




Domains of the Cerebral Palsy Quality of Life Questionnaire (CP QOL) for Children and Adolescents: Spanish Adaptation and Psychometric Properties

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Published online: 26 May 2020

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Abstract

Promoting quality of life (QOL) has become a goal of support services for people with disabilities and a key intervention outcome. The aim of this study was to examine the psychometric properties of the adapted Spanish version of the Cerebral Palsy Quality of Life Questionnaire (CP QOL) for children and adolescents, in its self-report and primary caregiver-report versions. The Spanish versions were translated and adapted following the guidelines for cross-cultural adaptation. Eighty-two children and adolescents with CP and 304 primary caregivers completed the final Spanish versions of the CP QOL, the KIDSCREEN-27, and instruments to measure functioning. Exploratory Factor Analysis yielded a distinguishable domain structure similar to the original English version. Cronbach's alpha ranged between .75 and .91 for primary caregiver reports and between .81 and .91 for child/teen self-reports. Moderate and weak correlations were observed between the CP QOL and the generic measure of QOL and functioning. This study provides a valid instrument to assess the QOL of children and adolescents with CP in the Spanish context.

Keywords Quality of life · Cerebral palsy · Children · Adolescents · Spanish · Psychometric properties

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Cerebral Palsy (CP) describes a group of permanent developmental disorders of movement and posture attributed to non-progressive alterations in fetal or infant brain development (Rosenbaum et al. 2007). Additionally to motor sequelae, other deficiencies can interfere with daily functioning in many children with CP, increasing activity limitations and reducing their quality of life (QOL) (Badia et al. 2015).

The current 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), promotes a change in the organization and planning of support services, aimed at improving the quality of life of the children and their families (Badia et al. 2015). The World Health Organization (WHO) (WHOQOL and Group 1995) defines QOL as people's perception of their place in the existence, cultural context, and values in relation to their goals, expectations, rules, and concerns. The Division of Mental Health of the WHO states that the instruments to assess QOL in children must contemplate the prospects of the parents or proxies, be cross-culturally comparable and take into account contextual factors (World Health Organization- Division of Mental Health 1994).

Currently, generic scales for chronic health conditions are available for measuring QOL. Generic instruments are designed to be applicable to all population subgroups and are useful for making comparisons among them (Bjornson and McLaughlin 2001), but they are less appropriate to evaluate the effectiveness of an intervention in children with specific disabilities. Specific scales allow addressing the QOL areas that are important to children with disabilities and detecting changes after an intervention (Bjornson and McLaughlin 2001; Sakzewski et al. 2012). Thus, for example, in a qualitative study with children with CP and their parents, Waters et al. (2005) found that many QOL areas are not addressed in generic questionnaires, such as, for example, the presence of pain and discomfort, communication skills, or participation in daily life activities.

The Cerebral Palsy Quality of Life Questionnaire (CP QOL) was the first questionnaire specifically designed to measure the QOL of children and adolescents with CP based on the ICF (Davis et al. 2013; Waters et al. 2007; Waters et al. 2005). Rather than functioning aspects, the CP QOL assesses different areas of children and adolescents' subjective QOL and is useful to establish a QOL profile (Waters et al. 2007; Waters et al. 2005). There are four modalities of the CP QOL: one for children, one for adolescents, one for the parents of children, and one for the parents of adolescents. Currently, CP QOL questionnaires are available in different languages and have become a cross-cultural tool to assess QOL in children and adolescents with CP. Previous research has shown that both the primary caregiver and the self-report questionnaires, both for children and adolescents, have good psychometric properties of reliability and validity (Atasavun Uysal et al. 2016; Chen et al. 2013; Davis et al. 2013; Dmitruk et al. 2014; Wang et al. 2010; Waters et al. 2007; Waters et al. 2005).

Nevertheless, although some different themes emerged in the qualitative interviews leading to the CP QOL-Teen construction, many QOL issues endured from childhood to adolescence (Davis et al. 2009) and most of the CP QOL-Teen domains overlap with the CP QOL-Child domains (all except School wellbeing) (Davis et al. 2013). Moreover, other high-accepted measures of QOL, such as the KIDSCREEN, have only one version for children and adolescents (8–18 years). In addition, previous studies aiming at identifying QOL domains in children and adolescents with intellectual disabilities

(ID), found no age-related differences in the domains (Davis et al. 2017; Murphy et al. 2017).

The purpose of this study is to present the results of the process of translation, adaptation, and validation of the CP QOL (Davis et al. 2013; Waters et al. 2007; Waters et al. 2005) (child/adolescent self-report and primary caregiver proxy report versions) to the Spanish context. The objectives of the study were: (1) to translate, adapt, and develop two questionnaires, one for self-report and one for proxy report, including both children and adolescents with CP, taken from the four questionnaires in the English version of the CP QOL; (2) to confirm the dimensional structure of the questionnaires; and (3) to analyze the internal consistency and construct validity with another instrument measuring of QOL and functioning scales.

Method

Participants

A convenience sample of children and adolescents with CP and their families was obtained from 24 different centres depending on the Spanish Confederation of Care for People with Cerebral Palsy (ASPACE) in 9 regions of Spain. A total of 82 children and adolescents with CP aged between 4 and 18 years ($M = 11.18$ years; $SD = 4.30$) and 304 primary caregivers participated in the study. Table 1 shows the clinical and demographic characteristics of the sample.

