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Predictors of Individual Quality of Life in Young People with Down Syndrome

Abstract

Objective: Although the concept of quality of life (QoL) has become a reference framework for the provision of support and services to people with intellectual disability (ID), its conceptualization and application for persons with Down syndrome (DS) has received little attention. This study analyzes QoL outcomes in children and young people with DS and examines the influence of several individual and environmental variables on QoL.

Research method: A cross-sectional study was conducted. Participants were 404 children and young people with DS aged 4 to 21 who were users of 73 organizations providing services to people with ID. The KidsLife-Down Scale was used to assess QoL-related personal outcomes perceived by professionals and relatives. Descriptive statistics were calculated. Correlation coefficients were computed and multiple regression analyses were conducted for each QoL domain and for the composite score.

Results: The highest scores were obtained in material wellbeing, physical wellbeing, and rights, whereas the lowest scores were observed in self-determination and social inclusion. Multiple regression analyses showed that age, level of ID, level of support needs, degree of dependency, type of schooling, and size of organization were predicting factors of scores in QoL domains.

Conclusions: This study underlines priority areas and relevant variables that must be considered when planning, implementing, and assessing supports and services to improve the QoL of children and young people with DS.

Keywords: Quality of life; Down syndrome; children; self-determination; social inclusion

Impact and implications

- Down syndrome (DS) is a lifelong developmental disability that has a substantial impact on a person's quality of life (QoL).
- QoL is a multidimensional concept which goes beyond health-related aspects and is influenced by individual and environmental factors.
- Rehabilitation programs should address the different domains of QoL, paying particular attention to the domains with the poorest results for people with DS: self-determination and social inclusion.
- Age, level of intellectual disability, level of support needs, degree of dependency, type of schooling and size of the organization are predicting factors of scores in QoL domains. Therefore, they must be taken into account when planning the rehabilitation process.

Down syndrome (DS) is a genetic condition caused by an extra copy of chromosome 21. It results in distinctive physical features and is the most common cause of intellectual disability (ID) (Antonaros et al., 2020). The overall incidence of DS is around one in every 700 births, increasing with maternal age (Huete-García & Otaola-Barranquero, 2021). Compared with the general population, people with DS have a higher prevalence of associated conditions, such as heart disease, gastrointestinal disorders, endocrine abnormalities, or vision and hearing impairments (Lagan et al., 2020). Considering the cognitive, social, emotional, behavioral, and contextual aspects that are unique to people with DS, and given the significant increase in their life expectancy in recent decades, there is a particular need to conduct focused research into the quality of life (QoL) of this population (Gómez et al., 2020a; Xanthopoulos et al., 2017).

From a review of the literature, it is clear that even if the concept of QoL has become a reference framework for the provision of supports and services to people with intellectual and developmental disability (IDD) (Gómez et al., 2021; Verdugo et al., 2021), its conceptualization and application for people with DS has received little attention (Gómez et al., 2020a; Lee et al., 2021a, 2021b; Sheridan et al., 2020; Xanthopoulos et al., 2017). The few studies that exist on the QoL of people with DS focus primarily on the QoL of their parents (e.g., Dinc et al., 2019; Ivins-Lukse & Lee, 2021; Pasqualucci-Ronca et al., 2019) or on the more limited construct of health-related quality of life (HrQoL) (e.g., Katsiana et al., 2020; Rofail et al., 2017; Shields et al., 2018; Xanthopoulos et al., 2017). While the results of these studies vary, most agree that people with DS obtain significantly lower scores than their peers without DS (Berástegui & Corral, 2020; Katsiana et al., 2020; Palomba et al., 2020; Rofail et al., 2017). Some studies on people with DS have focused on finding relationships between HrQoL and individual and environmental variables that may influence them. It was found that being an adolescent (Haddad et al., 2018; Rofail et al., 2017; Shields et al., 2018), having other associated medical conditions (Haddad et al., 2018), the presence of behavioral problems and parental stress (Haddad et al., 2018; Sarimski, 2019), participating in open employment, and living far away from the city (Haddad et al., 2018) are among the variables related to poorer scores when assessing the HrQoL of people with DS. However, other variables such as gender (Haddad et al., 2018) or type of schooling (Sarimski et al., 2019) did not have any influence on the results.

The body of research into the QoL of people with DS tends to focus on the concept of HrQoL (WHOQOL Group, 1995), which is limited to the influence of illness or disability on individual functioning. In contrast, the present study focuses on a construct that goes beyond this point and approaches QoL from a comprehensive perspective, taking into account not only health-related aspects, but encompassing all areas that are important in the person's life: this construct is known as individual QoL (Gómez et al., 2010).

