Health-related quality of life of intellectually disabled children attending a special school in Puducherry-A cross-sectional study

Karthikayini Sasinthar¹, Arun Sugumaran¹, Abhijit V. Boratne¹, Raj K. Patil²

¹Department of Community Medicine, Mahatma Gandhi Medical College and Research Institute Pillayarkuppam, Puducherry; ²Department of Community Medicine, All Indian Institute of Medical Science Bhopal, Madhya Pradesh, India

ABSTRACT

Introduction: Health-related quality of life (HRQOL) is a measure of an individual’s psychosocial, emotional, and physical well-being. Around 1 in 20 children are less than 15 years of age and are living with a moderate-to-severe form of disability. Thus, our study aims to determine the HRQOL of intellectual disabled (ID) children attending a special school in Puducherry and to determine the socio-demographic factors influencing the level of HRQOL. Methodology: A cross-sectional analytical study was conducted among 350 ID children attending a selected special school in Puducherry over 1 year. By the universal sampling method, all the caregivers of ID children were recruited and the parent proxy form of Pediatric Quality of life Inventory scale version 4.0 (PedsQL ver 4.0) was used to assess the level of HRQOL of ID children. The data were analyzed using the Statistical Package for Social Science version 16.0 (SPSS ver. 16.0) and the statistical significance was set at \( P \) value <0.05. Results: Among the 350 respondents, a majority of the caregivers were mothers (78.9%) and 65.7% were homemakers by occupation. Most of the respondents were from the nuclear family (77.7%) and 55.1% were from urban areas. The mean age of ID children was 12 (±3.8) years; 61.2% were males and 40.8% of the children had a moderate form of ID. Conclusion: The HRQOL of ID children is found to be lower. The factors influencing the lower HRQOL were age, the intelligent quotient (IQ) of ID children, and type of marriage of the caregivers.

Keywords: Children, health-related quality of life, intellectual disability

Introduction

According to the Rights of Persons with Disabilities Act 2016, there are seven categories of disability. One of the categories is the intellectual disability (ID) formerly known as mental retardation (MR). The ID is defined as a condition characterized by significant limitations both in intellectual functioning such as reasoning, learning, problem-solving, and adaptive behavior which covers a range of everyday activities, social, and practical skills. The ID includes two broad categories which are specific learning disabilities (SLD) and autism spectrum disorders (ASD).¹⁻⁴

The health-related quality of life (HRQOL) is a multidimensional model that includes physical, mental, emotional, and social functioning domains associated with an illness or treatment.⁵⁻⁶

Children with Intellectual Disability have medical, social, emotional, and educational needs which are significantly

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greater than their healthy peers. Hence, the role of primary care physicians is to lead a team of doctors who are capable of diagnosing, treating, and supporting the ID children to improve their HRQOL. Case management and specific interventions are the cornerstones in dealing with ID children. Early detection and proper management of the problems by the primary care physicians are expected to help these children to maximize their potential and integration in society.

**Subjects and Methods**

This is a cross-sectional analytical study conducted among ID children attending a special school in Puducherry from April 2019 to March 2020. The study was approved by the Institutional Research Committee on 26/02/2019, and by the respective authorities of the special school. Though the study involved a vulnerable group, i.e., <18 years of age with ID only, the caregivers were taken as a proxy, thus, our study had minimal risk. Yet, the following measures given as per the National Ethical Guidelines for Biomedical and Health Research involving human participants laid by the Indian Council of Medical Research (ICMR)2017 were taken to overcome the risk.

1. Written, informed consent was obtained from the caregivers before their recruitment into the study.
2. Privacy and confidentiality were maintained throughout the study period. An explicit participant information sheet had been prepared in both English and the regional language (Tamil). This document made the study participants understand all the details of the study before providing their consent.

By the universal sampling method, 350 caregivers of ID children were recruited as parent proxy to capture the ID children’s level of HRQOL by using the Pediatric Quality of Life Inventory scale 4.0 (PedsQL 4.0). All the caregivers of IDs aged between 5 and 18 years attending special school were included in the study. The diagnosis of ID was taken from the medical records maintained in a special school. The caregivers who were not willing to participate in the study were excluded. The PedsQL 4.0 questionnaire consists of 23 items divided into four domains: Physical functioning, emotional functioning, social functioning, and school functioning. The responses were provided on a five-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). The items were reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), such that the higher scores indicated better HRQOL.

The data were entered in MS Excel and analyzed using SPSS version 16. The qualitative variables were summarized using proportion and frequencies. The mean and standard deviation (SD) were calculated to summarize the quantitative variable. The association between the sociodemographic variables and total HRQOL score were determined by the Mann-Whitney U test and Kruskal–Wallis test. The statistical significance was set at P value <0.05.

