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ORIGINAL ARTICLE

Intellectual Disability and its Association with Care Givers Burden at Sasaram

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Abstract

Background: Intellectual Disability characterized by poor intellectual or mental ability and a lack of skills necessary for daily living. Care givers of person with intellectual disability experience countless situations in their daily routine. They experience emotional, physical and financial challenges that reflected as burden of care.

Aim: To know the level of burden among care givers of children with intellectual disability in northern India.

Methodology: Cross sectional hospital based technique was used for the study. Total 98 children with intellectual disability along with their caregivers were recruited through systematic sampling from outpatient department of District Mental Health Program Unit (DMHP), District Hospital, of Bihar. Informed consent was sought from the participants and structured socio-demographic data sheet and family burden interview schedule was administered.

Results: Burden was experienced by the caregivers in various aspect of family life: family routine, financial and mental health burden. Almost every domain of the burden is significantly high in the male caregivers in comparison to female caregivers.

Conclusion: Caregivers experience physical, economical, emotional, and personal burden while caring the intellectually disabled child throughout their life.

Keywords

Family, Intellectual disability, Caregivers, Burden

Introduction

Intellectual disability is the most common developmental disorder. Conditions with intellectual disability are not only suffered by the individual having it but it affects the family and community. Intellectual Disability characterized by poor intellectual or mental ability and a lack of skills necessary for daily living. Care givers of person with intellectual disability experience countless situations in their daily routine. They experience emotional, physical and financial challenges that reflected as burden of care. The term "*caregiver's burden*" is described as the physical, psychological, emotional, social and financial problem that is experienced by the family members take care of an individual with illness or disability. The possible areas of burden experienced may be at work place, getting employment, having a social life and leisure time, with physical and emotional/mental health, with managing finance, at school, getting education, raring of children and in interaction outside family. Gopinath & Rao [1] noted that due to the rapid industrialization, urbanization and subsequent changes in the family structure and role, care for psychiatric patients imposes a significant burden on the families in developing countries like India. The impact of mental illness is felt in other areas of family life too, such as leisure, work, income, and family health, relations with relatives, friends and neighbors. Trendley [2] first used the term burden on the family in relation to the consequences for those in close contact with psychiatric patient. Platt [3] presented a more elaborate definition which states that "burden refers to the presence of problem, difficulties or adverse events that affect the

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live of psychiatric patients". Although the entire family experiences burden of the illness, the responsibility of caring is often shouldered by the "primary caregiver" who experiences physical and emotional burden. The concept of burden share characteristics with that of social performance, for the person's poor social performance is another person's burden. The existence of burden indicates the breakdown of the reciprocal arrangements that people maintain in their relationship such that one person is doing more than a fair share. Study shows that having intellectual disability in addition to autism spectrum disorders is associated with greater negative impact on family financial and employment burden [4].

The birth of continuing care of person with intellectual disability are often stressful experience for family members as these children's difficulties touch the lives of those around them [5,6]. Not only caregivers but the person living with intellectual disability they also has multiple problems in the family. Family members have plenty of expectation with child. Many people are not aware about Intellectual Disability (ID). ID is characterized by below-average intellectual or mental ability and a lack of skills necessary for day-to-day living. Burden is significantly higher if the children with intellectual disability in the family. Also mothers are significantly more burdened that father, thought stress are highly correlated. Hence effective management of children with intellectual disability, addressing parental and especially maternal burden are essential [7].

The rigid structure of the societies in India is one of the significant barriers due to which an individual with intellectual disability is not included in the society itself. Also the existing prejudice and stereotypes is due to lack of information which makes the conditions of an individual worst. At present, individuals with ID are seen by the majority of people in India as fundamentally "flawed" and perceived to have diminished capabilities, thereby placing them at the bottom of the social structure regardless of their caste identity [8].

Aim: To assess the level of burden among care givers of person with intellectual disability. Present study try to assess level of burden on female care givers how they taking care of ID children when they have number of other responsibility at home, similarly male care givers after doing job or doing work outside at home how they taking care of children with ID and level of burden they felt.