Although several conceptual frameworks have been developed to operationalize the construct of individual QoL, in the field of IDD the model proposed by Schalock and Verdugo (2002) is of particular relevance. According to this model, individual QoL is a desired state of personal wellbeing that is multidimensional, has both universal and culture-dependent properties, has objective and subjective components, and is influenced by individual and environmental factors (Schalock et al., 2016). This framework has generated a considerable amount of empirical evidence to support its validity (Carbó-Carrete et al., 2015; Gómez et al., 2011, 2016; Fernández et al., 2018; Stone et al., 2020) and is the most well-known and widely used model among professionals who provide supports and services to people with ID in many countries, Spain in particular (Arias et al., 2018). In this sense, the operationalization of the concept in people with ID have allowed Spanish organizations and centers that provide services to people with ID to assess personal outcomes and thus to enhance the delivery of services and the planning of interventions based on their specific needs. Some of the improvement strategies derived from the individual QoL concept are the use of individualized support plans, person-centered planning, or organizational strategies from aggregated individualized assessments (Gómez et al., 2010).

However, to the best of our knowledge, only two recent studies have examined individual QoL in a broad group of children and young people with DS using an instrument that is developed from Schalock and Verdugo's model and that demonstrates sufficient levels of validity. Lee et al. (2020, 2021b) used this theoretical QoL model and observed the following: (a) children with DS had moderate or favorable QoL scores, except in the emotional wellbeing domain (Lee et al., 2021b); (b) there were no significant differences by gender, but there were differences by age in emotional and material wellbeing, interpersonal relationships, and social inclusion (Lee et al., 2021b); (c) family appraisals concerning the child and the family's ability predicted the children's physical and material wellbeing, personal development, self-determination, social inclusion, interpersonal relationships, and rights (Lee et al., 2020); and (d) family problem-solving served as a prominent predictor for children's physical and emotional wellbeing, personal development, interpersonal relationships, and rights. Also, family resources predicted various aspects of children's QoL including physical, emotional, and material wellbeing, self-determination, social inclusion, interpersonal relationships, and rights (Lee et al., 2020).

Both these investigations used the English version (Stone et al., 2020) of the KidsLife scale (Gómez et al., 2016), a QoL assessment questionnaire for people with ID and substantial support needs, to be completed by someone who knows the person with DS well, and who has had opportunities to observe that person in different contexts over extended periods of time. Although the KidsLife scale can be applied to people with IDD aged between 4 and 21 years, several limitations have been identified when it is used for people with DS. During the scale validation process, Gómez et al. (2017) found many of the items to be unsuitable for children and young people with DS, since a ceiling effect (i.e., maximum scores and zero discrimination) was often observed and informants considered some of the examples provided in the items to be inappropriate (Gómez et al., 2020a). For these reasons, the scale was adapted for people with DS: the KidsLife-Down Scale was developed (Gómez et al., 2017), and evidence of reliability and validity based on the internal structure was provided (Gómez et al., 2020a). To date, however, no QoL study has used the KidsLife-Down Scale in a broad enough sample to allow us to determine which are the strongest and weakest QoL domains for this group (Palomba et al., 2020).

In order to address this gap and pursue this research direction, the purpose of this study is twofold. First, we analyze and describe the individual QoL outcomes of children and young people with DS reported by professionals and families. We analyze the overall QoL score as well as scores for the eight domains of the QoL reference model: emotional wellbeing, physical wellbeing, material wellbeing, personal development, interpersonal relationships, social inclusion, self-determination, and rights. Second, we examine the influence of various individual (i.e., gender, age, level of ID, level of support needs, degree of dependency) and environmental (size of the organization providing the supports and type of schooling) variables on the QoL scores of this population.

We anticipated that our sample would obtain lower results in comparison with Lee et al. (2021b) given that the adapted scale for people with DS prevent the ceiling effect observed in the original KidsLife scale which was developed for people with ID and greater support needs. In line with the previous literature including this and other populations with disabilities (e.g., Arias et al., 2018; Haddad et al., 2018; Perry & Felce, 2005; Sarimski et al., 2019; Verdugo et al., 2019), we hypothesized that the older participants with higher levels of ID, support needs and degree of dependency that are enrolled in bigger organizations would obtain lower results in individual QoL. On the contrary, we expected that significant differences by gender and type of schooling would not be found.

