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Development of an assessment protocol to operationalize the core set of the International Classification of Functioning for people with cerebral palsy

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ABSTRACT

The core sets (CS) of the International Classification of Functioning, Disability and Health (ICF) for cerebral palsy (CP) have been applied in different contexts but have not been operationalized in the CP population in Argentina.

To select instruments for implementation, a four-stage cross-sectional study was conducted: training in ICF, consensus on instruments, evaluation of intra- and interobserver agreement, and pilot testing. Sixty-nine professionals participated in the training, and 13 in the consensus. In the first round, agreement was reached in 15 of 24 categories (92.8%), and new options were proposed for the remaining ones. The second round achieved 95.6% agreement. Intra-observer agreement was 0.84, and inter-observer agreement was 0.86. The pilot test (n = 7) allowed five categories to be adjusted. The first national protocol for assessing ICF CS in children with CP is thus proposed.

Keywords: *cerebral palsy; child; rehabilitation; International Classification of Functioning, Disability, and Health.*

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INTRODUCTION

Cerebral palsy (CP) is the most common physical disability in childhood, affecting 1 in 500 live births.[1] It is characterized by movement and posture disorders and is often associated with impairments in sensation, perception, cognition, communication, and behavior, which impact individuals' daily functioning.[2] Understanding the factors that influence functioning is crucial for planning effective interventions and improving service delivery.[3,4]

Given the diversity of assessment and treatment approaches for people with CP and the lack of consensus on data collection, it is essential to adopt a common framework and universal language to optimize service delivery and improve functional outcomes.[5] The International Classification of Functioning, Disability and Health (ICF) provides a valuable framework for systematically describing functioning.[6,7] To facilitate its application in clinical practice and research, core sets (CS) were developed.[8] A CS is a list of ICF categories that serve as an international standard for describing functioning, highlighting what should be measured and reported in a specific population. In 2014, Schiariti et al. published the first ICF CS for children and youth with CP along with guidelines for use to facilitate global adoption.[4]

Although the ICF CS for children and youth with CP has been applied in different contexts, they have not been operationalized (put into practice) in pediatric populations with CP in Argentina. Therefore, the overall purpose of this study was to develop a protocol that would allow for the operationalization of the abbreviated standard CS for CP, adopting culturally sensitive instruments in Argentina, for the creation of functioning profiles in this population.

MATERIALS AND METHODS

This was a cross-sectional, multicenter study conducted in five stages. Stage 5 (construction of functioning profiles) was described in another publication.[9] The stages are described in *Figure 1*. It was carried out in ten rehabilitation centers in eight cities in Argentina (San Salvador de Jujuy, Mendoza, Córdoba, Rosario, Reconquista, Autonomous City of Buenos Aires [CABA], La Plata, and General Pacheco).

The participating team was made up of professionals from different disciplines, with training in pediatric rehabilitation and more than six years of experience working with people with CP.

Statistical analysis

The consensus process was carried out using the Delphi methodology. The questions were analyzed using a five-level Likert scale. Consensus was reached when more than 80% agreement was obtained. Cohen's κ index was used to assess the level of inter- and intra-observer agreement. Statistical calculations were performed using the statistical program MedCalc 18.2.1.

Ethical considerations

This study was approved by the Ethics Committee of the Hospital Nacional de Clínicas de Córdoba (REPIS N.° 3262/3764).

RESULTS

The results of stages 1 to 4 are described below.