Measures

Gross Motor Function Classification System (GMFCS) (Palisano et al. 1997) ranges from Level I (independent gross motor function with few limitations) to Level V (complete dependence for all motor activities). The psychometric properties of the GMFCS have been thoroughly tested and reported, and include evidence supporting its content validity, construct validity, interrater reliability, and test-retest reliability (Wood and Rosenbaum 2000).

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 5 levels: Level I represents optimal manual skill, and Level V indicates lack of any active function in the hands. The MACS has shown good validity and reliability (Eliasson et al. 2006).

Communication Function Classification System (CFCS) (Hidecker et al. 2011) assesses the capacity for communication in daily life situations. It classifies communication in 5 levels according to the efficacy of current communication: Level I indicates that the emitter and receiver are efficacious with known and unknown interlocutors; Level V indicates that the emitter and receiver are rarely efficacious with known interlocutors. The CFCS has shown content validity and good reliability (Hidecker et al. 2011).

Eating and Drinking Ability Classification System (EDACS) (Sellers et al. 2014) describes the functional activities of eating, drinking, sucking, biting, chewing, swallowing, and keeping food or liquid in the mouth in children with PC. It consists of five levels, with Level I representing eating and drinking safely and efficiently, and Level V indicating the

Table 1 Demographic characteristics of children and adolescents with cerebral palsy

		Percentages
<i>Sex</i>		
	Boys	55.4%
	Girls	44.6%
<i>Functioning levels</i>		
<i>GMFCS</i>	I-II	28.5%
	III-V	71.5%
<i>MACS</i>	I-II	25.6%
	III-V	74.4%
<i>CFCS</i>	I-II	26.9%
	III-V	73.7%
<i>EDACS</i>	I-II	38.0%
	III-V	62.0%
<i>Intellectual disability</i>		
	None	15.1%
	Mild-moderate	17.3%
	Severe	67.6%
<i>Family economic status</i>		
	Income lower than 1000 €	9.8%
	Income between 1000 and 2000 €	43.3%
	Income higher than 2000 €	41.9%
<i>Parents educational level</i>		
	Secondary school	59.2%
	University	40.8%

GMFCS Gross motor function classification system, *MACS* Manual ability classification system, *CFCS* Communication Function Classification System, *EDACS* Eating and Drinking Ability Classification System

incapacity to eat and drink safely. The EDACS provides a valid and reliable system for classifying eating and drinking performance of people with CP (Tschirren et al. 2018).

Spanish version of the KIDSCREEN-27 (Aymerich et al. 2005; Ravens-Sieberer et al. 2007) is a generic questionnaire designed to measure QOL in children and adolescents aged 8–18 years. There are two versions available, one for children and one for parents, consisting of 27 items with five dimensions (Physical Well-Being, Psychological Well-Being, Autonomy and Parents, Friends and Social Support, School Environment). The construct validity of the instrument is satisfactory; the factor analysis results explain 56% of the variance, and the Cronbach alpha reliability of each of the five dimensions is >0.70. Rasch scores are computed for each dimension and transformed into values with a mean of 50 and a standard deviation of 10; higher scores indicate better QOL and well-being (Aymerich et al. 2005).

Cerebral Palsy Quality of Life Questionnaire (CP QOL). The CP QOL questionnaires evaluate the specific QOL of children and adolescents with PC. The CP QOL uses a 9-point rating scale to measure how caregivers think their child feels (in general, 1 = very unhappy, 9 = very happy), with scores subsequently being converted to a scale

ranging from 0 to 100. The primary caregiver QOL-Child form (children aged 4–12) contains 66 items in seven domains: Social well-being and Acceptance, Functioning, Participation and Physical Health, Emotional Well-being, Pain and Impact of Disability, Access to Services, and Family Health (Waters et al. 2007). The child self-report (children aged 9–12) contains 52 items with the same domains, except for Access to Services and Family Health. The primary caregiver QOL-Teen form (adolescents aged 13–18) includes 72 items in seven domains: Wellbeing and Participation, Communication and Physical Health, School Well-being, Social Wellbeing, Access to Services, Family Health, and Feelings about Functioning. The teen self-report, as it happens in the child self-report, does not include questions about access to services or caregiver's health (Davis et al. 2013). Items from both questionnaires include the concepts of emotional wellbeing, school wellbeing, physical wellbeing, participation, communication and pain, as well as access to services and caregiver health. All domains except School Wellbeing overlapped in both questionnaires (Davis et al. 2013), although 7 out of 10 questions in the domain School in the CP QOL-Teen questionnaire were included in other domains in the CP QOL-Child. For example, the domain Social Wellbeing and Acceptance includes questions such as “How do you think your child feels about the way they get along with other children at preschool or school?” or “...

the way they get along with their teachers and/or carers?”. Both the CP QOL versions for children and for teens have been shown to have good psychometric properties (Davis et al. 2013; Waters et al. 2007).

