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Measurement of activities and participation for children with cerebral palsy: A systematic review

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Abstract. Background: Effective assessment of outcomes in children with chronic health conditions is important to monitor their progress, evaluate interventions, and guide health policy. There is a limitation of the measures currently available for evaluating activities and participation in children with cerebral palsy according to Classification of Functioning, Disability and Health – Children & Youth Version (ICF-CY). The aim: On the ground of an available scientific literature, to identify and to analyze measures of activities and participation for paediatric patients with cerebral palsy. Materials and methods: A systematic search was performed in data basis EBSCO (Medline), Science Direct and Cochrane Library. On the ground of the previously conducted scientific research work publications, the identified evaluative measures were reviewed for their characteristics, psychometric properties of reliability and/or validity and analyzed for their utility. Their accordance to the activities and participation domains of the ICF-CY was identified and the practical use of the evaluative measures was proposed. Results and conclusion: 28 measures were identified; 15 were systematically reviewed and analyzed. Measures that assess only activities are found to be seven, only participation – two, and both activities and participation are assessed by six measures. When relating the measures to the domains of ICF-CY, the most appropriate for measuring activities is ASK*p*, participation – Life-H for Children, whereas for activities and participation – PEDI and COPM. The identified and analyzed measures reflect different activities and participation domains of ICF-CY; therefore, the choice and the practical use of the certain measure depend on the aim of the assessment.

Introduction

Cerebral palsy (CP) is a group of severe disabling conditions in childhood that places heavy demands on health, educational, and social services as well as on the families and children themselves. [1] When comparing participation between children with CP and their able-bodied peers, it has been found that frequency of participation in discretionary activities and social situations, such as community activities, games and pursuing cultural events, is significantly reduced. [2] Effective assessment of outcomes in children with chronic health conditions is important to monitor their progress, evaluate interventions, and guide health policy. [3, 4] The International Classification of Functioning, Disability and Health (ICF) provides a multidimensional perspective for measuring and documenting health outcomes. [5]

ICF codes can be used in pediatric practice to plan interventions aimed at improving a child's level of functioning and social participation. [6, 7] Understanding activities and participation and their relationship with impairments caused by CP is necessary in order to provide answers to questions from children and their parents about current and future functioning, to establish realistic goals for treatment, and to improve activities and participation [8–11].

There is a limitation of the measures currently available for assessing children's activities and participation. The measures do not fully represent all the domains in the ICF Version for Children and Youth (ICF-CY) [12].

Materials and methods

From November 2011 till March 2012, an electronic search was performed of the following data basis: EBSCO (Medline), Science Direct and Cochrane Library. Term "cerebral palsy" was collocated with words "measures", "activities" and "participation". Synonyms were used when needed and words that have variable endings were truncated with an asterisk. By reviewing titles and abstracts of scientific publications, appropriate publications were found, which were searched for the information of assessment measures. Having identified measures, they were individually connected with words "validity" and "reliability". Also systematic reviews of activities and/or participation assessment measures were included, as well as publications in which one of the measures was used to assess children with CP, and publications in which the assessment measure was tested for its reliability and/or validity. In order to find the open accessibility, the names of assessment measures were entered in public network.

The inclusion criteria for analysed publications and assessment measures were:

(1) publication was in English and accessible in full-text;
(2) the assessment measure evaluated activities and/or participation (according to ICF-CY);
(3) the measure was suitable for children older than 3 years;
(4) a publication where the measure was used to assess children with CP was found.

Excluded were measures which:

(1) primarily assessed quality of life or the functional status only of upper extremities;
(2) main purpose was to determine developmental delay;
(3) intended for gaining individual, only client-centered goals;
(4) had to be completed through the Internet;
(5) had no evidence of reliability and/or validity in use for patients with CP;
(6) connection with CP patients was found only in systematic reviews about activities and/or participation measures, and/or there was found only one publication where the tool was used for assessment of pediatric CP patients.

