Quality of Life in Children and Adolescents with Cerebral Palsy and Intellectual

Disability: Predictors and Personal Outcomes

Abstract

Although in recent years the interest in studying the quality of life (QoL) of children with cerebral palsy (CP) has been growing, there are hardly any studies that have specifically evaluated QoL in people with both CP and intellectual disability (ID). Therefore, this study aims to (1) describe the individual QoL of children and adolescents with CP and ID, and (2) examine the influence of several individual and environmental variables on the QoL scores. The sample encompassed a total of 165 participants with CP and ID aged 4 to 21 years old who were receiving support from 42 Spanish organizations. The KidsLife Scale was used. Descriptive statistics were obtained, and correlation and multiple regression analyses were performed. The highest values were obtained in physical well-being and rights, while the domains with the lowest scores were self-determination and social inclusion. Level of ID, percentage of disability, physical disability in the upper extremities and size of the organization were significant QoL predictors. This study provides useful information about strengths and needs of children and adolescents with CP and ID in the different domains of QoL and with insights into factors that may help to enhance their QoL.

Keywords: quality of life; children; adolescents; cerebral palsy; intellectual disability

1. Introduction

Cerebral palsy (CP) comprises a group of disorders characterized by the worsening of movement and posture, resulting from nonprogressive brain alterations that occur during fetal or infant development (Rosenbaum et al., 2007). It stands as the most prevalent cause of motor disability in early childhood, with an estimated overall prevalence of approximately 2-3 per 1,000 live births (Maenner et al., 2016). Often, this condition is accompanied by alterations in sensory, cognitive, communicative, and and perceptual impairments (Rosenbaum et al., 2007) that significantly impact (Badía et al., 2020) their participation and quality of life (QoL). Consequently, the concept of QoL assumes particular relevance in both the practical application and research within this field (Makris et al., 2021).

In recent years, there has been growing interest in studying the QoL of children and adolescents with CP (Badía et al., 2016). However, the majority of the research in this area has mainly focused on the milder forms of disability and the more limited construct of health-related QoL (Michalska et al., 2018). Thus, despite the fact that is estimated that around half of children with CP also have intellectual disability (ID; Davis et al., 2017), there is a notable scarcity of studies specifically evaluating the QoL of people with both CP and ID. Regrettably, the QoL of children and youth with the most severe disabilities has often overlooked (White-Koning et al., 2008).

Both self-reports and reports from others regarding the QoL of children and youth with CP mostly indicate that health-related QoL tends to be lower in children with CP when compared to their peers without disabilities (Cardoso et al., 2018; Glinac et al., 2016; Jeong et al., 2018; Koltuniuk et al., 2019; Power et al., 2018; Unver & Erdem, 2019). However, research conducted by the SPARCLE group, involving several European countries, found similar scores in self-reported health-related QoL of children and youth with CP compared to their peers without it (Colver et al., 2015; Dickinson et al., 2007). Varying study designs,

different participant characteristics (e.g., cognitive abilities) or different source populations

may account for these differences found in literature.

Some studies have also explored the influence of various variables on health-related

QoL in children and adolescents with CP. Some variables associated with poorer health-

related QoL in this population are: older age or adolescence (Omura et al., 2018; Radsel et al.,

2017; Rapp et al., 2017), being enrolled in mainstream education (Badía et al., 2016), lower

participation in leisure activities (Shikako-Thomas et al., 2012), higher dependency (Giray et

al., 2018; Williams et al., 2021), psychological problems (Rapp et al., 2017), pain (Colver et

al., 2015; Radsel et al., 2017), comorbidities (Reddihough et al., 2021), living in a low-middle

income country (Power et al., 2018), parental stress (Rapp et al., 2017), and limited access to

support and services (Milićević et al., 2022; Rezaei et al., 2021). Regarding gender, several

studies suggest that it does not significantly influence health-related QoL (Kołtuniuk et al.,

2019; Pérez-Ardanaz et al., 2020), except for Cardoso et al. (2018), who observed lower

scores in women.

In particular, the limited number of studies conducted specifically with children who

have both CP and ID has focused on identifying key areas related to their QoL, such as

physical health, body comfort, behaviour and emotions, communication, predictability and

routine, movement and physical activity, nature and outdoors, variety of activity,

independence and autonomy, social connectedness, and access to services (Davis et al., 2017).

These studies have reported generally positive scores in health-related QoL for this group,

with several factors influencing their QoL. These factors include the presence of pain or

parental stress, the degree of ID, and the type of schooling (Michalska et al., 2018; White-

Koning et al., 2008).