**Results**

**Sociodemographic characteristics of the caregivers of ID children**

A total of 350 caregivers of ID children attending a selected special school were recruited. The basic sociodemographic details of the study respondents are presented in Table 1. The majority of the caregivers of ID children were mothers (78.9%). The majority of the respondents were from an urban area (55.1%). Based on the modified BG Prasad classification 2020, a majority (40.6%) of the study participants belonged to the lower-middle socioeconomic group. Most of the mothers (45.7%) and fathers (39.6%) of ID children had education up to the secondary level. Nearly 65.7% of the mothers were homemakers by occupation and most of the fathers (42.3%) were skilled laborers by occupation.

**Profile of ID children**

The mean age of ID children of our current study was 12.6 ± 3.8 years. Most of the children, 40.8%, had a moderate...
form of an ID followed by a severe form with 24.9%. The degree of ID based on the intelligent quotient (IQ) was taken from the medical records maintained in a special school. A majority (70.9%) of the children with ID were born by the first order followed by 23.4% second order of birth.

Level of health-related quality of life using PedsQL

The HRQOL of children with ID was captured using the Pediatric Quality of Life Inventory scale version 4.0 using the parent proxy form, the caregivers were requested to rate how many problems their child experienced during the past 1 month pertaining to physical, social emotional, and school functioning domain. The median score was calculated for each domain and subdomain which is presented in Table 2. In our current study, the total HRQOL score above 70 was taken as a cut-off for labeling the ID children level of HRQOL. If the total HRQOL score was above 70, then the child was labeled to have a better HRQOL and a score below 70 was labeled as poor HRQOL and majority of the children's 64.5% had better HRQOL as depicted in [Figure 1]. Among the subdomain of HRQOL, the physical functioning domain was the least scored domain. Thus, in our current study, the level of HRQOL of ID children was found to be lower. The sociodemographic factors associated with the HRQOL scores are depicted in Table 3. The type of marriage of parents and degree of ID had a significant association with the HRQOL scores.

Predictors leading to low HRQOL

Multilinear regression was done to find the predictors leading to low HRQOL [Table 4]. The independent variables such as age, gender, and degree of ID, family type, residency, marriage, and type of parents were included and it was found that the degree of ID and type of marriage of the caregivers had a significant association.

Discussion

The present study aims to find the HRQOL of ID children and to compare the probably associated factors such as socio economic status (SES), type of family, residence, age, gender, and IQ of ID children. To date, there are only a few literatures about the HRQOL of ID children attending a special school in the Indian context. The HRQOL of ID children was assessed by using the PedsQL questionnaire developed by James Varni in the USA. This tool has been widely used among the disabled population to find their HRQOL both in developing and developed countries.[10-14] The PedsQL 4.0 tool is available as a self-reporting form and as a parent proxy form. This tool has been found to be having good feasibility and reliability among the Indian population.[15]

In our present study, the majority of the ID children were males. This can be because disability is more common in males than females according to a recent report by national sample survey organization (NSSSO)[16] and this might also explain the higher number of males in our current study. The study conducted by Gopalan R T et al.[17] conducted in Gujarat has found that ID is more common among males, which is similar to our study findings.

The effect of gender of ID children on the HRQOL in our study had no significant association. While some studies indicate that the HRQOL scores are higher for boys than girls,[18] other studies indicate vice versa while some indicate that there are no effects of gender on the HRQOL scores.[19] Thus, our study supports the study reporting that gender is not an influencing factor for HRQOL.

In our present study, a majority of the caregivers of ID children were mothers which may be due to the fact that mothers spent most of the time caring for the ID children.[20] Nearly two-thirds

### Table 2: Health-related quality of life score of intellectually disabled children across various subclasses of PedsQL (n=350)

| Domains                  | Mean  | Median | IQR       |
|--------------------------|-------|--------|-----------|
| Physical functioning     | 57.72 | 59.37  | 34.37-84.37 |
| Psychosocial functioning | 61.58 | 61.66  | 48.33-81.66 |
| Emotional functioning    | 65.89 | 70.00  | 50.00-90.00 |
| Social functioning       | 59.20 | 60.00  | 40.00-85.00 |
| School functioning       | 59.67 | 60.00  | 40.00-80.00 |
| Total HRQOL score        | 59.65 | 61.40  | 41.67-78.25 |

