

Profiles of functioning of a group of children with cerebral palsy in Argentina: Preliminary data from the first national study

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ABSTRACT

Cerebral palsy (CP) affects body posture and movement coordination and is the most common cause of severe disability in the pediatric population. The diagnosis of CP is not a description of a person's functioning or interaction with their environment. Therefore, the diagnosis should be complemented with a description of functioning, using tools based on the biopsychosocial model proposed by the World Health Organization's International Classification of Functioning, Disability and Health (ICF).

This report describes the preliminary data from a multicenter study conducted in Argentina with the aim of standardizing the description of the profiles of functioning of children and adolescents with CP. These data showed that the participants had some skills in sleep functions, mental functions of language, seeing functions, and in some environmental factors. They showed significant difficulties in categories such as maintaining body position, walking, and toileting.

Keywords: child; adolescent; cerebral palsy; disabled children; International Classification of Functioning, Disability and Health.

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INTRODUCTION

Cerebral palsy (CP) is a health condition of great interest for pediatricians and researchers in the field of neurodevelopment. Such interest is explained by several reasons, listed here: 1) it is the most frequent cause of severe motor disability in the pediatric population;^{1,2} 2) it is often one of the outcomes used to measure the impact of neonatal or perinatal therapies or programs; 3) it has been shown that CP can be diagnosed early with clinical observation tools;³ 4) the definition of CP has been a topic under review for more than 150 years.^{4,5}

Several classification systems have been developed for children with CP dedicated to specific areas of development: gross motor function, hand skills, language/communication, and eating and drinking skills.⁶ Recently, the world's first tool based on the biopsychosocial model of the International Classification of Functioning, Disability and Health (ICF) for the pediatric population, called ICF Core Sets for Cerebral Palsy, was developed.^{7,8} This tool allows to assess functioning in this population. The assessment of functioning has been currently proposed as a third health indicator, as a complement to mortality and morbidity, which are established indicators.⁹

The main purpose to develop the ICF Core Sets for CP was to enable the development of profiles of functioning (PF). To date, several benefits of their use have been reported: they facilitate interdisciplinary work, systematically include areas of activity and participation, identify environmental facilitators and barriers that can be modified, promote child- and family-centered care.¹⁰

In Argentina, several projects are advancing in the knowledge and implementation of PFs in the pediatric population.¹¹ The objective of this report was to describe the interim results of the development of the PF project in a group of children and adolescents with CP in 8 cities of 5 provinces of Argentina.

POPULATION AND METHODS

This was a descriptive, cross-sectional study. For the implementation of the PF, participants were children and adolescents aged 2 to 18 years with CP attending health and rehabilitation centers in 8 cities of Argentina (Jujuy, Mendoza, Córdoba, Ciudad Autónoma de Buenos Aires, La Plata, General Pacheco, Rosario, and Reconquista) in 2021 and 2022. The sample was selected using sequential sampling, which included

the highest number of cases possible at each participating site. Children and adolescents aged 2 to 18 years who had a confirmed diagnosis of CP, motor compromise of level I, II, III, IV, or V as per the Gross Motor Function Classification System (GMFCS),¹² and who regularly attended rehabilitation centers and agreed to participate were included.

The variables were the categories of the Brief Common Core Set for CP.⁷ The Core Sets for CP are based on ICF components that define 25 categories scored with a qualifier from 0 (no impairment) to 4 (complete impairment). Each category is assessed using a standard instrument validated in the previous stage¹³ (*Supplementary material, Table 1*). The assessments were performed by the healthcare providers from the centers, who had previously completed a course on the ICF and participated in the instrument's development and validation.

For data analysis, normal continuous variables were described as mean and standard deviation (SD), while categorical variables were expressed as percentage and 95% confidence interval (CI).

Ethical considerations

This study was approved by the Ethics Committee of Hospital Nacional de Clínicas de Córdoba (no. 184) and is registered before the Provincial Registry of Health Research (REPIS no. 3764), dated 5/2/2019. This study was also approved by the corresponding committee of each site included in the study. A written informed consent was obtained from each family, and an assent was obtained from children older than 13 years who were able to give their assent.

RESULTS

A total of 170 children with CP were invited to participate; 133 agreed to be included. Their average age was 7 ± 4 years. Their sociodemographic and clinical characteristics are described in *Table 1*.

Profiles of functioning are a graphic representation that summarize the skills and limitations of children and youth with CP. *Figure 1* shows the PFs for all study participants. The *Supplementary material* includes the table of absolute and relative frequencies used to develop the PF for the whole sample (*Supplementary material, Table 2*).

