# Parents' perception of the quality of life of children with intellectual disabilities

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**SUMMARY: Başgül ŞS, Üneri ÖŞ, Çakın-Memik N. Parents' perception of the quality of life of children with intellectual disabilities. Turk J Pediatr 2011; 53: 541-546.**

**There has been limited research conducted on the quality of life (QoL) of children with intellectual disabilities (IDs). We investigated the QoL in children aged 5-18 years with ID and compared the results with healthy children of the same age in this study. The results indicated that the scores of students with ID were lower on all scales and also that children with ID should be supported in all QoL dimensions (physical, social, emotional, and school functioning). Associations between QoL and factors such as the educational level of the mothers, income level of the family, age at diagnosis, age group, and level of ID were examined in the ID group. A diagnosis of ID before the age of 2 was found to have a statistically significant positive effect on QoL scores. Our findings highlight that early diagnosis is the most important measure to improve the QoL of people with ID.**

***Key words: intellectual disability, children, quality of life.***

The concept of quality of life (QoL) has been used widely for the assessment of health-related data for the last 20 years[1]. QoL is defined as the individual's perception of his/her condition in life in terms of his/her aims, expectations and standards within the culture and value systems in which he/she lives[2].

The last decade has witnessed a significant increase in the development and utilization of pediatric health-related quality of life (HRQoL) measures in an effort to improve patient health and well-being and to determine the value of healthcare services[3-5]. A HRQoL instrument should be multidimensional, consisting at a minimum of the physical, psychological (including emotional and cognitive), and social health dimensions delineated by the World Health Organization[6,7]. A generic HRQoL instrument enables comparisons across diverse pediatric populations, including chronic health conditions, as well as benchmarking with healthy populations[8,9]. While pediatric patient self-reporting should be considered the standard for measuring perceived HRQoL, there may be circumstances when the child is too young, too cognitively impaired, or too ill or fatigued to complete a HRQoL instrument, and a parent-proxy report is needed in such cases[10]. Further, it is typically the parents' perceptions of their children's HRQoL that influences healthcare utilization[11,12]. In those cases in which pediatric patients are not able to provide a self-report, reliable and valid parent-proxy report instruments are needed[10,13]. The Pediatric Quality of Life Inventory (PedsQL) was designed by Varni et al.[9,14] to measure the HRQoL of children and adolescents between the ages of 2-18 years, and is a general QoL scale that can be used by both healthy and unhealthy individuals. PedsQL consists of five subscales questioning the child's functioning in areas featuring the state of being healthy, defined by the World Health Organization as physical, emotional, social, and school. The scale is composed of a child self-report and parallel parent-proxy report that assesses the parents' perception of their children's HRQoL.

Intellectual disability (ID) is defined as retardation in cognitive abilities accompanied

by difficulty in adapting to daily life that starts before the age of 18, and is also termed mental retardation[15]. The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (DSM-IV) uses the intelligence quotient (IQ) level and adaptive functioning as ID criteria and requires the assessment of individual's self-care, home living, social and interpersonal relations, and use of community resources[16]. The incidence of ID is reported to be 2-3% in various countries[17,18].

Individuals with disability are regarded as the most vulnerable members of society[19]. Understanding and evaluating data about QoL and using them for the establishment of healthcare policies is therefore particularly important for people with disabilities[20].

Quality of life (QoL) is especially relevant to conditions that are chronic and impairing, such as pervasive developmental disorder (PDD), cerebral palsy (CP) and mental retardation[21].

Parents of children with developmental disabilities experience heightened stress, impaired mental health, a sense of decreased value and self-blame, impaired physical functioning, and tiredness or exhaustion[22]. The level of parental stress has been found to be related to the level of the severity of the child's condition and his/her disability and to coexisting behavioral problems.

Despite the high frequency reported in studies, there has been limited research on the QoL in children with IDs, and further studies are required[23,24]. Conducted studies have used parent-proxy reports in general[25]. We did not come across any study on the QoL of children with ID in Turkey during a literature review.

