in children with musculoskeletal disability. ASK is also a self-report measure for children; it is reliable, valid and responsive to physical disabilities.
RAMSTAD et al. (2012) <sup>21</sup>	Norway/Transversal study	To explore the contribution of recurrent musculoskeletal pain and mental health for the elements in children with CP.	14.0 (±3.0)	n = 105 Male= 54 Female = 51	GMFCS	I = 35(33.0) II = 42(40.0) III = 16(15.0) IV and V = = 12(11.0)	LIFE-H	LIFE-H has shown good discrimination among participation levels; the version for children has been validated in children with various disabilities, including CP, with moderate to excellent results.
CAMARGOS et al. (2012) <sup>22</sup>	Brazil/Transversal study	To assess the relation between functional independence and the quality of life of children with CP.	7.7 (± 2.3)	n = 30 Male= 21 Female = 09	GMFCS	I = 9(30.0) II = 6(20.0) III = 2(6.7) IV = 2(6.7) V = 11(36.6)	PEDI	Not informed.

Table 2. Continuation

Author/year	Place/Type of study:	Objectives	Average age and standard deviation (years)	Sample (n) Sex (n)	Classification of PC severity	Classification level n (%)	Instrument used	Justification for using the instrument
VOS et al. (2013) <sup>23</sup>	Netherlands/ Prospective Longitudinal study	Describe the development paths of mobility and performance in the daily life activities of children and young people with CP; and to explore the influence of the gross motor function and intellectual disabilities in these trajectories.	NI ( $\pm$ NI) <sup>***</sup> Age ranged between 1 and 16 years	n = 424 Male = NI <sup>***</sup> Female = NI <sup>***</sup>	GMFCS	I = 212(50.0) II = 55(13.0) III = 60(14.0) IV = 55(13.0) V = 42(10.0)	VABS	VABS is a reliable and validated instrument.
BJORNSON et al. (2013) <sup>24</sup>	United States/ Prospective Longitudinal study	To examine the hypothesis that the influence of the physical exercise ability on the participation is mediated through the activity performance.	6.2 ( $\pm$ 2.3)	n = 128 Male = 76 Female = 52	GMFCS	I = 44(35.0) II = 54(42.0) III = 30(23.0) IV = 0(0.0) V = 0(0.0)	LIFE-H ASKp CAPE/ CAP	LIFE-H and CAPE/CAP were chosen because they were developed from different theoretical models; and also they were validated with different methodologies and measure participation under complementary perspectives. ASKp is a self-reported measure or reported by parents for children aged between 5 and 15 years.
PARK; KIM (2013) <sup>25</sup>	Korea/Transversal study	To confirm the construct of motor impairment and to carry out a model of structural equations between motor impairment, gross motor function, and the functional outcomes on the daily life activities of children with CP.	11,4 ( $\pm$ 1.75)	n = 98 Male = 59 Female = 39	GMFCS	I = 16(16.3) II = 10(10.2) III = 15(15.3) IV = 6(6.1) V = 51(52.0)	PEDI	Not informed.
ELAD et al. (2013) <sup>26</sup>	Israel/Transversal study	To investigate the agreement between health professionals and mothers in relation to capacity and performance of children with CP, and the impact of PC severity in this agreement.	8.8 ( $\pm$ 2.1)	n = 73 Male = 40 Female = 33	GMFCS	I = 6(8.2) II = 26(35.6) III = 15(20.5) IV = 16(21.9) V = 10(13.7)	PEDI	PEDI is a measure widely used and well regarded in research about PC and in clinical environments; it is deemed valid and reliable for children with CP (aged between 6 and 12 years).
KWON et al. (2013) <sup>27</sup>	Korea/Transversal study	To investigate the relation between the gross motor function and functional daily skills in children with CP and to explore how this relationship is moderated by GMFCS, BFMF (Bimanual Fine Motor Function), neuromotor types and involvement of the limbs in CP.	5.9 ( $\pm$ 1.5)	n = 112 Male = 64 Female = 48	GMFCS	I = 32(28.6) II = 31(27.7) III = 28(25.0) IV = 16(14.3) V = 5(4.5)	PEDI	To evaluate daily functional abilities in children with CP for clinical and experimental purposes.
ASSIS-MADEIRA; CARVALHO; BLASCOVI-ASSIS (2013) <sup>28</sup>	Brazil/Transversal study	To investigate the influence of socioeconomic status on the functional performance of children with CP.	5.13 ( $\pm$ 1.4)	n = 49 Male = 24 Female = 25	GMFCS	I and II = 16(32.6) III = 17(34.7) IV and V = 16(32.6)	PEDI	Not informed.

