



## Burden and quality of life among caregivers of children with intellectual impairment: Across the gender

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### ABSTRACT

**Background:** Several studies have found that parents of children with chronic disease or disabilities have higher stress scores than parents of normal children. Parents with children having intellectual disability experience more stress compared to their counterpart who have children with no intellectual disability. **Objective:** To assess the role of gender in the account of quality of life and family burden among the parents of children with intellectual impairment. **Sample:** Total a group of 240 participants (120 children with intellectual impairment and 120 equally divided parents of the children) was selected in the study. Design: A cross-sectional study design was used and the study was conducted at a daycare centre of a non-governmental registered organization, Muzaffarpur, Bihar. **Tools:** Seguin Form Board Test (for children), WHO Quality of Life (BREF) Scale and Family Burden Schedule (for parents of the children). **Results and conclusion:** In the results, it has been found that both parents either mother or father showed an equal level of quality of life and family burden. There is a non-significant difference was seen between parents of children with a low level of intellectual functioning.

*Keywords: Intellectual impairment, quality of life, family burden, parents, gender*

### INTRODUCTION

Intellectual Disability (ID) as it persists throughout the lifetime. It contributes to 1.2% of the mental illness in Kerala (Celine & Antony, 2014). The ID is the most prevalent childhood psychiatric disorder, among them, the majority of the cases (85%) belong to mild mental retardation (Harris, 2006; Ganguli, 2000). A Meta-analysis on the prevalence of intellectually disabled children shows that 10.37/1000 population are affected (Maulik, 2011).

Parents with children having an intellectual disability use various coping strategies, which are ineffective most of the time. Parents with children having intellectual disability experience more stress than their counterparts, who have children with no intellectual disability (Gupta & Kaur, 2010).

Recent studies of caregiving have focused on the term, quality of life (QOL) and family burden. QOL is a complex concept, as there is no consensual definition of it and it can

mean different things to different people (Memisevic et al., 2017).

The concept, family burden, was noticed first by Grad and Sainsbury. They mentioned it as the negative expenditures created by the intellectually disabled children for their families (Chou, 2000). Intellectually disabled children significantly affect how their families live (Sari & Başbakkal, 2008; Houtrow & Okumura, 2011). Deficiency becomes the core of families' lives upon diagnosis and causes them many burdens. Family members' roles and responsibilities start to change. These changes may be seen in intrafamilial roles, private living spaces, social environments, expectations, plans and careers. Factors such as economic and educational status, profession, marital adjustment and cultures of the parents, lack of social support, difficulties in communication, severity of the disease, children's age, distortions of family routines, the level of need for medical aid and the financial burden caused by the disease all affect the stress levels of parents (Pelchat et al., 1999). Chronic stress causes families to have more perceived problems and raises their anxiety levels. It also causes serious problems with coping and worsens the family burden. Studies indicate that families face the most stress during the diagnoses, and families' energy levels are diminished as children's dependency on their parents' increases. Family members start to lock themselves in the house, and their private lives are disturbed. Social isolation and

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loneliness can occur. This diminishes satisfaction with life and quality of life (Deniz, Dimaç & Arıcak, 2009). This disease affects not only nuclear families but also extended families (Gopalan & Brannon, 2006). Parents who have intellectually disabled children have problems in their marriages due to stress. A study suggests that couples who have intellectually disabled children do not spare time for each other, and problems such as blaming one another emerge (Sarı, Baser, & Turan, 2013). A study of the couple having children with ID highlighted that couples do not display the same level of coping feel that they are not supported by their partners and feel emotions such as anger, vexation and despair. In particular, mothers undertake the main responsibility to provide care and thus get angry more frequently. This anger also affects families. The siblings of children with deficiencies are deprived of the attention of their parents when these children become the focus of attention. This causes tensions between the subsystems covering parents and siblings (Canam,1993).

**Objective:** To assess the gender difference in the account of family burden and quality of life of parents with intellectual impaired.

**Inclusion Criteria**

- Participants have at least primary education.
- Only primary caregivers of a child

**Exclusion Criteria for clinical sample**

- Participants having primary diagnoses of psychiatric illness.
- Presence of any major medical or neurological illness and other developmental disabilities in children.
- Refuse to give informed consent.

