

## Quality of Life and Family Burden of Parents with Intellectual Disability in North Bihar, India

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### ABSTRACT

**Background:** Intellectual impairment is a non-curable and non-treatable illness. It has so many physical and psychological issues for individuals with intellectual impairment as well as for their families. In the review, it has been found that these parents who have children with intellectual impairment experienced a high level of stress due to this disability and they also had issues in many psychosocial aspects such as quality of life, family burden etc. **Objective:** To assess the relationship between intellectual functioning, family burden and quality of life of parents of children with intellectual impairment. **Methods:** A total of 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 was designed 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) were used. **Results and conclusion:** It has been found that both parents either mother or father showed an equal level of quality of life and family burden. There is the non-significant difference was seen between parents of children with a low level of intellectual functioning.

**Keywords:** Intellectual functioning, Impairment, Quality of Life, Family Burden, Parents

### INTRODUCTION

Intellectual Disability (ID) is the most predominant psychiatric disorder in children and the majority of them (85%) belongs to a mild level of intellectual impairment (Harris, 2006; Ganguli, 2000). A Meta-analysis study on the prevalence of ID children shows that in the population, 10.37 out of 1000 are affected (Maulik, 2011). If to concentrate on worldwide prevalence It is reported to be 2.3% (Franklin, & Mansuy, 2011), whereas in India it is around 2% for mild intellectual impairment and 0.5% for severe intellectual impairment (Srinath & Girimaji, 1999).

The concept of family burden was coined by Grad and Sainsbury. According to them, it is a negative expenditure for the families of ID children (Chou, 2010). Intellectual impairment has a significant effect on the life of families of ID children (Sarı & Başbakkal, 2008). In the context of parenting of these children is also more challenging as compared to normal children, because it is characterized that intellectual impairment has significant impairment in cognitive and adaptive behaviour of ID children. Parents have been used various types of coping approaches, which are not effective most of the time and they experienced more stress (Gupta & Kaur, 2010). Other than these there are some other factors such as economic and educational status, profession, marital adjustment, lack of social support, difficulties in communication, severity in intellectual impairment, age of the child, disturbance in family routines etc. (Pelchat, et al., 1999). Chronic stress caused more perceived problems and also raises the anxiety level in the family members. Intellectual impairment also disturbed the private lives of the families along this social isolation and loneliness also occurred in

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families. In final these factors caused the dissatisfaction with life and quality of life of the family members of ID children (Deniz, et al., 2009). The effect of this disability not only in nuclear families but also equally influenced extended families (Gopalan, 2006). In particular, the mother has the main responsibility to provide care and thus she gets angry more frequently other than this siblings of these ID children are also deprived of the attention of their parents. This causes finally tensions between the subsystems covering parents and siblings (Canam, 1993).

The predominant view is that intellectual impairment creates stress and is a burden for caregivers (Sethi, et al 2007). Parents of ID children may be experienced the financial burden, restricted social interactions, mental worries and so on. The high level of stress or mental health problems experienced by parents of ID children could be related to many subjective factors i.e. feeling social isolation and life dissatisfaction (Majumdar, Pereira & Fernandes 2005). Based on a review of literature it has been found that there is a direct relationship between perceived burden, social-emotional burden, disruption of family routine and disturbance in family interactions etc.(Panday & Fatima (2016). Verma, et al. (2017) found that parents of male ID children have good Quality of Life in comparison to the parents of female ID children. And also found that mothers perceived more stress than fathers (Singh, et al 2016).

**Objectives:** To assess the relationship between intellectual functioning, family burden and quality of life of parents with intellectual impairment.

## **METHODOLOGY**

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 nearby 55 k. m. from Sitamarhi the great Indian mythological Ramayan character Mata Sita birthplace. The study was conducted between the periods of March 2019-June 2019.

**Sample:** A group of 240 participants were recruited in the present study. The one hundred twenty children with intellectual impairment (Mean  $\pm$  SD= 54.90 $\pm$ 11.33) and 120 parents (60 male and 60 female) were selected with the Mean  $\pm$  SD of (37.96 $\pm$ 6.97) based on their availability and purposive sampling techniques. The education of the caregivers was ranged with a Mean  $\pm$  SD of (12.45 $\pm$ 3.62). The Mean  $\pm$  SD of the children's age were 10.40 $\pm$ 4.27.