Procedure

The validation process of the Spanish CP QOL followed the “Translation Guidelines of the CP QOL” (www.cpqol.org.au/cpqol_translation_manual.pdf) (Davis et al. 2013; Waters et al. 2007) and the recommendations for the adaptation of tests proposed by Muñiz et al. (2013). Due to the high similarity between the CP QOL-Child and Teen versions, original authors were consulted about the unification of both questionnaires in a single one, comprehending all the main items of both versions. Formal permission to translate and adapt the English version into Spanish was obtained from the original authors. On the one hand, the translation process consisted of: (1) elaboration of one questionnaire, combining the Primary Caregiver versions of CP QOL-Child and CP QOL-Teen; (2) translation of each of the items to Spanish by three different translators with experience in the development of tests and QOL of children/adolescents with CP. On the other hand, the cultural adaptation was carried out through: (3) synthesis of the translations, obtaining the first version in Spanish of the questionnaire; (4) selection of two focus groups with 15 children and adolescents with CP and their parents in order to analyze the cultural acceptability, obtain suggestions, and ensure the suitability of the items; (5) concordance and synthesis performed by a committee of experts made up of four professionals from the area of childhood disability to achieve semantic, idiomatic, experiential, and conceptual equivalence; (6) backward translation carried out by one translator, whose maternal language was English and who was bilingual in Spanish. The Spanish version of the Primary Caregiver CP QOL for children and adolescents (4–18 years) previous from the field test consisted of 74 items and 9 scales: Family and Friends (17 items), Participation (4 items), Communication (4 items), Health (22 items), Pain and Bother (4 items), School (8 items), Access to Services (6 items),

Caregiver Health (4 items), and Final Questions (5 items). The CP QOL-child/teen self-report (8–18 years) consisted of 64 items and the same scales than in the primary caregiver report, except for the scales Access to Services and Caregiver's health, mirroring the original English versions. The CP QOL is reproduced in the "Table 6".

Data were collected between November 2017 and March 2018. For recruitment, an e-mail informing of the purpose and methods of the study was sent to the centres chiefs, and they informed parents of potential participants. If caregivers expressed interest in participating, they were given a written document explaining the purpose, instruments and procedure of the study and the consent form. Informed consent from parents was obtained prior to data collection.

In each center a research assistant (professionals with experience in providing services to children and families with CP) was formally trained by one of the members of the research team. The research assistants contacted with the families who had agreed to participate in each centre, and give them the parents' versions of the QOL-CP and the Kidscreen-27 to complete. In children/adolescents with enough communicative and cognitive skills, the self-report versions of the QOL-CP and the Kidscreen-27 were completed in a face to face interview with the research assistant. Both participants and professionals were native speakers. Moreover, in each centre, health care professionals (e.g. psychologist, physical therapists..) provided information about each participant's intellectual ability and functional capacity (GMFCS, MACS, EDADCS, and CFCS).

Data Analysis

First, an Exploratory Factor Analysis (EFA) was performed. Data of primary caregiver and child/teen reports were subjected to principal components analysis followed by varimax rotation. The appropriate number of factors was determined by screen plots, eigenvalue >1 , and conceptual meaningfulness of the items on each factor. Coefficients above .40 were considered salient and of practical significance and were used to retain items (Stevens 2002). Second, internal consistency of the CP QOL was analyzed by means of Cronbach's alpha. Values between .70 and .95 were considered acceptable as a measure of reliability (Tavakol and Dennick 2011). Third, to analyze concurrent validity, Pearson correlations were calculated to examine the associations of the domain scores with KIDSCREEN-27 and the functioning measures (GMFCS, MACS, CFCS, and EDACS).

Data were analyzed using SPSS version 23.0. All analyses used a significance level of $p < .01$.

Results

Missing Values

Most of the items had less than 5% missing data. However, 3 items in the Health Scale had as much as 50% missing values, so these items were deleted and excluded from the factor analysis.

Exploratory Factor Analysis

The Kaiser-Meyer-Olkin measure of sampling adequacy (.85) indicated that the primary caregiver sample was appropriate for EFA. EFA results revealed a seven-component solution that accounted for 61% of the total variance. All components had well-defined factor loadings ranging from 0.43 to 0.86. These domains were called: (1) Social Wellbeing, Acceptance and Participation, (2) School Wellbeing, (3) Emotional Wellbeing and Self-esteem, (4) Feelings about Functioning, (5) Access to Services, (6) Pain and Impact of Disability, and (7) Family Health (Table 1).

The Kaiser-Meyer-Olkin measure of sampling adequacy (.58) indicated that the child/teen sample was appropriate although its value was low for EFA. EFA results revealed a five-component solution that accounted for 60% of the total variance. All components had well-defined factor loadings ranging from 0.44 to 0.86. These domains were called: (1) Feelings about Functioning, (2) Emotional Well-being and Self-esteem, (3) School Well-being, (4) Pain and Impact of Disability, and (5) Social Well-being, Acceptance and Participation (Table 2).

Domain structures from the child/teen version (5 components) and the primary caregiver version (7 components) did not show to be equivalent.

Internal Consistency

Cronbach's alpha for the domains showed satisfactory internal consistency for the primary caregiver proxy report (Cronbach's alpha ranged from .75 to .91) and for the child/teen self-report (Cronbach's alpha ranged from .81 to .93) (Table 3).

Concurrent Validity Evidence

As expected, the correlations between the CP QOL domains and the KIDSCREEN-27 dimensions were positive and statistically significant in most cases, both for the primary caregivers (Table 4) and for the children/teens (Table 5), indicating a parallel evolution of both QOL scores (CP QOL/ Kidscreen) and confirming the capacity of our instrument for adequately measuring different aspects of QOL. In contrast, the correlations with the functioning scales were negative and significant in the case of the caregivers and nonsignificant in the case of the children/teens; indicating a non-consistent link of poorer function and better quality of life. These results seem to suggest that functioning has a weak influence in the QOL perception for children and adolescents with CP.

