Research in Developmental Disabilities 154 (2024) 104844

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

Proxy- and self-report evaluation of quality of life in cerebral palsy: Using Spanish version of CPQOL for Children and adolescents

Alba Aza[a,b,*,1], Inmaculada Riquelme[c,d,e,2], María Gómez Vela[a,b,3], Marta Badia[a,4]

[a] *Institute for Community Inclusion (INICO), University of Salamanca, Salamanca 37005, Spain*
[b] *Department of Personality, Assessment, and Psychological Treatments. University of Salamanca, Salamanca 37005, Spain*
[c] *Research Institute on Health Sciences (IUNICS), University of the Balearic Islands, Palma 07122, Spain*
[d] *Health Research Institute of the Balearic Islands (IdISBa), Palma 07010, Spain*
[e] *Department of Nursing and Physiotherapy, University of the Balearic Islands, Palma 07122, Spain*

ARTICLE INFO

Keywords:
Cerebral palsy
Quality of life
Children
Adolescents
Parents
Determinants
Functioning

ABSTRACT

Background: Promoting quality of life (QoL) is one of the main goals in interventions carried out with children and adolescents with cerebral palsy (CP).
Aims: The aim of this study was to analyze the determinants of QoL in children with CP, including evaluations by the children themselves and their parents, and to identify discrepancies between evaluators.
Methods and procedures: The adapted Spanish version of the Cerebral Palsy Quality of Life (CP-QOL) for children and adolescents (self-report and primary caregiver-reports versions) was applied to a sample of 74 children with CP and their respective parents (totaling 222 participants), as well as instruments to measure functioning (i.e., GMFCS, MACS, CFCS and EDACS). The average age of the children was 12.50 (SD=4.07), with a higher number of boys (55.7 %).
Outcomes and results: The lowest QoL levels were found in the Functional dimension in both assessments ($M_{children/adolescents}$=70.21, $M_{parents}$=58.14). For children, the highest rated dimension was Social Well-being (M=74.54), while for parents it was School (M=71.03). The degree of agreement between evaluators was low in almost all dimensions (ICC$\leq$.40). More satisfactory predictive models were constructed from the evaluations carried out by parents, except in the

---

Abbreviations: CP, Cerebral Palsy; QoL, Quality of life; EU, European Union; ICF, International Classification of Functioning, Disability and Health Status; WHOQOL, World Health Organization Quality of Life; CP-QOL, Cerebral Palsy Quality of Life Questionnaire; GMFCS, Gross Motor Function Classification System; MACS, Manual Ability Classification System; CFCS, Communication Function Classification System; EDACS, Eating and Drinking Classification System; ASPACE, Spanish Confederation of Care for People with Cerebral Palsy; SD, Standard deviation; ICC, Intraclass correlation coefficient; ID, Intellectual disability; AAC, Augmentative and alternative communication systems.

* Correspondence to: Institute for Community Inclusion (INICO), Department of Personality, Assessment, and Psychological Treatments, Faculty of Psychology, University of Salamanca, Avenida de la Merced, 109-131, Salamanca 37005, Spain.

E-mail addresses: azhernandez@usal.es (A. Aza), inma.riquelme@uib.es (I. Riquelme), mgv@usal.es (M. Gómez Vela), badia@usal.es (M. Badia).

[1] https://orcid.org/0000–0002-1460–1195
[2] https://orcid.org/0000–0003-4705–8325
[3] http://orcid.org/0000–0003-1390–700X
[4] https://orcid.org/0000–0001-6358–8057

https://doi.org/10.1016/j.ridd.2024.104844
Received 26 June 2024; Received in revised form 11 September 2024; Accepted 15 September 2024

case of the Access to Services dimension, with functioning measures being the main predictors of QoL levels.

Conclusions and implications: The CP-QOL in its two available versions is a useful and specific instrument for assessing QoL in children with CP in both research and professional fields.

What this paper adds?

Promoting quality of life (QoL) is one of the main goals in interventions for children and adolescents with cerebral palsy (CP). However, reports from children/adolescents may differ from those provided by their parents. In addition, knowing the factors that affect the different dimensions of QoL of children with CP may give important clues to the intervention. The objectives of this study were to evaluate the determinants of QoL in children and adolescents with CP, utilizing both self-reports from the children and adolescents as well as proxy reports from their parents, and to identify potential discrepancies between the evaluations provided by these groups. For these purposes, the adapted Spanish version of the Cerebral Palsy Quality of Life (CP-QOL) for children and adolescents (self-report and primary caregiver-reports versions) was completed by 70 children with CP and their parents; in addition, the level of gross motor, fine motor, communication, and eat and drinking functioning (i.e., GMFCS, MACS, CFCS y EDACS) were also reported. The lowest QoL levels were found in the Functional dimension in both assessments. Degree of agreement between evaluators was low in almost all dimensions. More satisfactory predictive models were constructed from the evaluations carried out by parents, with functioning measures being the main predictors of QoL levels. In conclusion, the CP-QOL is a useful and specific instrument for assessing QoL in children and adolescents with CP, as it provides information about the needs detected by children/adolescents and their parents, which is highly useful for guiding the rehabilitation activities.

Data Availability

Data will be made available on request.

1. Introduction

Cerebral palsy (CP) describes a group of permanent developmental motor and postural disorders that cause activity limitations, attributed to non-progressive disturbances in the developing fetal or infant brain (Bax et al., 2005). Motor disorders of CP are often accompanied by disturbances in sensation, perception, cognition, communication, and behavior; as well as by epilepsy and secondary musculoskeletal problems (Sadowska et al., 2020). Similarly, data indicate that about 10,000 new cases of CP are diagnosed each year in the European Union (EU). Early brain injury always leaves motor sequelae, but the presence of comorbidities associated with CP can cause limitations in functioning and have a negative impact on the Quality of Life (QoL) of children and adolescents with CP (Blasco et al., 2023). Depending on the type of CP, between 30 % and 89 % of children with CP have associated impairments (Viswanath et al., 2023).

The definition of CP, based on the socio-ecological model of human functioning proposed by the International Classification of Functioning, Disability and Health Status (ICF; World Health Organization, 2001), proposes a change in organizations and support services, aimed at improving the QoL of the children and their families (Almasri & Alquaqzeh, 2023). Results in QoL are considered one of the most important goals of services for children and adolescents with CP (Badia et al., 2015, 2020; Colver & the SPARCLE Group, 2006). The World Health Organization Quality of Life (WHOQOL) defines QoL as "an individual perception of their position in life in the context of the culture and value system in which they live and their relationship to their goals, expectations, standards, and concerns" (p.1570) (The Whoqol Group, 1998). WHOQOL proposes the following six QoL dimensions: physical, psychological, dependency level, social relations, environment, and spirituality/religion/personal beliefs. These dimensions are influenced by environmental and personal factors. QoL is, therefore, a multidimensional construct that includes subjective and objective components (Badia et al., 2013).