Method

Participants

The data of the participants of the present study were used first for the validation of the KidsLife-Down Scale published by [blinded for review]. Participants were 404 children and young people who were receiving support from a total of 73 Spanish organizations and centers for people with IDD. Their age ranged from 4 to 21 years (*M*=12.1; *SD*=4.6). Just over half the participants (58.9%) were male. According to official reports from the centers, most subjects had a moderate (65.6%) or severe (20.8%) level of ID, and an intermittent (41.1%) or extensive (30.4%) level of support needs. The most prevalent associated conditions were visual (10.6%) and hearing (3.5%) impairments, physical disability in the lower extremities (4%), and behavioral problems (3.2%). As regards legally recognized degree of dependency, most participants (46.0%) were classed as severe (level 2), 35.6% had a moderate dependency (level 1), while 18.3% were recognized as having maximum dependency (level 3). In all, 46.8% of the participants were studying in mainstream schools, 45.5% were attending special education schools, and 7.7% were in a combined educational setting (i.e., special education combined with general education). It should be noted that in Spain, type of schooling relies on the special educational needs of the student detected by a psychoeducational assessment (Amor et al., 2018). Almost all participants were living in their family home (99.2%). Demographic characteristics are further described in Supplementary Table 1.

The assessments were completed by 325 informants, mostly women (85.0%), whose mean age was 45.3 years (*SD*=7.0). The majority of informants (64.3%) were family members, primarily mothers (53.2%), while approximately one-third (35.7%) were professionals, mostly psychologists and teachers. The mean length of relationship with the person being assessed was 9.2 years (*SD*=5.3), and the frequency of contact was several times a week in most cases (85.6%). A total of 42.6% of the informants needed to consult other people—mainly family members (61%) and educators (23.8%)—in order to complete the scale.

The participating organizations provided private (61.1%) or subsidized (34.2%) services in the remit of education (69.3%), social care (28.5%), and health care (2.2%). Most (61.1%) were serving more than 100 users. Centers were located in 16 of Spain's 17 autonomous communities (all except Cantabria), primarily in urban settings (90.8%).

Instrument

The instrument used was the KidsLife-Down Scale (Gómez et al., 2017, 2020a), which assesses the QoL of children and young people with DS who are aged between 4 and 21 years and who are accessing educational, social, and health support services. The scale is completed by external observers who know the participant well (at least six months) and who have had opportunities to observe the child or young person in different contexts over extended periods of time (e.g., relatives, teachers, caregivers).

The questionnaire consists of 96 items structured around eight domains (social inclusion, self-determination, emotional wellbeing, physical wellbeing, material wellbeing, rights, personal development, and interpersonal relationships). All items are drafted in the third person and are answered using a four-option frequency scale (i.e., *never, sometimes, often, always*). In addition, the instrument has a section to collect sociodemographic data about the person with DS, the main informant, and the organization providing supports and services. Administration time varies from 20 to 30 minutes. The scale also includes standardized scores and percentiles for each of the QoL domains and it allows obtaining a QoL profile. The instrument shows excellent evidence of reliability and validity. For instance, all the internal consistency coefficients were adequate for the eight domains, ranging from .765 for physical wellbeing to .876 for social inclusion. Besides, evidences of validity of content (Gómez et al., 2014) and evidences based on the internal structure of the scale through confirmatory factor analysis confirming the eight intercorrelated domains model are available: RMSEA <.060; CFI and TLI above .92 (Gómez et al. 2020a). The Spanish version of the KidsLife-Down Scale is available by emailing the corresponding author and the English version can be consulted at Supplementary Table 2.

Procedure

Information about the study was announced at various conferences and events, on social media (e.g., Facebook, Twitter), and on the websites of the Institute on Community Integration (INICO, University of Salamanca) and Down España, the Spanish DS federation representing more than 90 organizations. Additionally, the research team carried out an exhaustive web search of centers offering supports to people with ID and did a mass mail-out inviting them to participate. The goal of this phase was to get the study known by as many potential participants as possible (not granting them the access to the questionnaire). To satisfy the selection criteria, participants had to (a) have DS; (b) be aged between 4 and 21 years; and (c) be a user of educational, social, or health services from a Spanish IDD support organization. The only exclusion criterion was not being in the education system, as the instrument includes items related to this area.