Discussion

The purpose of this study was to obtain an adaptation of the CP QOL that considers the characteristics of the population for which it was intended, mainly children and adolescents with CP who have severe limitations in their functioning and ID. Previous studies, which examined parents' observations to identify QOL domains in their

Table 2 Principal component analysis for primary caregiver report and child/teen report (child/teen report loadings in brackets)

	SWAP	SW	EWS	FF	AS	PID	FH
Their ability to participate in social events	.80			(.75)			
Their ability to participate in their community	.73		(.45)				
How they are accepted by adults	.68 (.70)		.44				
How they are accepted by people in general	.66		.42 (.54)				
How they are accepted by other children outside of school	.65		(.63)				
Their ability to participate in recreational activities	.64	(.46)		(.60)			
The way they get along with adults	.61 (.77)						
The way other people communicate with them	.58	(.67)					
The way they communicate with people they don't know well	.57					(.55)	
Hanging out with friends	.54			(.72)			
Their ability to participate in sporting activities	.53			(.52)			
The way they get along with people generally	.53	(.61)		(.45)			
The way they get along with other children outside school	.51			(.51)			
Their ability to play with friends	.50			(.61)			
The way they 'have a go' and try new things	.43						
How they are accepted by other children at school		.83 (.81)					
How they are accepted by the staff and teachers at their school	(.44)	.82					
Being treated the same as everyone else at their school		.79					
The way they get along with other children at school		.73 (.83)					
Their ability to participate at preschool or school		.72	(.63)				
The way they get along with their teachers and/or carers		.70 (.80)					
Their ability to keep up physically with their peers		.65		.43(.60)			
Their ability to keep up academically with their peers		.60	(.68)				

Table 2 (continued)

	SWAP	SW	EWS	FF	AS	PID	FH
Their opportunities in life			.82 (.56)	(.49)			
Their plans for the future			.79 (.76)				
Their future			.75 (.70)				
What may happen to them later in life		(.51)	.68 (.44)				
What they have achieved in their life			.66 (.71)				
The way they look		(.47)	.56				
Their ability to use the toilet by themselves			.78 (.86)				
Their ability to dress themselves			.76 (.82)				
Their ability to eat or drink independently			.67 (.81)				
Being able to do things by themselves without relying on others			.65 (.83)				
The way they use their legs		(.56)	.64 (.58)				
The way they use their arms and hands			.51 (.77)				
Your child's access to treatment					.86		
Your child's access to therapy					.83		
Your child's access to specialised medical or surgical care					.82		
Your ability to get advice from a paediatrician					.76		
Your child's access to extra help with learning at preschool or school					.59		
Your child's access to community services and facilities					.58		
How much pain does your child have						.86 (.81)	
How much discomfort does your child experience						.84 (.67)	
How does your child feel about the amount of pain they have						.83 (.85)	
Is your child bothered by hospital visits		(.47)				.46 (.53)	
Their life in general		(.65)				.45 (.41)	
Their overall health						.44 (.60)	

Table 2 (continued)

	SWAP	SW	EWS	FF	AS	PID	FH
How they sleep				(.69)		.43	
How happy is your child		(.51)				.43 (.61)	
Your work situation							.81
Your family's financial situation							.79
How happy are you							.68
Your physical health							.56
% Var	28.47	7.88	6.82	5.29	4.48	4.37	3.73

Social well-being, acceptance, participation, *SWAP* School well-being, *SW* Emotional well-being and self-esteem, *EWS* Feelings about functioning, *FF* Access to services, *AS* Pain and impact of disability, *PID* Family health *FH*

Table 3 Internal consistency and primary caregiver-child/teen concordance (N = 82)

CP QOL-Domains	No. of items	α Cronbach	
		Primary caregiver	Child/Teen
Social well-being, acceptance and participation	15	.91	.85
School well-being	8	.91	.81
Emotional well-being and self-esteem	6	.88	.83
Feelings about functioning	6	.88	.93
Access to services	6	.86	NA
Pain and impact of disability	8	.81	.84
Family health	4	.75	NA

* $p < .05$. ** $p < .01$. *** $p < .001$

children with intellectual disabilities (Down syndrome and CP), found no differences in the domains for children and adolescents (Davis et al. 2017; Murphy et al. 2017). Based on this, a process of adaptation of the original versions of the CP QOL into a single instrument for children and adolescents was performed. The results of this study show that the primary caregiver CP QOL-Child/Teen Spanish version has good psychometric properties in a Spanish sample.

One of the goals of this study was to empirically verify the seven-factor structure of the CP QOL primary caregiver report. The results of the EFA support a seven-factor model very similar to that of the original instruments (Davis et al. 2013; Waters et al. 2007). More specifically, the domains of the CP QOL-Child/Teen are more strongly related to the CP QOL-Child (Waters et al. 2007). The CP QOL-Child/Teen proxy would consist of the following seven domains: Social Wellbeing, Acceptance and Participation (15 items), School Wellbeing (8 items), Emotional Wellbeing and Self-esteem (6 items), Feelings about Functioning (6 items), Access to Services (6 items), Pain and Impact of Disability (8 items), and Family Health (4 items). We eliminated from the analysis all items whose factorial loads were lower than 0.40, whose reliability indices in their corresponding domain were lower than 0.50, and whose factorials loads were higher in a domain other than the corresponding one, considering the dimensions proposed by the original authors. However, the results revealed that the component structure of five extracted components for the child/teen self-report could not be properly considered as similar to the domain structures of the primary caregiver report. Comparable results have been reported in previous studies (Chen et al. 2013; Davis et al. 2007).