Traditionally, self-report questionnaires have been the primary method for measuring QoL. However, because of the cognitive immaturity of children with CP, their limited social experience, and high dependence, parents can better evaluate some aspects of the child's QoL (Blackmore et al., 2024). However, this approach/option is not without limitations, as parents can overlook children's opinions, desires, and needs. Consequently, the current trend is to employ measures that consider complementarily parents' and children's evaluation, sometimes including professionals (Badia et al., 2020; Sentenac et al., 2021). Generic scales to measure QoL, such as the Pediatric Quality of Life Inventory (PEDs-QL) or the KIDSCREEN, or even health-related questionnaires (e.g., the Childhood Health Assessment Questionnaire or Child Health Questionnaire) to measure health related quality of life, are applied under some chronic health conditions and have been applied to assess quality of life in children with CP (Kato et al., 2023; Lee et al. 2020; Mohammed et al., 2024; Park, 2018; Sentenac et al., 2021). These scales are useful for comparing different population (Badia et al., 2020), although they are less suitable for assessing the effectiveness of an intervention. In contrast, specific scales reflect aspects that are useful for detecting changes in QoL (Bahrampour et al., 2022). Some scales have been designed for the assessment of children with disabilities, as for example the HRQoL Caregiver Priorities & Child Health Index of Life with Disabilities or the Quality of Life Inventory-Disability; these scales are useful for the assessment of children with neurodevelopmental disabilities, among them, children with cerebral palsy (Jacoby et al., 2022; Larsen et al., 2023; Petry et al., 2009). Questionnaires such as the Quality of Life-Profound Multiple Disabilities, the Quality of Life Inventory-Disability or the KidsLife Scale have been specifically designed for children with intellectual disabilities and can be used in children with CP (Downs et al., 2019; Gómez et al., 2016; Petry et al. 2009). Some scales, such as the PEDs-QL, developed specific assessment modules for facilitating the assessment of specific issues of children with CP (PEDs-QL CP) (Varni et al., 2006). In this context, the Cerebral Palsy Quality of Life Questionnaire (CP-QOL) emerged as the first questionnaire specifically designed to measure QoL of children and adolescents with CP based on the ICF model (Davis et al., 2013; Waters et al., 2007). Since its publication, the CP-QOL has been extensively used for specifically assess quality of life in children and adolescents with CP (as some recent examples, Badgujar et al., 2024; Blasco et al., 2023). As recommended by Makris et al. (2021), "the selection of the appropriate QoL instrument depends on the assessment purpose, with available measures varying in their focus on functionality, subjectivity and illness-specific items" (p.1). In our study, the QOL will be assessed by the CP-QOL, as our purpose is to examine specific condition-related parameters in children and adolescents with CP within the ICF model.

Several studies have analyzed the QoL of children and adolescents with CP using generic or specific instruments. Some of them have compared their QoL scores with those of typical child development, finding that the QoL levels of children with CP are significantly lower (Power et al., 2018; Rapp et al., 2017). However, in the study carried out by Colver & the SPARCLE group (2006) and other published studies (Boldyreva et al., 2020; Böling et al., 2018; Makris et al., 2021), QoL levels were not as low as expected in the children with CP. In fact, differences in QoL have been reported depending on whether the evaluation is carried out by the child or the parents (Lennon et al., 2024; Öst et al., 2018; Shields et al., 2018), finding an undervaluation in parents (Boldyreva et al., 2020; Böling et al., 2018; Lennon et al., 2024; Makris et al., 2021). Agreement between children or adolescents' QOL self-reports and parents' reports is poor, with discrepancy increasing from childhood to adolescence (Sentenac et al., 2021). Disagreement seems more important in domains such as physical health or daily and school activities (Boldyreva et al., 2020; Ferreira et al., 2020). Although some factors, such as children's pain and behavioral problems or parental stress may affect parent's reports (Sentenac et al., 2021), it is widely admitted that children and parents provide unique and complementary views. Thus, children may highlight factors promoting social inclusion, as play and peer support, as well as self-identity and sense of agency, whereas parents have a wider view of external factors contributing to QoL, including family functioning, financial resources or time managing (Swift et al., 2023).

Concerning the factors that affect QoL of children with CP, environmental and contextual functioning factors show high correlations (Badia et al., 2013; Longo et al., 2017), exceeding the correlations with other traditional factors such as motor function, pain, or disability (Badia et al., 2014; Park, 2017). Similarly, the results found tend to fluctuate greatly depending on the QoL dimensions that are considered (Badia et al., 2016; Makris et al., 2021), being the physical well-being more affected. QoL may be the result of the compound effects of different interacting factors. The level of functioning has been a classical predictor of QoL in children with CP (Badgujar et al., 2024; Park, 2017; Sharawat & Panda, 2022; Tonmukayakul et al., 2020). Multiple elements affecting gross and fine motor function, such as the functional independence, physical energy expenditure, strength, pain or spasticity, indirectly influence participation and QoL (Burak & Kavlak, 2019; Marwa et al., 2022; Mohammed et al., 2024; Larsen et al., 2023; Lee et al. 2020; Park, 2018; Power et al., 2020). The presence of numerous comorbidities such as incontinence, swallowing disorders, seizures or poor sleep also reduce QoL (Bagazgoïtia et al. 2021; Horwood et al., 2019; Marwa et al., 2022; Türker & Özkeskin, 2023). In addition, emotion and behavior problems, intellectual disability, poor communication and reduced social interaction may reduce socioemotional wellbeing, peers support and school-related QoL (Kolman et al., 2018; Marwa et al., 2022; Milicévic, 2023). Interventions aiming at improving children's motor abilities, communication and social skills, as well as reducing comorbidities impact may be relevant (Almasri & Alquaqzeh, 2023). On the other hand, environmental factors such as attending schools for special needs, home adaptation, supportive policies or positive social attitudes predict higher QoL at physical or school domains (Kato et al., 2023; Milicévic, 2023).

Despite the progress that has been made, few studies with a Spanish sample have analyzed the determinants of QoL in children with CP from the ICF approach and used specific scales for that population, such as the CP-QOL. These studies have related factors such as the executive function, motor function, visual function and communication ability with the QoL domains Social Wellbeing and Acceptance, Feelings about Functioning, Emotional Wellbeing and Self-esteem, School well-being and Access to Services and Family Health (Blasco et al., 2023; Laporta-Hoyos et al., 2017). A multicenter study measuring QoL in children with CP and intellectual disabilities pointed to personal factors, such as the level of intellectual disability, percentage of disability and physical disability in the upper extremities, and environmental factors, such as the size of the care organization, as significant predictors of QoL (Morán et al., 2023). Other studies using generic QoL scales have associated social-emotional responses with sensory perception to emotional wellbeing (Jovellar-Isiegas et al., 2020), and reported that socioeconomic factors such as parents' occupation and education did not influence QoL (Pérez-Ardanaz et al., 2020). However, no study has jointly analyzed children/adolescents' and parents' reports with a CP specific scale. The primary objective of this study was to evaluate the determinants QoL in children and adolescents with CP, utilizing both self-reports from the children and adolescents as well as proxy reports from their parents. Additionally, the study aimed to identify any discrepancies between the evaluations provided by the children/adolescents and their parents. Based in previous research, we hypothesize that different factors will determine QoL in children and adolescents with CP, although its influence will vary depending of children/adolescent's or parents' perception.

2. Material and methods

2.1. Participants

The study includes children with CP and their parents, who received specialized services and supports from Spanish Confederation of Care for People with Cerebral Palsy (ASPACE) throughout the Spanish territory. The inclusion criteria to participate in this study were: (a) families whose child was between the age of 4 and 18 and had a diagnosis of CP; (b) children with sufficient cognitive and communicative abilities to report their own QoL; and (c) to have signed informed consent. All children diagnosed with progressive muscular dystrophy, Rett syndrome, and metabolic diseases were excluded from the study to ensure homogeneity of the data.

