

Therapies, bonds and quality of life of children and adolescents with cerebral palsy: experiences and perceptions of their caregivers during the pandemic

Terapias, vínculos y calidad de vida de niños, niñas y adolescentes con parálisis cerebral: vivencias y percepciones de sus cuidadores durante la pandemia

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What do we know about the subject matter of this study??

Research indicates that the isolation imposed by the COVID-19 pandemic has impacted the health and quality of life of children and adolescents in general. Studies on individuals with disabilities have focused on its physical impact due to the absence of therapies.

What does this study contribute to what is already known??

Complementing quantitative and qualitative data, we analyzed perceptions of impact and differences in dimensions of Health-Related Quality of Life (HRQoL) during the pandemic in Argentina of children and adolescents diagnosed with cerebral palsy. We found that the pandemic affected psychosocial dimensions of health such as psychological and emotional well-being, peer relationships, and school environment. Qualitative analysis reinforced these findings and highlighted the positive evaluation of self-care.

Abstract

The COVID-19 pandemic affected the health of children and adolescents (CA). Isolation-related conditions could have impacted not only the functionality of children and adolescents with cerebral palsy (CP) but also their social and emotional well-being, affecting their health-related quality of life (HRQoL). **Objective:** To analyze perceptions of impairment during the pandemic and differences in HRQoL dimensions compared with a previous registry in Argentinean children and adolescents diagnosed with CP from the perspective of their caregivers. **Subjects and Method:** Cross-sectional observational study at two time points (2019 and 2021) where 98 caregivers participated. We used the KIDSCREEN-27 and CP-QOL questionnaires for the assessment of HRQoL and an open-ended question regarding the impact of the pandemic on the health of children and adolescents, including

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in 2021. We compared mean scores of the dimensions of the questionnaires in both stages (significant differences: Cohen's $d \geq 0.3$). Responses to the open-ended question were analyzed via "open" and "axial" coding. **Results:** The scores of the dimensions Participation, Emotional well-being, Social well-being, and School environment (CP-QOL) and Psychological well-being, Friends, School environment, and General HRQoL index (KIDSCREEN-27) were lower during the pandemic (2021) compared with 2019 ($d > 0.3$). Regarding perceived affectation during the pandemic, we identified three main recurrences: "impairment due to interruption of therapies and treatments", "deterioration of peer bonding", and "increased and positive appraisal of self-care". **Conclusions:** The pandemic affected the psychosocial dimensions of health. Qualitative data highlight the positive assessment of self-care.

Introduction

At the end of 2019, the first cases of atypical viral pneumonia of unknown origin were reported in China. In the early months of the following year, the World Health Organization (WHO) characterized the spread of this disease caused by a coronavirus (SARS-CoV-2) as the COVID-19 pandemic¹. In line with international control recommendations, the Argentine government implemented a strategy of preventive and mandatory social isolation (ASPO in Spanish) until November 2020, followed by preventive and mandatory social distancing (DISPO in Spanish) until March 2021^{2,3}.

During this epidemiological situation, various symptoms and clinical conditions related to the pathology were described, but the health dimensions altered by different isolation conditions were studied to a lesser extent. Regarding the emotional impact, research reported that a high percentage of Argentine children and adolescents experienced mood and behavioral changes^{4,5}. These findings are replicated in European countries such as Spain and Italy, with an incidence rate exceeding 85%⁶.

Studies involving children and adolescents with disabilities in other countries have mainly focused on the physical impact of the disease or how the health of caregivers was affected. Changes in functional status, increased pain, and spasticity in people with motor disabilities⁷ were reported, along with a significant decrease in the quality of life of their caregivers⁸. Overall, multiple studies agree on the decrease in access to rehabilitation services and the interruption of different therapies^{7,9}.

Cerebral palsy (CP) is defined as a group of developmental and postural disorders causing a limitation in daily life activities due to non-progressive brain alterations during early childhood¹⁰. According to records from developing countries, the prevalence is estimated between 2 to 3 cases per 1000 live births¹¹, making it the most common motor disability in childhood¹², although its incidence in Argentina is unknown. Its heterogeneous clinic requires an approach that incorporates socio-environmental components of health

and disability, as proposed by the International Classification of Functioning, Disability, and Health (ICF)¹³. This perspective focuses on the subjective experience of the impact of disability on children and adolescents and their families.