These interim data show that children with CP have some skills; for example, in relation to

TABLE 1. Clinical and sociodemographic characteristics of the study population

Sociodemographic characteristics (N = 133)	N	%	95% CI
Sex			
Male	79	59.4	50.5–67.8
Female	54	40.6	32.7–49.4
Health coverage			
Yes	114	85.7	78.5–91.1
No	19	14.3	8.8–21.4
Province			
Buenos Aires*	70	52.6	43.7–61.3
Córdoba	20	15.0	9.4–22.2
Jujuy	12	9.0	4.7–15.2
Mendoza	7	5.3	2.1–10.5
Santa Fe**	24	18.0	11.8–25.5
Clinical characteristics (N = 133)			
Gross Motor Function Classification System severity level			
Level I (Walks without limitations)	30	22.6	15.8–30.6
Level II (Walks without support, but with limitations)	18	13.5	8.1–20.5
Level III (Walks with adaptive equipment assistance)	19	14.3	8.8–21.4
Level IV (Mobility assisted by others)	16	12.0	7.0–18.7
Level V (Dependent on wheelchair)	50	37.6	29.3–46.4
European Classification of CP			
Bilateral spastic	70	53.0	44.1–61.7
Unilateral spastic	36	27.3	19.9–35.7
Ataxic	5	3.8	1.2–8.1
Dyskinetic	17	12.8	7.6–19.6
Choreo-athetotic	4	3.0	0.8–7.5
Non-specific	1	0.75	0.01–4.1

* Ciudad Autónoma de Buenos Aires, La Plata, General Pacheco.

** Rosario, Reconquista.

N: number, CP: cerebral palsy. Gross Motor Function Classification System.

sleep functions, mental functions of language and seeing functions, as well as some related to the environment and the family (basic interpersonal interactions, family relationships), for which the qualifier value was 0. In turn, they have significant difficulties, described with a qualifier of 4 (complete difficulty) in categories such as maintaining a body position, walking, moving around in different locations, and toileting, which can be reduced with adaptations and context-based interventions.

Figure 2 shows the individual PF of study participants, whose age and GMFCS level varies: Figure 2a corresponds to a 5-year-old boy with unilateral spastic CP and GMFCS level I, while Figure 2b shows the PF of a 13-year-old girl with dystonic CP and GMFCS level V. These profiles allow to compare not only the impact of CP, but also of other variables, such as age, sex, and gross motor function involvement. These 2 graphs show the differences in lesser or greater degree of difficulty. The 5-year-old boy, who had a GMFCS

level I, had no difficulty in most categories of functioning, activities and participation, with some mild to moderate difficulties in categories such as mobility of joints, muscle tone, fine hand use, and toileting. On the contrary, the 13-year-old girl, with a GMFCS level V, showed severe or complete difficulties in most categories of both domains of the core set. Differences in environmental factors were also observed in both cases.

DISCUSSION

Notably, advances in the early detection of CP put greater focus on the efficacy of treatments, specifically on establishing which evidence-based interventions have an impact on daily functioning.¹⁴ It is important to recognize that an early and timely diagnosis of CP does not describe daily skills and limitations. Therefore, tools based on the biopsychosocial model of the ICF are necessary, which include both biomedical areas and also those of the social context using

FIGURE 1. Profile of functioning in children and adolescents (N = 133)

Code	Category name	ICF qualifier									
		Impairment					Difficulty				
BODY FUNCTIONS		0	1	2	3	4	0	1	2	3	4
b117	Intellectual functions										
b134	Sleep functions										
b167	Mental functions of language										
b210	Seeing functions										
b280	Sensation of pain										
b710	Mobility of joint functions										
b735	Muscle tone functions										
b760	Control of voluntary movement functions										
ACTIVITIES AND PARTICIPATION		0	1	2	3	4	0	1	2	3	4
d415	Maintaining a body position										
d440	Fine hand use										
d450	Walking										
d460	Moving around in different locations										
d530	Toileting										
d550	Eating										
d710	Basic interpersonal interactions										
d760	Family relationships										
ENVIRONMENTAL FACTORS		Facilitator				Barrier					
		+4	+3	+2	+1	0	1	2	3	4	
e115	Products and technology for personal use in daily living										
e120	Products and technology for personal indoor and outdoor mobility and transportation										
e125	Products and technology for communication										
e150	Design, construction and building products, and technology of buildings for public use										
e310	Immediate family										
e320	Friends										
e460	Societal attitudes										
e580	Health services, systems and policies										

For body functions and activities and participation, impairment and difficulty are defined based on the following values: 0 = no impairment, 1 = mild impairment, 2 = moderate impairment, 3 = severe impairment, 4 = complete impairment. For environmental factors, the values refer to: +4 = complete facilitator, +3 = substantial facilitator, +2 = moderate facilitator, +1 = mild facilitator, 0 = no facilitator or barrier, 1 = mild barrier, 2 = moderate barrier, 3 = severe barrier, 4 = complete barrier. The gray-shaded areas indicate the assigned qualifier value. ICF: International Classification of Functioning, Disability and Health. GMFCS: Gross Motor Function Classification System.