While most research on the QoL of people with CP primarily aims to assess health-

related QoL (WHOQOL Group, 1995), with a focus on how the disease or disability impacts

the person's functioning (Michalska et al., 2018; Makris et al., 2021), our study takes a different approach and is focused on a more comprehensive and holistic QoL construct, one that extends beyond health and incorporates the broader context and all significant domains in a person's life. This approach aligns with the concept of individual QoL (Gómez et al., 2021a; Morán et al., 2019a; Verdugo et al., 2021, 2023). Furthermore, our study specifically targets the population that concurrently presents both CP and ID. This focus is driven by the notable scarcity of specific studies addressing the QoL of this population.

Among the frameworks addressing individual QOL, the model proposed by Schalock and Verdugo (2002) stands out due to its widespread adoption by professionals and organizations working in the disability field across numerous countries. Moreover, it is known for its robust empirical evidence supporting its formulation, validation, and application (e.g., Arias et al., 2018; Gómez et al., 2016, 2020a, 2020b, 2021b; Fernández et al., 2018; Morán et al., 2019a; Stone et al., 2020; Swerts et al., 2022a, 2022b).

According to the Schalock and Verdugo model, individual QoL is understood as a desired state of personal well-being, comprising eight domains: social inclusion, self-determination, emotional well-being, physical well-being, material well-being, rights, personal development, and interpersonal relationships. The concept has both universal properties and others that depend on cultural factors. It encompasses both objective and subjective components, and is influenced by individual and environmental factors (Schalock and Verdugo, 2002). In this context, personal characteristics and environmental factors can play roles as mediator or moderator variables in influencing QoL- related personal outcomes (Gómez et al., 2020). A moderator factor alters the relation between two variables, thereby modifying the form or strength of that relationship (e.g., gender, level of ID). On the other hand, a mediator factor influences the relationship between two independent variables and the

outcome of interest, demonstrating indirect causation, connection, or relation between them (e.g., supports).

This more inclusive, comprehensive, and context-focused perspective on QoL, which extends beyond health-related aspects, has received limited attention and has been scarcely investigated in people with CP. In fact, based on this socioecological model, there are only two studies that specifically aim to assess individual QoL and its predictors in people with CP, and both of them are confined to adulthood (Badía et al., 2013; Maestro-González et al., 2018).

The sole study that includes people with CP and ID was conducted by Badía et al. (2013). This study revealed for aging participants with CP: (a) generally good QoL; (b) lower scores in the domains of interpersonal relationships, self-determination, social inclusion, and rights, but higher scores in emotional well-being; and (c) a significant negative relationship between the degree of ID and QoL scores, the presence of communication disorders and QoL scores, and the degree of motor impairments and scores in material and physical wellbeing, respectively.

In the context of childhood and adolescence, there is a single study focusing on the QoL of children and adolescents with CP in Spain, conducted by Longo et al. (2012). However, this research has several limitations: (a) it focuses on health-related QoL; (b) it only includes participants from a specific Spanish autonomous region, namely Castilla y León; (c) it employs a scale with questionable internal consistency in three domains, as evidenced by Cronbach's alpha coefficients ranging from .407 to .547; and (d) it utilizes a generic instrument, the Kidscreen Scale (Aymerich et al., 2005), which is not specifically adapted to children with disabilities or CP and may not be sensitive enough to capture specific aspects and priorities in the QoL of children with CP (Badía et al., 2020; Jovellar-Isiegas et al., 2020). Nonetheless, the study did reveal reduced levels of QoL reported by parents, and similar to

the findings of Badía et al. (2013) with adults with CP and ID, Longo et al. observed inverse

relationships with the level of ID, the degree of motor impairment, and communication

problems.

Therefore, it is important to note that the limited existing literature on individual QoL

in people with CP and ID has primarily examined level of ID and comorbidities as significant

variables. Hence, there is a need for research efforts to expand the range of individual and

environmental variables studied to develop a more comprehensive understanding of their

relationships with individual QoL. Such knowledge can have significant potential in guiding

and enhancing professional and organizational practices, especially paying attention to those

factors that can be shaped and influenced to promote and enhance users' QoL (Balboni et al.,

2020).

The KidsLife Scale (Gómez et al., 2016) is the sole instrument validated in Spain for

assessing the QoL of children and adolescents with ID who have extensive support needs. It is

structured based on the eight-domain model proposed by Schalock and Verdugo, and is

designed to be completed by proxy raters who are well-acquainted with the person being

evaluated and have ample opportunities to observe them in various contexts over extended

periods of time. This instrument has substantial evidence supporting its validity and reliability

for use with people with ID ranging from 4 to 21 years of age. The KidsLife Scale has been

applied to children with ID and other comorbid conditions, including autism spectrum

disorder (Arias et al., 2018; Gómez et al., 2020a; Morán et al., 2019a, 2019b), Down

syndrome (Gómez et al., 2020b; Morán et al., 2022), and rare diseases (González et al., 2016).