We consider that a comprehensive perspective centered on the individual can be strengthened through the study of Health-Related Quality of Life (HRQoL)¹⁴, which assesses health in multiple dimensions, incorporating the individuals' perspective on their functional status and well-being¹⁵. The WHO, in its World Report on Disability, promotes research on the quality of life and well-being of this population and encourages the development of internationally comparable research methodologies¹⁶.

Although children and adolescents were reported to have lower rates of severity and mortality from COVID-19, they are recognized as part of the population strongly affected by the pandemic and its containment measures, given that they were deprived of their school and social space¹⁷. These conditions related to isolation had a direct influence on children and adolescents with CP, who, in addition to being part of the vulnerable population at greater risk of complications due to the virus, had limited possibilities of accessing rehabilitation therapies and maintaining their participation in social activities.

This situation could influence not only the functionality of children and adolescents with CP but also their social and emotional well-being, significantly impacting their health, autonomy, and quality of life. The objective of this study was to analyze perceptions of the impact of the pandemic and differences in HRQoL dimensions, compared with a previous survey in Argentine children and adolescents diagnosed with CP, from the perspective of their caregivers.

Subjects and Methods

We conducted an observational study in a popu-

lation of mothers, fathers, or primary caregivers of children and adolescents diagnosed with CP. Data collection was carried out in two stages, both of cross-sectional design. Between May and November 2019, caregivers of children and adolescents attending public and private health and education institutions (such as special education and rehabilitation centers) in Córdoba were contacted and required to fill in a survey on paper. In the second stage, between January and March 2021, when measures to control the transmission of the SARS-CoV-2 virus were still in force, an open call was made through social networks, using an online survey on the LimeSurvey platform (UNC license). Both surveys were self-administered. Inclusion criteria limited the survey to caregivers of children and adolescents aged 3 to 24 years, diagnosed with CP, and residing in Argentina. Caregivers of children under 3 years old and those of individuals over 24 years old were excluded, as well as those who did not complete the survey. Thus, the sample was non-probabilistic and consisted of 98 people who decided to participate in the study confidentially and voluntarily, 75 of whom were part of the 2019 survey, and 23 of whom participated in the 2021 survey only. Responses were collected in Córdoba and other provinces such as Buenos Aires, Santa Fe, Entre Ríos, Salta, and Mendoza.

For the assessment of HRQoL, we used the parents/caregiver versions of the KIDSCREEN-27 and the Cerebral Palsy Quality of Life (CP-QOL) questionnaire. The KIDSCREEN is a generic instrument developed in Europe, based on focus groups of children and adolescents aged 8 to 18 years and later adapted and tested in Argentina (19,20). CP-QOL was developed in Australia based on interviews with children and adolescents with CP and parents and was also adapted and tested in Argentina (23,24). The complementary use of both instruments allows for the collection of dimensions of HRQoL common to any population (generic), as well as aspects of quality of life that may be specifically affected by CP. Thus, the KIDSCREEN-27 reports on the dimensions of Physical well-being, Psychological well-being, Autonomy & Parent Relation, Social Support & Peers and School environment, in addition to providing a General HRQoL Index, while the CP-QOL reports on Emotional well-being, Social well-being and acceptance, Family relationships, Participation, School well-being, Autonomy, Pain and impact of disability, and Access to services, with specific content. Scores from both instruments indicate better HRQoL as they increase. Data on age, sex, functionality level according to the Gross Motor Function Classification System (GMFCS), health coverage, and caregiver data (age, sex, relationship to the children and adolescents, and the highest level of education completed by the mother) were also collected. In the second stage, the

question was included: “*In your opinion, did the circumstances caused by the COVID-19 pandemic affect your child’s health in any way? How?*”

In the quantitative analysis of the data, sociodemographic characteristics of the sample were described with means (M) and standard deviations (SD) or proportions (%). The mean scores of the dimensions of CP-QOL-PCQ and KIDSCREEN-27 of the groups studied before and during the pandemic were compared with means and effect sizes using Cohen’s *d*, establishing differences as significant when $d \geq 0.3$. Statistical tests were performed using the SPSS-24 software. Qualitative analysis of responses to the open-ended question was conducted using grounded theory²⁵ criteria via “open coding,” where various response fragments sharing the same idea were given a common name, and “axial coding,” seeking relationships between the categories elaborated in open coding.

The protocol was approved by the Institutional Ethics Evaluation Committee for Health Research of the National Hospital of Clinics – *Universidad Nacional de Córdoba*, dated 12/12/2017.

