



## An Assessment of Burden of Care on Parents with Intellectual Disability in Eastern Indian Population

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### Abstract

*Caring a child with intellectual disability are associated with negative experiences and stresses in parents. That is measured by burden of care. For any chronic disability, measurement of burden of care is important for overall well-being of a family. 38 children with Intellectual disability and 34 children without intellectual disability who satisfy the inclusion and exclusion criteria and consented for the study were recruited. A socio-demographic questionnaire and Burden Assessment Schedule of SCARF were applied to both the parents of the children. Both the parents of children with intellectual disability were significantly more burdened than their counterparts with typically developing children ( $p=0.000$ ). Mothers were more burdened than fathers ( $p=0.000$ ), but the burdens were correlated (Pearson's  $r=0.912$ ). It supports the previous studies, both from India and abroad. It may be useful to plan an intervention module addressing the parental burden component, for intellectually disabled children. Burden, parents, intellectual disability*

**Keywords:** Parental Burden in Intellectual Disability.

### Introduction

Intellectual disability is characterized by significant limitations in both intellectual functioning and in adaptive skills, those comprises of many social and practical daily skills. This disability originates before the age of 18<sup>(1)</sup>. A recent meta-analysis finds the prevalence of this disability around 10.37/1000 population worldwide<sup>(2)</sup>. India also has a comparable prevalence (10.5/1000) of the disability<sup>(3)</sup>. The term 'Caregiver burden' denotes the physical, psychological, emotional, social and financial stresses experienced by a caregiver<sup>(4)</sup>. Though this

concept yet to be operationalised unitarily across studies<sup>(5)</sup>. But studies abroad<sup>(6)</sup> as well as from India<sup>(7)</sup> have shown that parenting children with intellectual disability is associated with higher care giver burden than parents of typically developing children. Though there are dearth of such studies from eastern Indian population. As India is a large country with multicultural and multi-linguistic society, hence the finding from one region may not be extrapolated to the whole of India.

Through this study, we tried to assess the followings.

1. The burden of care among parents of children with Intellectual disability in comparison to parents of children with normal intelligence.
2. The association of burden of care with various factors like behavioural abnormalities in the child with intellectual disability.
3. The difference and relation, if exists regarding perception of burden of care among fathers and mothers of children with intellectual disability.

### Material & Methods

It is an observational study done in psychiatry department of a medical college in eastern India. Mental retardation was diagnosed according to International Classification of Diseases, 10<sup>th</sup> edition, chapter V (F)<sup>(8)</sup>. A semi structured interview schedule was used for this study which contained demographic and clinical characteristics of the children. Cases (Children with intellectual disability hereafter mentioned as ID group) were diagnosed by a consultant psychiatrist according to ICD 10 criteria. IQ (intelligence quotient) and SQ (social quotient) were measured by a clinical psychologist by standard instruments. Cases were of both sexes and between ages 5-16 years and for whom both parents had given consent to take part in the study and present during the interview. Control (Children without intellectual disability,

hereafter mentioned as non-ID group) children were taken from normal school where the 5-16 years old children irrespective of sexes, when they scored non retarded (>70) range in Standard Progressive Matrices<sup>(9)</sup>, who had no complaints of any maladaptive behaviour and both parents had given consent and were present for interviewing during scheduled school visits with due permission from the respective school authorities. Where there were documented psychiatric abnormalities in parents or parents did not have a direct role in care giving of the concerned child, those children were excluded from the study. After satisfying all inclusion and exclusion criteria cases recruited in ID group is 38 and controls recruited in non-ID group is 34. Both the parents of the selected children (both cases and controls) were given a special questionnaire for this study comprising of relevant socio-demographic and clinical and developmental details as perceived. Then the parents are subjected to Burden Assessment Schedule of SCARF (BASS)<sup>(10)</sup> to generate individual item score and total score.

### Result & Analysis

Table 1 shows the two groups, (ID and non-ID) are matched for socio-demographic variables. Sex of the child, age of the child, family income, family size, family type and parental age did not differ significantly between these two groups.