**Inclusion Criteria and Exclusion Criteria:** The parents who were living with the child with Intellectual functioning (I.Q. between 40 to 70) and have at least primary education were included. Those participants who had primary diagnoses of psychiatric illness, presence of any major medical or neurological illness or other developmental disabilities in children and refuse to give informed consent were excluded from the study.

**Design:** The study was cross-sectional and correlational research.

### **Tools Used:**

**Inform Consent Form and Socio-demographic and Clinical data Sheet:** A consent form and socio-demographic record sheet was prepared for taking the written informed consent and collecting the information about various areas of social, demographic and clinical variables. Information relating to age, sex, residence, marital status, education, types of family, occupation, age of the child, level of intellectual impairment of child, duration of illness, other psychiatric illness, family history of psychiatric illness, were recorded in an structured interview setting and the investigator recorded the information.

- (i) **Seguin Form Board Test (SFBT):** It was developed by Seguin in 1856. This test was developed for the assessment of intellectual functions, and also assesses eye-hand coordination, concepts of shape, visual perception, and cognitive abilities. This test applied from age of 3 years to old age. In the test material, 10 different types of wooden shaped blocks were included. This test has adequate reliability and validity (Venkatesan 2014).
- (ii) **Family burden interview schedule (FBIS):** It was developed by Pai and Kapur (1981). It is used to measure the stress of the caregiver. In this test both subjective and objective burden of caregivers has been measured. It is a semi-structured interview schedule and comprised a total of 24 items. The inter-rater reliability of the scale in different items is 0.78.
- (iii) **WHO Quality of Life BREF Scale:** This scale is developed by World Health Organization (1995). This consists of 25 items that concern the four domains (Physical, Psychological, Environmental and Social relations) of the quality of life of a person. The scale of the Cronbach  $\alpha$  coefficient was calculated as 0.90. This scale has an adequate level of validity.

**Procedure:** A total of 120 children with intellectual impairment and 120 parents of intellectually impaired children were selected for the study, those who fulfilled the inclusion criteria. After explaining the purpose of the study to caregivers their written informed consent was taken and then the actual administration of the study was started. In the study first, the intellectual functioning of the children was assessed after that their parents were assessed on the family burden and quality of life scales respectively. The parents of the selected intellectual impaired children's were equally involved as father and mother.

**Statistical Analysis:** The data were analyzed using SPSS 16.0 as per analysis techniques including descriptive and inferential analysis. In the demographic variables, only caregivers information was analyzed (N=120), because the caregivers were actual participants of the present study that is why only their demographic details were recorded. The children's intellectual functioning and their age were taken as covariate variables in the present study. In the rest part of the analysis including descriptive and correlation the complete data Total N=240 (120 parents & 120 children with intellectual impairment) were included.

## RESULTS AND DISCUSSION

The present study was planned to assess the relationship between intellectual functioning, family burden and quality of life of parents with intellectual impairment and gender difference in the account of family burden and quality of life of parents with 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 research that has been seen particularly in the region North Bihar (India). So, authors/researchers have tried to minimize the gap.