2.2. *Instruments*

2.2.1. *Cerebral Palsy Quality of Life (CP-QOL)*

The assessment of Quality of Life in children and adolescents with CP is traditionally evaluated using the CP-QOL scale originally developed by Waters et al. (2013). For assessment in the Spanish context, the Spanish version of this scale developed and validated by Badia et al. (2020) is utilized. The reliability and validity of the CP-QOL scale has been corroborated in numerous studies (Chen et al., 2013; Das et al., 2017; Palisano et al., 1997; Wang et al., 2010; Waters et al., 2007). In the version recently validated in the Spanish population, Cronbach's alpha ranged between.75 and.91 for proxy-report and between.81 and.91 for self-report (Badia et al., 2020). These data indicate an excellent internal consistency of the adapted version of the CPQOL, comparable to the English versions.

In the version of Badia et al. (2020), self-reports and proxy reports aimed at the age groups of 4–12 and 13–18 have been combined to create a single self-report and proxy version. Following a process of item elimination and reformulation, the result was a scale consisting of 74 items and 9 dimensions (Family and Friends, Participation, Communication, Health, Pain and Discomfort, School, Access to Services, Caregiver Health, and Final Questions) for parents of children aged 4–18 years (Family and Friends, Participation, Communication, Health, Pain and Discomfort, School, Access to Services, Caregiver Health, and Final Questions), and a scale of 64 items with the same dimensions (except for Access to Services and Caregiver Health) that can be completed by children aged 8–18 years.

2.2.2. *Functional measures*

The *Gross Motor Function Classification System* (GMFCS; Palisano et al., 1997) ranges from Level I (independent gross motor function with few limitations) to V (complete dependence for all motor activities). The psychometric properties of the GMFCS have been thoroughly tested (Eliassion et al., 2006; Wood & Rosenbaum, 2007).

The *Manual Ability Classification System* (MACS; Eliasson et al., 2006) describes how children with CP use their hands to manipulate objects in daily activities. It has five levels too. The MACS has shown good validity and reliability (Hidecker et al., 2011).

The *Communication Function Classification System* (CFCS; Hidecker et al., 2011) assesses the capacity for communication in daily life situations. It classifies communication in five levels according to the efficacy of current communication. The CFCS has shown content validity and good reliability (Sellers et al., 2013).

The *Eating and Drinking Classification System* (EDACS; Sellers et al., 2013) describes the functional activities of eating, drinking, sucking, biting, chewing, swallowing, and keeping food or liquid in the mouth, divided in five competency levels. It has good psychometric properties and used in conjunction with GMFCS, MACS and CFCS offer a very complete view of performance in children with CP.

2.3. *Procedure*

This study was conducted according to the guidelines laid down in the Declaration of Helsinki and the ethical approval of the study was obtained from the Bioethics Committee of the University of Salamanca. Informed written consent was obtained from all parents and children over the age of 12.

To obtain a heterogeneous and representative sample of children and adolescents with CP, all ASPACE centers were invited to participate in the study. A member of the research team visited each center to explain the procedure and formally trained a research assistant at each location. The research assistant then contacted the parents who had agreed to participate to complete the questionnaires. For children/adolescents with sufficient communicative and cognitive skills, the self-report versions were administered through face-to-face interviews. Additionally, professionals provided information about each participant's functional capacity. Finally, the research assistant collected all the completed questionnaires and returned them to the investigators.

2.4. *Statistical analysis*

Statistical analyses were conducted using SPSS version 23.0, with a significance level set at .05.

Pearson correlations and intraclass correlation coefficient between parent and child scores were calculated to assess the degree of agreement/disagreement. The mean directional differences between child and parent scores were also computed and examined using a Student's *t*-test for related samples. Additionally, the mean difference and its standard deviation (SD*)* were calculated, as well as the effect size. This effect size was interpreted according to Cohen's criteria (1988): small ($d = 0.2$), medium ($d = 0.5$), and large ($d \geq 0.8$) (Sullivan & Feinn, 2012). Agreement was defined as an absolute difference of less than or equal to half a standard deviation from the children's score, based on the definition of clinically significant differences in health-related QoL (Norman et al., 2003).

Finally, to analyze the determinants of the QoL, the effect of the different functional measures on the CP-QOLs dimensions was calculated. For this purpose, multiple lineal regression analyses were performed for the dimensions answered by parents and children. Prior to these analyses, correlations between sociodemographic and disability-related variables with QoL dimensions were obtained. Significant variables from this preliminary analysis were included in the regression models, which were built using a stepwise (backward) method. All the variables met the assumptions of normality and had no similar multicollinearity ($rs < 0.70$). The results are presented as adjusted R^2s, F values, and standardized and non-standardized betas coefficients. Adjusted R^2 values was interpreted based on Cohen's (1988) guidelines: 0.02 for small, 0.13 for medium, and 0.26 for large effects.

3. Results

3.1. *Descriptive information*

A total of 74 children and their parents participated in this study, making a total of 222 participants. Table 1 presents the detailed characteristics of the sample. The average age of the children was 12.50 years (*SD*=4.07), with a higher proportion of boys (55.7 %). The sample exhibited a high prevalence of intellectual disabilities and visual limitations. Regarding functional levels, most children were classified as level V on the functional scales, which indicates the most severe level of impairment. However, for the EDACS, the most common classification was level III.

Table 1
Sociodemographic and clinical data of children with CP and their parents.

Variables	***n* (%)**	
Children's gender		
Male	39 (55.7)	
Female	31 (44.3)	
Children's age	(*M*=12.50; *SD*=4.07; Range= 4–18)	
Parent's age	(*M*=46.47; *SD*=6.41; Range= 32–60)	
Mother's age	(*M*=42.92; *SD*=6.50; Range= 25.54)	
Number of children (including the child with CP)	(*M*=2.03; *SD*=0.81; Range= 1–5)	
Education level	Father	Mother
None	1 (1.4)	2 (2.7)
Primary school	25 (35.2)	24 (32.4)
Secondary school	32 (45.1)	27 (36.5)
University	13 (18.3)	21 (28.4)
Employment situation	Father	Mother
Inactive	15 (21.1)	25 (35.2)
Active	56 (78.9)	46 (64.8)
Family economic status		
Income lower than 1000€	7 (9.7)	
Income between 1000 and 2000€	42 (58.3)	
Income higher than 2000€	23 (32.0)	
Municipality		
Less than 1000 inhabitants	6 (8.6)	
1000–5000 inhabitants	15 (21.4)	
More than 5000 inhabitants	49 (70.0)	
Intellectual disability	41 (74.5)	
Physical pain	18 (27.7)	
Visual limitations	39 (56.5)	
Hearing limitations	3 (6.1)	
Epilepsy	19 (28.4)	
AAC	19 (29.2)	
GMFCS		
I	9 (14.3)	
II	9 (14.3)	
III	8 (12.7)	
IV	9 (14.3)	
V	28 (44.4)	
MACS		
I	5 (8.1)	
II	15 (24.2)	
III	13 (21.0)	
IV	10 (16.1)	
V	19 (30.6)	
CFCS		
I	12 (20.0)	
II	13 (21.7)	
III	9(15.0)	
IV	7 (11.7)	
V	19 (31.7)	
EDACS		
I	15 (23.8)	
II	11 (17.5)	
III	18 (28.6)	
IV	7 (11.1)	
V	12 (19.0)	

3.2. Degree of agreement/disagreement of parents and children on QoL

In the children's reports, there were no significant differences across the different QoL dimensions [$F_{(4,292)}$=1.39, p=.24]. Ratings ranged from 70.21 for Functioning to 74.54 for Social Well-being. In contrast, parents' reports revealed significant differences among the QoL dimensions [$F_{(4,292)}$=21.72, p<.001, η^2=.23], specifically between Functioning and Emotional Well-being to Pain, Social Well-being, and School (p<.001). In this case, parents rated Functioning and Emotional Well-being lower (58.14 and 58.85, respectively) compared to their rating for School (71.03). As shown in Table 2, parent ratings were lower than those of children.