Regarding the internal consistency for the English version of the CQ QOL-Child, Waters et al. (2007) reported that the Cronbach alpha varied between 0.72 and 0.92 for the primary caregiver proxy report and from 0.80 to 0.90 for the child self-report. In the case of the CP QOL-Teen version, it varied between 0.81 and 0.96 for the primary caregiver proxy report and between 0.78 and 0.95 for the teen self-report (Davis et al. 2013). In this study, for the Spanish version of the CP QOL, Cronbach's alpha varied from 0.75 to 0.91 for the primary caregiver proxy report and from 0.81 to 0.93 for the child/teen self-report. These data indicate an excellent internal consistency of the adapted version of the CP QOL, comparable to the English versions.

Table 4 Correlation between CP QOL and KIDSCREEN-27 and functioning measures (primary caregiver)

	CP QOL-Domains						
	Social well-being, acceptance, participation	School well-being	Emotional well-being and self-esteem	Feelings about functioning	Access to services	Pain and impact of disability	Family health
KIDSCREEN-27							
Physical well-being	.43***	.28***	.33***	.35***	.12*	.52***	.09
Psychological well-being	.39***	.38***	.35***	.40***	.13*	.55***	.28***
Autonomy & parents	.27***	.18**	.29***	.16**	.08	.25**	.20**
Peers & social support	.47***	.30***	.42***	.33***	.23***	.27**	.13*
School environment	.36***	.56***	.33***	.18**	.31***	.41***	.22***
Functioning							
GMFCS	-.21***	.02	-.23***	-.38***	-.08	-.30***	.05
MACS	-.32***	.00	-.25***	-.41***	-.07	-.27***	-.01
CFCS	-.38***	-.03	-.28***	-.26***	-.03	-.26***	.04
EDACS	-.30***	.02	-.22***	-.31***	-.05	-.25***	-.05

* $p < .05$. ** $p < .01$. *** $p < .001$

Weak correlations between the self-reports of children/adolescents and the report of the primary caregiver were found, especially for the most subjective domains such as Emotional Wellbeing and Self-esteem, and Social Wellbeing, Acceptance and Participation, indicating that children and adolescents may have a different perception of their QOL than their parents. Several studies have reported low to moderate correlations between the QOL reports of parents and children (Davis et al. 2007; Longo et al. 2017; Shelly et al. 2008; Upton et al. 2008; Waters et al. 2007; White-Koning et al. 2007), which are usually stronger in the domains of physical health (Eiser and Morse 2001; Majnemer et al. 2008; Waters et al. 2007). These results emphasize the importance of self-reports in QOL whenever they are possible, as proxy's reports could not adequately express the child's perception in less visible domains.

The CP QOL domains were weakly to moderately correlated to KIDSCREEN-27 domains both for the caregiver reports and self-reports. Thus, the dimensions Social Wellbeing, Acceptance and Participation, Emotional Wellbeing and Self-esteem, Feelings about Functioning, Pain and Impact of Disability, and School Wellbeing correlated moderately with the KIDSCREEN-27. In accordance with Davis et al. (2007), the KIDSCREEN evaluates wellbeing and feelings and is in accordance with the QOL construct of the CP QOL. However, the weak or non-correlation of the KIDSCREEN-27 with the domains Access to Services and Family Health suggests that the KIDSCREEN is not sensitive enough to capture specific aspects of CP (Waters et al. 2007). The weak correlations found with measures of functioning are consistent with previous studies reporting that functioning and QOL are two different concepts (Shelly

Table 5 Correlation between CP QOL and KIDSCREEN-27 and functioning measures (child/teen)

	CP QOL-Domains				
	Social well-being, acceptance, participation	School well-being	Emotional well-being and self-esteem	Feelings about functioning	Pain and impact of disability
Kidscreen-27					
Physical well-being	.22	.28*	.19	.18	.20
Psychological well-being	.54***	.44***	.41***	.48***	.57***
Autonomy & parents	.31**	.19	.31**	.22	.33**
Peers & social support	.61***	.36**	.35**	.54***	.32**
School environment	.38**	.54***	.29*	.13	.52***
Functioning					
GMFCS	-.06	-.01	-.12	-.27*	-.01
MACS	.12	-.07	-.11	-.10	-.07
CFCS	-.04	-.14	-.10	.06	-.14
EDACS	-.03	-.07	-.10	-.19	-.07

* $p < .05$. ** $p < .01$. *** $p < .001$

et al. 2008; Wake et al. 2003). These conclusions can also be applied, for the child/teen self-report, where moderate correlations were found between the two QOL instruments, indicating that CP QOL is a valid tool for measuring QOL although each instrument capture specific aspects of it. In addition, physical domains were more strongly associated with functioning than psychosocial domains, suggesting that function has a limited influence in subjective aspects of QOL.

One of the limitations of the study was the failure to check the factor structure of the child/teen version of the questionnaire, as these results suggest that parents and children have different perceptions of the different QOL domains. Another limitation, due to high presence of cognitive impairment in our study sample, is not having considered the inclusion of specific life areas that can contribute to the QOL of children/adolescents with PC and ID. The specificity of our sample, although representative of the CP population, could suppose a bias and future studies must include broader samples.