FIGURE 2. Profile of functioning

2a. 5-years-old boy, unilateral spastic CP, GMFCS I										
Code	Category name	ICF qualifier								
BODY FUNCTIONS		Impairment								
		0	1	2	3	4				
b117	Intellectual functions									
b134	Sleep functions									
b167	Mental functions of language									
b210	Seeing functions									
b280	Sensation of pain									
b710	Mobility of joint functions									
b735	Muscle tone functions									
b760	Control of voluntary movement functions									
ACTIVITIES AND PARTICIPATION		Difficulty								
		0	1	2	3	4				
d415	Maintaining a body position									
d440	Fine hand use									
d450	Walking									
d450	Moving around in different locations									
d530	Toileting									
d550	Eating									
d710	Basic interpersonal interactions									
d760	Family relationships									
ENVIRONMENTAL FACTORS		Facilitator				Barrier				
		+4	+3	+2	+1	0	1	2	3	4
e115	Products and technology for personal use in daily living									
e120	Products and technology for personal indoor and outdoor mobility and transportation									
e125	Products and technology for communication									
e150	Design, construction and building products, and technology of buildings for public use									
e310	Immediate family									
e320	Friends									
e460	Societal attitudes									
e580	Health services, systems and policies									

2b. 13-years-old girl, dystonic CP, GMFCS V										
Code	Category name	ICF qualifier								
BODY FUNCTIONS		Impairment								
		0	1	2	3	4				
b117	Intellectual functions									
b134	Sleep functions									
b167	Mental functions of language									
b210	Seeing functions									
b280	Sensation of pain									
b710	Mobility of joint functions									
b735	Muscle tone functions									
b760	Control of voluntary movement functions									
ACTIVITIES AND PARTICIPATION		Difficulty								
		0	1	2	3	4				
d415	Maintaining a body position									
d440	Fine hand use									
d450	Walking									
d450	Moving around in different locations									
d530	Toileting									
d550	Eating									
d710	Basic interpersonal interactions									
d760	Family relationships									
ENVIRONMENTAL FACTORS		Facilitator				Barrier				
		+4	+3	+2	+1	0	1	2	3	4
e115	Products and technology for personal use in daily living									
e120	Products and technology for personal indoor and outdoor mobility and transportation									
e125	Products and technology for communication									
e150	Design, construction and building products, and technology of buildings for public use									
e310	Immediate family									
e320	Friends									
e460	Societal attitudes									
e580	Health services, systems and policies									

For body functions and activities and participation, impairment and difficulty are defined based on the following values: 0 = no impairment, 1 = mild impairment, 2 = moderate impairment, 3 = severe impairment, 4 = complete impairment. For environmental factors, the values refer to: +4 = complete facilitator, +3 = substantial facilitator, +2 = moderate facilitator, +1 = mild facilitator, 0 = no facilitator or barrier, 1 = mild barrier, 2 = moderate barrier, 3 = severe barrier, 4 = complete barrier. The gray-shaded areas indicate the assigned qualifier value. ICF: International Classification of Functioning, Disability and Health. GMFCS: Gross Motor Function Classification System; CP: cerebral palsy.

the language of the ICF.¹⁵

These PFs, both at the individual and group levels, help to identify functional goals and to initiate a conversation with children, adolescents, and their families about their perspectives and interest in the rehabilitation process. PFs may be used in clinical practice to help pediatricians complement the diagnosis with relevant functional information on children’s daily functioning. In turn, these profiles are useful for interdisciplinary teamwork because they facilitate communication

among healthcare providers. Finally, these profiles may be used as educational material to advocate for a change in the perspective towards disability, introducing the skills, opinions, and interests of children, adolescents, and their families. There are reports of similar experiences developing profiles of functioning of children with CP in Brazil, Russia, Poland, and Malawi, among other countries, which showed similar benefits of their use in rehabilitation.¹⁰

One of the limitations of this study is the

representativeness of the sample. Future studies should expand the sample to a national level to make it more representative. Another potential limitation to carry out the assessment as such was the time availability of the healthcare providers for each consultation; for this reason, we plan to make the protocol as short and practical as possible.