The interaction between report sources (parent vs. child) and QoL dimensions was significant [$F_{(4,292)}$=7.43, p<.001, η^2=.09]. Post-hoc analyses revealed significant differences between parent and child reports for Social Well-being [$F_{(1,3)}$=13.44, p<.001, η^2=.16], Functioning [$F_{(1,73)}$=15.55, p<.001, η^2=.18], and Emotional Well-being [$F_{(1,73)}$=23.48, p<.001, η^2=.24].

Regarding the degree of agreement, significant correlations were found parent and child reports for the dimensions of Functioning, Pain, and School. However, when intraclass correlation coefficients were considered, low agreement was obtained across all dimensions (ICC≤.40). Only in the cases of Pain and School were ICCs of .40 obtained (see Table 3). Finally, when considering the differences between the reports of children and parents, moderate effect sizes were observed in Emotional Well-being, Social Well-being, and Functioning, while small effect sizes were found in Pain and School.

3.3. Determinants of QoL

Concerning the proxy-report, significant relationships were found between disability-related variables such as visual limitations and ID with the dimensions of Social Well-being and Pain. Additionally, visual limitations were notably correlated with Emotional Well-being. Functional measures also showed significant relationships: MACS and CFCS were correlated with Social Well-being; GMFCS was linked to Functioning; CFCS was associated with Emotional Well-being; and EDACS was related to Pain. All these correlations were negative, indicating that the presence of these limitations is related to lower QoL. Conversely, the School dimension showed a positive correlation with GMFCS, and Family Health with the augmentative and alternative communication systems (AAC) and MACS. This indicates that the use of AAC and higher scores on the functional measures are associated with better QoL (see Table 4).

In the children's self-report, Functioning correlated negatively with both income level and GMFCS (i.e., higher income and GMFCS level corresponded to lower QoL) (see Table 4).

Predictive models were developed using multiple linear regression analyses. For the parents' reports, the only dimension not explained by the predictor variables was Access to Services, as no significant predictors were identified in the preliminary correlation analyses. In contrast, Social Well-being (R^2adj=0.22) and Emotional Well-being (R^2adj=0.17) were the dimensions best explained by the predictor variables. Disability-related variables, particularly visual limitations, contributed significantly and negatively only to the Pain dimension. Functional measures showed that GMFCS scores negatively influenced Functioning and School performance, while CFCS scores negatively impacted Social and Emotional Well-being (see Table 5).

For the children's self-reports, only the Functioning dimension was explained by the predictors (R^2adj=0.11), with income level and GMFCS contributing negatively (see Table 5).

4. Discussion

This study analyses the determinants that affect QoL of children with CP and is the first research to analyze them with a specific instrument validated for the Spanish population (Badia et al., 2020) and following the conceptual model of the ICF.

It has been shown that CP is accompanied by multiple associated conditions, such as major limitations in motor function, manipulative and communicative skills, as well as significant but less serious limitations on the ability to eat and drink, in line with other current publications (Badia et al., 2014; Tschirren et al., 2018; Wood and Rosenbaum, 2007). In this sense, one might expect that lowest QoL levels would be found in the Functional dimension in both assessments. In the case of the children, the high-profile dimension has been Social Well-being, and, for parents, it was School (Chen et al., 2013). QoL is considered worse in all dimensions when the parents carry out the evaluation compared with children do it (Lennon et al., 2024; Shields et al., 2018). The degree of agreement is especially low in the dimensions of Social Well-being, Functioning, and Emotional Well-being. In the study of Davis et al. (2013), low correlations were found in Social Well-being and Functioning between adolescents and parent scores, but not in Emotional Well-being. Dimensions with observable components showed stronger agreement and dimensions with non-observable

Table 2
Descriptive and internal consistency of CPQOL dimensions reported by parents and children.

Dimension	*Full pairs n (%)*	*Children's report Mean (SD)*	*Parents' report Mean (SD)*
Social Well-being, Acceptance, and Participation	74 (100)	74.54 (11.99)	67.80 (13.01)
Feelings about Functioning	74 (100)	70.21 (27.13)	58.14 (17.49)
Emotional Well-being and Self-Esteem	74 (100)	70.71 (17.90)	58.85 (13.99)
Pain and Impact of Disability	74 (100)	72.55 (12.67)	69.57 (14.02)
School	74 (100)	73.68 (13.69)	71.03 (14.66)

Table 3
Measures according to reports of children and parents.

Dimension	Correlation		Directional difference				Absolute difference
	Pearson	ICC	*Mean (SD)*	Se	95 % CI	Effect's size	*Mean (SD)*
Social Well-being, Acceptance, and Participation	0.20	0.18	6.74 (15.81)***	1.84	(3.08–10.41)	0.54	13.76 (10.20)
Feelings about functioning	0.37**	0.30	12.07 (26.32)***	3.06	(5.97–18.17)	0.51	23.17 (17.21)
Emotional Well-being and Self-Esteem	0.14	0.11	11.87 (21.07)***	2.45	(6.99–16.75)	0.74	19.39 (14.33)
Pain and Impact of Disability	0.41***	0.40	2.98 (14.52)	1.69	(−0.39–6.34)	0.22	11.96 (8.65)
School	0.41***	0.40	2.65 (15.43)	1.79	(−0.93–6.22)	0.19	11.47 (10.57)

Note. CI= Confidence Interval; ICC= Intraclass Correlation Coefficent; Se= Standard error.*p < .05, **p < .01, ***p < .001

Table 4
Correlations between CP-QOL (parents and children) and sociodemographic and disability-related variables of the child and functional measures.

Dimensions	**CP-QOL dimensions**						
	Social Well-being, Acceptance, and Participation	Feelings about Functioning	Emotional Well-being and Self-Esteem	Pain and Impact of Disability	School	Access to services	Family health
Number of children	−.10 (.02)	−.03 (.08)	−.14 (.03)	−.06 (.03)	−.05 (.04)	−.10	.07
Family economic status	.11 (−.11)	−.03 (−.29*)	−.06 (−.14)	.11 (.11)	.01 (.11)	−.11	.22
Municipality (Inhabitants)	.02 (.09)	.12 (.15)	.00 (−.02)	−.04 (.07)	.04 (.07)	.03	.16
Intellectual disability (0: No, 1: Yes)	−.37** (.02)	−.03 (.13)	−.26 (−.18)	−.27* (−.02)	.05 (.07)	.02	.13
Pain (0: No, 1: Yes)	.20 (−.04)	.00 (.03)	−.10 (−.04)	−.15 (.00)	.07 (.01)	.03	−.02
Visual limitations (0: No, 1: Yes)	−.34** (.21)	.11 (.17)	−.30* (.23)	−.30* (−.14)	.00 (.00)	−.17	.11
Hearing limitations (0:No, 1: Yes)	−.04 (−.06)	−.13 (.07)	.05 (.07)	.11 (−.14)	.01 (−.15)	.24	−.08
Epilepsy (0: No, 1: Yes)	−.24 (.01)	.05 (.08)	−.11 (.06)	−.24 (−.18)	.16 (−.04)	−.03	.11
AAC (0:No, 1: Yes)	−.07 (.05)	−.13 (−.04)	−.17 (.02)	−.14 (.04)	.24 (.12)	−.04	.28*
Functioning							
GMFCS	−.04 (−.06)	−.30* (−.27*)	−.18 (−.09)	−.15 (−.11)	.25* (.10)	−.12	.21
MACS	−.26* (.13)	−.21 (−.09)	−.20 (−.06)	−.23 (−.06)	.11 (.02)	−.20	.26*
CFCS	−.43*** (.02)	−.07 (.10)	−.33** (−.02)	−.25 (−.14)	.19 (−.05)	−.15	.22
EDACS	−.16 (−.02)	−.16 (.17)	−.17 (−.06)	−.25* (−.10)	.11 (−.02)	−.19	.12

Note. Children's scores are indicated in parentheses. *p < .05, **p < .01***p < .001.

emotional components, for example Social Well-being, showed weaker agreement (Power et al., 2019).