Results

After the two stages of data collection, the participation of 98 caregivers (84 mothers, 7 fathers, 6 other relatives, and 1 who did not report relationship) was achieved, mostly residents of the province of Córdoba (88%). The mean age of the total sample of caregivers was 42.7 years (SD = 9.6). The participating children and adolescents were aged between 3 and 24 years (M = 13.2; SD = 4.8), 53% were male, 56% had severe motor impairments (GMFCS levels IV and V), and 34% had only public health coverage. When comparing the sample obtained before and during the pandemic (Table 1), their characteristics were similar, except that in the 2021 sample, there was a higher percentage of individuals with the highest level of education.

Regarding HRQoL in the two study periods, statistically significant differences were found with lower mean scores in the group that responded during the pandemic, in the dimensions of Participation ($d = -0.55$), Emotional well-being ($d = -0.45$), Social well-being and acceptance ($d = -0.38$), and School well-being ($d = -0.41$) of the specific CP instrument (Table 2).

The scores from the KIDSCREEN-27, a generic HRQoL instrument, also showed lower scores during the pandemic stage in the following dimensions: School environment ($d = -0.71$), Psychological well-being ($d = -0.36$), Social Support & Peers ($d = -0.30$), and in the HRQoL Index ($d = -0.36$) (Table 3).

Regarding the open-ended question asking

whether the pandemic had affected the health of their child, three main recurrences were identified (Figure 1). In the first place, parents and caregivers noticed “an impact due to the interruption of therapies and treatments” during this epidemiological situation, resulting in some signs of deterioration in their respiratory function, mood, and motor skills. A “deterioration of peer relationships” due to “lack of socialization” and difficulties in interaction through online platforms was also observed. Finally, these observations often coexisted with “increased and positive assessment of self-care.” Self-care is based on the diagnosis, prevention, and management of ailments carried out by the individual or immediate groups within which the individual’s life

unfolds²⁶. During the pandemic, the opportunities for rest and family bonding were appreciated as caregiving practices in the context of confinement.

Discussion

This study reports on the repercussions of the COVID-19 pandemic on the quality of life of children and adolescents with disabilities, particularly those with CP in Argentina. Specifically, it provides evidence of health impairment by considering various dimensions of HRQoL and the opinions of their caregivers. Our results show significant differences between the period

Table 1. Sociodemographic and clinical characteristics of the samples

	Sample 2019 (Pre pandemic)		Sample 2021 (Pandemic)	
	M	SD	M	SD
Age of primary caregiver	42.69	9.68	42.77	9.41
Age of children and adolescents	M	DE	M	DE
	13.5	4.58	12.35	5.62
Age group	<i>f</i>	%	<i>f</i>	%
Children (4 a 12 years)	29	38.7	9	39.2
Adolescent (13 a 18 years)	33	44	11	47.8
Jouth (19 a 24 years)	13	17.3	3	13
Gender of children and adolescent	<i>f</i>	%	<i>f</i>	%
Male	40	53.3	12	52.2
Female	35	46.7	11	47.8
Groups according to GMFCS	<i>f</i>	%	<i>f</i>	%
Slight-moderate (Level I to III)	20	26.7	9	39.1
Stern (Level IV and V)	23	30.7	14	60.9
Missing values	32	42.7	0	0
Declared health coverage	<i>f</i>	%	<i>f</i>	%
Private	45	60	18	78.3
Public only	27	36	5	21.7
Missing values	3	4	0	0
Province of residence	<i>f</i>	%	<i>f</i>	%
Córdoba	75	100	11	47.8
Other provinces	0	0	12	52.2
Relationship of the respondent to	<i>f</i>	%	<i>f</i>	%
Mother	62	82.7	22	95.7
Father	7	9.3	0	0
Another relative	6	8	0	0
Missing values	0	0	1	4.3
Mother’s highest level of education	<i>f</i>	%	<i>f</i>	%
Low (incomplete high school)	35	46.7	6	26.1
Medium (incomplete higher education)	24	32	5	21.7
High (complete higher education)	16	21.3	11	47.8
Missing values	0	0	1	4.3

GMFCS: Gross Motor Function Classification System; M= mean; SD= standard deviation; *f*= absolute frequency.

before this epidemiological issue and the subsequent stage of isolation, predominantly in social and psychological dimensions measured by the two instruments used. Additionally, during distancing measures, caregivers expressed concern about the effects of therapy interruption, as well as a positive assessment of family bonds and self-care during confinement.