Stage 1: ICF training course for participating professionals

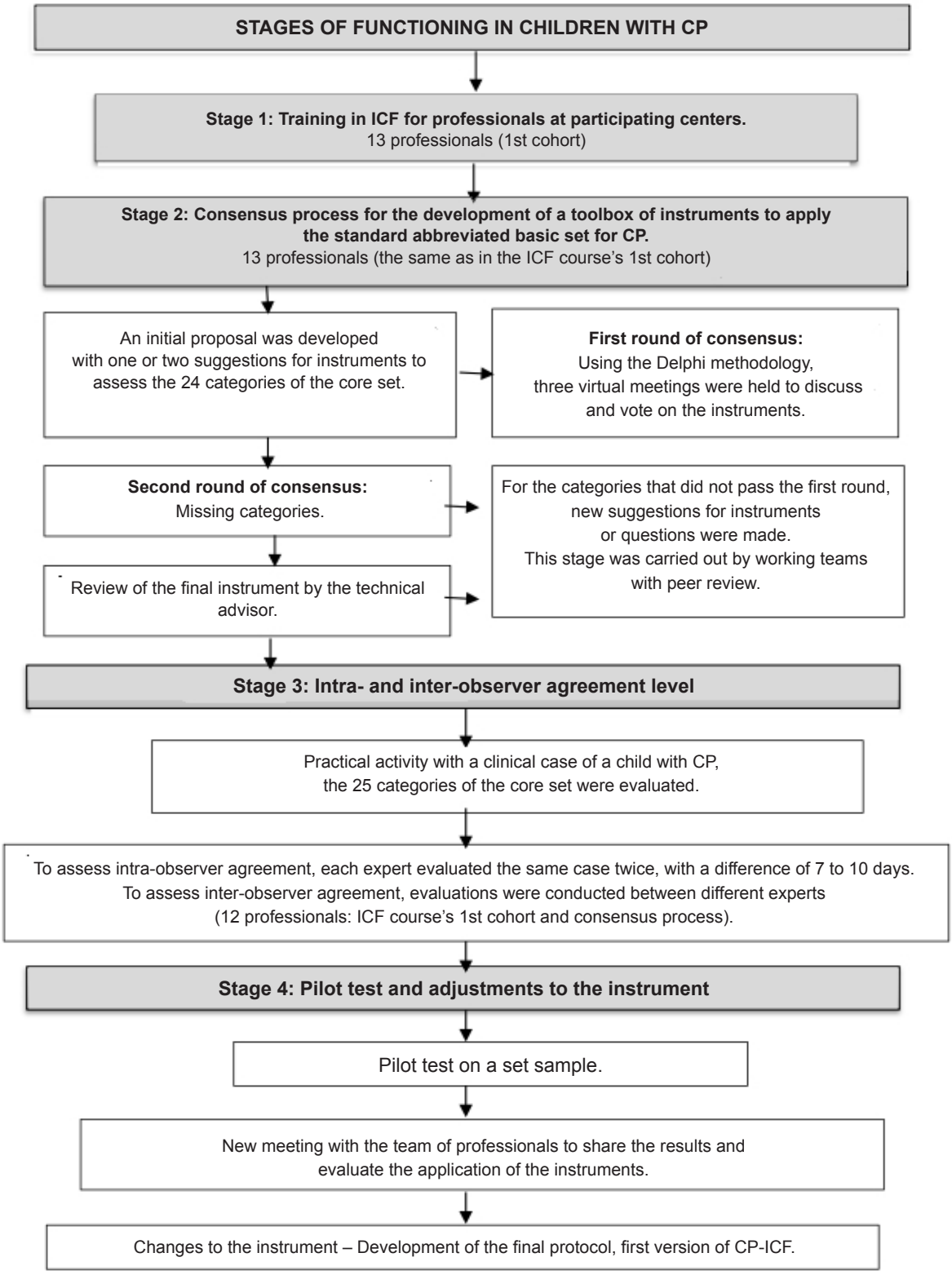
To ensure that the study team had advanced knowledge of the ICF, a course was offered, which had two cohorts. The first consisted of 13 professionals (participants after the consensus process and intra- and interobserver evaluation), and the second of 56 professionals from the same centers, who were to participate in the protocol implementation process. One hundred percent of participants reported that their knowledge of the ICF and the use of CS had increased after completing the course. A post-test was conducted to assess some of the course content; the average score was 88.6%.