Visual limitations and/or ID are associated with lower QoL. Additionally, greater limitations, measured through the classification systems (GMFCS, MACS, CFCS y EDACS), are also linked to lower QoL (Chen et al., 2014; Lestari et al., 2024). The use of AAC has shown a good influence on QoL levels (Kato et al., 2023; Milićević, 2023; Rapp et al., 2017). However, some results go beyond what is expected, such as positive correlations between GMFCS and the School dimension, and between MACS and Family Health. The support level received by the child/adolescent (i.e, personal and environmental factors) may be mediating the effect between GMFCS and QoL (Badia et al., 2013; Longo et al., 2017), in the sense that fewer limitations in functioning are accompanied by fewer supports, which negatively affects the child/adolescent's social performance (Albrecht & Khetani, 2016). On the other hand, correlations with self-report are much lower than those measured by parents. Children/adolescents may not be aware of their limitations and, therefore, there may be a worse fit with predictor variables. Children with disability have adapted to their condition from the beginning. This process, known as the *"disability paradox"* has been widely reported (Carona et al., 2013).

Predictive models indicate that all QoL dimensions, except for Access to Services when assessed by parents, can be predicted to a small to medium degree (Cohen, 1988).This result is contrary to that found by Chen et al. (2014), where the Access to Services was one of the best models. This discrepancy may be because Chen's study measured family variables that were not included here, as for example, parents' mental health, parents' stress, family life impact, family coping or domestic help. In our study, the focus of the predictors is on the functioning variables. This is extremely positive, as it indicates that there is scope for improvement of QoL through intervention in these variables, unlike sociodemographic variables (Milićević, 2023).

Table 5
Multiple regressions of dimensions of QoL on functioning, controlling for child and parents sociodemographic and disability variables (for parent's and children's scores).

Dependent variables		**Variables (Final Model)**	**B**	***B***	**95 % CI**	***p***
Parent's scores	Social Wellbeing, Acceptance, and Participation	CFCS	−3.86	−.48	(−5.89 to −1.83)	<.001
			$\mathrm{F}_{(1,48)} = 14.64, p < .001$ $\boldsymbol{R^2 adj = 0.22}$			
	Feelings about Functioning	GMFCS	−3.36	−.30	(−6.13 to −0.58)	.019
			$F_{(1,61)} = 5.83, p = .019$ $\boldsymbol{R^2 adj = 0.07}$			
	Emotional Wellbeing and Self-stem	CFCS	−3.43	−.43	(−5.36 to −1.50)	<.001
			$F_{(1,57)} = 12.68, p < .001$ $\boldsymbol{R^2 adj = 0.17}$			
	Pain and Impact of Disability	Visual limitations (0: No, 1: Yes)	−11.52	−.40	(−19.12 to −3.92)	.004
			$F_{(1,49)} = 9.29, p = .004$ $\boldsymbol{R^2 adj = 0.14}$			
	School	GMFCS	2.39	.25	(.01 to 4.76)	.049
			$F_{(1,61)} = 4.03, p = .049$ $\boldsymbol{R^2 adj = 0.05}$			
	Family Health	MACS	3.39	.27	(.17 to 6.61)	.039
			$F_{(1,56)} = 4.46, p = .039$ $\boldsymbol{R^2 adj = 0.06}$			
Children's scores	Feelings about Functioning	Family economic status	−13.43	−.27	(−25.38 to −1.47)	.028
		GMFCS	−4.57	−.25	(−9.11 to −.03)	.049
			$F_{(2,58)} = 4.80, p = .012$ $\boldsymbol{R^2 adj = .11}$			

Note. Only the Quality-of-Life dimensions with significant predictor variables were included. B= Beta Unstandardized Coefficient; *B*= Beta Standardized Coefficient; CI= Confidence Interval.

In the case of the evaluation carried out by the children/adolescents, the model could only predict Functioning through the income level and GMFCS. Motor constraints, measured through GMFCS, also proved to be a predictor of Functioning, as mentioned, when the evaluation was carried out by the parents, which reveals the great importance of motor constraints within CP (Sharawat & Panda, 2022).

Some limitations of the study should be mentioned. Firstly, the sample was obtained through snowball sampling to achieve a larger sample of participants, and this procedure can introduce biases in the selected sample. Secondly, a small number of evaluations were carried out by children/adolescents with CP, due to their limitations in completing the evaluation. The need of completing the questionnaires excluded from the study children with cognitive and communicative impairments unable to answer the QoL questionnaire, preventing the generalization of results to children with more severe disability. However, it is highly advantageous and uncommon to have two respondents to be able to compare the data. Finally, it would have been interesting to use other measuring instruments to evaluate other variables, such as environmental barriers and facilitators, which could have contributed to increasing the percentage of QoL variability explained.

5. Conclusions

In conclusion, CP-QOL, in its two available versions, is a useful and specific instrument for assessing QoL in children with CP in both research and clinical settings. In research, it serves as an important source of knowledge of the characteristics of this population. In the clinical practice, it provides information about the needs detected by children/adolescents with CP as well as by their parents. This information is invaluable to professionals, guiding rehabilitation efforts and ultimately contributing to improved QoL outcomes for these children.

Ethics approval statement

This study was conducted according to the guidelines laid down in the Declaration of Helsinki and the ethical approval of the study was obtained from the Bioethics Committee of the University of Salamanca. Informed written consent was obtained from all parents and children over the age of 12.

Funding information

This research was supported by framework of Financing Programs of research groups of the University of Salamanca, approved in the meeting of the Research Council held on April 18, 2017.

CRediT authorship contribution statement

Marta Badia: Supervision, Project administration, Funding acquisition, Conceptualization. **María Gómez Vela:** Writing – original draft, Methodology, Funding acquisition, Conceptualization. **Inmaculada Riquelme:** Writing – review & editing, Supervision, Conceptualization. **Alba Aza:** Writing – original draft, Methodology, Formal analysis, Conceptualization.

Data Availability

Data will be made available on request.

Acknowledgements

We offer special thanks to the children who participated in this study and their families.

