

## Quality of Life Among Parents of Intellectually Impaired Children with Reference to Gender and Locality

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### ABSTRACT

The challenges and unease experienced by children with disabilities can place a significant load on their family members, particularly their parents, who serve as their primary caretakers over an extended period of time (Ellis, Upton & Thompson, 2000). According to Evans, Dingus, and Haselkorn (1993), parents' quality of life (QOL) may be impacted by having children with impairments. The main objective of this study is to know and compare the scores of Quality of life among parents of intellectually impaired children with regard to their gender and residing areas. The researcher employed a quantitative descriptive research approach to achieve the study's aims. The researcher selected a sample of 70 parents out of which 36 were female parents and 32 were male parents of intellectually disabled children. The sample was collected from special schools of Anand district of Gujarat state. World Health Organization Quality of Life (WHOQOL-BREF) was used to measure the parent's quality of life. Further, results revealed that fathers of ID children have a better quality of life as compared to mothers of ID children. The significant difference was also reported for the parent's locality. Parents who have children with intellectual disabilities have challenges in caring for their children, including social, economic, and financial issues. Rural parents bear a significant burden due to the absence of support and resources from both the government and non-governmental organizations.

**Keywords:** *Quality of Life, Intellectual Disability, Gender, Locality*

The challenges and unease experienced by children with disabilities can place a significant load on their family members, particularly their parents, who serve as their primary caretakers over an extended period of time (Ellis, Upton & Thompson, 2000). According to Evans, Dingus, and Haselkorn (1993), parents' quality of life (QOL) may be impacted by having children with impairments. Parents may be required to allocate a significant portion of their time to attend to the needs of their disabled kid, particularly if the child has profound impairments. Consequently, parents may be unable to participate in other activities, resulting in a reduction of their social interactions and adversely impacting their quality of life.

The quality of life for parents of children with intellectual disabilities has become a significant concern in modern times. The pressures of modern society and the disruption of

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the traditional Indian joint family arrangement have further intensified this state of stress. Intellectual disability (ID) is marked by substantial cognitive and adaptive behavior impairment. The terminology used to define this disease has undergone several revisions throughout the years as a result of societal and political pressures. The primary motivation behind the quest for a new phrase was to identify a language that minimizes the negative social connotations associated with it. Therefore, the term "mental retardation," which was commonly used worldwide until the late 20th century, has now been substituted with "intellectual disability" in the majority of English-speaking nations (Chavan & Rozatkar, 2014). The global incidence of intellectual impairment is estimated to be as high as 2.3% (Franklin & Mansuy, 2011), whereas, in India, it is stated to be around 2% for moderate intellectual disability and 0.5% for severe intellectual disability (Srinath & Girimaji, 1999). Quality of life is a complex concept that includes several important aspects such as material situations, physical health and abilities, social connections, and emotional well-being (Schipper et al., 1996). Irrespective of the particular definition of individual quality of life, it generally refers to one's overall sense of well-being, good social engagement, and the ability to fulfill personal potential (Schalock et al., 2002). They have also reached a consensus that the concept of quality of life should incorporate all aspects of life and be seen as a whole, covering all aspects of life (Felce & Perry, 1997).

The limitations and discomfort experienced by children can place a significant load on their family members, particularly their parents, who serve as their primary caretakers over an extended period of time (Cooper, 1991; Ellis, Upton & Thompson, 2000; Elmstahl, Malmberg & Annerstedt, 1996). Parents' quality of life may be impacted by having children with impairments (Evans, Dingus & Haselkorn, 1993). Parents may be required to allocate a significant portion of their time to attend to the needs of their disabled kid, particularly if the child has profound impairments. Consequently, parents may be unable to participate in other activities, resulting in a reduction of their social interactions and a detrimental impact on their overall well-being.

Parents face unique hurdles while raising children with impairments. The purpose of this study was to enhance comprehension of the quality of life experienced by parents who have children with disabilities. The findings of this study might enhance the comprehension of rehabilitation experts regarding the challenges faced by impaired children and the subsequent effects on their parents' overall well-being.