In sum, this study presents the psychometric properties of Spanish version of the CP QOL for child/adolescent, in its self-report and primary caregiver report. It offers researchers and service providers a reliable and valid instrument to establish QOL profiles and to assess the effectiveness of interventions for children and adolescents with CP between ages 4 to 18 years. The little influence of functioning in the QOL perceived by children/adolescents with CP supports a change of paradigm, from function to QOL and participation. In this sense, the use of the CP QOL in clinical settings would provide the health and social systems with a valid instrument to assess and plan interventions related to this new paradigm and should be promoted.

Acknowledgments 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.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

Appendix

Table 6 Spanish version of CP QOL

Versión Padres	Versión Niño/adolescente
Familia y amigos	
1. su capacidad para jugar con los amigos?	1. tu capacidad para jugar con los amigos?
2. la forma en que se lleva bien con la gente?	2. la a forma como te llevas bien con la gente?
3. la forma en que se lleva con usted?	3. la forma como te llevas con tus padres?
4. el apoyo que recibe de su familia?	4. el apoyo que recibes de tu familia?
5. cómo se lleva con sus hermanos/as?	5. la forma como te llevas con tus hermanos?
6. la forma en que se lleva con otros niños fuera del colegio	6. la forma como te llevas con otros chicos fuera del colegio?
7. la forma en que se lleva con los adultos?	7. la forma como te llevas con los adultos?
8. ir de viaje con la familia?	8. ir de viaje con tu familia?
9. la forma en que es aceptado por su familia?	9. la forma como eres aceptado por tu familia?
10. la forma en que es aceptado por otros chicos fuera del colegio?	10. la forma como eres aceptado por otros chicos fuera del colegio?
11. la forma en que es aceptado por los adultos?	11. la forma como eres aceptado por los adultos?
12. la forma en que es aceptado por la gente?	12. la forma como eres aceptado por la gente?
13. su capacidad para jugar solo?	13. tu capacidad para jugar solo?
14. el ser capaz de hacer las cosas que quiere hacer?	14. el ser capaz de hacer las cosas que quieres hacer?
15. pasar el rato solo?	15. pasar el rato tú solo?
16. pasar el rato con amigos?	16. pasando el rato con amigos?
17. la forma en que intenta cosas nuevas?	17. la forma como intentas cosas nuevas?
Participación	
18. su capacidad para participar en actividades de ocio?	18. tu capacidad para participar en actividades de ocio?
19. su capacidad para participar en actividades deportivas?	19. tu capacidad para participar en actividades deportivas?
20. su capacidad para participar en actividades sociales?	20. tu capacidad para participar en eventos sociales?
21. su capacidad para participar en la comunidad?	21. tu capacidad para participar en la comunidad?
Comunicación	

Table 6 (continued)

Versión Padres	Versión Niño/adolescente
22. la forma de comunicarse con gente que conoce bien?	22. la forma de comunicarte con la gente que conoces bien?
23. la forma de comunicarse con gente que no conoce bien?	23. la forma de comunicarte con gente que no conoces bien?
24. la forma de comunicarse otra gente con él?	24. la forma de comunicarse otra gente contigo?
25. la forma de comunicarse con gente usando la tecnología?	25. la forma como te comunicas con gente usando la tecnología?
Salud (niño/adolescente)	
26. su salud general?	26. tu salud general?
27. su salud física?	27. tu salud física?
28. la forma como se mueve?	28. la forma como te mueves?
29. la forma como duerme?	29. la forma como duermes?
30. la forma como le miran?	30. la forma como te miran?
31. la manera en que usa sus brazos y manos?	31. la forma como usas tus brazos y manos?
32. la forma como usa sus piernas?	32. la forma como usas tus piernas?
33. su vida?	33. tu vida?
34. con él mismo/?	34. contigo mismo?
35. su futuro?	35. tu futuro?
36. sus oportunidades en la vida?	36. tus oportunidades en la vida?
37. su capacidad para vestirse solo?	37. tu capacidad para vestirse solo?
38. su capacidad para beber solo?	38. tu capacidad para beber solo?
39. su capacidad para ir solo al baño?	39. tu capacidad para ir solo al baño?
40. conseguir las cosas en las que quiere ser bueno?	40. conseguir las cosas en las que quieres ser bueno?
41. su capacidad para desplazarse por su barrio?	41. tu capacidad para desplazarte por tu barrio?
42. su capacidad para ir de un sitio a otro (ej.: transporte)?	42. tu capacidad para ir de un sitio a otro (ej.: transporte)?
43. los cambios que pasan en su cuerpo relacionados con la pubertad?	43. los cambios que pasan en tu cuerpo relacionados con la pubertad?
44. su capacidad de hacer cosas por él mismo, sin depender de otros?	44. tu capacidad de hacer cosas por ti mismo, sin depender de otros?
45. lo que le puede pasar después en la vida?	45. lo que te puede pasar después en la vida?
46. lo que ha conseguido en su vida?	46. lo que has conseguido en tu vida?
47. sus planes para el futuro?	47. tus planes para el futuro?
Dolor y molestias	
48. ¿Está tu hijo molesto por las visitas al hospital?	48. ¿Estás molesto por las visitas al hospital?
49. ¿Está tu hijo molesto cuando falta al colegio por razones de salud?	49. ¿Estás molesto cuando faltas al colegio por razones de salud?
50. ¿Está tu hijo molesto cuando siendo asistido por otras personas?	50. ¿Estás molesto siendo asistido por otras personas?
51. ¿Está tu hijo preocupado por quién le cuidará en el futuro?	51. ¿Estás preocupado con quién cuidará de en el futuro?
Escuela	
52. la forma en que se lleva con sus compañeros en el colegio?	52. la forma en que te llevas con los otros chicos/compañeros en el colegio?