However, there is currently a dearth of studies about QoL-related personal outcomes and

predictors within the population of CP.

For this reason, the objectives of the current study are: (1) to provide a description of

the individual QoL-related outcomes and the results in the eight domains of children and

adolescents with CP and ID as reported by professionals and families; and (2) to examine the influence of several individual factors (i.e., gender, age, level of ID, level of support needs, degree of dependency, percentage of disability, comorbidities) and environmental factors (i.e., size of the organization providing the supports, type of schooling) on the QoL scores of the participants. Based on the insights from prior research conducted with this and other groups with disabilities, we hypothesize that participants with a greater age, comorbidities, higher degree of dependency, higher percentage of disability, higher levels of ID, and increased support needs who are enrolled in mainstream education and in smaller organizations will exhibit lower levels of QoL (Badía et al., 2016; Michalska et al., 2018; Morán et al., 2022; Omura et al., 2018; Reddihough et al., 2021; Williams et al., 2021). Conversely, we do not anticipate significant gender differences (Pérez-Ardanaz et al., 2020).

As a result, this study aims to offer valuable insights the strengths and challenges faced by children and adolescents with CP and ID across the different QoL domains. Additionally, it seeks to shed light on the factors that can be leveraged to develop and assess the effectiveness of person-centered plannings, organizational strategies, and social policies aimed at enhancing the QoL of this particular group.

2. Method

2.1 Participants

The total sample consisted of 165 participants who met the following criteria for inclusion: (a) having both CP and ID; (b) falling withing the age range of 4 to 21 years; and (c) attending any Spanish organization that offers educational, social, or health services. The only exclusion criterion was not being part of the education system, as the scale used in this study includes items related to educational settings. The sample comprised a majority of male participants, with 94 individuals (57%) being male. The ages of the participants ranged from 4 to 21 years, with a mean age of 12.9 years ($SD = 4.9$).

According to official records at organizations in which participants were recruited, the majority of participants had severe (43%) or profound (38%) levels of ID, with generalized support needs (82%). All participants presented other associated conditions, the most prevalent ones were physical disability in the lower (70%) and upper extremities (58%); epilepsy (33%); visual impairments (28%); serious health problems (16%); hearing impairments (8%); behavioral problems (6%); or autism spectrum disorders (4%). With regard to legally recognized degree of dependency, most participants (87%) had great dependency (level 3), while 8% had severe dependency (level 2) and only 5% had moderate dependency (level 1). Almost all lived in their family home (79%) or in a residential center (10%). The great majority (91%) were attending special schools, only 3% attended mainstream schools and 6% were enrolled in both types of schools at the same time. Further sociodemographic characteristics of participants with CP can be seen in Table 1.

Participants were receiving support and services from 42 organizations in 15 of the 17 Spanish autonomous regions (except for La Rioja and País Vasco). Children and adolescents with CP received subsidized (87%), private (12%) or public (1%) services from educational centers (92%) more often than social (7%) and health (1%) services. Most organizations (63%) were serving more than 50 users and were located primarily in urban settings (78%).

The QoL assessments for these participants were completed by 98 respondents. Each of these evaluators completed between 1 and 5 scales. The majority of these respondents were women (79%). Their average age was 41.9 years old ($SD = 9.7$). In terms of their relationship with the individual being assessed, the vast majority (89%) were direct-care staff, primarily teachers (61%), whereas 11% were parents, mainly mothers (9%). To complete the questionnaire, over half of the respondents (60%) needed to consult other people, primarily professionals (48%) and family members (23%). The main informants had known the people

being evaluated for a period ranging from 6 months to 21 years ($M = 5$; $SD = 4.3$) and most of them had daily interactions with the person with CP daily (94%).

< Insert Table 1 here >

2.2 Instrument

We used the KidsLife Scale (Gómez et al., 2016), which is designed to assess the individual QoL of people with ID, aged from 4 to 21 years old, and who are receiving support in educational, social, or health services. The scale is intended to be completed by proxy raters (e.g., relatives, teachers, caregivers), who have known the person well (for at least 6 months) and have had ample opportunities to observe them across different settings over extended periods of time. It comprises 96 items, organized into the eight QoL domains (social inclusion, self-determination, emotional well-being, physical well-being, material well-being, rights, personal development, and interpersonal relationships). Each item is drafted in the third person and is answered using a four-point frequency scale ("never," "sometimes," "often," "always"). The scale also contains a section for sociodemographic data about the person being evaluated, the principal respondent, and the organization or entity where they receive support or services. The average time spent completing the scale is around 29 minutes ($SD = 17$).