### *Statement of Problem*

The exact problem of the present research is **“Quality of Life Among Parents of Intellectually Impaired Children with Reference to Gender and Locality”**

### *Definition of key terms*

- **Quality of life:** defined by the World Health Organization (WHO) as an individual's perception of their position in life in the context of the culture and value systems in which they live, and about their goals, expectations, standards, and concerns.
- **Intellectual disability:** An intellectual impairment may affect an individual's capacity to acquire new knowledge, communicate, adapt, and independently resolve difficulties.

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### *Objectives*

- To know and compare the scores of Quality of life among male and female parents of intellectually impaired children.
- To know and compare the scores of Quality of life among parents of intellectually impaired children residing in rural and urban areas.

### *Hypotheses:*

- (*H<sub>01</sub>*) There will be no significant mean difference between the male and female parents of intellectually impaired children for the dimensions of quality of life.
- (*H<sub>02</sub>*) There will be no significant mean difference between the parents of intellectually impaired children from rural and urban areas for the dimensions of quality of life.

### *Research Design*

The current study is not feasible experimentally due to the nature of the investigation. The researcher employed a quantitative descriptive research approach to achieve the study's aims. This survey is a form of quantitative study that examines the influence of variables through qualitative analysis after the event has already taken place.

### *Sample*

The researcher selected a sample of 70 parents out of which 36 were female parents and 32 were male parents of intellectually disabled children. The sample was collected from special schools of Anand district of Gujarat state. The mean age for the mothers and fathers was 33.46 ( $\pm 7.45$ ) years ranging from 25 to 42 years of age. The mean age of intellectually disabled children was 10.02 ( $\pm 5.21$ ) years ranging from 4 years to 15 years. To know the effect of area they were classified according to rural (27) and urban (29) locality.

### *Inclusion criteria*

- Parents whose children were diagnosed with mild intellectual disability.
- Parents who were in the age group of 25 – 42 years.
- Parents who were willing to participate in the study.

### *Exclusion criteria*

- Parents who had medical and psychological disorders were not included.

### *Tool*

The investigator after screening a number of available tests finally selected the following tool to collect the data:

**World Health Organization Quality of Life (WHOQOL-BREF):** The scale is developed by WHOQOL-BREF Group. The concept of Quality of Life of the WHOQOL-BREF is based on the same definition as the WHOQOL100 and defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. Whilst the WHOQOL100 permits a detailed assessment of individual facets relating to quality of life, it may be too lengthy for some uses. In these occurrences, a briefer version has been created to be more convenient. The WHOQOL-BREF instrument contains 26 items, which measure four comprehensive domains: physical health, psychological health, social relationships, and environment. The WHOQOL-BREF is a shorter version of the original QOL tool.

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### *Procedure*

The investigators arranged meetings with the families of intellectually impaired children who fulfilled the inclusion requirements in order to provide them with information on the nature of the project, its aims, and to seek their cooperation. Parents who willingly decided to take part were provided with a paper including details about the study and then signed their informed consent to participate. All of the parents who were approached agreed to participate in the study, and none of them received payment for their involvement. After collecting data from the many special and inclusive schools in the Anand district, we took measures to maintain confidentiality. The WHOQOL-BREF scale was administered to the parents in groups. The parents were directed to read each statement in order and submit their opinions in the relevant column by picking the replies they considered to be correct and appropriate for each statement.

### *Scoring*

Scoring of the obtained data was done with the help of respective manuals available for the tests in the present investigation. The data have been arranged in the respective tables according to the statistical test applied.

### *Statistical Analysis*

The present research work is to find out the significant mean difference between the scores of quality of life factors groups of male and female parents of children with intellectual disability. Statistical measures like independent sample 't' tests, Mean, and SD were conducted.

## RESULTS AND DISCUSSION

*Table: 1 Indicating Mean, SD & and t-ratio for the various factors of Quality of life among Mothers and Fathers of Intellectually Impaired Children.*

Measures	Groups	N	Mean	SD	t-values	Sig. Level
<i>Physical Health</i>	Mothers	36	22.90	5.92	0.90	NS
	Fathers	32	24.22	6.11		
<i>Psychological Health</i>	Mothers	36	17.21	3.32	5.38	p<.01
	Fathers	32	22.30	4.45		
<i>Social Health</i>	Mothers	36	8.21	2.12	7.41	p<.01
	Fathers	32	12.42	2.56		
<i>Environmental Health</i>	Mothers	36	21.11	5.21	4.27	p<.01
	Fathers	32	26.90	5.97		
<i>Overall QoL</i>	Mothers	36	69.43	16.57	4.95	p<.01
	Fathers	32	85.84	19.09		