Table 6 (continued)

Versión Padres	Versión Niño/adolescente
53. la forma en que se lleva con sus profesores o cuidadores?	53. la forma como te llevas con tus profesores o cuidadores?
54. la forma como es aceptado por sus compañeros del colegio?	54. la forma como eres aceptado por otros compañeros del colegio?
55. la forma como se lleva con otros chicos de fuera del colegio?	55. la forma como te llevas con otros chicos de fuera del colegio?
56. cómo es aceptado por los profesores y el personal del colegio?	56. la forma como eres aceptado por los profesores y el personal del colegio?
57. el ser tratado igual que todos los demás en el colegio?	57. el ser tratado igual que todos los demás en el colegio?
58. su capacidad para llevar el ritmo físico de sus compañeros?	58. tu capacidad para seguir el ritmo físico de tus compañeros
59. su capacidad para seguir el ritmo académico de sus compañeros?	59. tu capacidad para seguir el ritmo académico de sus compañeros?
60. su capacidad para participar en el colegio?	60. tu capacidad para participar en el colegio?
Acceso a los servicios	
61. el acceso de su hijo a los tratamientos?	
62. el acceso de su hijo a terapias?	
63. el acceso de su hijo a la atención médica o quirúrgica especializada?	
64. su capacidad para obtener consejo de un pediatra/médico?	
65. el acceso de su hijo para recibir apoyo para el aprendizaje en el colegio?	
66. el acceso de su hijo a los servicios e instalaciones de la comunidad?	
Salud (cuidadores)	
67. su salud?	
68. su situación laboral?	
69. su situación económica familiar?	
70. ¿Es usted feliz?	
Preguntas finales	
71. ¿Está preocupado su hijo por tener parálisis cerebral?	52. ¿Estás preocupado por tener parálisis cerebral?
72. ¿Cuánto dolor tiene tu hijo?	53. ¿Cuánto dolor tienes?
73. ¿Cómo se siente su hijo con la intensidad de dolor que sufre?	54. ¿Cómo te sientes con la cantidad de dolor que sufres?
74. ¿Cuánto malestar experimenta tu hijo/a?	55. ¿Cuánto malestar experimentas?
75. ¿Es su hijo feliz?	56. ¿Lo feliz que eres?

References

- Atasavun Uysal, S., Düger, T., Elbasan, B., Karabulut, E., & Toylan, İ. (2016). Reliability and validity of the cerebral palsy quality of life questionnaire in the Turkish population. *Perceptual and Motor Skills*, 122(1), 150–164. <https://doi.org/10.1177/0031512515625388>.
- Aymerich, M., Berra, S., Guillaumon, I., Herdman, M., Alonso, J., Ravens-Sieberer, U., & Rajmil, L. (2005). Development of the Spanish version of the KIDSCREEN, a health-related quality of life instrument for children and adolescents. *Gaceta Sanitaria*, 19(2), 93–102.
- Badia, M., Orgaz, B., Riquelme, I., & Montoya, P. (2015). The relationship of cerebral palsy comorbid conditions with participation and quality of life. In J. L. Matson & M. L. Matson (Eds.), *Comorbid conditions among children with intellectual disabilities* (pp. 389–415). Can: Springer.
- Bjornson, K. F., & McLaughlin, J. F. (2001). The measurement of health-related quality of life (HRQL) in children with cerebral palsy. *European Journal of Neurology*, 8(Suppl 5), 183–193. <https://doi.org/10.1046/j.1468-1331.2001.00051.x>.
- Chen, K.-L., Wang, H.-Y., Tseng, M.-H., Shieh, J.-Y., Lu, L., Yao, K.-P. G., & Huang, C.-Y. (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>.
- 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>.
- Davis, E., Nicolas, C., Waters, E., Cook, K., Gibbs, L., Gosch, A., & Ravens-Sieberer, U. (2007). Parent-proxy and child self-reported health-related quality of life: Using qualitative methods to explain the discordance. *Quality of Life Research*, 16(5), 863–871.
- Davis, E., Reddihough, D., Murphy, N., Epstein, A., Reid, S. M., Whitehouse, A., Williams, K., Leonard, H., & Downs, J. (2017). Exploring quality of life of children with cerebral palsy and intellectual disability: What are the important domains of life? *Child: Care, Health and Development*, 43(6), 854–860. <https://doi.org/10.1111/cch.12501>.
- Davis, E., Shelly, A., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., & Graham, H. K. (2009). Quality of life of adolescents with cerebral palsy: Perspectives of adolescents and parents. *Developmental Medicine and Child Neurology*, 51(3), 193–199. <https://doi.org/10.1111/j.1469-8749.2008.03194.x>.
- Dmitruk, E., Mirska, A., Kułak, W., Kalinowska, A. K., Okulczyk, K., & Wojtkowski, J. (2014). Psychometric properties and validation of the polish CP QOL-child questionnaire: A pilot study. *Scandinavian Journal of Caring Sciences*, 28(4), 878–884. <https://doi.org/10.1111/scs.12095>.
- Eiser, C., & Morse, R. (2001). Quality-of-life measures in chronic diseases of childhood. *Health Technology Assessment*, 5(4), 1–157.
- Eliasson, A. C., Krumlinde-Sundholm, L., Rosblad, B., Beckung, E., Arner, M., Ohrvall, 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>.
- Hidecker, M. J., Paneth, N., Rosenbaum, P. L., Kent, R. D., Lillie, J., Eulenberg, J. B., et al. (2011). Developing and validating the communication function classification system 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>.
- Longo, E., Badia, M., Begoña Orgaz, M., & 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>.
- Majnemer, A., Shevell, M., Law, M., Poulin, C., & Rosenbaum, P. (2008). Reliability in the ratings of quality of life between parents and their children of school age with cerebral palsy. *Quality of Life Research*, 17(9), 1163–1171. <https://doi.org/10.1007/s11136-008-9394-6>.
- Murphy, N., Epstein, A., Leonard, H., Davis, E., Reddihough, D., Whitehouse, A., Jacoby, P., Bourke, J., Williams, K., & Downs, J. (2017). Qualitative analysis of parental observations on quality of life in Australian children with down syndrome. *Journal of Developmental and Behavioral Pediatrics*, 38(2), 161–168. <https://doi.org/10.1097/DBP.0000000000000385>.
- Muñiz, J., Elosua, P., & Hambleton, R. K. (2013). Directrices para la traducción y adaptación de los tests: Segunda edición. *Psicothema*, 25(2), 151–157.