CONCLUSION

These data describe the functional skills of the surveyed population, as well as their main difficulties. Based on the examples of the cases described here, it is possible to identify, both at a group and an individual level, the impact on and the differences in the profiles of functioning of children with CP according to different variables. In addition to being innovative and novel, the profiles of functioning help to standardize the identification of functional needs and therapeutic goals based on ICF terms. ■

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Supplementary material available at: https://www.sap.org.ar/docs/publicaciones/archivosarg/2024/10257_CB_Escobar_Anexo.pdf

REFERENCES

- Oskoui M, Coutinho F, Dykeman J, Jetté N, Pringsheim T. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol.* 2013;55(6):509-19.
- Galea C, Mcintyre S, Smithers Sheedy H, Reid SM, et al. Cerebral palsy trends in Australia (1995–2009): a population-based observational study. *Dev Med Child Neurol.* 2019;61(2):186-93.
- Morgan C, Fetters L, Adde L, Badawi N, et al. Early Intervention for Children Aged 0 to 2 Years With or at High Risk of Cerebral Palsy: International Clinical Practice Guideline Based on Systematic Review. *JAMA Pediatr.* 2021;175(8):846-58.
- Ruiz Brunner M de las M, Cuestas E. La construcción de la definición parálisis cerebral: un recorrido histórico hasta la actualidad. *Rev Fac Cienc Med Univ Nac Cordoba.* 2019;76(2):113-7.
- MacLennan AH, Thompson SC, Geetz J. Cerebral palsy: causes, pathways, and the role of genetic variants. *Am J Obstet Gynecol.* 2015;213(6):779-88.
- Ruiz Brunner M de las M, Escobar Zuluaga J, Cieri ME, Ayllón C, Cuestas E. Sistemas de clasificación para niños, niñas y adolescentes con parálisis cerebral: su uso en la práctica clínica. *Rev Fac Cienc Med Univ Nac Cordoba.* 2020;77(3):191-8.
- Schiariti V, Selb M, Cieza A, O'Donnell M. International Classification of Functioning, Disability and Health Core Sets for children and youth with cerebral palsy: a consensus meeting. *Dev Med Child Neurol.* 2015;57(2):149-58.
- Schiariti V. Focus on functioning: let's apply the ICF model. *Clin Teach.* 2016;13(5):378-80.
- Stucki G, Bickenbach J. Functioning: the third health indicator in the health system and the key indicator for rehabilitation. *Eur J Phys Rehabil Med.* 2017;53(1):134-8.
- Schiariti V, Longo E, Shoshmin A, Kozhushko L, et al. Implementation of the International Classification of Functioning, Disability, and Health (ICF) Core Sets for Children and Youth with Cerebral Palsy: Global Initiatives Promoting Optimal Functioning. *Int J Environ Res Public Health.* 2018;15(9):1899.
- Napoli SB, Vitale MP, Cafiero PJ, Micheletti MB, et al. Developing a Culturally Sensitive ICF-Based Tool to Describe Functioning of Children with Autism Spectrum Disorder: TEA-CIFunctiona Version 1.0 Pilot Study. *Int J Environ Res Public Health.* 2021;18(7):3720.
- Rosenbaum PL, Palisano RJ, Bartlett DJ, Galuppi BE, Russell DJ. Development of the Gross Motor Function Classification System for cerebral palsy. *Dev Med Child Neurol.* 2008;50(4):249-53.
- Escobar Zuluaga LJ, Ruiz Brunner MM, Cieri M, Cuestas E, Schiariti V. Creation of a culturally sensitive toolbox of measures to operationalize the ICF core sets for CP in Argentina. In 75th Annual Meeting AACPD. Scientific Posters SP42. October 7, 2021. *Dev Med Child Neurol.* 2021;63(Suppl 3):89.
- Novak I, Morgan C, Fahey M, Finch-Edmondson M, et al. State of the Evidence Traffic Lights 2019: Systematic Review of Interventions for Preventing and Treating Children with Cerebral Palsy. *Curr Neurol Neurosci Rep.* 2020;20(2):3.
- Organización Mundial de la Salud. Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud: CIF. Ginebra, 2001. [Accessed on: February 2nd, 2024]. Available at: https://aspace.org/assets/uploads/publicaciones/e74e4-cif_2001.pdf