A perusal of Table 1.1 indicated that the two groups of parents of intellectually disabled children under study i.e. mothers and fathers do not differ significantly on the quality of life trait physical health. The significant mean difference was not highlighted for the quality of life domain physical health ('t' = 0.90,  $p > .05$ ). The mean scores observed for the quality of life of fathers and mothers are (M = 24.22, SD = 6.11) and (M = 22.90, SD = 5.92) respectively. Both fathers and mothers of intellectually impaired children have more or less equal physical health.

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The male and female parents of intellectually disabled children have significant difference for the quality of life trait psychological health. The t-ratio is obtained as significant ( $t = 5.38, p < .01$ ). The fathers scored higher mean ( $M = 22.30, SD = 4.45$ ) than the mothers ( $M = 17.21, SD = 3.32$ ) for the quality of life factor psychological health. Fathers of intellectually disabled children have better psychological health than the mothers.

Similarly, the table indicates the mean scores of social health of male and female parents of intellectually disabled children, in which male parents obtained a higher mean value ( $M = 12.42, SD = 2.56$ ) as compared to female parents of intellectually disabled children ( $M = 8.21, SD = 2.12$ ). The t-value is also reported significant ( $t = 7.41, p < .01$ ). Thus, it can be calculated that male parents have better social health than female parents.

The environmental health dimension of quality of life is to be highlighted significantly between mothers and fathers of intellectually disabled children ( $t = 4.27, p < .01$ ). The mean scores revealed for the fathers and mothers of intellectually disabled children are 26.90 ( $SD = 5.97$ ) and 21.11 ( $SD = 5.21$ ) respectively. Fathers of ID children have feelings of greater environmental health in comparison to mothers of ID children.

As seen from the table fathers of ID children have a better quality of life than the mothers of ID children. The t-ratio for the overall quality of life is exposed significant ( $t = 4.95, p < .01$ ). The fathers of ID children have scored higher mean value ( $M = 85.84, SD = 19.09$ ) in comparison of mothers of ID children ( $M = 69.43, SD = 16.57$ ). These significant findings indicated that male parents of ID children have overall better quality of life as compared to female parents of ID children.

Therefore, (H01) There will be no significant mean difference between the male and female parents of intellectually impaired children for the dimensions of quality of life is rejected for the dimensions of quality of life like psychological health, social health, environmental health and overall quality of life whereas, it is accepted for only one dimension of quality of life, i.e. physical health. Some of the previous studies have shown gender differences in the quality of life of parents of children with disabilities (Mugno, D., et al. 2007 & Allik, H., et al. 2006). Research by Mugno, D., et al. 2007 indicated that the quality of life of mothers of children with PDDs (Pervasive Developmental Disorder) is lower than the fathers of PDD children.

**Table: 2 Indicating Mean, SD & and t-ratio for the various factors of Quality of life among Rural and Urban parents of Intellectually Impaired Children.**

Measures	Groups	N	Mean	SD	t-values	Sig. Level
<i>Physical Health</i>	Rural	27	21.96	6.37	1.87	NS
	Urban	29	25.31	6.98		
<i>Psychological Health</i>	Rural	27	18.33	3.88	5.47	$p < .01$
	Urban	29	24.63	4.66		
<i>Social Health</i>	Rural	27	10.36	2.77	1.56	NS
	Urban	29	9.11	3.16		
<i>Environmental Health</i>	Rural	27	20.91	6.44	3.84	$p < .01$
	Urban	29	27.85	7.01		
<i>Overall QoL</i>	Rural	27	71.56	19.46	2.76	$p < .01$
	Urban	29	86.90	21.81		

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It is evident from Table 2 that a significant difference is to be demonstrated between scores of parents of ID children living in rural and urban localities on quality of life factor physical health ( $t' = 1.87, p > .05$ ). The mean scores of parents living in rural and urban areas are 21.96 (SD = 6.37) and 25.31 (SD = 6.98) respectively. The results suggested that there is no statistically significant mean difference was highlighted.