Methods

The study was a hospital based cross-sectional study systematic sampling method was used to recruit the participants. Sample consisted of total 98 participants female and male caregivers of person with intellectual disability. Samples were drawn from at outpatient department of District Mental Health Program Unit, District Hospital, in Bihar by the using purposive sampling technique. Participants diagnosed with Mental Retardation as per ICD-10 [9], DCR, and Providing care to the patient for at least past 6 months were included from the study and participant having any physical or psychiatric co-morbidity or taking care of more than one person (Physical or Psychiatric) in family were excluded from the study. Tools used in study Socio-demographic data sheet for assessing the Name, age, gender, demographic details. For assessed Intelligent Quiescent of the children Developmental Screening Test (Indian adoption by Bharat Raj 1983 [10], developmental screening test is designed to identify problems or delays during normal childhood development), Seguin Form Board Test (The Revised Seguin Form Board Test by S K Goel in 1990 [11], is based on the single factor theory of intelligence, measures speed and accuracy. it is useful is evaluating a child's eye-hand co-ordination, shape-concept, visual perception and cognitive ability. The test primarily used to assess visuo-motor skills. Test material consists of ten differently shaped wooden blocks and a large form board with recessed corresponding shapes.) and Gessel Drawing Test (this is one of the most frequently used screening measures of intelligence for clinical population, such as children with intellectual disability and other development disabilities in India, Develped by Verma, et al.) [12] were applied. Family Burden Interview Schedule (Family Burden Interview Schedule developed by Pai and Kapur in 1982 [13], consist of 24 items classified into 6 different domains Financial Burden, Disruption of Routine family activity, disruption of family leisure, disruption of interaction, effect on physical health and mental health of others).

Ethical permission was obtained from the concerned authorities. Samples matching to the study criteria were selected from the out-patient department of the district hospital. Caregivers of the patients were briefly explained about the study and written consent was taken. DST, SFBT and GST were administered as applicable to each individual patient and they were classified on the basis of score to mild, moderate, severe and profound mental retardation. FBIS was administered on the caregivers. Once the data was collected it was computed and analyzed on SPSS version 21.

SPSS version 21 was used to compute and analyze the data. Descriptive analysis was done for the Socio-demographic variables, for assessing the difference between sub-groups t-test was analyzed. Pearson Product Moment Correlation was administered to evaluate the relationship between caregiver's burden and IQ. One-way ANOVA was administered to know the caregiver's burden of deferent levels of mental retardation.

Results

Result Table 1 shows the socio-demographic details of the participants of the study with 46 male participants and 52 female participants. 11 male and 16 female participants were primary educated, 19 males and 13 females were educated upto higher secondary, 0 male and 10 female participants were graduates, 7 male and 12 female participants were post-graduates and 9 male and only 1 female participant had some other educational qualifications. Table 1 also shows that there were 37 male and only 1 female participants doing farming, 2 male and 0 female were involved in business, 1 male and 18 female participants were professionals, 0 male and 32 female participants were homemakers and 6 male and 1 female participants were involved in some other livelihood. 21 males and 24 females hailed from rural area, 19 males and 14 females from urban area and 6 male and 14 females belonged to semi-urban area of Sasaram, Bihar. 21 males and 30 females were diagnosed with mild mental retardation, 18 males and 17 females with moderate mental retardation and 9 males and 3 females with severe mental retardation as per ICD-10 [9], DCR. The mean age of male individuals' diagnosed with mental retardation as per ICD-10 [9], DCR was 10.27 and 11.56 for females. Mean age of male caregivers was 37.98 and of female caregivers was 36.42.

Table 1: Socio-demographic profile of participants.

Variables	**Participant (N = 98)**	
	Male (46)	**Female (52)**
Caregiver Education		
Primary	11	16
H Secondary	19	13
Graduate	0	10
PG	7	12
Other	9	1
Caregiver Occupation		
Farmer	37	1
Business	2	0
Professional	1	18
Homemaker	0	32
Other	6	1
Domicile		
Rural	21	24
Urban	19	14
Semi urban	6	14
IQ		
Mild	21	30
Moderate	18	17
Severe	9	3
Patient Age		
MEAN + SD	10.27 ± 5.84 (N = 48)	11.56 ± 3.78 (N = 50)
Caregivers Age		
MEAN + SD	37.98 ± 11.72	36.42 ± 12.18

Result shown in Table 2 is about the comparison between burden felt by male and female caregivers. In the area of financial burden t-value of 3.611 with p = 0.000 shows a significant difference between the two groups males with Mean-6.78 and SD-2.50 and females with Mean-4.92 and SD-2.58. There was a significant difference in Daily routine family burden experience by male with Mean-5.04 and SD-1.60 and female with Mean-3.29 and SD-1.43 and a t-value of 5.720 (p = 0.000). In the area of family leisure burden result shows significant difference between the two groups of male and female caregivers with Mean 4.15 & 3.06 and SD 1.01 & 1.72 for male and female participants respectively. In the area of family interaction burden the t-value is 2.637 (p = 0.010) which show slight difference between the two groups with Mean and SD 5.07 ± 1.54 for male and 4.17 ± 1.78 for females. No significant difference was found the areas of physical and mental health burden with t-values of 1.985 (p = 0.050) and 2.342 (p = 021). However, there is a significant difference between the two groups on overall burden experienced with a t-value of 4.690 (p = 0.000) and Mean and SD of male 25.07 ± 5.42 and females 19.17 ± 6.83.