The KidsLife Scale provides total scores for the eight domains and a general QoL score. It also yields standardized scores ($M = 10$; $SD = 3$) and percentiles for the eight domains and a total QoL index ($M = 100$; $SD = 15$). The obtained standard scores can also be reported graphically in a QoL profile to facilitate their interpretation. They can be used for benchmarking or for determining gains by conducting longitudinal or cross-sectional studies. The Spanish (together with its translation into English and Korean) is freely available at https://sid-inico.usal.es/documentacion/escala-kidslife.

The KidsLife Scale shows a great amount of evidence related to its validity and reliability. Thereby, evidence of content validity was provided by Gómez et al. (2014). In the validation study (Gómez et al., 2016) conducted with participants with ID and mostly other associated conditions (e.g. autism, Down syndrome, cerebral palsy), Cronbach's alpha for the whole scale was .96, while for the domains it ranged from .78 (rights) and .90 (personal development). Concerning the validity based on the internal structure of the scale, the intercorrelated eight-domain model showed adequate fit indexes (RMSEA < .06; CFI and TLI > .98; SRMR < .50). In the present study, Cronbach's alpha for the whole scale was .96, while for the domains it ranged from .71 (physical wellbeing) and .90 (personal development).

2.3 Procedure

Participants were recruited through contact with organizations, centers, and service providers working with people with ID under 21 years old in Spain. In order to get the study known by as many potential participants as possible, a thorough web search of entities, organizations, and services was performed. The study was also disseminated through the Institute of Community Integration (INICO) website, social networks (e.g., Twitter and Facebook), and scientific conferences and meetings. A mass-email was sent to all potential participants explaining the aims of this research, specifying the inclusion and exclusion criteria for participants and inviting them to participate. Once they expressed their willingness to participate, they were sent a link to an online survey requesting information about their center, the number of people to be assessed, and the person in charge of coordinating the assessment and distributing the information to potential participants (professionals and relatives).

In addition to the the KidsLife scale administration booklets, a protocol of instructions to implement the scale was sent via email to the coordinator in each center with the aim of standardizing the assessment procedures. The protocol encompassed detailed information about the research, access to the electronic and printable versions of the scale, the instruction

manual, and the informed consent to be signed by participants or their legal guardians. The

scale could be completed electronically or on paper. The research team was available by

email, phone, or in person to address questions, comments, and suggestions.

The study was approved by the ethics committee of the [deleted for the purpose of a

masked review] and followed the principles of the Declaration of Helsinki. To ensure

confidentiality, we used alphanumeric codes that were anonymous to the research team. These

codes allowed us to send the organizations a report with the results obtained by participants in

their center, so that they could use them in individualized support plannings and

organizational strategies aim to enhance the QoL of the people they support.

2.4 Data Analyses

Data were analyzed with IBM SPSS Statistics (Version 27). Descriptive statistics of the total

and domain-specific raw scores (i.e., skewness, kurtosis, minimum, maximum, mean,

standard deviation, median and mode) were obtained. Furthermore, the KidsLife total and

domain-specific raw scores, and the two continuous variables age and percentage of disability

have been checked for the presence of univariate outliers (i.e., participants with a z-value

higher than |3.29|) and multivariate outliers (i.e., participants for whom the probability

associated with the Mahalanobis distance was lower than 0.001).

We computed coefficients among each variable (i.e., gender, age, level of ID, level of

support needs, degree of dependency, percentage of disability, physical disability in the lower

extremities, physical disability in the upper extremities, epilepsy, visual impairments and size

of the organization) and each domain and the QoL total score. All the continuous variables

were normalized before being used. Pearson's correlation coefficient was performed for the

continuous variables (i.e., age, percentage of disability), Spearman's correlation coefficients

for the ordinal variables (i.e., level of ID and size of the organization), and point-biserial

correlation coefficient for the dichotomous variables (i.e., gender, physical disability in the

lower extremities, physical disability in the upper extremities, epilepsy, visual impairments, level of support needs and degree of dependency). It must be noted that we computed point-biserial correlation coefficients for level of support needs and degree of dependency since the number of participants distributed in some specific levels was very low for both of them, and thus it was necessary to fuse them into two new categories. In accord with Cicchetti et al. (2011), the magnitude of the correlation coefficients was interpreted as very large ($\geq .70$), large ($.50 - .69$), medium ($.30 - .49$), small ($.10 - .29$) and trivial ($< .10$).