The strategy for searching publications and assessment measures which were selected for analysis, is represented in Figure 1.

Each assessment measure was described considering its characteristics, utility, and the conformity of its aims and sections to activities and/or participation (by ICF-CY). For practical use it was interesting to find out whether any of these measures were openly accessible. It was also examined if the sections and/or questions of the measures conformed to each of nine ICF-CY activities and participation domains. The information was acquired from scientific publications that describe the measures, their application in research or testing for reliability and/or validity for use in children with CP. The official representative home pages of the assessment measures and/or the original measures or their samples were used as information sources as well.

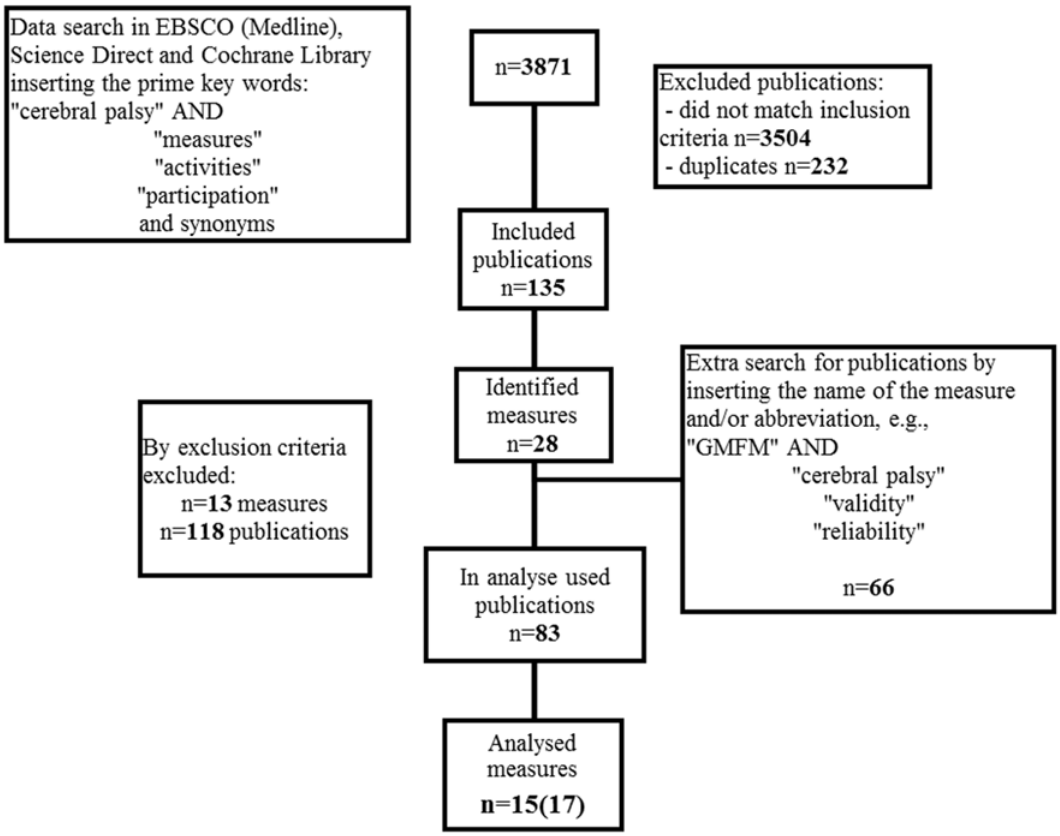

Figure 1.

Results

28 measures were identified, 13 of which were excluded based on exclusion criteria. 15 measures and extra versions of two measures were reviewed and analyzed systematically in the research work. The results are presented in Table 1.