Our results suggest an impairment of psychosocial well-being domains, in line with the increased incidence of mental health problems reported in pediatric and adolescent populations in Argentina, such as symptoms of anxiety, depression, and behavioral disorders after the pandemic²⁷. Likewise, a systematic review of the mental health of children and adolescents during the COVID-19 pandemic reported that most of the negative effects observed come from isolation conditions, such as school closures and limited physical activities, among others¹⁷. In this regard, the impact on the dimensions of participation and school well-being re-

flects a negative repercussion of these restrictions and, as described by some authors, denotes the significant limitation of the participation of people with disabilities²⁸.

Added to the psychological impact were changes in family life and uncertainty about the economic situation²⁹. This particularly affected families of children and adolescents with some kinds of disabilities³⁰, who identified the deterioration of their children's physical and functional conditions^{6,8} and the lack of medical supplies during confinement³¹ as major concerns. In our study, the testimonies read from a qualitative perspective show that the caregivers expressed as a relevant problem the interruption of treatments and rehabilitation therapies of their children, allowing us to reconsider the impairment of their motor skills in particular. However, in their responses regarding HRQoL, although a lower score in the domains of autonomy and pain was noted in the group analyzed during the

Table 2. Mean differences of the HRQoL questionnaire specific for Cerebral Palsy according to pre-pandemic^a and pandemic^b stages

CP QOL-PCQ domains	Pre-Pandemic M (SD)	Pandemic M (SD)	<i>d</i>
Emotional well-being	70.17 (18.33)	62.39 (15.80)	-0.45
Social well-being and acceptance	72.63 (14.43)	67.11 (15.18)	-0.38
Family relationships	89.63 (14.05)	86.77 (12.35)	-0.21
Participation	74.02 (18.73)	64.13 (16.93)	-0.55
School well-being	82.36 (12.77)	76.39 (15.54)	-0.41
Autonomy	56.82 (18.03)	52.98 (20.78)	-0.19
Pain and impact of disability	25.11 (21.77)	30.50 (29.44)	0.21
Access to services	78.83 (14.57)	75.86 (18.50)	-0.18

HRQoL: Health-Related Quality of Life; CP-QOL-PCQ: Cerebral Palsy-specific HRQoL questionnaire; ^aYear 2019; ^bYear 2021; M = mean; (SD)=standard deviation; *d*: Cohen's *d* (effect size), where $d \geq 0.3$ represents significant differences.

Table 3. Mean differences of the KIDSCREEN-27^a according to pre-pandemic^b and pandemic^c stages

KIDSCREEN-27 domains	Pre-Pandemic M (SD)	Pandemic M (SD)	<i>d</i>
Physical Well-being	38.08 (8.71)	38.02 (9.72)	-0.01
Psychological Well-being	54.80 (12.89)	50.51 (10.77)	-0.36
Autonomy & Parent Relation	48.65 (11.09)	50.45 (10.60)	0.16
Social Support & Peers	42.30 (14.77)	36.87 (20.77)	-0.30
School Environment	56.42 (10.66)	47.34 (14.57)	-0.71
KIDSCREEN-10 Index	51.62 (12.40)	47.44 (10.14)	-0.36

HRQoL: Health-Related Quality of Life; ^aGeneric HRQoL questionnaire; ^bYear 2019; ^cYear 2021; M = mean; (SD) = standard deviation; *d*: Cohen's *d* (effect size), where $d \geq 0.3$ represents significant differences.

