

## Psychosocial well-being of parents with intellectual disabled children, Mathura, Uttar Pradesh, India

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### ABSTRACT

**Background:** Children with intellectual disabilities are common and are increasing in number as more children survive globally. Parents of children with intellectual disabilities have facing many challenges in their life. They often reported to have physical and psychological distress related to caring for their children, thus affecting their quality of life and increasing family burden. **Aim:** The aim of the present study was to assess the psychosocial well-being of parents with intellectual disability children on quality of life and family burden. **Sample:** Quality of life and family burden scale was administered on 300 parents of children diagnosed with Intellectual Impairment. **Design:** This study was cross-sectional study and conducted at Kalyanam Karoti ((NGO), Mathura, UP. **Results and conclusion:** It have been found that quality of life negatively related with economic family burden, family functioning, family relations, interpersonal relations of parents, other family burden and the quality of life positively related with intellectual functioning. It indicates that the level of intellectual functioning will increase then quality of life become also better.

**Keywords:** *Quality of Life, family burden, parents, intellectual impairment.*

Intellectual disabilities, characterized by limitations in intellectual functioning as well as adaptive behaviors, are very common in children worldwide, with rates likely to increase as more children survive due to improved medical care [Dave et al., 2017]. The relationship between caring for these children and psychological distress for their parents has been studied but mainly in developed world settings [Dykens et al., 2014]. Some studies have been conducted in Low and Middle Income Countries such as Kenya, Kuwait, Qatar

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and India which similarly report rates of 47–50% prevalence of psychological disorders amongst these parents [Fido et al., 2017]. Parenting such children may lead to difficulties with family functioning, parenting stress, and different parenting style compared to parenting normally developing children [Cuzzocrea et al., 2013].

Parenting style of intellectual disable (ID) children is more challenging in comparison to normal children, because, ID is characterized by significant impairment in cognitive and adaptive behaviour. The term used to describe this condition has gone under constant change over the years due to social and political compulsions. The main reason to search for a new term was to find a least stigmatizing terminology. Thus, mental retardation, which was in use world over till late 20th century, has now been replaced with ID in most English-speaking countries (Chavan, Rozatkar, & Abhijit, 2014).

The prevalence of intellectual disability among children in developing countries is estimated as being particularly high [Zaman et al., 1992]. Worldwide prevalence of intellectual impairment is reported to be as high as 2.3% (Franklin & Mansuy, 2011) and in India it is reported to be around 2% for mild intellectual impairment and 0.5% for severe intellectual impairment (Srinath & Girimaji, 1999). According to National Sample Survey of 2004, 94 people per 100,000 were found to be mentally retarded.

Earlier studies have shown that parents of children with disabilities feel the sense of failure, helplessness and guilt (Dervishali 2013). The predominant view is that mental retardation creates stress and burden for the care givers (Sethi, Bhargava & Dhiman, 2007). Parents may experience the impact of financial burden, restricted social interactions, and mental worries and so on and the high level of stress or mental health problems experienced by parents of children with ID could be related to subjective factors such as feeling social isolation and life dissatisfaction (Majumdar, Pereira & Fernandes 2005). According to a 2012 report from the National Council on Impairment, in custody cases, “removal rates where parents have a psychiatric impairment have been found to be as high as 70 percent to 80 percent; where the parent has an intellectual impairment, 40 percent to 80 percent. Parents of these children may struggle with a multitude of emotions interchangeably over years, and often have feelings of guilt that somehow, they caused the child to be disabled, for logical or illogical reasons (Upadhyaya & Havalappanavar 2008). Panday and Fatima (2016) have found that direct relationship between the degree of perceived burden, social emotional burden, disruption of family routine and disturbance in family interactions for women with intellectually disabled children rather than men. Another finding indicated that parents of male children have good Quality of Life in comparison to the parents of female children. There was a significant gender difference in perceived stress among parents having children with I D. Mothers perceive more stress than father (Verma et al 2017). Mothers of children with ID displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of the environment (Singh et al 2016). 41.2% of parents of children with intellectual disabilities reported psychological distress. Univariate and multivariate analysis showed that area of residence ( $P < 0.05$ ), low socio-economic status ( $P < 0.05$ ), knowledge of the disability of one’s child ( $P < 0.05$ ), low confidence in managing the disabled child ( $P < 0.05$ ), increased perceived burden of care ( $P = 0.05$ ), and having no sources for psychological support ( $P < 0.05$ ) significantly predicted psychological distress among the parents for children with disabilities. ( Charles et al 2018). Family burden and quality of life are important area of the psychosocial well being . The field of intellectual impairment (ID) is strongly influenced by the Quality of Life paradigm (QOL), from a

research, a practice based, and a policy-oriented perspective (Claes, van Hove & van Loon et al., 2010).