The gathered results show that six measures could be used for assessing activities and participation: AMPS, COPM, LAQ-CP, PEDI, PODCI and WeeFIM, with PODCI putting emphasis on measuring participation. Activities could be evaluated by seven measures: ASK*p*, FMS, Gillette FAQ, GMFM-66,-88, GMPM, MobQues-47,-28 and PDMS-2, while participation could be measured by two measures: Life-H for Children and CAPE/PAC. It can be seen that the most represented domain is "Mobility" which is measured by all the measures. The second one is "Community, social and civic life" which is assessed by nine measures. Eight measures assess "General tasks and demands" and "Self-care". Seven measures assess domains "Domestic life" and "Major life areas", whereas "Learning and applying knowledge" and "Interpersonal interactions and relationships" is assessed by six measures. "Communication" was the least likely measured domain – evaluated only by five measures. Appropriateness of the sections of measures for assessing domains of activities and participation as defined by ICF-CY are presented in Table 2.

Table 1. The characteristics of the measures (aim of the assessment, including the description of its application and contents, target population, and the proper age, as well as whether the measure assesses activities (A) and/or participation (P) (by ICF-CY)), utility (format, administration (by who), time that the assessment takes) and the possible open accessibility of the measure.

Measure, authors, year	*Description, aim*	*Target population, age*	*Format, administration*	*Time (min.)*	*A / P*	*Open access-ibility*
1	2	3	4	5	6	7
AMPS Fisher et al., 2001, 2009	Standardized assessment of the performance of daily activities in an adequate environment, taking into account the difficulty level, assistive devices and adaptations. [13, 14]	Risk patients having difficulties to perform daily activities. [15] Variable developmental disorders. 4–68y. (with proven validity for CP patients) [13], > 2y. [14]	Observation. [14] Occupational therapist. [13, 14]	30–40 [15]	A/P [16]	no
ASK *p* Young et al., 2000	Assessment of child's physical disability both in the current and post-therapeutic period with regard to such domains as personal care, dressing, locomotion, play, standing skills, transfers etc. [17, 18]	Variable physical disorders, including neuromuscular disorders. [18] 5–15y. [17–19]	Questionnaire. [18] Patient himself. [18] < 9*y*. assisstance may be required. [17]	?	A [17, 18]	yes * [20]
CAPE/PAC King et. al., 2004	Measures the participation of children in a wide range of out-of-school activities. [16] Aims to find out whether participation is associated with personal choice or environmental and/or personal limitations. [21]	Children with/without activity limitations. [16, 21, 22] 6–21y. [16, 21–23]	Questionnaire. Patient himself with/without the assistance of guardian or by an interview. [16, 21]	CAPE 30–45, PAC 15–20. [16, 23]	P [21]	no
COPM Law et al., 1991, 2005	Measures change in self-perception, in ability to carry out leisure activities and self-care; to highlight most important aims of therapy relying on patient's most essential problems and the level of dissatisfaction. [24–26]	All patients regardless of diagnosis. [27] Adults. [26] < 8y. and if cognitive disorder – with presence of guardian. [28]	Semi structured interview. [27] Occupational therapist. [24]	20–40 [25]	A/P	no

Table 1. Continued.