Stage 2: Consensus process for selecting a set of instruments/scales to apply the CS

The objective was to reach a consensus on how to assess the 25 categories of the CS. Professionals could select different assessment options, including clinical observation, structured questions, and technical tests. Thirteen professionals from the disciplines of physiatry (3), pediatrics (3), general medicine (1), kinesiology (3), speech therapy (1), nutrition (2), and two experienced coordinators in investigation participated.

Two rounds of consensus were held, during which the panel of experts assessed the relevance and clarity of each item. In the first round, the instruments for 15 of the 24 categories were approved (category s110 Brain structure is assessed as established by the ICF). New options were developed for the remaining categories.

Figure 1. Stages in the development of the CP-ICF protocol



CP: cerebral palsy; ICF: International Classification of Functioning.

Finally, in the second round, the instruments for the remaining categories were approved, after which a final version of the protocol consisting of 24 instruments was approved.

Stage 3: Intra- and inter-observer agreement

This step aimed to test the reliability of the protocol. The level of agreement was determined by constructing a performance profile using a clinical case; 12 professionals applied the protocol using the same case study. The agreement index was 0.84 intra-observers and 0.86 inter-observers. The protocol was considered ready for pilot testing.

Stage 4: Pilot test – CP-ICF

The objective of this step was to conduct a pilot test. For this, 5 to 10 cases were deemed necessary. The sample consisted of seven children with CP, selected for convenience, seeking cases that represented different levels of gross motor function (GMFCS). Before the evaluation, the children who were able to participate gave their consent, and informed consent was signed by their parents, guardians, and/or caregivers. The average age was 6 ± 2 years. Once completed, changes had to be made to the five-category protocol to improve and facilitate its application. *Table 1* describes these changes. Finally, the first version of the CP-ICF protocol was available to construct the performance profiles.

An essential part of working with the ICF is translating scale scores or qualitative information into ICF qualifiers. Therefore, a rigorous process was developed and tested for applying CP-ICF. For example, for scores from instruments that yield a numerical result, such as the gross motor function measure (GMFM-88)[10] and the Peabody Developmental Motor Scale (PDMS-2),[11] equivalence was established based on the percentages of the ICF qualifiers. Instruments with a categorical response modality, such as the CPQOL, were directly converted into ICF qualifiers. *Table 2* and the supplementary material provide a complete description of the categories included in the CS and the instruments used to assess them.

DISCUSSION

This study describes the process of selecting instruments to operationalize the ICF CS for children with CP. Through this, relevant contributions were made, such as raising awareness of the importance of investing in ICF training and proposing a single protocol to standardize the collection of functional data to create performance profiles.

The CP-ICF protocol was developed considering the toolbox of measures aligned with the ICF CS for children and young people with CP developed by Schiariti et al.,[4,12] and the ICF linking standards proposed by Cieza et al.[13]

At a general level, the participating professionals acknowledged that the use of instruments to measure outcomes in rehabilitation systematically is a weakness. Although there has been increasing emphasis on evidence-based practice (EBP) and the use of standardized outcome measures to document improvements in interventions over the past decade, this remains a challenge in rehabilitation.[14] In addition to this perceived situation, finding instruments that have been translated and cross-culturally adapted for Argentina added to the challenge; this difficulty has been present in other similar experiences.[3]

Table 1. Changes in categories after the pilot test

Category	Modification
b280 Sensation of pain	The number of questions was reduced, and the Wong-Baker facial scale was added to assess pain level.
b710 Mobility of joint functions	A table of equivalents for normal goniometric degrees was created based on the percentages of the ICF qualifiers.
d415 Maintaining a body position	It was decided to use dimensions B and D of the GMFM-88 scale instead of the GMFM-66.
d450 Walking	It was decided to use dimension E from the GMFM-88 scale instead of the GMFM-66.
d440 Fine hand use	The number of questions in the set for children aged 2 to 5 years was reduced.