Result Table 3 shows the correlation between burdens experienced by the caregivers living with individuals' diagnosed with mental retardation. Highly significant burden is experienced by the caregivers in the areas of financial and daily routine family burden with r = 0.328 and 0.425 at 0.01 level. Also significant burden is felt by the caregivers in the areas of family leisure, family interaction, physical health, mental health and over all burden with r = 0.213, 0.215, 0.201, 0.227 and 0.320 respectively, at 0.05 level.

Table 2: Level of burden on male and female care givers.

Variable	**MEAN ± SD (N = 98)**		**t (df = 96)**	**P**
	Male	**Female**		
Financial burden	6.78 ± 2.50	4.92 ± 2.58	3.611	0
Daily routine family burden	5.04 ± 1.60	3.29 ± 1.43	5.72	0
Family leisure burden	4.15 ± 1.01	3.06 ± 1.72	3.777	0
Family interaction burden	5.07 ± 1.54	4.17 ± 1.78	2.637	0.01
Physical health burden	1.96 ± 0.76	2.27 ± 0.79	1.985	0.05
Mental health burden	2.06 ± 1.36	1.46 ± 1.20	2.342	0.021
Overall burden	25.07 ± 5.42	19.17 ± 6.83	4.69	0

Table 4 shows the comparison between the mental retardation categories and burden experienced by the caregivers. Result shows significant difference between the three categories of mental retardation Mild, Moderate and Severe in the area of Daily routine family burden with F = 11.729 (p = 0.000) and Mean and SD as 3.57 ± 1.77, 4.26 ± 1.36 and 6.00 ± 1.28 respectively. No significant difference was found in the areas of family interaction burden, physical and mental health burden with F = 2.330 (p = 0.103), F = 2.097 (p = 0.128) and F = 3.729 (p = 0.028). Though not significant still the results shows difference in experiencing financial, family leisure (F = 6.232 p = 0.003; F = 2.682 p = 0.078; F = 5.772 p = 0.004) and overall burden by the caregivers.

Discussion

The result of socio-demographic details suggests that there were 46 male and 52 female caregivers as participants who gave written consent for the study after being selected for the study as per the inclusion and exclusion criteria. According to the census 2011 [14] population of Sasaram constituted of 52% male and 48% female with a literacy rate of 80.26% (male 85% and female 75%). Thus, sample of the study comprised of 11 male and 16 female participants having primary education, 19 males and 13 females were educated upto higher secondary and 10 female participants were graduates, 7 male and 12 female participants were post-graduates and 9 male and only 1 female participants had some other educational qualifications respectively. Sasaram's economy mainly consists of agriculture and agriculture related industries, thus in the current study out of total 98 samples 37 male and only 1 female participants were involved in farming directly, only 2 male participants had a business of their own, 1 male and 18 female participants were professionals, majority of 32 female participants were homemakers and 6 male and 1 female participants were involved in some other livelihood. According to census 2011 [14] 41.1% population of Sasaram lives in urban areas and 58.9% lives in the rural areas. Hence, in the present study 21 males and 24 females hailed from rural area, 19 males and 14 females from urban area and 6 male and 14 females belonged to semi-urban area of Sasaram, Bihar. 21 males and 30 females were diagnosed with mild mental retardation, 18 males and 17 females with moderate mental retardation and 9 males and 3 females with severe mental retardation as per ICD-10 [9], DCR. The mean age of male individuals' diagnosed with mental retardation as per ICD-10 [9], DCR was 10.27 and 11.56 for females. Mean age of male caregivers was 37.98 and of female caregivers was 36.42.

Table 3: Association of IQ with caregiver's burden.

Variable	IQ
Financial burden	0.328**
Daily routine family burden	0.425**
Family leisure burden	0.213*
Family interaction burden	0.215*
Physical health burden	0.201*
Mental health burden	0.227*
Overall burden	0.320*

*Co-relation is significant at 0.05 level (2 tailed); **Co-relation is significant at 0.01 level (2 tailed).