Measure, authors, year	*Description, aim*	*Target population, age*	*Format, administration*	*Time (min.)*	*A / P*	*Open access-ibility*
1	2	3	4	5	6	7
FMS Graham et al., 2004	Aims to find out the functional mobility and necessity for different assistive devices at home (5m), school (50m), and public (500m) environment. [29–31]	Children with CP. [29, 30] 4–18y. [30]	Semi structured interview. [29] Health care specialist, using child's or his/her parents' answers. [29, 32]	5–10 [30]	A [30]	no
Gillette FAQ Novacheck et Stout, 1994, 2001	Focuses on finding out the level of independence and the necessity for assistive devices or orthosis by classifying the ambulant function and functional locomotor activity level. [33]	Children with different levels of gait abilities. [33] 3.4–19y. [33]	Structured questionnaire. [34] Patient himself or authorized guardian. [33]	?	A	yes †[34]
GMFM-66, −88 Russell et al., 1989, 2002	Assessment of gross motor function in such activities as lying, rolling, walking, running and jumping. The measurement of the level of difficulties in performance of each activity. [35]	GMFM- 88: CP, Down's syndrome [35] and spinal muscular atrophy[36] GMFM- 66: CP. [35, 37] 5months-16y. [35]	Observative test filled by a paediatric specialist who is competent in motor development. [35]	45–60 [37]	A [37]	no ‡ [38]
GMPM Boyce et al., 1998	Evaluates change over time in gross motor performance activities (rolling, crawling/ kneeling, sitting, standing, walking/ running/jumping). [39, 40]	CP. [39–41] 5months-12y. [39–41]	Observation that is based on specific signs. [39] Physiotherapist. [41]	45–60 [39]	A	no
LAQ- CP Mackie et al., 1998	Determines child's and family's level of participation limitations in such domains as physical independence, mobility, education, social interaction, economics and clinics. [42, 43]	CP. [42] 4-6y. [42] Is used also for 5–16y. old patients. [43]	Questionnaire. Child's parents. [42, 43]	?	A/P	no
Life- H for children Fougeyrol las et al., 1998, 2007	Assesses individual's performance of daily and social activities, taking into account the difficulties of performing habitual actions, and the necessity for assistance. [44, 45]	Persons with activity limitations. [44–46] 0–4y. and 5–13y. [44–46]	Questionnaire. Child's parents, patient himself, or a professional assessor. [46]	Sort version 20–40. Long version 20–120. [47]	P [48]	no‡ [46]

Table 1. Continued.

Measure, authors, year	*Description, aim*	*Target population, age*	*Format, administration*	*Time (min.)*	*A / P*	*Open access-ibility*
MobQues −47, −28 van Ravesteyn et al., 2009	Measures limitations of both daily indoor and outdoor mobility activities by taking into account the necessity for assis-tive devices. [49]	CP (GMFCS I–IV) [50] 2–13y. 2–3y. (GMFCS IV) advisable MobQues47; 3–13y. (GMFCS I-III) possible MobQues28 [50]	Questionnaire. [50] Parents or a guardian. [50]	Pilot-version n (26 quest.) mean 10.7 [49]	A [49]	yes[¶] [51]
PDMS-2 Folio et al., 2000	Measures gross (ref-lexes, locomotions, manipulations) and fine (grasping, visual-motor integration) motor function for diagnosing or developmental delay for the assess-ment of therapeutic effectiveness. [52]	Children with/without developmental disorders. [52] Birth- 5y. [53, 54] 2–5y. [52]	Standardized [52] Physiotherapist. test. [52]	Each sub-sectio n 20–30, whole test-45–60 [53]	A	no
1	2	3	4	5	6	7
PEDI Haley et al., 1992	Assesses child's functional abilities, performance and change in functional skills. With regard to the scales of functional skills, caregiver's assistance and modifications, measures the ability of self-care, mobility and social function. [55]	Children with functional activity limitations. [55] 6months-7.5y. [56] In case of functional development delay- also older children. [57]	Detailed and structured interview with child's parents and/or guardians. Physiotherapist and other specialists whoare competent in questions related to paediatric patients with activity limitations. [55]	45–60 [55]	A/P	no
PODCI Daltroy et al., 1998, 2005	Reflects child's current partici-pation in daily and social activities, also measures change after orthopaedic inter-vention. [58–60]	Orthopaedic patients of paediatry with various diagnoses. [59–61] 11–18y. and 2–10y. [60]	Questionnaire [58–60] For adolescents: patient himself or parent/guardian; for children: parent/guardian. [60]	?	A/P [58]	yes [60]
WeeFIM UDSMR, 1993	Measures patient's level of functional independence dependence in terms of daily motor and cog-nitive activities. [62–68]	Traumatic brain injuries, multiple amputations, burns [63], CP [67], spina bifida, genetic disorders [62] 3–18y. [63] 7–18y. [64]	Scale. A direct observation and/or structured interview by an authorized patient's care specialist or an observer, who is acknowledged by the leadership of the institution. [62, 63, 68]	10–15 [64]	A/P [62–68]	no[**] [69]

? – Was not possible to find out; * in certain situations when contacting with official representative; [†] no information of existence of a hand-book or courses of administration; [‡] samples are available; [¶]only MobQues47 version; [**] available are administration forms and information of result collection.