Organizations that expressed an interest in participating received 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. For the scale distribution, once this survey was returned, the centers were sent all the necessary material to carry out the assessments (i.e., more detailed information about the study, the instruction manual, informed consent forms, and the access to the questionnaire). The questionnaires could be completed electronically or on paper.

Some questionnaires were administered to parents (at their request) through individual interviews with a member of the research team. At all times 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 institution where the study was conducted and followed the principles of the Declaration of Helsinki. To ensure the confidentiality of the assessments, we used identification codes that were anonymous to the research team (alphanumeric codes). These codes allowed us to send the organizations a report with the assessments and results obtained for their center, enabling the scores to be used to inform their individualized support plans and organizational strategies aimed at enhancing the QoL of the people they support.

Data analysis

Data were analyzed using SPSS.24 for Windows. Descriptive statistics of the total and domain-specific raw scores were calculated. Correlation coefficients were computed to assess the relationship between each individual factor (i.e., gender, age, level of ID, level of support needs, degree of dependency) and environmental factor (size of the organization and type of schooling) and each QoL domain and the QoL total score. The type of correlation coefficient depended on the characteristics of the individual and environmental variables. We computed Pearson's correlation coefficient for the metric variable (i.e., age), Spearman's correlation coefficients for the ordinal variables (i.e., level of ID, level of support needs, degree of dependency, size of the organization, and type of schooling), and point-biserial correlation coefficients for the dichotomous variable (i.e., gender). As per Cicchetti et al. (2011), the magnitude of the correlation coefficients was evaluated as trivial (<.10), small (.10–.29), medium (.30–.49), large (.50–.69), or very large (≥.70).

Next, multiple regression analyses were conducted for each QoL domain and for the composite score to examine the influence of individual and environmental factors on QoL when considered simultaneously. Third-party perspectives on participants for each of the eight QoL domains or the total QoL score formed the dependent variable. All the significant individual and environmental factors related to the QoL domain or the QoL total score ($p \leq .05$) were entered simultaneously as independent variables to identify which variables were significant in the set. The squared semipartial correlation coefficient (sr^2) of each statistically significant independent variable was run to analyze its unique contribution to the total explained variance of QoL in children with DS.

Prior to performing the regression analyses, regression assumptions were verified according to a five-step procedure (Tabachnick & Fidell, 2013). Step 1: the suitability of the number of participants was examined to comply with the assumption that $N \geq 104 + m$ (where m was the number of independent variables). Step 2: cases of univariate outliers (i.e., participants with z values in excess of |3.29|) and multivariate outliers (i.e., participants whose Mahalanobis distance was at $p < .001$) were tested for all the independent and dependent variables. Univariate normality of the distribution was ascertained by running asymmetry and kurtosis indexes, considering as suitable values ranging from approximately −1.00 to 1.00. Normality of the multivariate distribution was verified using Mardia's test as appropriate. Step 3: multicollinearity between independent variables was examined by calculating the tolerance index and the variance inflation factor (VIF). The absence of collinearity was contemplated for tolerance indexes higher than .50 and VIF lower than 2. Step 4: normality, linearity, and homoscedasticity of residuals were ascertained. We assessed the shape of the residual distribution scatterplots by comparing the residual scatterplots with the theoretical distributions provided by Tabachnick and Fidell (2013), for the sets of independent variables and for each dependent variable. Step 5: independence of residuals was analyzed by running Durbin–Watson statistics, considering as suitable values ranging from 1.5 to 2.2, and the presence of outliers (i.e., extreme values in excess of |3.29|) was detected by examining the standardized errors. Normalized scores obtained on the KidsLife-Down were used for the measurement of individual and environmental factors in all the regression analyses. Although other associated conditions (i.e. physical disability, ASD, challenging behavior, hearing impairments, visual impairments, mental health problems) and informants' demographic characteristics (i.e., age, gender, type of informant, length of relationship, and frequency of contact) were initially considered, these variables were finally excluded from the analysis given the low number of participants with comorbid diagnoses in the study sample (Supplementary Table 1) and the presence of multiple informants for almost half (43%) of the assessments.