Then, multiple regression analyses were performed for the total and each QoL domain score to analyze the influence of variables on QoL. All the variables found to be statistically significant related to the QoL domain or the QoL total score ($p < .05$) were entered simultaneously as independent variables. Proxy perspectives on participants for the total QoL score or each of the eight QoL domains formed the dependent variables. The squared semipartial correlation coefficient (sr^2) of each statistically significant correlated independent variable was performed to detect its unique contribution to the total explained variance of QoL. Following Tabachnick and Fidell (2013) suggestion's, the absence of multicollinearity between independent variables was verified for each regression run by examining that the tolerance index and the variance inflation factor (VIF) were higher than .50 and lower than 2, respectively. Moreover, the residuals were screened after conducting the regression analyses. Specifically, the normality, linearity, and homoscedasticity of errors was checked, by examining the shape of the residual distribution scatterplots for each dependent variable and the sets of independent variables. Furthermore, independence of residuals was assessed through Durbin-Watson statistics (appropriate values ranging from 1.5 to 2.2), and verifying the absence of outliers in standardized residuals (Tabachnick & Fidell, 2013). The minimum number of participants to perform regression analysis was checked in accordance with the

assumption that $n \geq 104 + m$ (where m is the number of independent variables) (Tabachnick & Fidell, 2013).

We initially contemplated other associated conditions (i.e., serious health problems, hearing impairments, behavioral problems, autism spectrum disorder, mental health problems, or West syndrome), type of schooling or respondent's sociodemographic factors (i.e., type of informant, gender, age, frequency of contact, and length of relation). However, these variables were finally excluded from the data analysis due to the small number of participants (Table 1), as well as the existence of multiple informants for the majority (60%) of the questionnaires.

3. Results

Table 2 reports the descriptive statistics of the raw scores obtained at the KidsLife Scale domains. As shown, the scores were normally distributed except that for the EW (i.e., skewness and kurtosis within the range |1|). None univariate or multivariate outliers were detected, neither for the KidsLife Scale scores nor for the two continuous variables age and percentage of disability. The scores on the KidsLife Scale domains ranged from 187 to 367. The mean 294.82 ($SD = 35.16$) and the median 292 were above the theoretical midpoint of the scale (theoretical midpoint = 192). Also, the most frequent score obtained by participants was 319. Concerning QoL domains, the highest values were obtained in physical well-being ($M = 42.73$, $SD = 3.81$), and rights ($M = 40.28$, $SD = 4.81$), while the domains with the lowest scores were self-determination ($M = 28.34$, $SD = 7.42$) and social inclusion ($M = 31.47$, $SD = 6.47$).

< Insert Table 2 here >

3.1 Relationships Between Factors and QoL of Children and Adolescents with CP and ID

As shown in Table 3, gender exhibited no statistically significant relationships with any QoL domain or the total score of the KidsLife Scale. Age was statistically significantly positively associated with self-determination with a small correlation coefficient magnitude.

Level of ID showed statistically significantly negative correlations with the total score, and self-determination, material well-being, interpersonal relationships, and personal development domains. Magnitude of the correlation coefficients was large for self-determination, small for material wellbeing and medium for the total score and the other domains.

Level of support needs and degree of dependency were statistically significantly negatively associated with self-determination, interpersonal relationships and personal development, whereas they were statistically significantly positively associated with physical wellbeing. Level of support needs was also significantly negatively associated with the total score. Correlation coefficient sizes were small.

Percentage of disability showed statistically significantly negative correlations with self-determination, emotional wellbeing, interpersonal relationships, personal development and the total score. Magnitude of the correlation coefficient was small in all cases except for the medium magnitude found for self-determination and personal development domains.

Regarding associated conditions, physical disability in the upper extremities was statistically positively related to social inclusion, but also to physical wellbeing and rights. Visual impairments were statistically significantly negatively associated with self-determination and personal development. All these correlation coefficient magnitudes were small. Epilepsy and physical disability in the lower extremities were not correlated with any QoL domain or the total score.

Finally, the environmental variable size of the organization was statistically significantly positively associated with rights with a small correlation coefficient magnitude.

< Insert Table 3 here >

3.2 Factors Affecting QoL of Children and Adolescents with CP and ID

The factors that were statistically significantly correlated with the children's QoL and consequently were entered as independent variables in the regression analyses were: eight individual factors (i.e. age, level of ID, level of support needs, degree of dependency, percentage of disability, physical disability in the lower extremities, physical disability in the upper extremities, visual impairments) and one environmental factor (i.e. size of the organization). A maximum of six independent variables were entered simultaneously in the regression models. Hence, the required minimum number of 110 participants for the factor regression analyses was met. The absence of multicollinearity among independent variables was suggested since all the tolerance indexes were higher than .50 and all VIFs lower than 2. All the other assumptions concerning residuals were met for each regression performed.