Table 2. Appropriateness of measures for assessing domains of activities and participation as defined by ICF-CY.

Domains of activities and participation by ICF-CY	AMPS	ASK*p*	CAPE/PAC	COPM	FMS	Gillette FAQ	GMFM-66, -88	GMPM	LAQ-CP	Life-H for Children	MobQues-47, -28	PDMS-2	PEDI	PODCI	WeeFIM
Learning and applying knowledge	–	–	+	+	–	–	–	–	–	+	–	+†	+	–	+
General tasks and demands	+	+	+	+	–	–	–	–	+	+	–	–	+	+	-
Communication	–	–	+	+	–	–	–	–	–	+	–	–	+	–	+
Mobility	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Self-care	+	+	–	+	–	–	–	–	+	+	–	–	+	+	+
Domestic life	+	+	+	+	–	–	–	–	+	+	–	–	+	–	–
Interpersonal – interactions and Relationships	–	+	+	–	–	–	–	+	+	–	–	+	+	–	
Major life areas	–	+	+	+	–	–	–	–	+	+	–	–	+	+	–
Community, social and civic life	–	+	+	+	–	–	–	–	+	+	+*	–	+	+	+

* Only MobQues47, † visual-motor integration.

Discussion

On the basis of accessible scientific publications, 15 psychometrically reliable measures that vary in terms of utility and are meant for paediatric patients with CP were identified.

An important factor that determines the choice of a measure is time necessary for administration, as the specialist who works with the patient has limited time. However, the results of this work suggest that the more detailed the assessment is, the more time is required for administration. For example, it takes only 5 minutes to administer FMS, which consists only of 3 questions and is used to determine the assistive device that is necessary for the patient to cover a certain distance in three different environments. However, administration of GMFM-88 requires up to 60 minutes since gross motor function is assessed by considering 88 aspects. In turn, administration of Life-H for Children (long version) can take up to 120 minutes, but it must be taken into account that assessment involves all the domains of ICF-CY and that each question is assessed in detail.

When gathering the results, it can be assumed be made that only two of the measures are specially designed for measuring participation: CAPE/PAC and Life-H for Children. It is seen that these two measures, unlike the rest of the measures, examine a wide ICF-CY activities and participation spectrum. Accordingly, CAPE/PAC examines 8 of 9 domains, but Life-H for Children – all the 9 of 9 domains. It may be assumed that almost all aspects that are connected with patient's involvement in life situations are taken into account when measuring participation. Nevertheless, when examining the seven activities assessment measures, it can be noticed that they mostly concentrate on domain "Mobility", except for ASK*p*,which looks at other aspects as well. Measures that assess both activities and participation differ among themselves. Firstly, they are different in terms of whether more attention is paid to activities or participation. Secondly, they differ in terms of the conformity to a certain count of ICF-CY activities and participation domains. It can be assumed that the choice whether to use a certain measure for assessing activities, participation, or both of them, depends on the specialist.

The results show that only three measures could fully represent all ICF-CY activities and participation domains (COPM, Life-H for Children, PEDI). Meanwhile, it must be taken in consideration that COPM is an individualized measure, Life-H for Children is frequently used to measure only participation [44] [70–74], and more than 70% questions of PEDI examine only domains of activities. [75] When choosing a measure, attention should be paid to its primary aim and, whenever possible, to the questions' quantitative conformity to the ICF-CY activities and participation domains, as well as the qualitative content of questions typical of each assessment measure.