**Table 1:** Comparison of socio demographic variables in case and control groups (SD= Standard deviation)

		Children with Intellectually Disability	Children without intellectually disability	
SEX	Male	29	18	X <sup>2</sup> Test p=0.067
	Female	9	16	
Age of the child		Mean=10.76, SD= 1.42	Mean=11.75, SD= 3.14	ANOVA, p=0.063
Family Income		Mean= 5784.74, SD= 4569.84	Mean= 6532.35, SD= 7911.04	t-test, p=0.487
Family Size		Mean=4.39, SD=1.57	Mean=4.03, SD= 0.90	Mann Whitney's U test, p=0.383
Family Type	Nuclear	31	26	X <sup>2</sup> Test p=0.809
	Joint	7	8	
Parental age	Mothers' Age	Mean rank=39.86	Mean rank=32.75	Kruskal Walis test. P=0.146
	Fathers' Age	Mean Rank=40.61	Mean Rank= 31.91	KruskalWalis test. P=0.075

Table 2: Shows, both the parents of children with intellectual disability have significantly more burden than their counterparts with children without intellectual disability. Clearly mothers feel more burden than fathers in both the groups and that difference was statistically significant ( $p=0.000$ ). Mean burden score difference ID

group is 4.5, and in non-ID group is 1.4. This study showed that, in ID group, mothers' excess burden than father is significantly more than non-ID group ( $t=2.596$ ,  $df=70$ ,  $p=0.011$ ). Pearson's correlation showed that the burden of the both the parents are highly correlated.

**Table 2:** Comparison of burden score between cases and controls groups (SD= Standard Deviation)

	Children with Intellectually Disability	Children without intellectually disability	ANOVA	Comparison of burden among two parents	Correlation of burden among parents
Burden score of Mother	Mean= 76.4737 SD= 11.3035	Mean= 63.7941 SD= 10.8342	F= 23.479, p= 0.000	t-test for paired observation by difference method: $t=4.926$ , $df=71$ , $p(2\text{-tailed})= 0.000$	Pearson's $r= 0.912$
Burden Score of Father	Mean =71.9737 SD= 10.6530	Mean= 62.3824 SD= 11.4522	F= 13.552, p= 0.000		

## Discussion

Numerous studies had shown that the parents of children with intellectual disability had significant burden<sup>(11)</sup>. Studies had also shown parents with normal developing small children also had their share of burden<sup>(12)</sup>. Hence in this study it was examined, if having a child with intellectual disability add significantly more burden on parents. As expected, the study had shown that both the parents, i.e. father and mother of ID group were more burdened than their respective counterparts from non-ID group. This results supported the previous results shown in numerous other studies from other parts of India<sup>(13-15)</sup>. A lot of studies of parental burden and stress focussed only on mothers, both from India<sup>(13,14)</sup> and abroad<sup>(16,17)</sup>. But researches had also shown that fathers also had sources of stresses, which is different from mother's parenting experiences<sup>(18)</sup>. Parents with normal children also had stresses which were significantly more in mother but this difference in stresses and burden become aggravated in mothers' of moderate or severely disabled children that their male counterparts. Interestingly the difference in burden and stress among parents are not significant in mild or borderline intellectually challenged children<sup>(11,19)</sup>. This study

also supported this view that mothers definitely is more burdened than fathers both in ID and non-ID groups. The difference is more in ID group. But it also showed that the burden of care in both the parents were highly correlated.

## Conclusion

Rearing up of children is a burdensome task for both the parents. This burden in aggravated significantly if the children are intellectually disabled. As in typically developing children, in intellectually disabled children also mothers are significantly more burdened than fathers, though stresses are highly correlated. Hence for effective management of children with intellectual disability, addressing parental and especially maternal burden are essential. A therapy module for parents are worth formulating routinely while managing intellectually disabled children.

**Source of Funding:** Nil

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