Table 4 shows the results of the multiple regression analyses performed to examine individual and environmental factors affecting proxy perspectives on QoL, when entered simultaneously. Concerning individual factors, level of ID negatively influenced the total score, self-determination, interpersonal relationships and personal development. Also, the percentage of disability negatively affected self-determination, emotional wellbeing, interpersonal relationships and personal development. On the other hand, physical disability in upper extremities positively influenced social inclusion and rights. Even though age, level of support needs, degree of dependency, physical disability in the lower extremities and visual impairments were significantly correlated with the total score or specific domains, they did not affect QoL when considered simultaneously with the other variables. Regarding environmental factors, size of the organization had a positive influence on rights. Lastly, as shown by the squared semipartial correlation coefficients (sr^2), the strongest association was that of level of ID on self-determination (.15), while in all other cases the sr^2 range was .02-

.05. This regression model was also the one for which the independent variable (i.e, level of ID) explained the highest portion of variance (30%) of the dependent variable (i.e., self-determination).

< Insert Table 4 here >

4. Discussion

This study presents the individual QoL-related outcomes of a group of children and adolescents with CP and ID in Spain, according to proxy perspectives and examines variables that predict their QoL. It is aimed to fill the gap existing in the evaluation of individual QoL and its predictors specifically in this population. Overall, QoL scores were favorable: mean, median and mode of the total QoL score of children with CP and ID surpassed the theoretical midpoint of the scale. These positive findings are consistent with the two only studies that evaluated individual QoL in CP population (Badía et al., 2013; Maestro-González et al., 2018). However, it is important to note that we do not have a comparison group to conclude whether, despite these favorable results, the quality of life of this collective is lower than that of their peers without disabilities.

The results by domains showed that the highest values were obtained in physical well-being and rights. Regardless of the physical difficulties that children with PC may have, these positive results in physical wellbeing are, to some extent, expected if we consider that given the motoric nature of the CP, a great part of the efforts may focus on the treatment of physical and health problems. These outcomes do not look surprising since they are in consonance with those obtained in other populations with disability (e.g. González et al., 2016; Morán et al., 2019a, 2022; Verdugo et al., 2019) and if we take into consideration that the rehabilitation paradigm aimed at providing basic care and reducing the impact of disabilities has prevailed in recent years.

It is somewhat unexpected to find such positive results in the domain of rights, especially considering that Badía et al. (2013) reported low scores in this domain for aging participants with CP and ID. Despite the existing challenges in the implementation of the Convention on the Rights of Persons with Disabilities (United Nations, 2006) for people with ID (Gómez et al., 2020c, 2022, 2023), these high scores among our participants could be partially explained by the possibility that they are receiving better support in terms of intimacy, confidentiality, and respect. Another possible explanation is that respondents might relax their criteria for respecting privacy or confidentiality when it comes to minors. In this sense, our results align with other studies conducted with children with ID and other associated conditions (e.g., González et al., 2016; Morán et al., 2022). Nevertheless, promoting the effective implementation of rights should be an on-going effort throughout the lifespan, and it would be desirable to ascertain whether the rights of young people with CP and ID are genuinely respected from their own perspective (Gómez et al., 2022).

The lowest scores were obtained in self-determination and social inclusion, which aligns with findings from previous studies involving this population and other disability groups (e.g., Badía et al., 2013; González et al., 2016; Leonard et al., 2022; Morán et al., 2022; Radsel et al., 2017; Sentenac et al., 2021; Verdugo et al., 2019). This trend may be attributed to the fact that a great part of interventions aims to improve physical health of people with CP, whereas other crucial areas in the life of the person may be dismissed (Radsel et al., 2017). In this context, while active participation in natural environments is associated with enjoyment, relief of stress and pain, and improved QoL (Davis et al., 2017; Longo et al., 2017; Omura et al., 2018), several studies have highlighted the lack of available social and leisure activities for children with CP (Arnaud et al., 2008; Longo et al., 2017). Likewise, despite some recent progress, society continues to perceive people with disabilities as incapable of taking control over their lives (Maestro-González et al., 2018). Contrary to this

perception, ample evidence demonstrates that people with disability can gain self-determination skills with appropriate support and opportunities, and these skills have numerous positive implications for their adult life and overall QoL (Burke et al., 2020; Morán et al., 2020). Thus, it is crucial to prioritize and address the domains of self-determination and social inclusion when planning, implementing, and evaluating support and services aimed at enhancing the QoL of children and adolescents with CP.

Regarding the relationship between several individual and environmental variables and the QoL scores, gender did not have a significant impact on the total QoL score and domain scores, aligning with several previous studies (Kołtuniuk et al., 2019; Michalska et al., 2018; Pérez-Ardanaz et al., 2020), and contrary to Cardoso et al. (2018), who reported lower values in females. Unexpectedly, age did not exhibit any significant variance in the children's total QoL score and domain scores, contrary to prior literature (Omura et al., 2018; Radsel et al., 2017; Rapp et al., 2017).