Results

First, we analyzed the distribution of the scores obtained from the KidsLife-Down Scale, which showed a slight negative asymmetry (asymmetry= -.33; kurtosis= -.05). The observed scores ranged from 184 to 381 with a mean of 308.90 (*Md*=310; *SD*=31.30). Both mean and median were above the theoretical midpoint of the scale (Theoretical Midpoint=192). Regarding the domains, the highest scores were obtained in material wellbeing (*M*=43.35; *SD*=4.42), physical wellbeing (*M*=41.42; *SD*=5.25), and rights (*M*=40.66; *SD*=5.33), whereas the lowest scores were observed in self-determination (*M*=31.18; *SD*=6.02), and social inclusion (*M*=33.95; *SD*=6.73). Personal development (*M*=39.24; *SD*=5.19), interpersonal relationships (*M*=40.33; *SD*=5.14), and emotional wellbeing (*M*=38.77; *SD*=5.79) showed intermediate scores. These scores were positive but not particularly high. Results are set out in Table 1.

<Table 1>

Related factors to QoL: Correlation analysis

Table 2 shows the correlation values among individual and environmental factors and QoL domains and composite score. With respect to the individual factors, age was positively and statistically significantly associated with the composite score, self-determination, and emotional, physical, and material wellbeing, whereas it was negatively and statistically significantly associated with social inclusion. Correlation coefficient sizes were small or medium (except in self-determination). Degree of dependency, level of ID, and level of support needs showed statistically significant negative correlations (with values of small magnitude) with the composite score and all the QoL domains, except for physical wellbeing (for degree of dependency, level of ID, and level of support needs), emotional wellbeing (for level of ID and level of support needs), and personal development (for level of support needs). Gender showed no significant relationships with any QoL domain or the composite score. Concerning environmental factors, size of the organization was positively and statistically significantly associated with material wellbeing, rights, and social inclusion. Type of schooling was positively statistically related to self-determination, emotional wellbeing, physical wellbeing, and the composite score. All these statistically significant correlation values showed a small size.

< Table 2 >

Factors affecting QoL: Multiple regression analysis

Four individual factors (age, level of ID, level of support needs, and degree of dependency) and two environmental factors (size of the organization and type of schooling) were statistically significantly correlated with the children's QoL and therefore were entered as independent variables in the regression analyses. In this way, a maximum of five and a minimum of two independent variables were entered in the multiple regression analysis to examine individual and environmental factors affecting QoL and its domains. Therefore, the required minimum numbers of 106 up to 109 participants for the individual and environmental factor regression analyses were fulfilled. No univariate or multivariate outliers were identified, apart from in the multiple regression analyses for the composite score and the self-determination domain; in both cases one participant had a probability associated with the Mahalanobis distance lower than .001. However, after deleting the extreme case and repeating the analysis (starting from the normalization of the variables' raw scores), the normality of the univariate and multivariate distributions of the scores measuring individual and environmental factors was satisfied for all the domains and the composite score. All the tolerance index values were higher than .05 and all the VIF lower than 2, ascertaining the absence of multicollinearity. For the sets of independent variables and for each dependent variable, the shape of the residual distributions and the comparison of the residual scatterplots with the theoretical distributions provided by Tabachnick and Fidell (2013) showed no issues related to the normality, linearity, and, homoscedasticity of residuals. All the Durbin–Watson values were between 1.5 and 2.2, exhibiting no autocorrelations between the errors. Lastly, no extreme cases in the standardized residuals were detected except in multiple regression analyses for the self-determination (z=-3.31) and social inclusion domains (z=-3.49). After deleting the cases and repeating the analysis (starting from the normalization of the variables' raw scores), no other outliers in the standardized residuals were found.

Table 3 shows the outcomes of the multiple regression analyses to examine the influence of individual and environmental factors, when entered simultaneously, on third-party perspectives on QoL. Children's age positively affected the composite score, self-determination, emotional, physical, and material wellbeing, whereas it was negatively and statistically significantly associated with social inclusion. On the other hand, level of ID negatively influenced all domains and the composite score (except for emotional and physical wellbeing with which it was not even related). Also, level of support needs negatively affected self-determination, rights, and social inclusion. Even though degree of dependency was significantly negatively correlated with the composite scale and all the QoL domains (apart from physical wellbeing), it did not affect any QoL domains when entered simultaneously with the other individual and environmental factors (except for a negative influence on the self-determination domain). Concerning environmental factors, type of schooling positively affected emotional wellbeing, whereas size of the organization had a positive influence on material wellbeing, rights, and social inclusion.

Finally, as shown by the squared semipartial correlation coefficients (sr^2), children's age was the independent variable that exerted the strongest influence on the composite scale and almost all QoL domains, with values ranging from .07 to .01. Further information about the mean scores by QOL domain and age groups may be consulted at Supplementary Figure 1. Level of ID, level of support needs, degree of dependency, type of schooling, and size of the organization affected specific children's QoL domains, obtaining squared semipartial correlation coefficients ranging from .02 to .01.