Knowing a person's perception of his/her QoL is important in terms of the functional impact of disease and observation of the effectiveness of different treatment methods. In the present study, our aim was to evaluate QoL in a group of children aged 5-18 years with ID living in İstanbul through a parent form and to compare the data taken from healthy children. It has been emphasized that self-report scales should be preferable in the treatment and follow-up or in studies as children reflect their own subjective perceptions. The most commonly recommended method to obtain the best information on PedsQL is to use parent-proxy reports and child self-reports together. However, we used only the PedsQL parent-proxy report in our study and obtained information from the parents, as we felt any self-report scales completed by children with ID would not enable a healthy evaluation.

## Material and Methods

The study was conducted in İstanbul between April 2008 and May 2009. The ID group was comprised of children aged 5-18 years. The sample included ID children who received individual education at two different special education centers located on the European and Asian sides of İstanbul and an elementary school for disabled children, and those who came to the Erenköy Mental Health Hospital demanding special education; the control group included age- and sex-matched healthy children from the database of another study. We had the mothers complete the parent-proxy report, as we believed that the children included in the study would not be able to complete the self-report scales satisfactorily due to the mental disability. Mothers of disabled children in the education centers were informed about the study and those who accepted to participate in the study were asked to complete the parent form of PedsQL that was prepared according to the age groups. ID was evaluated by the first author after reviewing the information on the children's files according to the DSM-IV diagnosis criteria. A sociodemographic data form prepared by the authors was also completed by the first author after the informational interview. Children whose mothers were at least elementary school graduates and the primary caregivers of those children and whose files did not have missing information were included in the study.

## Measures

The Pediatric Quality of Life Inventory™ 4.0 (PedsQL™ 4.0) is a QoL scale designed by Varni et al.[14] to measure QoL in 2- to 18-year-old children. It is suitable for application both to healthy and sick children from various age groups, as 2-4 years, 5-7 years, 8-12 years, and 13-18 years. The scale is composed of a child self-report and parallel parent-proxy report that assesses parents' perception of their

children's QoL for ages 5-7, 8-12 and 13-18. The 2-4-year-old version has only the parent-proxy report. It consists of four subscales questioning the child's functioning in the physical (8 items), emotional (5 items), social (5 items), and school (3 items in the 2-4 years group and 5 items in all other age groups) areas. The response scale is a 5-point Likert scale (0=never a problem; 1=almost never a problem; 2=sometimes a problem; 3=often a problem; 4=almost always a problem) for all age groups except the 5-7 years version, in which the response scale is reworded and simplified to a 3-point Likert scale (0=not a problem at all; 2=sometimes a problem; 4=a significant problem) for better understanding of the child. The items are reverse scored between 0 and 100 (0=100, 1=75, 2=50, 3=25, 4=0), with a higher total PedsQL™ 4.0 score thus indicating a better HRQoL. The Physical Health Summary Score (PHSS) is calculated by dividing the sum of the reverse scores of the items answered in the Physical Functioning subscale by the number of items in the scale (8 items). The Psychosocial Health Summary Score is computed as the sum of the items divided by the number of items answered in the Emotional, Social and School Functioning subscales. To obtain a Total Scale Score, the sum of the reverse scores of all answered items is divided by the number of all items answered. If less than 50% of items in a child's scale are missing, the missing items are not considered and scale scores are computed as the sum of the items divided by the number of items answered in each area. If more than 50% of the items in a child's scale are missing, the scale is then not scored for that child. The most important properties of PedsQL are that it is short, it can be completed in approximately 5-10 minutes, and it can be easily implemented for scored investigators[14]. The validity and reliability study for the Turkish version of the scale for children aged 2-4 and 5-7 years was conducted by Uneri et al.[26], while the validity and reliability study for the Turkish version of the scale for children aged 8-12 and 13-18 years was conducted by Memik et al.[27]

### Statistical Methods

SPSS (Statistical Package for the Social Sciences) 13.0 was used for the statistical analyses in the study. In addition to the descriptive statistical methods (mean, standard deviation), normality of distribution was examined for the comparison of quantitative data while analyzing the data. The effect of ID on the PedsQL scores was examined by one-tailed analysis of variance (ANOVA). Results were evaluated within a 95% reliability range and with significance at $p \leq 0.05$.