(continues)

Table 2. Continuation

Author/year	Place/Type of study:	Objectives	Average age and standard deviation (years)	Sample (n) Sex (n)	Classification of PC severity	Classification level n (%)	Instru-ment used	Justification for using the instrument
BULT et al. (2012) <sup>29</sup>	Netherlands/ Longitudinal study	Determine which child, family and environmental variables measured at the age of 2 years predict the participation in leisure, in formal and informal activities of school-age children and with PC.	2.6 (±1.0)	n = 46 Male = 26 Female = 20	GMFCS	I = 14(30.0) II = 3(7.0) III = 13(28.0) IV = 11(24.0) V = 5(11.0)	CAPE/ PAC VABS PEDI	Not informed.
BJORNSON et al. (2014) <sup>30</sup>	United States/ Cohort study	To examine the relationship between the gait performance and participation in mobility related to daily life habits in children with PC.	6.2 (± 2.3)	n = 128 Male= 76 Female = 52	GMFCS	I = 44(35.0) II = 54(42.0) III = 30(23.0) IV = 0(0.0) V = 0(0.0)	LIFE-H	Not informed.
SMITS et al. (2014) <sup>31</sup>	Netherlands/ Prospective Longitudinal study	To investigate the relationship between changes in motor skills (what the individual does in a standardized environment and what he/she can do in the daily environment), and the motor performance in children with CP.	6.6 (± 3.9)	n = 321 Male = 200 Female = 121	GMFCS	I = 135(42.0) II = 48(15.0) III = 54(17.0) IV = 42(13.0) V = 42(13.0)	PEDI	PEDI identifies changes in motor skills and in the motor performance of children with CP.
KETELAAR et al. (2014) <sup>32</sup>	Netherlands/ Cohort	To describe the development of mobility and self-care in children with CP and to analyze if the development of these capabilities differs by the degree of The CP severity.	NI*** (± NI)*** Age ranged between 1 and 4 years	n = 92 Male = 54 Female = 38	GMFCS	I = 28(30.4) II = 12(13.0) III = 23(25.0) IV = 20(21.7) V = 09(9.8)	PEDI	PEDI is a standardized instrument that uses the parent's report through a structured interview.

\* Cerebral palsy \*\* Typical Development \*\* Not informed, the age was turned into years

## RESULTS

We identified a total of seven instruments that sought to assess functional independence of children with cerebral palsy. As can be seen in Table 2, PEDI was the most used instrument (15 studies), followed by LIFE-H (4 studies), ASK and PODCI (each one used in 3 studies), and WeeFIM, VABS-II, and CAPE/PAC (each one used in two studies). Some studies have used more than one instrument to assess children's functionality. These instruments assess different areas to try to characterize functional independence, as shown in Table 3.

The Gross Motor Function Classification System (GMFCS) was the instrument used by all studies of this review to classify the severity of CP. It was the most used scale to classify the severity of CP by the instruments that assessed functionality. This consists of

a scale that uses child's locomotion for the evaluation, ranking the child in five levels of motor performance<sup>6</sup>.

The Pediatric Evaluation of Disability Inventory (PEDI) is a standardized instrument that uses information provided by parents or guardians of the child (from 6 months to 7 years and a half) in the form of a structured interview. The questionnaire items are grouped into three areas: self-care, mobility, and social function, and, for each domain, three independent scores are calculated: 1) functional ability level 2) help from a caregiver, and 3) modifications<sup>22</sup>.