### Socio-demographic Profile

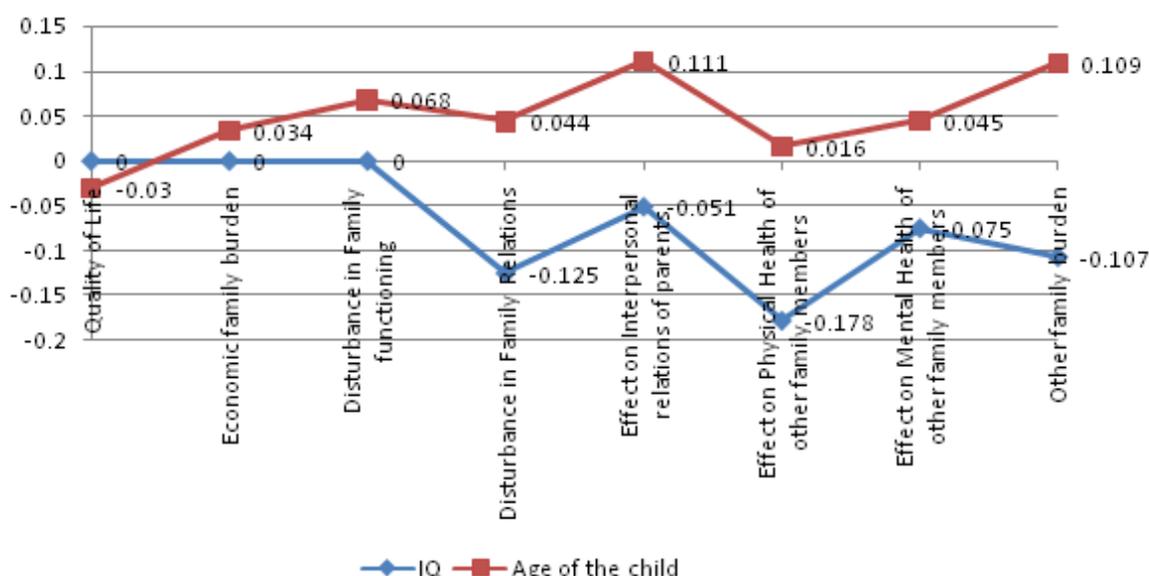
The socio-demographic findings of the present study indicated that the sample was equally divided (Male=50% & female= 50%). In the residence variable, 20% sample belongs to the rural background, 76.7% were urban and 3.3% were sub-urban. Occupation-wise distribution indicated that 0.8% sample was students and 18.3% were businessmen, whereas in a government job and other work were found as 14.2% and 66.7% respectively. Of the total participant, 95% were Hindu and 5% were Muslim.

**Table 3 Correlation between IQ of Children's, Family Burden & QoL of their Parents**

Variables	1	2	3	4	5	6	7	IQ	Age
Quality of Life	-0.483**	-0.323**	-0.253**	-0.200*	-0.171	-0.116	-0.284**	0.211*	-0.03
1. Economic family burden								-0.251**	0.034
2. Disturbance in Family functioning								-0.190**	0.068
3. Disturbance in Family Relations								-0.125	0.044
4. Effect on Interpersonal relations of parents								-0.051	0.111
5. Effect on Physical Health of other family members								-0.178	0.016
6. Effect on Mental Health of other family members								-0.075	0.045
7. Other family burden								-0.107	0.109

\*significant at 0.05 level \*\* significant at 0.01 level

**Figure 1 Relationship between IQ of Children's, Family Burden & QoL of their Parents**



Previous studies emphasized the relationship between a low level of quality of life and the hope of parents with intellectual impairment. Findings indicated that high levels of 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 effects on QOL (Yoong & Koritsas, 2012). It has been found, good to the excellent QOL among parents who availing respite care (Caples & Sweeney, 2011). A family with ID has low QOL with support from others, lowest QOL in the aspect of spiritual being (Boehm, et al., 2015).

Present findings has been showed that there is no significant difference between males and females as caregivers of intellectual impaired children in quality of life ( $t=0.11$ ,  $p<0.916$ ,  $df=1;118$ ), and various dimensions of family burden scale i.e. Financial burden ( $t=1.12$ ,  $p<0.266$ ,  $df=1;118$ ), Disruption of routine family activities ( $t=0.22$ ,  $p<0.828$ ,  $df=1;118$ ), Disruption of family leisure ( $t= 1.07$ ,  $p<0.289$ ,  $df=1;118$ ), Disruption of family interaction ( $t=0.20$ ,  $p<0.839$ ,  $df=1;118$ ), Effect on physical health of others ( $t=. 0.99$ ,  $p<0.325$ ,  $df=1;118$ ), Effect on mental health of others ( $t= 0.36$ ,  $p<0.719$ ,  $df=1;118$ ), Other family burden( $t=0.07$ ,  $p<0.942$ ,  $df=1;118$ ). Ravindranadan and 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 that 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 autistic 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 the parents had an equal level of family burden and poor quality of life. Gallagher et al. (2008) also highlighted in their study that caregiver reports higher level of depression and anxiety. From the point of mean value, we have observed that females showed a 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 and Broberg, (2013) also observed in their study that also found that mothers with children having intellectual disabilities showed low wellbeing and poor marital and couple QOL.