**Table I.** Sociodemographic Characteristics

| | Intellectual disability group n (%) | Control group n (%) |
|---|---|---|
| Age groups of the children | | |
| 5-7 | 36 (16.3) | 41 (18.9) |
| 8-12 | 96 (43.4) | 82 (37.8) |
| 13-18 | 89 (40.3) | 94 (43.3) |
| Total | 221 (100.0) | 217 (100.0) |
| Gender | | |
| Girls | 78 (35.9) | 91 (41.2) |
| Boys | 139 (64.1) | 130 (58.8) |
| Total | 217 (100.0) | 221 (100) |
| Educational level of the participant parent | | |
| Elementary school | 139 (64.1) | 59 (26.7) |
| Secondary school | 21 (9.7) | 28 (12.7) |
| High school | 39 (18.0) | 90 (40.7) |
| College or University | 18 (8.3) | 44 (19.9) |
| Occupational status of the participant parent | | |
| Working | 32 (14.7) | 119 (53.8) |
| Not working | 179 (82.5) | 89 (40.3) |
| Retired | 6 (2.8) | 13 (5.9) |

## Results

The files of 271 ID children were evaluated during the study, and it was found that 217 met the inclusion criteria of the study. Girls constituted 38.6% (n=169) of the sample and boys 61.4% (n=269). There was no statistically significant relationship between PedsQL scores and gender in the healthy or ID group. Of the ID children, 2.3% (n=5) were determined as borderline, 39.2% (n=85) as mild, 33.6% (n=73) as moderate, and 5.1% (n= 11) as severe level of disability. IQ evaluations of 19.8% (n=43) of children were not available. We found no significant relationship between the PedsQL scores and IQ level of the child within the ID group. Sociodemographic variables are presented in Table I. The mean total scale score was 60.41±17.05 in the ID group and 81.78±11.81 in the control group. Means and standard deviations (SDs) of the total scale score and subscale scores, and the effect of ID on PedsQL scores are presented in Table II. As presented in this Table, ID had a significant effect on all scale scores, and the PedsQL scores of the ID group were found to be significantly lower than of the healthy group. We examined the relationship between PedsQL and education level of the mothers, income level of family, age at diagnosis, age group, and level of ID in the ID group. There was no significant relation between PedsQL scores and the education level of the mother, income level of family or the ID level. There was a statistically significant relationship between PedsQL and the age groups in terms of school functioning in the ID group, and the school functioning score was significantly higher in the 13-18 years group than the 5-7 years group (Table III). We also found that a diagnosis of ID before the age of 2 had a statistically significant positive effect on PedsQL scores, except for the school functioning subscale scores (Table IV).

## Discussion

There were more boys than girls in the ID group of the study. ID is reported to be more frequent in boys than girls[17] and this might also explain the higher number of boys in the current sample. The findings of the studies on the effect of gender on QoL are contradictory. While some studies indicate that QoL is higher for boys than girls[28,29], other studies indicate the opposite[30], and still others report no effect of gender on QoL scores[26,31]. The findings of our study support studies reporting that gender is not effective on QoL scale scores. Some of the previous studies conducted with ID children, in which the QoL of children with IDs was compared with that of healthy children, found that the QoL of ID children was lower in almost all areas[32], whereas some studies found no difference in QoL between children with IDs and physically healthy children[33]. The results of our study showed that all QoL subscale scores were lower in the ID group than in the healthy group.

An important finding of the studies conducted with the intellectually disabled at the beginning of the 20th century was that individual differences appear through proper education. Most children with IDs apply to the physician after the age of 3; it is difficult to detect mental-motor development during infancy without a systematic assessment. Motor functions are examined, while mental development is generally ignored in the clinical practice of pediatric examinations, which may result in