References

Albrecht, E. C., & Khetani, M. A. (2016). Environmental impact on young children's participation in home-based activities. *Developmental Medicine Child Neurology, 59*, 388–394. https://doi.org/10.1111/dmcn.13360

Almasri, N. A., & Alquaqzeh, F. A. (2023). Determinants of quality of life of children and adolescents with cerebral palsy: A systematic review. *Physical Occupational Therapy in Pediatrics, 43*(4), 367–388. https://doi.org/10.1080/01942638.2022.2162358

Badgujar, S., Dixit, J., Kuril, B. M., Deshmukh, L. S., Khaire, P., Vaidya, V., & Shelke, M. (2024). Epidemiological predictors of quality of life and the role of early markers in children with cerebral palsy: A multi-centric cross-sectional study. *Pediatric Neonatology, 14,, S1875-9572*(24), 00071–00078. https://doi.org/10.1016/j.pedneo.2024.04.003

Badia, M., Longo, E., Orgaz, M. B., & Gómez-Vela, M. (2013). The influence of participation in leisure activities on quality of life in Spanish children and adolescents with cerebral palsy. *Research in Developmental Disabilities, 34*(9), 2864–2871. https://doi.org/10.1016/j.ridd.2013.06.017

Badia, M., Orgaz, M. B., Gómez-Vela, M., Verdugo, M. A., Ullán, A. M., & Longo, E. (2016). Do environmental barriers affect the parent-reported quality of life of children and adolescents with cerebral palsy? *Research in Developmental Disabilities, 49-50*, 312–321. https://doi.org/10.1016/j.ridd.2015.12.011

Badia, M., Orgaz, M. B., Riquelme, I., & Gómez-Iruretagoyena, J. (2020). Domains of the Cerebral Palsy Quality of Life Questionnaire (CP QOL) for children and adolescents: Spanish adaptation and psychometric properties. *Journal of Developmental and Physical Disabilities, 33*, 331–339. https://doi.org/10.1007/s10882-020-09751-z

Badia, M., Orgaz, M. B., Riquelme, I., & Montoya, P. (2015). The Relationship of Cerebral Palsy Comorbid Conditions with Participation and Quality of Life. In Johnny L. Matson, & Michael L. Matson (Eds.), *Comorbid Conditions among Children with Intellectual Disabilities* (pp. 389–415). Autism and Child Psychopathology Series.

Badia, M., Riquelme, I., Orgaz, B., Acevedo, R., Longo, E., & Montoya, P. (2014). Pain, motor function and health-related quality of life in children with cerebral palsy as reported by their physiotherapists. *BMC Pediatrics, 14*(1). https://doi.org/10.1186/1471-2431-14-19

Bagazgoïtia, N. V. E., Ehlinger, V., Duffaut, C., Fauconnier, J., Schmidt-Schuchert, S., Thyen, U., Himmelmann, K., Marcelli, M., & Arnaud, C. (2021). Quality of life in young adults with cerebral palsy: A longitudinal analysis of the SPARCLE study. *Frontiers in Neurology, 12*, Article 733978. https://doi.org/10.3389/fneur.2021.733978

Bahrampour, M., Downes, M., Scuffham, P. A., & Byrnes, J. (2022). Comparing multi-attribute utility instruments: CP-6D, a cerebral palsy specific instrument, vs AQoL-4D. *Expert Review of Pharmacoeconomics Outcomes Research, 22*(*2*), 217–224. https://doi.org/10.1080/14737167.2021.1909477

Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., Jacobsson, B., & Damiano, D. (2005). Proposed definition and classification of cerebral palsy, April 2005. *Developmental Medicine Child Neurology, 47*(8), 571–576. https://doi.org/10.1017/s001216220500112x

Blackmore, A. M., Mulhern, B., Norman, R., Reddihough, D., Choong, C. S., Jacoby, P., & Downs, J. (2024). How well does the EP-5D-Y-5L describe children with intellectual disability?: "There's a lot more to my child than that she can't wash or dress herself.". *Value Health. 27*(*2*), 190–198. https://doi.org/10.1016/j.jval.2023.11.005

Blasco, M., García-Galant, M., Berenguer-González, A., Caldú, X., Arqué, M., Laporta-Hoyos, O., Ballester-Plané, J., Miralbell, J., Jurado, M.Á., & Roser Pueyo. (2023). Interventions with an impact on cognitive functions in cerebral palsy: a systematic review. *Neuropsychology Review, 33*(2), 551–577. https://doi.org/10.1007/s11065-022-09550-7

Boldyreva, U., Streiner, D. L., Rosenbaum, P. L., & Ronen, G. M. (2020). Quality of life in adolescents with epilepsy, cerebral palsy, and population norms. *Developmental Medicine Child Neurology, 62*(*5*), 609–614. https://doi.org/10.1111/dmcn.14450

Böling, S., Varho, T., & Haataja, L. (2018). Longitudinal study showed that the quality of life of Finnish adolescents with cerebral palsy continued to be relatively good. *Acta Paediatrica, 107*(*3*), 469–476. https://doi.org/10.1111/apa.14123

Burak, M., & Kavlak, E. (2019). Investigation of the relationship between quality of life, activity participation and environmental factors in adolescents with cerebral palsy. *NeuroRehabilitation, 45*(*4*), 555–565. https://doi.org/10.3233/NRE-191288

Carona, C., Pereira, M., Moreira, H., Silva, N., & Canavarro, M. C. (2013). The disability paradox revisited: Quality of life and family caregiving in pediatric cerebral palsy. *Journal of Child and Family Studies, 22*, 971–986. https://doi.org/10.1007/s10826-012-9659-0

Chen, K., Tseng, M., Shieh, J., Lu, L., & Huang, C. (2014). Determinants of quality of life in children with cerebral palsy: A Comprehensive biopsychosocial approach. *Research in Developmental Disabilities, 35*(2), 520–528. https://doi.org/10.1016/j.ridd.2013.12.002

Chen, K., Wang, H., Tseng, M., Shieh, J., Lu, L., Yao, K. G., & Huang, C. (2013). The cerebral palsy quality of life for children (CP QOL-child): Evidence of construct validity. *Research in Developmental Disabilities, 34*(3), 994–1000. https://doi.org/10.1016/j.ridd.2012.11.025

Cohen, J. (1988). StatisticaL Power Analysis for the Behavioral Sciences, 2nd ed. Lawrence Earlbaum Associate.

Colver, A., & the SPARCLE group. (2006). Study protocol: SPARCLE – a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *BMC Public Health, 6*, 105. https://doi.org/10.1186/1471-2458-6-105

Das, S., Aggarwal, A., Roy, S., & Kumar, P. (2017). Quality of life in Indian Children with cerebral palsy using cerebral palsy- quality of life questionnaire. *Journal of Pediatric Neurosciences, 12*(3), 251–254. https://doi.org/10.4103/jpn.JPN_127_16

Davis, E., Mackinnon, A., Davern, M., Boyd, R., Bohanna, I., Waters, E., Graham, H. K., Reid, S., & Reddihough, D. (2013). Description and psychometric properties of the CP QOL-Teen: A quality of life questionnaire for adolescents with cerebral palsy. *Research in Developmental Disabilities, 34*(1), 344–352. https://doi.org/10.1016/j.ridd.2012.08.018

Downs, J., Jacoby, P., Leonard, H., Epstein, A., Murphy, N., Davis, E., Reddihough, D., Whitehouse, A., & Williams, K. (2019). Psychometric properties of the quality of life Inventory-Disability (QI-Disability) measure. *Quality of Life Research, 28*(3), 783–794. https://doi.org/10.1007/s11136-018-2057-3

Eliasson, A. C., Krumlinde, L., Rösblad, B., Beckung, E., Arner, M., Öhrvall, A. M., & Rosenbaum, P. (2006). The Manual Ability Classification System (MACS) for children with cerebral palsy: Scale development and evidence of validity and reliability. *Developmental Medicine and Child Neurology, 48*(7), 549–554. https://doi.org/10.1017/S0012162206001162