< Table 3 >

Discussion

Research into the QoL of children and young people with DS from an individual QoL perspective (Gómez et al., 2010), beyond what is strictly health-related, is a recent phenomenon. One of the reasons for this delay has been the lack of assessment instruments with proven validity and reliability (Gómez et al., 2017, 2020a). The knock-on effect of this assessment gap is far-reaching: not only has it prevented the study of QoL in this specific population, it has also limited QoL improvement interventions, the implementation of evidence-based practices, and efforts to verify their effectiveness (Schalock et al., 2017).

As underlined by the 12th definition of ID proposed by the American Association on Intellectual and Developmental Disabilities (AAIDD; Schalock, Luckasson, & Tassé, 2021), QoL-related outcomes place people with IDD at the center of the service and support delivery system. In this respect, the KidsLife-Down Scale (Gómez et al., 2020) fulfills all the recommendations made by Schalock et al. (2021) for the assessment of valued outcomes related to the QoL of this population; the scale (a) uses an adequately formulated and validated conceptual model (i.e., the QoL model of eight intercorrelated domains); (b) it employs culturally sensitive indicators (Gómez et al., 2014); and (c) it uses qualified evaluators (i.e., relatives and close others who have known the person for at least 6 months and who have had opportunities to observe that person in different contexts over extended periods of time). This study, therefore, constitutes a further step toward implementing practices that are based on the current best evidence, obtained from credible sources and reliable and valid methods derived from a clearly articulated and empirically validated theory for children and young people with DS (Schalock et al., 2016). It responds to the urgent need to assess QoL in a broad sample in order to determine which QoL domains are strongest for this population and which should be improved (Gómez & Verdugo, 2016; Palomba et al., 2020).

Our first step was to analyze the QoL scores of a group of children and young people with DS in Spain. We found the overall mean QoL of our broad group to be “adequate”, since it exceeded the theoretical midpoint of the scale, in line with findings from the few studies carried out recently in Australia and the United States (Lee et al., 2021b; Shields et al., 2018). From a closer look at the results by QoL domain, it is worth noting that, as with other groups with disabilities (Gómez et al., 2012; Morán et al., 2019; Verdugo et al., 2019), the highest scores were obtained for material wellbeing and physical wellbeing. The persistence of the welfare paradigm in the care of people with ID in Spain—often focused on the provision of basic care, material resources and rehabilitation—could account for these results. The results for rights are particularly interesting: it was the third highest-scoring domain, despite existing limitations in the effective implementation of many of the rights set out in the International Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) for people with ID (Gómez et al., 2020b; Morales et al., 2021). These results may be linked to the fact that DS tends to be a well-known disability in our society, and therefore, when compared with other disabilities, is more likely to prompt more positive attitudes, more natural supports, and better access to organizations providing assistance and information (Berástegui & Corral, 2020). However, the study by Berástegui and Corral (2020) found that when young people with DS were directly asked about their rights and material wellbeing, they obtained significantly lower scores than their peers with ID, but without DS, suggesting that using proxy reports rather than asking the young people themselves may have a considerable impact on the results.

The lowest scores were observed in self-determination and social inclusion, and this despite the importance of personal autonomy and social participation (Scott et al., 2014; Sheridan et al., 2019; van Gameren-Oosterom et al., 2011) in people's lives. The low scores could be explained by possible overprotection and the lack of opportunities experienced by people with DS (Callus et al., 2019; Polo et al., 2020), by their family's lack of time to facilitate community participation (Shields et al., 2020), and by the lack of supports, adaptations and programs to forge self-determination skills and promote effective social inclusion (Lee et al., 2021b; Scott et al. 2014).

These poor results in self-determination and social inclusion serve to highlight the priority areas for the design and evaluation of supports and services aimed at enhancing the QoL of children and young people with DS. They are also consistent with the recommendations of similar recent studies conducted with other groups with disabilities (Katsiana et al., 2019; Morán et al., 2019; Verdugo et al., 2019). It is interesting and worth noting that the low scores for these two domains differ radically from those observed by Lee et al. (2021b), whose study assessing the QoL of youth with DS primarily from the United States found that self-determination and social inclusion had the highest scores. We believe this is because the KidsLife (Gómez et al., 2016) rather than the KidsLife-Down (Gómez et al., 2017) was used. The former scale was developed for young people with ID (including DS) who have extensive support needs and significant disabilities, which may lead to a ceiling effect in some domains when applied to high-functioning youth with DS. However, differences could also be related to context and cultural setting, and therefore transcultural studies using the KidsLife-Down Scale would be necessary to test if these differences among countries persist.