It is interesting to observe that significant difference was seen between parents of intellectually disabled children living in rural and urban locality for the quality of life factor psychological health ( $t = 5.47, p < .01$ ). Parents of ID children living in urban locality have scored higher mean 24.63 (SD = 4.66) as compared to parents living in rural locality 18.33 (SD = 3.88). Thus, it can be said that parents living in urban areas have better psychological health in comparison of parents residing in the rural community.

Quality of life dimension social health is found more or less equal between the parents of ID children living in the rural and urban areas. The t-value is observed as insignificant ( $t = 1.56, p > .05$ ). The mean scores of parents of ID children from rural and urban areas are 10.36 (SD = 2.77) and 9.11 (SD = 3.16) respectively.

The Table illustrates that the two categories of parents of ID children under study i.e. parents residing in rural and urban localities differ significantly on the quality of life factor environmental health ( $t' = 3.84, p > .01$ ). Parents with intellectually disabled children living in the urban locality have scored higher mean ( $M = 27.85, SD = 7.01$ ) than parents of ID children living in the rural locality ( $M = 20.91, SD = 6.44$ ). It may be said that parents with ID children from urban communities have better environmental health than parents of ID children from rural communities.

An analysis of the Table highlighted that a significant difference was found between scores of parents of ID children from rural and urban communities on the overall quality of life ( $t' = 2.76, p < .01$ ). The mean scores of parents of ID children from rural and urban communities are 71.56 (SD = 19.46) and 86.90 (SD = 21.81) respectively. Thus, it can be concluded that parents living in urban communities have a better quality of life as compared to parents from rural communities.

On the basis of the above findings ( $H_0_2$ ) *There will be no significant mean difference between the parents of intellectually impaired children from rural and urban areas for the dimensions of quality of life* was partly accepted and partly rejected. It is accepted for quality of life factors like physical and social health, whereas it is rejected for factors like psychological health, environmental health, and overall quality of life. Findings might be interpreted in terms of Parents who have children with intellectual disabilities have challenges in caring for their children, including social, economic, and financial issues. Rural parents bear a significant burden due to the absence of support and resources from both the government and non-governmental organizations.

## CONCLUSION

In conclusion, this study emphasizes the level of quality of life experienced by the parents of intellectually impaired children in the Anand district in Gujarat state. The findings provide insight into how the gender and residential locations of parents with intellectually disabled children affect several elements of their quality of life. Factors such as education level, the

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severity of the disability, and the presence of multiple disabled children in the family influenced parents' quality of life and these factors were not studied in the present study.

### REFERENCES

- Allik, H., Larsson, J.O. & Smedje, H. (2006). Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism. *Health Qual Life Outcomes*, 4:1.
- Chavan, B. S., Rozatkar, & Abhijit, R. (2014). Intellectual disability in India: Charity to right based. *Indian Journal of Psychiatry*, 56(2), 113–116.
- Ellis, N., Upton, D. & Thompson, P. (2000). Epilepsy and the family: a review of current literature. *Seizure*, 9, 22–30.
- Evans, R.L. Dingus, C.M. & Haselkorn, J.K. (1993). Living with a disability: a synthesis and critique of the literature on quality of life, 1985- 1989. *Psychological Reports*, 72, 771–777.
- Felce, D. (1997). Defining and applying the concept of quality of life. *Journal of Intellectual Disability Research*, 41 (2),126-135.
- Mugno, D., Ruta, L., D'Arrigo, V.G. & Mazzone, L. (2007). Impairment of quality of life in parents of children and adolescents with pervasive developmental disorder, *Health Qual Life Outcomes*, 5, 22.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., & Matikka, L. (2002). Conceptualization, Measurement, and Application of Quality of Life for Persons with Intellectual Disabilities: Report of an International Panel of Experts. *Mental Retardation*, 40(6), 457-70.
- Schipper, H., Clinch, J.J., & Olweny, C.L.M. (1996). Quality of life studies: definitions and conceptual issues. In: Spilker B, editor. *Quality of Life and Pharmacoeconomics in Clinical Trials*. 2nd edn. Philadelphia: Lippincott Raven, 11–23.
- Srinath, S., & Girimaji, S.R. (1999). Epidemiology of child and adolescent mental health problems and mental retardation. *NIMHANS Journal*,17(4),355-366.

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### **Conflict of Interest**

The author(s) declared no conflict of interest.

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