Ferreira, M. C., Ribeiro Garcia, N., Martins Prudente, C. O., & Martins Ribeiro, M. F. (2020). Quality of life of adolescents with cerebral palsy: Agreement between self-report and caregiver's report. *Revista Latino Americana Enfermagem, 28*, Article e3300. https://doi.org/10.1590/1518-8345.3928.3300

Gómez, L. E., Alcedo, M.Á., Arias, B., Fontanil, Y., Arias, V. B., Monsalve, A., & Verdugo, M.Á. (2016). A new scale for the measurement of quality of life in children with intellectual disability. *Research in Developmental Disabilities, 53-54*, 399–410. https://doi.org/10.1016/j.ridd.2016.03.005

Hidecker, M. J. C., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., Chester Jr, K., Johnson, B., Michalsen, L., Evatt, M., & Taylor, K. (2011). Developing and validating the Communication Function Classification System (CFCS) for individuals with cerebral palsy. *Developmental Medicine and Child Neurology, 53*(8), 704–710. https://doi.org/10.1111/j.1469-8749.2011.03996.x

Horwood, L., Li, P., Mok, E., Oskoui, M., Shevell, M., & Constantin, E. (2019). Health-related quality of life in Canadian children with cerebral palsy: What role does sleep play? *Sleeping Medicine, 54*, 213–222. https://doi.org/10.1016/j.sleep.2018.10.022

Jacoby, P., Williams, K., Reddihough, D., Leonard, H., Whitehouse, A., & Downs, J. (2022). Modelling quality of life in children with intellectual disability using regression trees. *Developmental Medicine Child Neurology, 64*(*9*), 1145–1155. https://doi.org/10.1111/dmcn.15206

Jovellar-Isiegas, P., Resa Collados, I., Jaén-Carrillo, D., Roche-Seruendo, L. E., & Cuesta García, C. (2020). Sensory processing, functional performance and quality of life in unilateral cerebral palsy children: A Cross-sectional study. *International Journal of Environmental Research Public Health, 17*(19), 7116. https://doi.org/10.3390/ijerph17197116

Kato, M., Arai, H., Komatsu, K., Tateyama, K., & Nishikawa, T. (2023). The lower the physical function, the higher the quality of Life in Japanese adolescents with cerebral palsy. *Physical Occupational Therapy in Pediatrics, 43*(6), 713–724. https://doi.org/10.1080/01942638.2023.2186197

Kolman, S. E., Glanzman, A. M., Prosser, L., Spiegel, D. A., & Baldwin, K. D. (2018). Factors that predict overall health and quality of life in non-ambulatory individuals with cerebral palsy. *Iowa Orthopedics Journal, 38*, 147–152.

Laporta-Hoyos, O., Ballester-Plané, J., Póo, P., Macaya, A., Meléndez-Plumed, M., Vázquez, E., Delgado, I., Zubiaurre-Elorza, L., Botellero, V. L., Narberhaus, A., Toro-Tamargo, E., Segarra, D., & Pueyo, R. (2017). Proxy-reported quality of life in adolescents and adults with dyskinetic cerebral palsy is associated with executive functions and cortical thickness. *Quality of Life Research, 26*(*5*), 1209–1222. https://doi.org/10.1007/s11136-016-1433-0

Larsen, S. M., Terjesen, T., Jahnsen, R. B., Diseth, T. H., & Ramstad, K. (2023). Health-related quality of life in adolescents with cerebral palsy; A cross-sectional and longitudinal population-based study. *Child Care Health Development, 49*(*2*), 373–381. https://doi.org/10.1111/cch.13055

Lee, J., Suk, M., Yoo, S., & Kwon, J. (2020). Physical activity energy expenditure predicts quality of life in ambulatory school-age children with cerebral palsy. *Journal of Clinical Medicine, 11*(*12*), 3362. https://doi.org/10.3390/jcm11123362

Lennon, N., Kalisperis, F., Church, C., Niiler, T., Miller, F., Biermann, I., Davey, J., Sees, J. P., & Shrader, M. W. (2024). Self-reported health-related quality of life in adolescents with cerebral palsy. *Journal of Pediatric Orthopedics, 44*(1), e46–e50. https://doi.org/10.1097/BPO.0000000000002519

Lestari, A. F., Sitaresmi, M. N., Sutomo, R., & Ridhayani, F. (2024). Factors affecting the health-related quality of life of children with cerebral palsy in Indonesia: A cross-sectional study. *Child Health Nursing Research, 30*(1), 7–16. https://doi.org/10.4094/chnr.2023.027

Longo, E., Badia, M., Orgaz, M. B., & Gómez-Vela, M. (2017). Comparing parent and child reports of health-related quality of life and their relationship with leisure participation in children and adolescents with cerebral palsy. *Research in Developmental Disabilities, 71*, 214–222. https://doi.org/10.1016/j.ridd.2017.09.020

Makris, T., Dorstyn, D., & Crettenden, A. (2021). Quality of life in children and adolescents with cerebral palsy: A Systematic review with meta-analysis. *Disability and Rehabilitation, 43*(3), 299–308. https://doi.org/10.1080/09638288.2019.1623852

Marwa, G., Mtawaa, S., Toulgui, E., Moncer, R., Wannes, W., Maaref, K., & Jemni, S. (2022). Quality of life and its predicting factors for Tunisian children with cerebral palsy. *African Journal of Disability, 11*, 1046. https://doi.org/10.4102/ajod.v11i0.1046

Milićević, M. (2023). Functional and environmental predictors of health-related quality of life of school-age children with cerebral palsy: a cross-sectional study of caregiver perspectives. *Child: Care, Health and Development, 49*(1), 62–72. https://doi.org/10.1111/cch.13007

Mohammed, S. S., Abdelwahab, M. S., Zaky, N. A., & Abdelazeim, F. H. (2024). Impact of mother's care burden, fatigue and child's functional level on quality of life in spastic cerebral palsy. *Physiotherapy Research International, 29*(*1*), Article e2067. https://doi.org/10.1002/pri.2067

Morán, M. L., Gómez, L. E., Balboni, G., Bacherini, A., & Monsalve, A. (2023). Quality of Life in children and adolescents with cerebral palsy and intellectual disability: Predictors and personal outcomes. *Child Indicators Research, 17*, 123–143. https://doi.org/10.1007/s12187-023-10079-1

Norman, G. R., Sloan, J. A., & Wyrwich, K. W. (2003). Interpretation of changes in health-related quality of life. *Medical Care, 41*(5), 582–592. https://doi.org/10.1097/01.MLR.0000062554.74615.4C

Öst, E., Frenckner, B., Nisell, M., Burgos, C. M., & Öjmyr-Joelsson, M. (2018). Health-related quality of life in children born with congenital diaphragmatic hernia. *Pediatric Surgery International, 34*(4), 405–414. https://doi.org/10.1007/s00383-018-4237-1

Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). Development and reliability of a system to classify gross motor function in children with cerebral palsy. *Developmental Medicine Child Neurology, 39*(4), 214–223. https://doi.org/10.1111/j.1469-8749.1997.tb07414.x

Park, E. Y. (2017). Relationship between activity limitation and health-related quality of life in school-aged children with cerebral palsy: A cross-sectional study. *Health and Quality of Life Outcomes, 15*(1), 87–93. https://doi.org/10.1186/s12955-017-0650-8

Park, E. Y. (2018). Path analysis of strength, spasticity, gross motor function, and health-related quality of life in children with spastic cerebral palsy. *Health Quality of Life Outcomes, 16*(1), 70. https://doi.org/10.1186/s12955-018-0891-1