Family burden and quality of life are important area of the psychosocial well being . The field of intellectual impairment (ID) is strongly influenced by the Quality of Life paradigm (QOL), from a research, a practice based, and a policy-oriented perspective (Claes, van Hove & van Loon et al., 2010). Kumar et al., (2019) emphasized that quality of life negatively related with economic family burden, family functioning, family relations, interpersonal relations of parents, other family burden. It has also found that both parents perceive an equal level of psychosocial well-being on family burden and quality of life (Rathee, et al., 2019)

### ***Aims and objectives***

This paper describes the psychosocial wellbeing of parents with intellectual disability on quality of life and family burden. The main objectives of this study was,

1. To assess the quality of life and family burden in parents of children with intellectual disability.
2. To assess the relationship among various domains i.e., Intellectual Functioning, Age of child, Quality of Life and Family burden.

## **MATERIALS AND METHOD**

This study was cross-sectional study and conducted at Kalyanam Karoti ((NGO), Mathura, UP. The study was conducted between the periods of May 2019- July 2019. This study was cross sectional and correlational research.

### ***Sample***

A group 600 sample was recruited in the present study. The three hundred children with intellectual impairment and 300 parents (150 male and 150 female) were selected on the basis of their avail ability and purposive sampling techniques.

### ***Inclusion Criteria***

1. The parents who were living with intellectual disabled child (I.Q. between 69-40)
2. Participants have at least primary education.

### ***Exclusion Criteria***

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

### ***Tools***

**Inform Consent Form and Socio-demographic:** A consent form and socio-demographic record sheet was prepared for taking the written inform 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 child, level of intellectual impairment of child, duration of illness, other psychiatric illness, family history of psychiatric illness, were recorded in as structured interview setting.

**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 total 10 different types of

wooden shaped blocks. On the basis of 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 care giving activities of any family member with any chronic illness. This consist 24 items categorized in to 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 has been shown to be satisfactory. The inter-rater reliability for all items was reported to be more than 0.78.

**WHO Quality of Life BREF Scale:** This scale is developed by World Health Organization. This consists of 25 items that concerns 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 adequate level of validity (Barcaccia, Barbara, 2013).

### **Procedure**

A total 300 children with intellectual impairment and 300 parents of intellectual impaired children were selected for the study, those who fulfilling the inclusion criteria. After explaining the purpose of 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 family burden and quality of life scales respectively. The parents of the selected intellectual impaired children were equally involved as father and mother. The scoring of the scales was done with the help of them respective manual.

## **RESULTS**

The data was analysed with using SPSS 20 as per suitable analysis techniques including descriptive and inferential analysis. In the demographic variables only caregiver's information was analysed (N=300), because the caregivers were actual participants of the present study that is why only them 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 analysis including descriptive and correlation the complete data (N=600) was included.

**Table 1: Showing the characteristics of demographic variables**

<b>Socio-Demographic Variables</b>		<b>Frequency</b>	<b>Percent</b>
Gender	Male	150	50
	Female	150	50
Residence	Rural	92	30.7
	Urban	115	38.3
	Sub-Urban	93	31
Occupation	Government Job	53	17.6
	Private Job	108	36
	Business	119	39.6
	Other	20	6.6
Family History of Psychiatric Illness	Yes	90	30
	No	210	70

**Table: 2 Descriptive analysis of IQ & Age of child, Age of parents**

Variables	Mean	Standard Deviation
IQ	55.01	8.87
Age of Child	12.54	5.44
Age of parents	37.96	6.97

**Table :3 Descriptive analysis of Quality of life**

Variables	Mean	Standard Deviation
Physical Health	23.04	4.42
Psychological Health	21.48	4.33
Social Health	10.07	2.51
Environmental Health	27.29	5.81
Quality of Life	81.95	14.28

**Table: 4 Descriptive analysis of Family Burden**

Variables	Mean	Standard Deviation
Financial burden	4.39	2.95
Disruption of routine family activities	3.30	2.26
Disruption of family leisure	2.93	1.59
Disruption of family interaction	3.54	2.34
Effect on Physical health to other	1.44	0.99
Effect on Mental health to other	1.57	1.23
Family Burden	17.17	11.36

**Table: 5 Correlation among Intellectual Functioning, Age of child, Quality of Life and Family burden**

	IQ of Child	Age of Child	Quality of Life	Family Burden
IQ of Child	1			
Age of Child	-.050	1		
Quality of Life	-.018*	-.329**	1	
Family Burden	-.123*	.132*	-.171**	1

**Table: 6 Correlation among Intellectual Functioning, Age of child, Quality of Life**

	IQ of Child	Age of Child	Physical Health	Psyc. Health	Social Health	Evir. Health	Quality of Life
IQ of Child	1						
Age of Child	-.050	1					
Physical Health	-.032	-.364**	1				
Psychological Health	-.004	.858**	-.180**	1			
Social Health	-.032	-.364**	.557**	.623**	1		
Environmental Health	-.308	-.235**	.496**	.666**	.667**	1	
Quality of Life	-.018	-.329**	.777**	.858**	.805**	.877**	1

## DISCUSSION

The present study has been planned with the main objective to assess and find out the relationship between intellectual disability of the child and family burden and quality of life of their caregivers/ parents. The socio-demographic findings of the present study indicated that the sample was equally divided (Male=50% & female= 50%). In the residence variable 30.7% sample belongs to rural background, 38.3% were urban and 31% were sub-urban. Occupation-wise distribution indicated that 17.6% sample was government employee and 39.6% were businessmen, whereas in private job and other work were found as 36% and 6.6% respectively.