The Pediatric Functional Independence Measure (WeeFIM) was developed to measure the functional independence of children with disabilities. It is a questionnaire filled out by the answers given by parents/guardians, and can also be carried out by observations of the child<sup>33</sup>. WeeFIM was designed to measure the need for aid and the severity of the disability in children aged

between 6 months and 7 years. This instrument measures the level of independence in self-care, sphincter control, locomotion, mobility, communication, and social function<sup>34</sup>.

Table 3. Domains assessed by instruments

Assessment tool	Number of domains assessed	Domains assessed
PEDI	3	Self-care, mobility, and social function.
WeeFIM	3	Self-care, mobility, and cognition.
ASK	9	Self-care, dressing skills, feeding (eating and drinking), locomotion, games, standing abilities, transfers, use of stairs, and other tasks.
PODCI	5	Upper extremity and physical function; transfers and mobility; sports and physical activity; pain and comfort; expectation of the treatment, happiness and satisfaction with the symptoms.
VABS	5	Communication, daily living skills (self-care, feeding, and personal hygiene), socialization, motor skills and non-adaptive behavior.
LIFE-H	12	Nutrition, self-care, physical fitness, communication, domestic activities, mobility, responsibility, interpersonal relationships, life in community, education, work, and recreation.
CAPE/PAC	5	Physical activity, recreation, social activities, self-care, and abilities.

The Activities Scale for Kids (ASK) is an instrument that assesses and monitors functional changes in children of 5 to 15 years with physical limitations caused by musculoskeletal disorders. It is a self-administered questionnaire, and it can be answered by parents or caregivers when the child is not able. The instrument has 30 items, grouped into 9 areas: self-care, dressing up, eating and drinking, other skills, locomotion, playtime, standing skills, transfers, and use of stairs<sup>35,36</sup>.

The Pediatric Outcomes Data Collection Instrument (PODCI) assesses general health, pain, and participation in daily life activities. It is used for children between 2 and 18 years with general health problems. It consists of 108 items, grouped into 5 areas: upper extremity and physical function, transfers and mobility, sports and physical activity, pain and comfort, treatment expectations, happiness, and satisfaction with the symptoms<sup>35,36</sup>.

The Vineland Adaptive Behavior Scale (VABS) was developed to assess adaptive behaviors of individuals from zero to 90 years old. Vineland has 5 domains (with 2 or 3 subdomains each): communication, daily living abilities (self-care, personal care, feeding),

socialization, motor skills, and non-adaptive behavior (unwanted)<sup>37</sup>. It is used for evaluating functionality in everyday life, measuring deficits in adaptive behavior, and complementing diagnoses of autistic spectrum disorder, emotional and behavioral disorders, and delays in development<sup>37</sup>.

The Assessment of Life Habits (LIFE-H) was developed for adults and children and seeks to assess life habits and disadvantageous situations, which are concepts related to social participation. The instrument includes 12 categories: nutrition, self-care, physical fitness, communication, domestic activities, mobility, responsibilities, interpersonal relationships, life in community, education, work, and recreation<sup>38</sup>.

The Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities in Children (PAC) are instruments developed together to evaluate the nature of participation and the effectiveness of interventions aimed at increasing such participation (social and community). It was developed for children from 6 to 21 years old<sup>39</sup>, and can be self-administered or applied by a interview. The CAPE/PAC includes 55 formal and informal activities, which are organized into 5 categories: physical activity, recreation, social activities, self-care, and skills<sup>39</sup>.

## DISCUSSION

We found, in the analyzed studies, a total of seven instruments that aim to assess functional independence of children with cerebral palsy. These instruments sought to evaluate the degree of independence, mobility, impairment, social participation, performance in daily life activities (DLA), and overall health. They are instruments widely used and disseminated in the clinical and academic areas. Some are used exclusively for children, others for children with or without disabilities, and some are used to evaluate the functionality of adults and older adults. The instruments found in this review sought to evaluate children with CP with different objectives: complementing clinical diagnoses, helping strategies of interventions (medicine, physiotherapy, occupational therapy, education, among others), expanding academic research, and validating new instruments (concurrent validity).