Results show that caregiver of individual's diagnosed with mental retardation experience burden in different spheres of life. The study results indicate that the burden experienced by caregivers at significant level at various domains. Male and female participants experiencing overall burden is very differently perceived by them. Male participants perceive overall burden far more than the female participant's significant (p = 0.000) level. Similarly, financial burden, family leisure burden and daily routine family burden is highly perceived by the male participants when compared to female participants in the study at (p = 0.000) level. Similarly study conducted by Ray [7], both the parents of children with intellectual disability were significant (p = 0.000). Females performing the role of homemaker are supposed to be responsible for caring of all the household chores and also caring for all the family members all together - looking after food, laundry, timely medicine, cleansing, and so on. Mother were more burden than father (p = 0.000) Ray [7]. One of the reasons for the findings of the study is thus, because female as homemakers are already responsible for caring and thus the subjective experience

Table 4: Burden experienced by caregivers in relation IQ range.

Variables	Groups (N = 98)			F	P
	Mild (N = 51) MEAN ± SD	**Moderate (N = 32) MEAN ± SD**	**Severe (N = 12) MEAN ± SD**		
Financial burden	5.14 ± 2.02	6.00 ± 2.52	8.00 ± 4.31	6.232	0.003
Daily routine family burden	3.57 ± 1.77	4.26 ± 1.36	6.00 ± 1.28	11.729	0
Family leisure burden	4.38 ± 1.06	3.11 ± 1.35	3.50 ± 1.73	2.682	0.078
Family interaction burden	4.25 ± 1.87	4.86 ± 1.57	5.25 ± 1.114	2.33	0.103
Physical health burden	2.00 ± 0.87	2.17 ± 0.71	2.50 ± 0.52	2.097	0.128
Mental health burden	1.41 ± 1.31	2.14 ± 1.19	2.00 ± 1.28	3.729	0.028
Overall burden	20.27 ± 6.56	22.54 ± 5.21	27.25 ± 9.44	5.772	0.004

of burden is low. This difference is highly significant in the study. Though not significant yet family interaction burden and mental health burden is perceived more by the male participants in comparison to female participants in the study at (p = 0.01) and (p = 0.21) respectively. The current study results show that physical health burden is experienced more by the female participants than male participants, however when the result is not significant. Hailemariam KW (2015) [15] found no significant difference between male and female caregivers of both psychotic and affective disorder patients.

Result further explained in Table 3 it is indicated that burden is significantly experienced by the caregivers of the individual's diagnosed with mental retardation in all spheres of life: financial, daily routine, family leisure, family interaction, physical and mental health and overall burden. Ampalam, Gunturu & Padma in the year 2012 [16] found that burden experienced by caregivers was experienced more with psychiatric ill individuals in comparison to physically ill patients. A study conducted by Maheshwari [17] supports the finding of the study.

The above association between burdens of caregivers of individual's with mental retardation is rightly explained by the results of Table 4. The results indicate that caregivers of severe mental retarded individuals have more daily routine family burden when compared to caregivers of mild and moderate mental retardation individuals. It is also suggested that daily routine family burden is more in the caregivers of moderate mental retardation individuals than mild mental retardation individuals. Though the following result is not statistically significant still the results indicate that financial burden, family interaction burden, physical and mental health burden and overall burden is experienced most by caregivers of severe mental retarded individual, then by caregivers of moderate mental retarded individuals and least by caregivers of mild mental retarded individuals. Results indicate that family leisure burden was experienced and perceived more by the caregivers of mild mental retardation when compared with caregivers of moderate and severe mental retardation in the study.

Conclusion

Present study shows higher level of burden in varies domains of Family Burden Interview Schedule by the caregivers. This is well known that every family work as primary support system for persons having any problem: Like disability, in our society. Upbringing a child with a condition of mental retardation can be scary and exhausting task. There are many appointments to keep. Family members must cope with the daily stress of seeing their child struggle. Furthermore, family members must cope with all this, knowing these difficulties will last a lifetime. Finally, family members experience a range of burden to upbringing children with intellectual disability. It is natural to feel grief, resentment, disappointment, and frustration. Sometimes these feelings can lead to mental health burden. The study concludes that management of caregivers burden should be an initiative made by the mental health professionals whenever encountering with a caregiver of a mental retarded individual.

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