Pérez-Ardanaz, B., Morales-Asencio, J. M., León-Campos, A., Kaknani-Uttumchandani, S., López-Leiva, I., Garcia-Piñero, J. M., Martí-García, C., & García-Mayor, S. (2020). Quality of life and health services utilization for Spanish children with cerebral palsy. *Journal of Pediatric Nursing, 53*, e121–e128. https://doi.org/10.1016/j.pedn.2020.03.001

Petry, K., Maes, B., & Vlaskamp, C. (2009). Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: First results. *Research in Developmental Disabilities, 30*(6), 1394–1405. https://doi.org/10.1016/j.ridd.2009.06.007

Power, R., Akhter, R., Muhit, M., Wadud, S., Heanoy, E., Karim, T., Badawi, N., & Khandaker, G. (2019). A quality of life questionnaire for adolescents with cerebral palsy: Psychometric properties of the Bengali CPQoL-teens. *Health and Quality of Life Outcomes, 17*(135), 1–11. https://doi.org/10.1186/s12955-019-1206-x

Power, R., Galea, C., Muhit, M., Heanoy, E., Karim, T., Badawi, N., & Khandaker, G. (2020). What predicts the proxy-reported health-related quality of life of adolescents with cerebral palsy in Bangladesh? *BMC Public Health, 20*(*1*), 18. https://doi.org/10.1186/s12889-019-8130-1

Power, R., King, C., Muhit, M., Heanoy, E., Galea, C., Jones, C., Badawi, N., & Khandaker, G. (2018). Health-related quality of life of children and adolescents with cerebral palsy in low- and middle-income countries: A Systematic review. *Developmental Medicine Child Neurology, 60*(5), 469–479. https://doi.org/10.1111/dmcn.13681

Rapp, M., Eisemann, N., Arnaud, C., Ehlinger, V., Fauconnier, J., Marcelli, M., Michelsen, S. I., Nystrand, M., Colver, A., & Thyen, U. (2017). Predictors of parent-reported quality of life of adolescents with cerebral palsy: A Longitudinal study. *Research in Developmental Disabilities, 62*, 259–270. https://doi.org/10.1016/j.ridd.2016.12.005

Sadowska, M., Sarecka-Hujar, B., & Kopyta, I. (2020). Cerebral Palsy: Current opinions on definition, epidemiology, risk factors, classification and treatment options. *Neuropsychiatric Disease and Treatment, 16*, 1505–1518. https://doi.org/10.2147/NDT.S235165

Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C. (2013). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Child Neurology, 56*(3), 245–251. https://doi.org/10.1111/dmcn.12352

Sentenac, M., Rapp, M., Ehlinger, V., Colver, A., Thyen, U., & Arnaud, C. (2021). Disparity of child/parent-reported quality of life in cerebral palsy persists into adolescence. *Developmental Child Neurology, 63*(*1*), 68–74. https://doi.org/10.1111/dmcn.14638

Sharawat, I. K., & Panda, P. K. (2022). Quality of Life and Its Association with Level of Functioning in Young Children with Cerebral Palsy. *Neuropediatrics, 53*(4), 227–234. https://doi.org/10.1055/s-0042-1743432

Shields, N., Leonard, H., Munteanu, S., Bourke, J., Lim, P., Taylor, N. F., & Downs, J. (2018). Parent-reported health-related quality of life of children with down syndrome: A descriptive study. *Developmental Medicine and Child Neurology, 60*(4), 402–408. https://doi.org/10.1111/dmcn.13670

Sullivan, G. M., & Feinn, R. (2012). Using effect size-or why the P value is not enough. *Journal of Graduate Medical Education, 4*(3), 279–282. https://doi.org/10.4300/JGME-D-12-00156.1

Swift, E., Gibbs, L., Reddihough, D., Mackinnon, A., & Davis, E. (2023). Qualitative differences in perspective on children's quality of life between children with cerebral palsy and their parents. *Journal of Patient Reports Outcomes, 7*(*1*), 118. https://doi.org/10.1186/s41687-023-00656-x

The Whoqol Group. (1998). The World Health Organization quality of life assessment (WHOQOL): Development and general psychometric properties. *Social Science Medicine, 46*(12), 1569–1585. https://doi.org/10.1016/S0277-9536(98)00009-4

Tonmukayakul, U., Imms, C., Mihalopoulos, C., Reddihough, D., Carter, R., Mulhern, B., & Chen, G. (2020). Health-related quality of life and upper-limb impairment in children with cerebral palsy: Developing a mapping algorithm. *Developmental Medicine Child Neurology, 62*(*7*), 854–860. https://doi.org/10.1111/dmcn.14488

Tschirren, L., Bauer, S., Hanser, C., Marsico, P., Sellers, D., & van Hedel, H. J. A. (2018). The eating and drinking ability classification system: Concurrent validity and reliability in children with cerebral palsy. *Developmental Medicine and Child Neurology, 60*(6), 611–617. https://doi.org/10.1111/dmcn.13751

Türker, A., & Özkeskin, M. (2023). Investigation of urinary disorders, functional independence, and quality of life in children with cerebral palsy. *Neurourology Urodynamics, 42*(*3*), 597–606. https://doi.org/10.1002/nau.25135

World Health Organization. (2001). *International Classification of Functioning, Disability and Health (ICF)*. World Health Organization. ⟨https://iris.who.int/bitstream/handle/10665/42407/9241545429-eng.pdf⟩.

Varni, J. W., Burwinkle, T. M., Berrin, S. J., Sherman, S. A., Artavia, K., Malcarne, V. L., & Chambers, H. G. (2006). The PedsQL in pediatric cerebral palsy: Reliability, validity, and sensitivity of the generic core scales and cerebral palsy module. *Developmental Medicine Child Neurology, 48*(6), 442–449.

Viswanath, M., Jha, R., Gambhirao, A. D., Kurup, A., Badal, S., Kohli, S., Parappil, P., John, B. M., Adhikari, K. M., Kovilapu, U. B., & Sondhi, V. (2023). Comorbidities in children with cerebral palsy: A single-centre cross-sectional hospital-based study from India. *BMJ Open, 13*(7), Article e072365. https://doi.org/10.1136/bmjopen-2023-072365

Wang, H., Cheng, C., Hung, J., Ju, Y., Lin, J., & Lo, S. (2010). Validating the cerebral palsy quality of life for children (CP QOL-child) questionnaire for use in Chinese populations. *Neuropsychological Rehabilitation, 20*(6), 883–898. https://doi.org/10.1080/09602011.2010.509190

Waters, E., Davis, E., Body, R., Reddihough, D., Mackinnon, A., Graham, H.K., & Ravens-Sieberer, U. (2013). Cerebral palsy quality of life for children (CP-QOL Child) Manual, University of Melbourne. ⟨https://www.ausacpdm.org.au/wp-content/uploads/2019/01/CPQOL-Child-manual.pdf⟩.

Waters, E., Davis, E., Mackinnon, A., Boyd, R., Graham, H. K., Kai Lo, S., Wolfe, R., Stevenson, R., Bjornson, K., Blair, E., Hoare, P., Ravens-Sieberer, U., & Reddihough, D. (2007). Psychometric properties of the quality of life questionnaire for children with CP. *Developmental Medicine Child Neurology, 49*(1), 49–55. https://doi.org/10.1017/S0012162207000126.x

Wood, E., & Rosenbaum, P. (2007). The gross motor function classification system for cerebral palsy: A study of reliability and stability over time. *Developmental Medicine Child Neurology, 42*(5), 292–296. https://doi.org/10.1111/j.1469-8749.2000.tb00093.x