Currently, functionality is considered a component of health, and the instruments used to evaluate children with CP must be able to describe in detail their

development, quantifying the function, and allowing the objective analysis of their evolution. Children with CP must have their development followed, and the use of these instruments helps the forwarding of strategies, interventions and treatments, and also verifies their effectiveness<sup>40</sup>.

The instruments that seek to evaluate functionality are based on ICF and seek to prioritize functionality as a component of health and environment as a facilitator or barrier to the performance of daily life actions and tasks. Therefore, these instruments seek to assess “body structure” (anatomical parts, as the musculoskeletal system), “body function” (physiological and psychological functions: digestion, growth, behavior, and memory), “activities” (communication, clothing, reading, and problem solving), and “participation” (involvement in family and community life)<sup>6,40</sup>.

PEDI is a very widespread instrument and one of the most used to measure the functionality of children with disabilities. It examines the motor and self-care function, as well as the participation of the children in their social dimension. PEDI, therefore, reflects more closely the areas of activity and participation of ICF than other instruments. Its clinical relevance is also supported by the evidence that motor skills are not necessarily representative of all functional improvements followed by therapeutic interventions<sup>22,41,42</sup>. In Brazil, PEDI was validated in 2000, and, since then, it is an instrument that has been fairly used in clinical practice and that has several studies published in the country, which supports its use. It presents evidence of good clinical utility and, for covering a wide age range, is useful in the planning of programs focused on improving the functional performance of children<sup>43</sup>.

PEDI, WeeFIM, and PODCI are generic questionnaires that measure the effect of a condition on an individual's functionality, health and/or self-care in a variety of environments<sup>41</sup>. These instruments are widely used in research with children and largely accepted. WeeFIM is little used in Brazil, and this is due to the fact that it has not yet been validated in Brazilian Portuguese<sup>6</sup>.

PODCI is a multidisciplinary instrument and can be applied by professionals from various research fields. It is considered a sensitive instrument to detect changes in health conditions and also comprehensive, as it can be used to assess children, adolescents, and caregivers. It is widely used for pediatric patients and a variety of conditions, such as asthma, sleep apnea, neuromuscular and musculoskeletal disorders<sup>44</sup>. LIFE-H and ASK, in

the study of Andrade<sup>45</sup>, were selected as being among the instruments that meet most of the criteria of ICF's evaluation. VABS is the most used instrument for the assessment of social adaptation in Brazil<sup>46</sup>.

The child with CP must be evaluated in various environments (school, home, clinics, parks, leisure time) and not only in controlled environments, as many instruments do. Thus, some instruments are more suitable than others and some are complementary. The essential is to know which instrument is best suited for the situation, for the child, and for meeting the goal of the evaluation and/or treatment.

Movement is crucial to the independence of the human being, and is through it that people explore the environment in which they live. Children with CP should be encouraged, because the improvement of their motor skills means the acquisition of their independence and ability to adapt to society. Evaluating the functional impact of motor disability is critical in the evaluation of children with CP, because functional capacity is related to their health and is one of the determining factors of their quality of life<sup>40</sup>. The importance of independence in daily routine for the integral development of children with CP is essential because, as children acquire autonomy in performing simple tasks, they become less dependent, which helps and enables their insertion in social life.

## CONCLUSION

Currently, there is a wide variety of instruments developed to evaluate children with and without disabilities. Some were developed exclusively for children with cerebral palsy, but are already widespread and used for other diseases. This review aimed to find instruments used in the evaluation of functional independence of children with CP. PEDI was the most found and, according to the literature, it is an instrument that follows most recommendations of the WHO and ICF; thus, it is reliable, sensitive, and widely disseminated and used. Some of the instruments found are not used exclusively for children, which could explain their lower use in the studies.

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