To our knowledge, no previous study has examined the relationship between percentage of disability and QoL in this population. More specifically, percentage of disability is a legal qualification of the degree of disability in Spain. It is assessed by a multidisciplinary team that carries out a comprehensive evaluation. A percentage of 33% is necessary for the disability to be recognized as such. In this study the percentage of disability negatively affected self-determination, emotional wellbeing, interpersonal relationships and personal development. Similarly, level of ID affected self-determination, interpersonal relationships, personal development, and the total score negatively. In fact, the strongest association found in this study was that of the level of ID on self-determination. These results are in consonance with prior studies (Badía et al., 2013; Longo et al., 2012) and could be due to the fact that people with severe and profound ID tend to be seen as if they were unable to develop self-determination skills and they are provided with less opportunities. For people

with severe disabilities, self-determination often relies on actions conducted by others. Therefore, there is an urgent need to implement adaptations to foster their self-determination and QoL, such as using technology devices, paying attention to non-verbal behaviors, or promoting supported decision making (Davis et al., 2017; Shogren et al., 2017). On the other hand, level of support needs and level of dependency did not affect QoL or its domains when considered simultaneously with the other variables, contrary to several studies conducted with this and other groups with disability (Giray et al., 2018; Morán et al., 2022; Verdugo et al., 2019; Williams et al., 2021).

Physical disability in upper extremities positively influenced social inclusion and rights. A possible explanation is that people with physical disability in upper extremities might be systematically receiving better support aimed at treating their physical disabilities and have better opportunities to exercise their rights and be socially included. Maybe, they cope with physical limitations and potential barriers better. Conversely, physical disability in the lower extremities and visual impairments did not affect QoL when considered simultaneously with the other variables.

Regarding environmental variables, according to other studies (Morán et al., 2022), the size of the organization has a positive influence on rights. Maybe because larger organizations have more economical and human resources that allow them to provide a wider variety of services and support and consequently, implement their user's rights to a greater extent. It's essential to note that the size of the organization in our study refers to the total number of individuals for whom the organization provides support, but these individuals may receive their support in smaller units or centers within the organization, and this finer level of granularity was not included in our analysis.

Therefore, like most research, this study is not free of limitations. In addition to the ones mentioned, the conclusions are only applicable to those children and adolescents with

CP and a comorbid diagnosis of ID. However, due to the lack of an official census of people with CP and ID in Spain, participants were selected based on a convenience sampling of individuals who agreed to participate. Therefore, outcomes should be interpreted cautiously.

Moreover, we did not evaluate the perspectives of children and youth on their own QoL, but scores were based on reports from proxy raters with the aim of overcoming the difficulties of gathering valid information from children with marked communication difficulties or higher levels of ID and CP severity. Thus, examining methods to reliably capture the perspectives of children with CP and different support needs, and combine them with proxy reports is highly recommended for future studies (Davis et al., 2017; Makris et al., 2021; Sentenac et al., 2021).

Furthermore, it is important to note that this study establishes cross-sectional connections between several predictors and QoL scores, not causal relationships. In addition, given that some observations were not independent ($n = 105$), it would have been beneficial to a linear model to further check the robustness of our regression analysis. However, this was not feasible due to the small sample size, just as the validation of the internal structure of the KidsLife Scale using Confirmatory Factor Analysis remained unviable due to this restricted participant count. Finally, the inclusion of other potential variables in the regression model, such as the type of schooling, the presence of other associated conditions, family characteristics, or respondent's sociodemographic data (Badía et al., 2016; Bacherini et al., 2020; Balboni et al., 2020, 2021; Kołtuniuk et al., 2019; Menardo et al., 2017; Rapp et al., 2017) might increment the explained variance and should be considered in future studies, together with examining the relationships between different variables.

In conclusion, to the best of our knowledge, this is the first study that evaluates individual QoL and its predictors specifically in children and adolescents with CP and ID. While total QoL scores of our sample were generally positive, self-determination and social

inclusion were the domains with the lowest scores. Hence, they should be key areas in the design, implementation and assessment of individualized supports, organizational strategies and policies targeting their QoL. Furthermore, level of ID, percentage of disability, physical disability in the upper extremities and size of the organization had a significant impact on their QoL so they should be taken into account in the supply of support and services aimed at their QoL enhancement.

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Table 1 Sociodemographic characteristics of participants with CP (N =165)