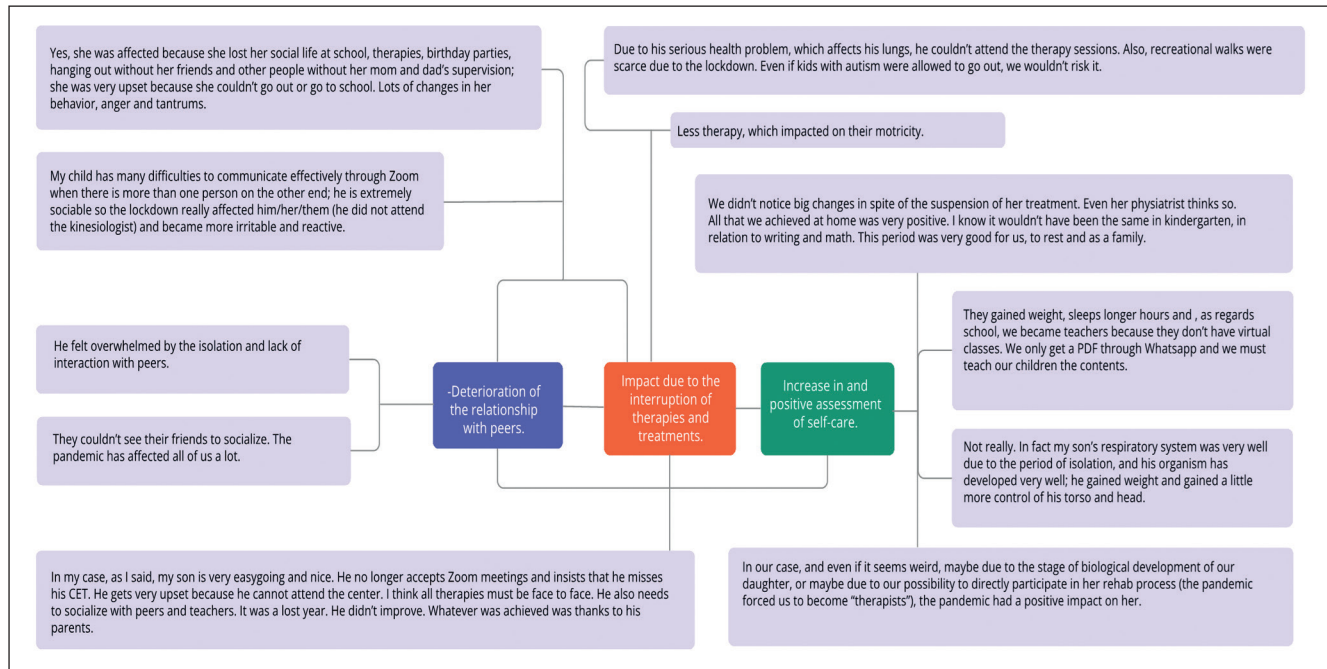


Figure 1. Responses to the open-ended question: In your opinion, did the circumstances caused by the COVID-19 pandemic affect your child's health in any way? How?

period of restricted contact compared with the period previously surveyed, the differences were not statistically significant. Furthermore, no significant differences were found in this study compared with the HRQoL dimensions that explore relationships and family life, but the qualitative analysis allowed us to highlight a positive assessment of self-care and family bonding in the context of confinement. This finding is similar to the data provided by other articles and reports. Firstly, the National Institute of Statistics and Censuses (INDEC) described that in 32% of households in Greater Buenos Aires, the time dedicated to household care work increased, and in 66% of households, the time dedicated to school work increased since the pandemic³². Similarly, a study conducted on a population with CP showed that the level of participation in home-based play activities increased in more than half of the children⁷. Lastly, an Argentine study on children with autism spectrum disorders positively highlighted the importance of time spent at home as an opportunity to strengthen family bonds and consider interventions which are family oriented³³.

As a strength of this research, we can point out the complementation of data through the subsidiary inclusion of qualitative information, allowing for greater breadth and depth in the analysis, opening up space for the appearance of emerging elements. In addition, the use of validated HRQoL instruments culturally adapted to our context provides reliability to the results ob-

tained and would allow comparison at a national or international level³⁴.

The main limitation of this study lies in its design, as comparable and concurrent groups could not be formed naturally due to the extent of the health situation. The studied samples were different in quantity due to difficulties in contacting participants, although similar in many of their characteristics. Furthermore, the qualitative approach was limited to an open-ended and exploratory question in a self-administered questionnaire, without the possibility of delving into some directions that spontaneously opened in the responses.

Conclusions

This study analyzes the impact of the COVID-19 pandemic by describing dimensions of HRQoL in people with disabilities, providing an overview of the subjective aspects of health that were most affected. Our results suggest that this epidemiological situation mainly and significantly affected psychosocial dimensions of health in children and adolescents with CP in Argentina. Likewise, qualitative research allowed us to highlight the importance of self-care for caregivers as a complement to traditional therapies. These testimonies could be useful for thinking about health and disability policies that consider the home as a space for care.

Abbreviations

ASPO:	Acronym in Spanish for Mandatory Preventive Social Isolation.
ICF:	International Classification of Functioning, Disability, and Health.
CP-QOL:	Cerebral Palsy Quality of Life
CP-QOL-PCQ:	Cerebral Palsy Quality of Life Primary Caregiver Questionnaire.
HRQoL:	Health-related Quality of Life.
DISPO:	Acronym in Spanish for Mandatory Preventive Social Distancing.
INDEC:	Acronym in Spanish for National Institute of Statistics and Censuses.
NNA:	Acronym in Spanish for Children and Adolescents.
WHO:	World Health Organization.
CP:	Cerebral Palsy
UNC:	Universidad Nacional de Córdoba.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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