**METHOD**

The study was conducted at a daycare centre HOPE special school, a unit of Sachin Divyang Jan Sewa Sansthan, a non-governmental registered organization at Juran Chapra Road, Muzaffarpur, Bihar. The study was conducted between the periods of March-June 2019.

**Sample:** The recruited sample comprised of 120 children and both parents (either mother or father) of these children. The caregivers equally divided (60 males and 60 females) and the purposive sampling techniques was used.

**Measures**

**Socio-demographic and Clinical data Sheet:** A consent form and socio-demographic and clinical data sheet was prepared for taking the written informed consent and collecting the information about various areas of social, demographic and clinical variables. Information related to age, sex, residence, education, occupation, age of the child, level of intellectual functioning of the child, duration of illness, other developmental disabilities, family history of psychiatric illness

**Seguin Form Board Test (SFBT):** This test developed by Seguin in 1856 to assess the mental age of children above 3 years of age. This test consists of a total 10 different types of wooden shaped blocks. On the basis of the standard chart, the intelligence quotient (IQ) was determined (Venkatesan, 2014).

**Family burden interview schedule (FBIS):** This is developed by Pai and Kapur in 1981. This scale is widely used to measure caregiver stress of those who are performing caregiving activities of any family member with any chronic illness. This consist of 24 items categorized into six areas viz. financial burden, disruption of routine family activities, family leisure, family interactions, effect on physical and mental health of others. The validity and reliability of the scale have been shown to be satisfactory. The inter-rater reliability for all items was reported to be more than 0.78.

**(iii) WHO Quality of Life BREF Scale:** This scale is developed by the World Health Organization. This consists of 25 items that concern with the four domains (Physical, Psychological, Environmental and Social relations) of quality of life of a person. The scale of Cronbach  $\alpha$ coefficient was calculated as 0.90. This scale has an adequate level of validity (Saxena, Chandiramani, & Bhargava, 1998).

**Procedure:** After explaining the purpose of the study to the caregivers their written informed consent was taken and then the actual administration of the study was started. In the interview session, the necessary information related to socio-demographic and clinical data of the study was collected. A group of 120 children were administered on Seguin Form Board Test to assess the level of intellectual functioning and the group of 120 parents (either mother or father) was administered on family burden scale and quality of life scale.

**Data analysis:** The data was analyzed using SPSS 16.0. The frequency and percentage were calculated on discrete variables, descriptive analysis (Mean & SD) and t-test were applied to find out the gender difference in the area of family burden and quality of life.

**RESULTS**

**Table 1 Demographic characteristics**

Variables		Frequency	Percent
Residence	Rural	24	20.00
	Urban	92	76.70
	Sub-urban	4	3.30
Religion	Hindu	114	95.00
	Muslim	6	5.00
Occupation	Business	22	18.30
	Govt. Job	17	14.20
	Student	1	0.80
	Others	80	66.70
Family history	No	109	90.80
	Yes	11	9.20

In the results it has been found that the sample in the residence variable 20% sample belongs to the rural background, 76.7% were urban and 3.3% were sub-urban. On occupation variable 0.8% sample was students and 18.3% were businessmen, whereas in a government job and other work were found as 14.2% and 66.7% respectively. In the sample 95% were Hindu and 9.2% were Muslim.

**Table 2 Comparison between mother & father**

Variables	Group	Mean	SD*	t	p
IQ level of Children	I	53.77	11.82	1.10	0.275
	II	56.03	10.79		
Quality of life	I	78.25	12.03	0.11	0.916
	II	78.48	12.09		
Financial burden	I	8.13	3.95	1.12	0.266
	II	8.90	3.55		
Disruption of Routine Family Activities	I	5.73	2.48	0.22	0.828
	II	5.63	2.54		
Disruption of Family leisure	I	4.30	1.93	1.07	0.289
	II	4.68	2.00		
Disruption of Family interaction	I	5.55	2.14	0.20	0.839
	II	5.63	2.34		
Effect on Physical Health of others	I	2.68	1.36	0.99	0.325
	II	2.93	1.41		
Effect on Mental Health of others	I	2.75	1.22	0.36	0.719
	II	2.83	1.32		
Other family burden	I	2.78	1.26	0.07	0.942
	II	2.80	1.23		
Total family burden	I	31.93	10.32	0.81	0.421
	II	33.42	9.80		

\* Std. Deviation (df=118) I = Mother II = Father

**DISCUSSION**

The aim of the present study was to assess the gender difference in the account of family burden and quality of life of intellectually impaired children. Several studies have been done having these objectives in the country like India and some other countries, but there is a dearth of the research has been seen as particular in the region North Bihar, India. So, authors/researchers have tried to minimize the gap.