### Table 3: Sociodemographic factors associated with health-related quality of life score (n=350)

| Variable                                | Total HRQOL scores | P     |
|-----------------------------------------|--------------------|-------|
| Gender of the caregivers                  |                    |       |
| Male (n=291)                             | 62.81              | 42.68-78.75 |
| Female (n=350)                           | 58.12              | 40.55-73.82 |
| Residence                               |                    |       |
| Urban (n=193)                            | 61.98              | 42.13-78.02 |
| Rural (n=157)                            | 61.04              | 41.46-78.33 |
| Type of marriage of parents              |                    |       |
| Consanguineous (n=55)                    | 66.67              | 50.94-85.31 |
| Non-consanguineous (n=295)               | 61.15              | 41.04-77.29 |
| Socioeconomic status                     |                    |       |
| Upper class (n=14)                       | 66.30              | 38.80-77.73 |
| Upper-middle (n=48)                      | 58.96              | 40.78-76.51 |
| Middle class (n=85)                      | 61.35              | 38.80-78.17 |
| Lower-middle (n=142)                     | 63.85              | 42.68-82.18 |
| Lower class (n=61)                       | 58.02              | 43.80-72.97 |
| Age of ID children (in years)            |                    |       |
| 5-7 (n=21)                               | 68.33              | 48.67-98.33 |
| 8-12 (n=87)                              | 58.85              | 41.04-72.50 |
| 13-18 (n=106)                            | 62.81              | 42.60-80.00 |
| Degree of intellectual disability        |                    |       |
| Mild (n=79)                              | 70.21              | 49.48-86.14 |
| Moderate (n=143)                         | 63.33              | 45.83-78.75 |
| Severe (n=87)                            | 59.06              | 40.00-79.06 |
| Profound (n=41)                          | 51.46              | 36.35-71.25 |

*P value derived by Mann-Whitney U test. *P value derived by Kruskal-Wallis test
of the respondents were from a nuclear family (77.7%) and one-third from a joint family (22.3%). Our study finding is similar to the study done by Karnavat D et al. (2020) to find the impact of the caregivers’ children with ID. They found that 68% were from the nuclear family. A majority of the respondents were from the urban area (55.1%) which is in line with the study done by Bunga D et al. The effect of sociodemographic variables such as type of family, residences, and socioeconomic status on the HRQOL of ID children had no significant association. ID seemed to be more prevalent among the first order of birth of the child. This literature evidence is in line with our study that a majority of our ID children were born as first children.

In our study, a majority of the children fall under a moderate degree of ID which is in contrast to the study done by Nagarkar et al., where most of the ID children belong to a mild degree. This difference is due to the different tools used to assess the degree of ID in both studies. The physical functioning, social functioning, and school functioning domain had a significant association with the HRQOL in our study. This is in line with a study conducted by Mugno et al. and their study concluded that early diagnosis is the main measure for improving the HRQOL of children with ID.

In our study, we found a significant relationship between the HRQOL and the IQ level of ID children. A similar study done in Maharashtra has also found that HRQOL of ID children had a significant association with the level of IQ.

When analyzing the PedsQL subscales, our study found that the median HRQOL score was 61.40 (41.67–78.25) of ID children. The lowest PedsQL subscale score was the physical functioning score with a median score of 59.37 (34.37–84.37). A similar study was done by Michalska et al. also found the physical functioning score to be the lowest PedsQL subscale score.

Contrary to the findings of our study, the physical functioning subscale was found to be the highest score in the study done by Mugno et al. But the author has claimed that the respondent did not understand the meaning of the questionnaire. The social functioning score was the next least scored domain in our study. This can be compared with the study done by Dobha et al. in New Delhi among cerebral palsy (CP) children which showed that the social functioning domain of HRQOL was a much more severely affected domain. This can be attributed to the fact that differently-abled children are exposed to horrible forms of discrimination by the Indian society and as a result ID children face ill health, socioeconomic burden, and destitution.

A study by Jenkins et al. in the United States also found that people with disabilities tend to develop lower self-esteem over time, which affects their social functioning, which is in concordance with our study findings.

The overall HRQOL of ID children in our study is found to be lower in comparison with a reference study done by Viecili and Weiss among ID children. The researchers found that the total mean HRQOL score was 66.3, the physical functioning mean score was 74.4, the psychosocial health mean score was 61.8, the emotional functioning mean score was 66.3, the school functioning mean score was 66.3 and the social functioning mean score was 57.0. Thus, our study supports the literature, implying that HRQOL is lower among the disabled population.

### Conclusion

In our present study, the overall HRQOL of ID children is found to be lower. Among the physical, emotional, social, and school functioning domains of the PedsQL scale, the physical functioning domain is the least scored domain. The significant factors determining the lower HRQOL of ID children were age, IQ of ID children, and the type of marriage of the caregivers.

### Limitations

1. Single-point measurement of HRQOL might have influenced the quality of data collected in the study. Collecting the same data during multiple visits from each respondent on a longitudinal basis would have reduced the random error and provided us with better average estimates.

2. The enrolment of the participants in our study was done directly from the facilities for ID children and not from the community. Since the children who are not coming to the facilities are not included, this could result in a selection bias.

### Recommendation

1. As ID children in our current study had lower HRQOL, they should be enrolled in the District Disability Rehabilitation Centers (DDRC) for improving their HRQOL.

2. The Sahyogi Caregiver training scheme should be adopted...
by the special schools for providing caregiver training and to create a skilled workforce to support disabled children.

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**Conflicts of interest**

There are no conflicts of interest.

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