The descriptive analysis of variables (Socio demographic, intellectual functioning, quality of life and family burden) disclose that that mean age of the sample was  $39.76 \pm 5.87$ . Age of the child found as mean value of 12.54(5.44) while the intellectual functioning of child the mean value of the sample is 55.01 (8.87). The mean value of Physical Health of respondents  $23.04 \pm 4.42$ , Psychological Health of respondents  $21.48 \pm 4.33$ , Social Health of respondents  $10.07 \pm 2.51$ , Environmental Health of respondents  $27.29 \pm 5.81$  and Quality of life of respondents  $81.95 \pm 14.28$ . The table 3 show the Mean and SD score of quality of life and its domain. Many research studies indicate that mean range of 90 and greater is good quality of life (Burckhardt & Anderson (2003). In this study researcher has taken respondents as parents of children with intellectual disability so the mean score of Quality of life is poor in compare to healthy quality of life because parents faces many obstacles in daily life due to children with intellectual disability. Parenting of these children is very challenging and lot of other responsibilities, they face many difficulty day to day life so their quality of life impacted these reasons.

The mean value of family burden of respondents is  $17.17 \pm 11.36$ . The table 4 show the Mean and SD value of family burden scale and its domains. High score shows high level of burden. In this table Mean and SD value is very high because parents of children with intellectual disability and they always worry about the caring of their child along with future of child. Parents have lots of family responsibly along with this so they unable to give proper time for selfcare. Due to this their mental and physical health suffer, financial burden also increased due to care giving of child, family interaction and recreational activities also hampered because child has special needs. We can say these reasons influences the family burden of parents with intellectual disability.

Table 4 revealed the positive correlations between Quality of life of parents and intellectual functioning of their children. This indicates that if the intellectual functioning of child is poor then quality of life of parents is also poor vice versa. Family burden of parents and intellectual functioning of child is showing negative correlation because intellectual functioning of child is decrease than family burden of parents is increased. Quality of life and Family burden of parents also showing negative correlation because Quality of Life increase then family burden is decrease. In the results it has been also found that the subdomain of quality of life negatively correlated with age of the child variables. It suggests that as the age of their children's increase the quality of life decrease. It also means that as the age of child increase they face more problems and issues. And similar results have been observed on family burden scales. Family burden and age of child positively correlated it means both increase with the time. The present findings also supported by study conducted at Muzafferpur, Bihar having parents with intellectual disability, where findings showed that quality of life negatively related with economic family burden, family functioning, family relations, interpersonal relations of parents, other family burden. (Kumar et al., 2019).

Venkatesan and Das (1994) report that the type of burden reported by family members may range from difficulties in transportation of the child to the place of service delivery, management of behaviour problems, disruption of their daily routine, economic, physical and social burden. Kermanshahi et al., (2008) in their study on perceptions of lives with children with intellectual impairment found six major themes: challenging 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. Lin et al., (2009) found the reduced quality of life of caregivers of children with intellectual disabilities, which are caused by factors such as health of caregivers, family income and the stress caused by a lack of social supports.

There are so many barriers and challenges still present in our country for the main streaming, rehabilitation, reintegration, and welfare for the person with ID as well as his/her family members. The challenges faced by parents with ID are accessibility (parents are not able to approach intuitional care or professional help), strong attached social stigma, financial problems, lack of awareness, negligence, huge gap between total number of professional/special educator/mental health professional and family/caregivers/parents with ID etc. At present its demand of our society to achieve the goal of positive mental health and enhance the quality of life as well as psychosocial functioning of parents with ID. So, it's great responsibilities of professionals/policy makers/researchers to accept this challenge and provide care to this vulnerable as well as needy person. The professionals (mainly special educators/mental health professionals) can help the parents to cope with the crisis by examining the resources of the Family, including role structure, emotional and financial stability and can help them to deal effectively with the situation (Kumar et al., 2019).

## **CONCLUSION**

Parents of intellectual disability child have been perceived poor psychosocial well beings especially on area of quality of life and family burden domain. Negative correlations have been found between Quality of life, Family burden and IQ functioning. This indicates that IQ functioning of Child is low then Quality of life of parents is also poor. There are negative correlation has been found between quality of life and Family burden of parents, it means quality of life increase then family burden of the parents is decrease. In the same way if family burden reduces then quality of become improve as well as better.

### ***Limitations***

First, the sample size is small and generalization of the present findings should take into consideration. 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.

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### ***Conflict of Interest***

The author declared no conflict of interest.

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