**Table II.** PedsQL Scores in Intellectual Disability and Control Groups

| PedsQL | Intellectual disability group | Control group | t | df | p |
|---|---|---|---|---|---|
| **PSS** | 59.70±25.39 | 78.83±18.26 | 9.040 | 391.969 | 0.000* |
| EFS | 64.12±18.99 | 76.97±14.91 | 7.868 | 409.380 | 0.000* |
| SFS | 59.55±25.68 | 89.69±13.05 | 15.436 | 319.256 | 0.000* |
| SchFS | 54.24±26.61 | 86.23±13.17 | 15.891 | 314.962 | 0.000* |
| PsychoFS | 60.84±17.66 | 83.36±11.05 | 15.961 | 361.527 | 0.000* |
| TSS | 60.41±17.05 | 81.78±11.81 | 15.224 | 383.848 | 0.000* |

*p<0.01

PedsQL: Pediatric Quality of Life Inventory. PSS: Physical health summary score. EFS: Emotional functioning score. SFS: Social functioning score. SchFS: School functioning score. PsychoSS: Psychosocial health summary score. TSS: Total scale score.

**Table III.** Mean PedsQL Scores of Children and Adolescents with Intellectual Disabilities According to the Age Groups

| PedsQL | 5-7 y age group | 8-12 y age group | 13-18 y age group | F | p |
|---|---|---|---|---|---|
| PSS | 60.93±27.92 | 58.19±23.40 | 60.47±26.10 | 0.233 | 0.792 |
| EFS | 62.03±20.90 | 63.09±18.92 | 65.93±18.21 | 0.793 | 0.454 |
| SFS | 56.95±25.46 | 59.81±24.50 | 60.46±26.96 | 0.272 | 0.762 |
| SchFS | 45.84±36.39 | 52.92±22.99 | 59.06±23.62 | 3.781 | 0.024* |
| PsychoFS | 60.63±20.00 | 59.58±15.54 | 62.02±18.42 | 0.417 | 0.659 |
| TSS | 59.83±17.73 | 59.44±15.08 | 61.50±18.43 | 0.344 | 0.709 |

*p<0.05

PedsQL: Pediatric Quality of Life Inventory. PSS: Physical health summary score. EFS: Emotional functioning score. SFS: Social functioning score. SchFS: School functioning score. PsychoSS: Psychosocial health summary score. TSS: Total scale score.

ignoring the detection of mental retardation and delays in diagnosis and education during early development[15,34]. In a recent study, family-centered professional support was suggested to be one of the most important predictors of family QoL[35]. Our finding that the diagnosis of ID before the age of 2 is a factor that positively affects PedsQL scores highlights the importance of early diagnosis and early education to improve the QoL of people with IDs.

The finding that the school functioning score of the 13-18 years group was significantly higher than in the 5-7 years group might be the result of the sample characteristics but may also suggest that the parents of children with IDs understand the disorder better as these children get older, and their expectations about the children's academic life match the level of ID.

One of the limitations of the present study is not using the self-report simultaneously with the parent-proxy report. Another limitation is the inadequacy of the sample to represent different levels of education. To our knowledge, this the first study to be conducted in Turkey on the QoL of children with IDs. Further studies with multiple sites, large sample sizes and children with IDs from various socioeconomic levels are needed to understand QoL and the factors that affect the QoL of people with IDs.

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**Table IV.** Effect of Age at Diagnosis on the PedsQL Scores of Children with Intellectual Disabilities

| PedsQL | >2 years Mean | SD | <2 years Mean | SD | F | p |
|---|---|---|---|---|---|---|
| PSS | 64.89 | 23.86 | 56.22 | 24.34 | 0.026 | 0.019* |
| EFS | 68.65 | 20.72 | 61.65 | 17.54 | 2.881 | 0.018* |
| SFS | 62.48 | 23.59 | 53.94 | 27.85 | 3.929 | 0.029* |
| SchFS | 56.97 | 25.93 | 52.89 | 25.62 | 0.074 | 0.298 |
| PsychoFS | 64.22 | 16.88 | 57.05 | 18.30 | 0.888 | 0.008** |
| TSS | 63.83 | 17.49 | 57.32 | 16.07 | 0.770 | 0.012* |

*p<0.05 **p<0.01

PedsQL: Pediatric Quality of Life Inventory. PSS: Physical health summary score. EFS: Emotional functioning score. SFS: Social functioning score. SchFS: School functioning score. PsychoSS: Psychosocial health summary score. TSS: Total scale score.

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