In 2007, there was an opinion that none of the participation measures assess participation fully according to ICF domains of participation. However, it was assumed that the most appropriate way of measuring participation in children with CP could be the combination of three measures – CAPE, Life-H and SFA [58], which accordingly measure participation at home, school and social environments. [75] Life-H for Children was also highlighted among the other measures in another research on the measures that assess activities and participation. [76] That time (year 2009) there was still no proof of reliability for using Life-H for Children in paediatric patients with CP. The absence of reliability was the only deficiency in applicability of Life-H for Children. By conducting a systematic review, confirmation of Life-H for Children's reliability in use for children with CP was found in 2007. [44] Therefore, it could be assumed that Life-H for Children can be reliably used for measuring CP-diagnosed children's participation according to ICF-CY. In 2008, measures that assess activities were reviewed, and no measure that assesses activities according to all ICF domains was found. [77] Measures were grouped by (1) their strength in psychometric properties, with GMFM and ASK*p* as the strongest ones, and also by (2) their clinical application. It was concluded that choice of a measure should be based on the psychometric properties of the measure, on the assessment aim and on the individual features of the patient [77].

Summarizing the aforementioned data and the information obtained in this research, it can be proposed that the most appropriate means for measuring participation is Life-H for Children, which assesses all ICF-CY activities and participation domains. In turn, when measuring activities, the most suitable measure is ASK*p*, which assesses six of nine activities and participation domains. Relating the sections of a measure to the ICF-CY activities and participation domains, it was detected that PEDI measures all domains. Therefore, it can be assumed that PEDI is the most appropriate measure for assessing activities and participation, although the focus on specific aspects in the process of patient assessment and setting of therapy goals still depends on the specialists' choice. Grounding on the results of the research, it can be assumed that there are measures that assess all ICF-CY activities and participation domains or most of them, as well as perceive child's functioning in more general level. There also are measures that go deeply into certain ICF-CY domain and assess it in detail. The first type of measures includes AMPS, ASK*p*, CAPE/PAC, COPM, LAQ-CP, Life-H for Children, PEDI, PODCI and WeeFIM, while the second encompasses FMS, Gillette FAQ, GMFM-66,-88, GMPM, MobQues-47, -28 and PDMS-2. Basically, a presumption can be made that the choice of the measure depends on the specialist, who is chosen by the patient, and the therapeutic goals that are relevant to the patient and/or his family. For example, if an orthopaedic operation for structures of lower extremities is planned, it could be recommended to use Gillette FAQ or PODCI, but if the goal is strictly certain, for example, to improve locomotion at home without assistive devices, then FMS or MobQues-47, -28 could be applied. Such evaluation must be done by each specialist when choosing an assessment measure and the choice should be made by gaining detailed anamnesis, cooperating with patient and/or his family and setting a precise therapy goal.

The research would be more precise if the reliability and validity of each measure was analyzed in detail, if activities and participation assessment measures were analyzed separately, if more full-text publications about reliability and/or validity of a measure were found, and if it was possible to view samples of each assessment measure.

Conclusions

28 measures, 13 of which were excluded based on exclusion criteria were identified. In the research work, 15 measures and extra versions of two measures were reviewed and analyzed systematically. Measures that assess only activities were found to be seven, only participation – two, and both activities and participation are assessed by six measures. The utility of the measures can be grouped according to the purposes of the preferable aim of the assessment: the level of physical limitations, the activities of daily living, the functional independence, the restrictions of participation, the mobility, and the changes following orthopedic intervention or the gross motor function. When relating the measures to the domains of ICF-CY, the most appropriate measure for assessing activities is ASK*p*, for measuring participation – Life-H for Children, whereas for both activities and participation – PEDI and COPM. The identified and analyzed measures reflect different activities and participation domains of ICF-CY; therefore, the choice and the practical use of a certain measure depend on the aim of the assessment.

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