Our second step was to analyze the influence of different individual and environmental variables on the QoL scores of children and young people with DS. The children's total QoL score and domain scores showed no variance by gender, in accord with other studies (Haddad et al., 2018; Lee et al., 2021b). Surprisingly, the older participants showed better QoL, self-determination, emotional, physical, and material wellbeing compared with the younger subjects. Conversely, the younger respondents obtained significantly higher scores in social inclusion than the older participants. The younger respondents' advantage over their older peers in social inclusion, also observed in previous studies (Lee et al., 2021b; Shields et al., 2018), is most likely attributable to multiple causes. It may be because there are fewer opportunities to establish and maintain social relationships as life progresses (Oates et al., 2011), but especially because contextual demands and people's expectations also increase with age. There is therefore an urgent need to ensure the provision of support services and public policies that will not only facilitate access to the environment and information, but also promote normalization and generate awareness about ID, sensitizing and ensuring the realization of their rights, promoting equality, and providing individualized support to live independently, be included in the community, enjoy personal mobility, and participate in political and cultural life, recreation, leisure, and sports (Gómez et al., 2020b).

To the best of our knowledge no previous study has examined the relationship between individual QoL in children with DS and their level of ID, support needs, and degree of dependency. Level of ID negatively influenced all domains (except for emotional and physical wellbeing) and the total QoL score. Level of support needs negatively affected the self-determination, rights, and social inclusion domains, whereas degree of dependency had a negative influence on self-determination. This is not surprising considering that the personal outcomes of people with more severe disabilities depend to a large extent on opportunities that are often not offered to this group. In view of this gap, support organizations need to ensure that people with the most significant disabilities are also able to participate in the community, while promoting the training of professionals in methodologies such as person-centered planning, active support, and supported decision-making (Beadle-Brown et al., 2016; Shogren et al., 2017).

Another surprising finding in our study is that children in special schools scored significantly higher in emotional wellbeing than their peers in mainstream schools or combined education settings. One possible explanation is that students in special education schools may be being compared to their peers with more severe emotional and behavioral challenges. This is also probably due to special education teachers' more positive attitudes toward disability (Arcangeli et al., 2020), prompting them to pay more attention to their pupils' emotional state and provide more supports aimed at preventing behavioral disturbances (e.g., taking measures to make the environment more predictable, informing students in advance about activities and possible changes, and reflecting on whether students enjoy the activities they are given). These findings highlight the need for mainstream education teachers to receive specific training and to adopt positive attitudes toward ID (Alcedo et al., 2013; Arcangeli et al., 2020). In addition, it is important to pay particular attention to the issues of bullying and cyberbullying: emotional and behavioral problems put youth with ID at greater risk of exposure to bullying (Martínez-Cao et al., 2021), and there is an increasing risk of this population engaging in cyberbullying or being cyberbullied (Begara et al., 2019). Further, participants attending organizations serving a larger number of users obtained better results in material wellbeing, rights, and social inclusion. One possible explanation is that these organizations have more financial and professional resources, allowing them to offer a greater range of services, programs, activities, and supports. It may also be that participants receive more natural supports from fellow service users in these organizations, which also increases the social inclusion score.

There are some research limitations to bear in mind when interpreting our results. First, in the absence of official census data on people with DS, the sample selection was not random, and therefore the results must be interpreted with caution and cannot be generalized. We sought to overcome this limitation by recruiting a large number of participants from different regions across Spain. Second, our study used proxy reports, despite the importance of including the direct perceptions of young people with DS in assessing their own QoL (Balboni et al., 2013; Berástegui & Corral, 2020; Schalock et al., 2021). Even so, it should be noted that the views of family members and other close contacts when assessing the QoL of people with ID is not only common (e.g., Shields et al., 2018; Xanthopoulos et al., 2017), but important (Schalock et al., 2021), particularly when dealing with early childhood. To address this limitation, future research should focus on developing a self-report version that enables young people with DS to give their own views on their QoL (Berástegui & Corral, 2020; Palomba et al., 2020; Sheridan et al., 2019). Third, the results of this study show relationships between different predictor variables and QoL scores, but causal relationships were not established. Finally, we were unable to provide additional data on the relationship between QoL and other relevant variables, such as adaptive behavior, the presence of associated conditions, informants' demographic characteristics, parental socio-economic status, or family factors (Bacherini et al., 2021; Balboni et al., 2020; 2021; Haddad et al., 2018; Lee et al., 2021b; Menardo et al., 2017), which could increase the value of the explained variance. Future investigations on individual QoL in this population should therefore study the role of other variables, especially those that are susceptible to change (Shields et al., 2018, 2020), and that could act as mediating and moderating variables of QoL-related personal outcomes (Gómez et al., 2020c).