- Palisano, R., Rosenbaum, P., Walter, S., Russell, D., Wood, E., & Galuppi, B. (1997). The gross motor function classification system for cerebral palsy. *Developmental Medicine and Child Neurology*, *39*, 214–223.
- Ravens-Sieberer, U., Auquier, P., Erhart, M., Gosch, A., Rajmil, L., Bruil, J., et al. (2007). The KIDSCREEN-27 quality of life measure for children and adolescents: Psychometric results from a cross-cultural survey in 13 European countries. *Quality of Life Research*, *16*(8), 1347–1356.
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B., & Jacobsson, B. (2007). A report: The definition and classification of cerebral palsy April 2006. *Developmental Medicine and Child Neurology*, *109*, 8–14.
- Sakzewski, L., Carlon, S., Shields, N., Ziviani, J., Ware, R. S., & Boyd, R. N. (2012). Impact of intensive upper limb rehabilitation on quality of life: A randomized trial in children with unilateral cerebral palsy. *Developmental Medicine and Child Neurology*, *54*(5), 415–423. <https://doi.org/10.1111/j.1469-8749.2012.04272.x>.
- Sellers, D., Mandy, A., Pennington, L., Hankins, M., & Morris, C. (2014). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. *Developmental Medicine and Child Neurology*, *56*(3), 245–251. <https://doi.org/10.1111/dmcn.12352>.
- Shelly, A., Davis, E., Waters, E., Mackinnon, A., Reddihough, D., Boyd, R., Reid, S., & Graham, H. K. (2008). The relationship between quality of life and functioning for children with cerebral palsy. *Developmental Medicine and Child Neurology*, *50*(3), 199–203.
- Stevens, J. (2002). *Applied multivariate statistics for the social sciences* (4th ed.). Mahwah: Lawrence Erlbaum Associates.
- Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, *2*, 53–55. <https://doi.org/10.5116/ijme.4dfb.8dfd>.
- 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*, 611–617. <https://doi.org/10.1111/dmcn.13751>.
- Upton, P., Lawford, J., & Eiser, C. (2008). Parent-child agreement across child health-related quality of life instruments: A review of the literature. *Quality of Life Research*, *17*(6), 895–913. <https://doi.org/10.1007/s11136-008-9350-5>.
- Wake, M., Salmon, L., & Reddihough, D. (2003). Health status of Australian children with mild to severe cerebral palsy: Cross-sectional survey using the child health questionnaire. *Developmental Medicine and Child Neurology*, *45*(3), 194–199.
- Wang, H. Y., Cheng, C. C., Hung, J. W., Ju, Y. H., Lin, J. H., & Lo, S. K. (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., Mackinnon, A., Boyd, R., Graham, H. K., Lo, S. K., et al. (2007). Psychometric properties of the quality of life questionnaire for children with CP. *Developmental Medicine and Child Neurology*, *49*(1), 49–55. <https://doi.org/10.1017/S0012162207000126.x>.
- Waters, E., Maher, E., Salmon, L., Reddihough, D., & Boyd, R. (2005). Development of a condition-specific measure of quality of life for children with cerebral palsy: Empirical thematic data reported by parents and children. *Child: Care, Health and Development*, *31*(2), 127–135.
- White-Koning, M., Arnaud, C., Dickinson, H. O., Thyen, U., Beckung, E., Fauconnier, J., McManus, V., Michelsen, S. I., Parkes, J., Parkinson, K., Schirripa, G., & Colver, A. (2007). Determinants of child-parent agreement in quality-of-life reports: A European study of children with cerebral palsy. *Pediatrics*, *120*(4), e804–e814. <https://doi.org/10.1542/peds.2006-3272>.
- WHOQOL, & Group. (1995). The World Health Organization quality of life assessment (WHOQOL): Position paper from the World Health Organization. *Social Science & Medicine* (1982), *41*(10), 1403–1409.
- Wood, E., & Rosenbaum, P. (2000). The gross motor function classification system for cerebral palsy: A study of reliability and stability over time. *Developmental Medicine and Child Neurology*, *42*(5), 292–296.
- World Health Organization. (2001). *International classification of functioning, disability and health*. Geneva: World Health Organization.
- World Health Organization- Division of Mental Health (1994). *Measurement of quality of life in children*. MNH/PSF/94. Geneva, Switzerland: World Health Organization.

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