Previous studies emphasized the relation between low level of QOL and hope of parents with ID. Findings indicated that high levels hope correlated with a low level of depression scores (Lloyd & Hastings, 2009). A study showed that caring for adult intellectually disabled children has both positive and negative effect on QOL (Yoong & Koritsas, 2012). It has found, good to the excellent QOL among parents of children with intellectual disability availing respite care (Caples & Sweeney 2011). Family with ID have low QOL with support from others, the lowest QOL in the aspect of spiritual being (Boehm, Carter, & Taylor, 2015).

Present findings have been revealed that there is no significant difference found between males and females as caregivers of intellectually impaired children in quality of life and various dimensions of family burden scale. Ravindranadan & Raju (2008) also found that there is no gender difference in emotional intelligence among parents irrespective of the

condition of the child with ID. These findings more or less also supported our present findings. Similar results were found in another study compared the parents of healthy children, parents in the intellectually impaired and autism group. The results reported impairment in all the four domains of QoL in the intellectually impaired and autism children's parents than normal control. Such impairments were found in both fathers and mothers (Malhotra, Khan, & Bhatia, 2012).

In another way, we can also say that present findings emphasized that both parents had an equal level of family burden and poor quality of life. Gallagher et al., (2008) also highlighted that parents of children with intellectual disabilities report higher levels of depression and anxiety.

From the point of mean value, we have observed that females showed slightly higher mean value than males. It means females showed a higher level of a family burden than males but not at a significant level. Norlin & Broberg (2013) also observed in their study that also found that mothers with children having intellectual disability showed low wellbeing and poor marital and couple QOL.

On the variable of family burden in the review found against the results of the present study in which mothers scores was quite high (4.16±0.53). The sub-factors that have the highest score were perceived inadequacy (4.62±0.53), time requirement (4.51±0.51), and emotional burden (4.39±0.59). Physical burden (4.278±1.284), emotional burden (4.632±0.515), economic burden (3.942±1.073), social burden (4.130±0.619) and time requirement (4.788±0.219) of the family increased with the intellectual disability level of the children (Gürhopur, Dilek & Dalgıç, 2017). A study by Singh et al. (2016) on caregivers of children with intellectual impairment found that mothers were displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment. In another study, poor QOL is also seen among mothers of intellectually disabled children (Kumar, Santhosh & Joseph, 2013).

**LIMITATIONS**

The sample size is small so this should take into consideration before the generalization of the present findings. We need a large sample to validate the findings of this study. This is a cross-sectional study that does not allow us to find causal relations. More variables could be included to understand the relationship between various variables better.

**CONCLUSIONS**

The goal of the present study was to examine the quality of life and family burden across gender. Generally, it was seen that parents of children with intellectual impairment display higher burden and significant impairment in their quality of life. But in the present findings, both parents either father or mother showed equal level of family burden and low quality of life. Overall, on the basis of results, the message is conveyed that the effective and sustainable psycho-social programs are needed to provide the necessary support for the special needs of

the children and their families because the care, treatment and rehabilitation of children with intellectual disability require more manpower, cost and time than healthy children. So, Children and parents who attend special education, as well as special treatment, should support from health and psychosocial professionals in care and coping with.

**REFERENCES**

Boehm, T. L., Carter, E. W., & Taylor, J. L. (2015). Family quality of life during the transition to adulthood for individuals with intellectual disability and/or autism spectrum disorders. *American journal on intellectual and developmental disabilities, 120*(5), 395-411.

Canam, C. (1993). Common adaptive tasks facing parents of children with chronic conditions. *Journal of Advanced Nursing, 18*, 46–53.

Caples, M., & Sweeney, J. (2011). Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care. *British Journal of Learning Disabilities, 39*(1), 64-72.

Celine, T. M., & Antony, J. (2014). A study on mental disorders: 5-year retrospective study. *Journal of family medicine and primary care, 3*(1), 12.