ICF: International Classification of Functioning, Disability and Health; GMFM: gross motor function measure.

Table 2. Proposed tools for applying the Brief International Classification of Functioning Core Set for cerebral palsy

ICF domain	ICF code	Category	Selected instrument	Method
Body functions	b117	Intellectual functions	Questions developed according to the age group *Available in supplementary material*	Questionnaire
	b134	Sleep functions	CPQOL - Question 8	
	b167	Mental functions of language	Comprehensive and expressive language items from the cognitive domain of the WeeFIM	Clinical
	b210	Seeing functions	Questionnaire administered to the caregiver or the child with visual card assistance *Available in supplementary material*	Questionnaire
	b280	Sensation of pain	CPQOL - Question 49	Questionnaire
	b710	Mobility of joint functions	Goniometry	Clinical examination
	b735	Muscle tone functions	Modified Asworth scale	Clinical examination
	b760	Control of voluntary movement functions	PDMS-2	Clinical Examination
Body structures	s110	Structure of brain	Imaging test results	Technical research
Activities and participation	d415	Maintaining a body position	GMFM-88	Clinical examination
	d440	Fine hand use	Questions developed according to age group *Available in supplementary material*	Questionnaire
	d450	Walking	GMFM-88	Clinical examination
	d460	Moving around in different locations	Elaborate questions *Available in supplementary material*	Questionnaire
	d530	Toileting	Questions *Available in supplementary material*	Questionnaire
	d550	Eating	Questions developed by the EDACS level *Available in supplementary material*	Questionnaire
	d710	Basic interpersonal interactions	CPQOL - Question 18	Questionnaire
	d760	Family relationships	CPQOL - Questions 20, 26, 27	Questionnaire
Environmental factors	e115	Products and technology for personal use un daily living	Elaborated questions *Available in supplementary material*	Questionnaire
	e120	Products and technology for personal indoor and outdoor mobility and transportation	Detailed questions *Available in supplementary material*	Questionnaire
	e125	Products and technology for communication	Elaborated questions *Available in supplementary material*	Questionnaire
	e150	Design, construction, and building products and technology of buildings for public use	CPQOL – Question 70	Questionnaire
	e310	Immediate family	CPQOL - Questions 19 and 21	Questionnaire
	e320	Friends	CPQOL - Question 25	Questionnaire
	e460	Societal attitudes	CPQOL - Questions 22, 23, and 30	Questionnaire
	e580	Health services, systems, and policies	CPQOL – Questions 71 and 6 (section “Questions about you”)	Questionnaire

CPQOL: Cerebral Palsy Quality of Life Questionnaire; PDMS-2: Peabody Motor Development Scale, second edition; GMFM-88: gross motor function measure; Wee-FIM: functional independence measure for children; EDACS: eating and drinking skills classification system.

We sought to maintain the use of instruments known and used by professionals in rehabilitation centers, such as the GMFM-88 and the PDMS-21, in categories related to mobility. It is essential to mention that we identified several measures to assess intellectual functions, mental language functions, and self-care categories, which are consistent with other international experiences.[1]

This study has some limitations. One of them is the limited availability of validated tools for pediatric populations diagnosed with CP in Argentina. However, additional efforts were made to create questions that were culturally meaningful for those categories not covered. Another limitation is that the pilot test sample did not include adolescents.

An essential strength of this study is that it describes the construction of the first protocol for the implementation of CS. The methodology detailed here can be replicated in different countries for the construction of their protocols.

CONCLUSION

CP-ICF is a novel standardized protocol that contributes to the description of functional abilities, as well as environmental factors that influence the daily functioning of children with CP. It can be applied at the national level to provide essential functional information to guide individualized interventions, monitor response to treatments, and provide evidence-based information. ■

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The supplementary material provided with this article is presented as submitted by the authors. It is available at: https://www.sap.org.ar/docs/publicaciones/archivosarg/2026/10550_CB_EscobarZuluaga_Anexo.pdf

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