Despite these limitations, this study contributes to our current understanding of QoL for the DS population and helps to illuminate the relationships between the various QoL domains and individual and environmental variables that can influence it (Gómez et al., 2020c; Schalock et al., 2016). Our results reveal self-determination and social inclusion as priority areas for the provision of supports and services aimed at enhancing the QoL of children and young people with DS in Spain. These two domains can therefore be considered the most valued outcomes from a sociocultural and psychoeducational perspective of ID (Schalock et al. 2018). Although the role of other variables needs to be further investigated, it would appear that age, level of ID, support needs and degree of dependency, as well as type of schooling and size of the organization all play a significant role in the QoL of children with DS. It is important, therefore, that these variables be taken into account when developing, implementing, and assessing the effectiveness of person-centered planning, organizational strategies, and social policies targeting the QoL of this group.

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Table 1

Descriptive data for the composite scale and QoL domains (N= 404)

	SD	EW	PW	MW	RI	IR	SI	PD	Total
n items	12	12	12	12	12	12	12	12	96
Mean	31.18	38.77	41.42	43.35	40.66	40.33	33.95	39.24	308.90
Median	31	39	43	45	41	41	34	39	310
Mode	32	42	48	48	46	39	35	40	289
SD	6.02	5.79	5.25	4.42	5.33	5.14	6.73	5.19	31.30
Min.	15	17	25	27	20	21	15	26	184
Max.	47	48	48	48	48	48	48	48	381
Skewness	.21	-.37	-.85	-1.12	-.64	-.48	.09	-.22	-.33
Kurtosis	-.47	-.20	.15	.90	.04	-.14	-.41	-.67	.05

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

Table 2

Pearson's, Spearman's, or point-biserial correlation coefficients among individual and environmental factors and QoL domains and composite score (N=404)

	SD	EW	PW	MW	RI	IR	SI	PD	QoL
Individual factors									
Gender	.02	-.04	.05	.06	.05	-.01	.02	.03	.03
Age	.33***	.16***	.12*	.19***	.07	.05	-.17***	-.02	.12*
Level of ID	-.15**	-.06	-.08	-.19***	-.21***	-.22***	-.25***	-.16***	-.23***
Level of support needs	-.26***	-.06	-.01	-.10*	-.21***	-.12*	-.18***	-.05	-.18***
Degree of dependency	-.22***	-.12*	-.05	-.13*	-.17***	-.16***	-.14**	-.11*	-.18***
Environmental factors									
Size of the organization	-.04	-.06	.02	.11*	.13**	.05	.14**	.02	.05
Type of schooling	.10*	.19***	.11*	.09	.06	.06	-.09	.06	.10*

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

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

Table 3

Standard multiple regression analysis of individual and environmental factors influencing third-party perspective on QoL domains and composite score for children with DS

	SD (*n*= 402)		EW (n= 404)		PW (*n*= 404)		MW (*n*= 404)		RI (*n*= 404)		IR (*n*= 404)		SI (*n*= 403)		PD (*n*= 404)		Composite score (*n*= 403)	
Factors	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}	*β*	*sr*^{2}
Age	.31***	.08	.12*	.01	.11*	.01	.22***	.04					-.15**	.02			.10*	.01
Level of ID	-.11*	.01					-.18***	.02	-.12*	.01	-.17***	.02	-.17**	.02	-.13*	.01	-.18***	.02
Level of support needs	-.14**	.01					.02		-.12*	.01	by-.03		-.12*	.01			-.07	
Degree of dependency	-.11*	.01	-.09				-.05		-.09		-.10		-.06		-.08		-.10	
Type of schooling	.03		.13**	.02	.06												.07	
Size of the organization							.14**	.02	.11*	.01			.11*	.01				
Adjusted R^2	.19		.05		.01		.08		.07		.06		.10		.02		.08	
F	19.37***		7.41***		3.81*		7.87***		8.77***		8.39***		10.28***		5.98**		8.19***	

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

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