In the results, it has been found that the findings of the present study emphasized that quality of life is negatively related to economic family burden ( $r=-0.483$ ,  $p<0.01$ ), disturb family functioning ( $r=-0.323$ ,  $p<0.01$ ), disturb family relations ( $r=-0.253$ ,  $p<0.01$ ), interpersonal relations of parents ( $r=-0.200$ ,  $p<0.05$ ), other family burdens ( $r=-0.284$ ,  $p<0.01$ ).

Several studies have been done, showing the relationship between QOL and the family burden of parents with ID. Venkatesan and Das (1994) reported in their study that the type of burden may range from management of behavioural problems to disruption in their daily routine etc. Kermanshahi et al., (2008) in their study they found six major themes i.e. the process of acceptance, painful emotional reactions, the interrelatedness of mother's health and child's well-being, struggles to deal with oneself or the child, inadequate support from the family and the community, and the anxiety related to child's uncertain future. In another way, we can say that the quality of life increases the level of family burden in all dimensions decrease.

The quality of life is positively related to intellectual functioning ( $r=0.211$ ,  $p<0.05$ ). It indicates that when the level of intellectual functioning increases the quality of life become healthy and much better. Similarly in the results, a negative relationship was found between quality of life and age of the child ( $r=-0.03$ ) that is not significant but it indicates that as the age of the child increase the quality of life decrease. In the dimension of family burden i.e. economic family burden ( $r=-0.251$ ,  $p<0.01$ ), reduction in family functioning ( $r=-0.190$ ,  $p<0.01$ ) due to family burden negatively related with the level of intellectual functioning at a significant level. It indicates that the level of intellectual functioning is increased the family burden in this dimension be reduced. Other domains of family burden (Family Relations, Interpersonal relations of parents, Effect on physical health, Effect on mental health and other family burden) were also negatively related to intellectual functioning. There is always a major challenge i.e. to manage the negative consequence of caregiving and to develop and implement realistic and appropriate response strategies.

On other domains i.e. Effect on Physical Health of other family members ( $r= -0.171$ ), Effect on Mental Health of other family members ( $r= -0.116$ ), Disturbance in Family Relations ( $r= -0.125$ ), Effect on Interpersonal relations of parents ( $r= -0.051$ ), Effect on Physical Health of other family members ( $r= -0.178$ ), Effect on Mental Health of other family members ( $r= -0.075$ ) has a non-significant relationship with intellectual functions as well as similar results were found with Age of the child ( $r= 0.044$ ,  $r=0.111$ ,  $r=0.016$ ,  $r=0.045$ ) respectively.

## CONCLUSION

Quality of life of caregivers was negatively related to an economic family burden, family functioning, family relations, interpersonal relations of parents, other family burdens. It has been found that both parents either mother or father showed an equal level of quality of life and family burden. There is the non-significant difference was seen between parents of children with a low level of intellectual functioning. The findings of this study can have enormous useful effects. Parents are undoubtedly the pillar of the family. They are not only concerned with the issues associated with the child's impairment but also have to maintain the others and additional household activity as well as functioning. Therefore, parents should be provided individual and group-based intervention and support for handling day to challenges. Such initiative helps them to cope with the crisis and in the development of competencies for the parental role. That will empower them to advocate for the rights of their children. It has been seen that mothers with ID are more vulnerable. So the priority should be given to her. For reducing financial burden, mothers can be facilitated with additional financial resources from the state, which will help in getting better childcare and enjoying motherhood in a comparatively better way. Regarding employment and working hour, mothers should also have some benefits, especially in the sense of flexible working hours. Society should be aware and also recognize the significant role of mothers, which make help in the treatment, rehabilitation, welfare and mainstreaming of the individual with ID. It is time to accept the challenges and responsibilities; especially the mental health professionals and special educators. That makes available care to these helpless as well as penurious inhabitants. Reduce the level of stress and burden and improve the quality of life of this person, the findings of the study should be utilized in policymaking. That will provide better and more specific support and interventions for parents of children with intellectual impairment.

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