	Frequency (%)
Age (years)	
Mean (SD)	12.9 (4.9)
Range	4-21
Gender	
Male	94 (57%)
Female	71 (43%)
Level of ID	
Mild	9 (6%)
Moderate	22 (13%)
Severe	71 (43%)
Profound	63 (38%)
Level of support needs	
Limited	1 (1%)
Intermittent	9 (6%)
Extensive	19 (11%)
Generalized	136 (82%)
Percentage of disability	
Mean (SD)	80.36 (12.13)
Range	35-99
Other associated conditions	
Physical disability in the lower extremities	115 (70%)
Physical disability in the upper extremities	96 (58%)
Epilepsy	54 (33%)
Visual impairments	47 (28%)
Serious health problems	26 (16%)
Hearing impairments	14 (8%)
Behavioral problems	10 (6%)
Autism spectrum disorders	7 (4%)
Mental health/emotional problems	5 (3%)
West syndrome	3 (2%)
Degree of dependency	
Grade I (moderate)	8 (5%)
Grade II (severe)	14 (8%)
Grade III (maximum)	143 (87%)
Type of school	
Special	150 (91%)
Mainstream	5 (3%)
Both	10 (6%)
Size of the organization	
Less than 51 users	61 (37%)
51-100	72 (44%)
101-200	9 (5%)
More than 200 users	23 (14%)

Table 2 Descriptive Data of Raw Scores on QoL Domains of the KidsLife Scale (N = 165)

	SI	SD	EW	PW	MW	RI	IR	PD	Total
n items	12	12	12	12	12	12	12	12	96
Skewness	.05	.22	-.91	-.65	-.33	-.17	-.19	-.21	-.15
Kurtosis	-.15	-.72	1.97	-.23	-.52	-.76	-.49	-.60	-.10
Min.	15	13	17	33	22	30	20	16	187
Max.	48	45	48	48	48	48	48	48	367
Mean	31.47	28.34	39.88	42.73	38.82	40.28	36.95	36.34	294.82
SD	6.47	7.42	5.47	3.81	5.93	4.81	6.41	7.23	35.16
Median	31	27	40	44	39	40	36	36	292
Mode	27	26	37	44	39	39	32	36	319

Note. SI= social inclusion; SD= self-determination; EW= emotional wellbeing; PW= physical wellbeing; MW= material wellbeing; RI= rights; IR= interpersonal relationships; PD= personal development.

Table 3 Spearman's, Pearson's, or Point-Biserial Correlation Coefficients Among Variables and QoL Domains and Total Score of the KidsLife Scale (N=165)

Variables	SI	SD	EW	PW	MW	RI	IR	PD	Total
Gender	.05	.04	.01	.00	-.09	-.08	-.07	-.07	-.04
Age	-.03	.16*	-.11	-.05	-.01	-.03	.02	-.04	.00
Level of ID	-10	-.56***	-.15	.06	-.15*	-.09	-.38***	-.34***	-.36***
Level of support needs	-.10	-.29***	.01	.15*	-.13	.03	-.26***	-.21**	-.18*
Degree of dependency	-.01	.-22**	.03	.17*	-.12	.02	-.19*	-.17*	-.12
Percentage of disability	-.14	-.30***	-.16*	.11	-.11	-.01	-.28***	-.32***	-.23**
Physical disability in the lower extremities	.15	-.02	.05	.11	.02	.01	.05	-.01	.06
Physical disability in the upper extremities	.18*	-.03	.13	.19*	.14	.17*	.06	.03	.14
Epilepsy	.06	-.13	-.06	-.10	-.02	-.11	-.12	-.06	-.09
Visual impairments	-.02	-.21**	-.02	.11	-.02	.09	-.13	-.25***	-.10
Size of the organization	-.05	.04	.14	.07	.05	.25***	.07	.07	.09

Note. SI= social inclusion; SD= self-determination; EW= emotional wellbeing; PW= physical wellbeing; MW= material wellbeing; RI= rights; IR= interpersonal relationships; PD= personal development.

*** $p \le .001$; **$p \le .01$; *$p \le .05$

Table 4 Standard Multiple Regressions of Factors on Proxy Perspectives on QoL Domains and Total Score for Children and Adolescents with CP and ID

Factors	SI ($n= 165$) β	sr^2	SD ($n= 157$) β	sr^2	EW ($n= 157$) β	sr^2	PW ($n= 165$) β	sr^2	MW ($n= 165$) β	sr^2	RI ($n= 165$) β	sr^2	IR ($n= 157$) β	sr^2	PD ($n= 157$) β	sr^2	Total score ($n= 157$) β	sr^2
Level of ID			-.47***	.15									-.23**	.04	-.18*	.02	-.27***	.05
Percentage of disability			-.15*	.02	-.16*	.02							-.18*	.03	-.21*	.03		
Physical disability in upper extremities	.18*	.03									.16*	.03						
Size of the organization											.22**	.05						
Adjusted R^2	.03		.30		.02		.04		.02		.06		.14		.14		.11	
F	5.50*		12.37***		3.92*		3.066*		3.58		6.74**		7.51***		6.16***		7.60***	

Note. SD= self-determination; PW= physical wellbeing; EW= emotional wellbeing; MW= material wellbeing; RI= rights; PD= personal development; SI= social inclusion; IR= interpersonal relationships.

*** $p \leq .001$; ** $p \leq .01$; * $p \leq .05$.