Chou, K.R. (2000). Caregiver burden: a concept analysis. *Journal of Pediatric Nursing, 15*, 398–407.

Deniz, E. M., Dimaç, B., Arıcaç, T. O. (2009). An analysis of life satisfaction and state trait anxiety of the parents with handicapped children. *Uluslararası İnsan Bilimleri Dergisi, 6*,1303–5134

Gallagher, S., Phillips, A.C., Oliver, C. Carroll, D. (2008). Predictors of Psychological Morbidity and Parents of Children with Intellectual Disability. *Journal of Pediatric Psychology, 33* (10).1129-36.

Ganguli, H. C. (2000). Epidemiological findings on prevalence of mental disorders in India. *Indian Journal of Psychiatry, 42*(1), 14.

Gopalan, N., & Brannon, L. A. (2006). Increasing family members’ appreciation of family caregiving stress. *Journal of Psychology, 140*, 85–94.

Gupta, R. K., & Kaur, H. (2010). Stress among parents of children with intellectual disability. *Asia Pacific Disability Rehabilitation Journal, 21*(2), 118-126.

Gürhopur, T., Dilek, F., & Dalgıç, A. İ. (2017). Family burden among parents of children with intellectual disability. *Journal of Psychiatric Nursing, 8*(1), 9-16.

Harris, J. C. (2006). *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment.* Oxford University Press. Pp 42-98.

Houtrow, A. J, & Okumura, M. J. (2011). Pediatric mental health problems and associated burden on families. *Vulnerable Child Youth Stud. 6*, 222–33.

Kumar, N., Santhosh, C.D., & Joseph, P. (2013). Quality of life of parents of an individual with autism, ADHD, cerebral palsy & mental retardation in India. *Indian Journal of Health & Wellbeing, 7*65-771.

Lloyd, T. J., & Hastings, R. (2009). Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities. *Journal of Intellectual Disability Research, 53*(12), 957-968.

Malhotra, S., Khan, W., & Bhatia, M.S. (2012). Quality of Life of Parents having Children with Developmental Disability. *Delhi Psychiatry Journal, 15* (1), 222-227.

Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: a meta-analysis of population-based studies. *Research in Developmental Disabilities, 32*(2), 419-436.

Memisevic, H., Hadzic, S., Biscevic, I. I., & Mujkanovic, E. (2017). Quality of life of people with disabilities in Bosnia and Herzegovina—is there a moderating effect of the health status? *Scandinavian Journal of Disability, 19*(4), 375-382.

Norlin, D., & Broberg, M. (2013). Parents of children with and without intellectual disability: couple relationship and individual well-being. *Journal of Intellectual Disability Research, 57*(6), 552-566.

Pai, S. & Kapur, R.L. (1981). The burden of the family of a psychiatric patient: development of an interview schedule. *British Journal of Psychiatry, 138*, 331-335.

Pelchat D, Ricard N, Bouchard JM, Perreault M, et al. (1999). Adaptation of parents in relation to their 6-month-old infant's type of disability. *Child: care, health and development. 25*, 377-397.

Ravindranadan, V., & Raju, S. (2008). Emotional intelligence and quality of life of parents of children with special needs. *Journal of the Indian Academy of Applied Psychology, 34*, 34-39.

Sari, H. Y., & Başbakkal, Z. (2008). Developing a family burden assessment scale for the families of children with intellectual disability. *Journal of Ataturk University School of Nursing, 11*(3), 86-95.

Sari, H.Y., Baser, G., & Turan. J.M. (2006). Experiences of mothers of children with down syndrome. *Pediatric Nursing, 18*:29–32.

Saxena, S., Chandiramani, K., & Bhargava, R. (1998). WHOQOL-Hindi: A questionnaire for assessing quality of life in health care settings in India. *National Medical Journal of India, 11*,160-165.

Singh, K., Kumar, P., Kumar, R. & Chakarborti, S. (2016). Quality of Life among Parents of Children with Intellectual Disability. *Journal of Disability Management and Rehabilitation, 2*(1),13-17.

Venkatesan, S. (2014). Celebrating a century on form boards with special reference to Seguin Form Board as a measure of intelligence in children. *Global Journal of Interdisciplinary Social Sciences, 3*(6), 43-51.

Young, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research, 56*(6), 609-619.

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