

Exploring the Level of Parenting Stress, General Health and Social Support Among the Caregivers of Children with Intellectual Disability—A Mixed Method Study

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ABSTRACT

The birth of a child with intellectual deficits has been associated with various difficulties in the lives of the caregivers and parents. Although, there has been numerous Western studies illustrating and contributing to the present literature of the plight of individuals suffering with intellectual disability, in the Indian context, the various psychological and social aspects are not holistically explored. A different research gap observed in past studies was the use of quantitative approach, thereby neglecting the need for in-depth qualitative understanding of the caregivers' experiences. In the present study, sample selection was based on convenience sampling, comprising of primary care providers visiting the out-patient department of RINPAS, Ranchi. The sample consisted of a total of 40 caregivers, 10 from each group (mild, moderate, severe and profound), as per the ICD-10 DCR. Data was analyzed using a mixed method design, using both quantitative and qualitative research designs. The results showed significant level of distress in the domain of parental distress, somatic symptom presentations and depression levels among the four subgroups. Further thematic analysis explored four global themes from the detailed semi-structured interviews with 14 caregivers: "my positive experiences of caregiving"; "my unpleasant times during caregiving"; commonalities in the issues jointly shared and "How I am grappling with the negativities".

Keywords: *Intellectual Disability, Caregivers, Parental Distress, Psychological and Social Aspects, Mixed Method Study*

The birth of a neurotypical child often comes with positive experiences and reactions in the family. But the scenario gets reversed when the parents and caregivers come to gradually understand that their child is 'special', leading to developmental disabilities in their milestones. As per the ICD-10 DCR and DSM 5, intellectual disability refers to a condition of regression due to incomplete development of the mind and other cognitive functions, which manifests in the affected child's intellectual abilities, social, motor and linguistic functioning. Prevalence of developmental disabilities among Indian children is rising alarmingly, which has consequently, been a great reason of distress for their

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caregivers, affecting their quality of life. Hence, in this present study, the degree of parenting stress of such caregivers is explored with other important variables of general health conditions and social support available to them throughout the process of childrearing practices.

Parenting can be understood as the process comprising of promoting and abiding the physical, emotional, social as well as intellectual development of a child spanning from infancy to adulthood. Mudhovozi et al. (2012) stated that caregivers having children with intellectual disability construed their enduring roles of caregiving as a “pain”, since they could not bear to have high expectations for them, as they could have for their neurotypical counterparts.

The phenomenon of parenting stress act as a crucial role in the development of child, both challenged as well as normal, this study was conducted with the aim to compare the level of parenting stress among caregivers having children with varying degrees of severity, affected by intellectual disability. Numerous studies have highlighted various psychosocial experiences; including parenting stress among the caregivers, while caring for the disabled child. These experiences further may bloom into feelings of guilt for having a disabled child or as feelings of shame and inadequacy in their local settings (Upadhyay & Singh, 2009).

Social support networks work towards creating cohesiveness within family members, even though one of them has acquired some intellectual deficiency. Maintenance of unchanging social support systems provide emotional and informational accompaniment to families, easing their roles as caregivers. In the recent times, researches have taken into consideration of families as well as the extended families in providing social support to the caregivers, along with emergence of the internet, which revealed to be a practical medium for various social engagements (Perkins et al. 2002).

Present Study

Due to high relevance of missing out on the direct experiences of the parents and caregivers, who have been taking care of the children suffering from intellectual disability and consequently, considering the impact, the present study examines the level of parenting stress, general health as well as social support available, using a mixed method study. The extent and degree of variables namely, parenting stress and general health was computed using quantitative analysis. The extent and quality of social support was understood from a handful sample of caregivers using the qualitative approach.

METHODOLOGY

Sample

The present study included a sample comprising of 10 caregivers having children from each level of intellectual disability (diagnosed as mental retardation, as per the ICD-10 DCR) [WHO, 1993]. In total, a sample of 40 caregivers was taken. The sample was chosen on the basis of the researcher’s convenience, solely from the out-patient department of RINPAS. Only those caregivers/parents, who had been staying with their children for more than 2 years was taken in for the study. Written consent was obtained from all of them.

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Design

The design of the study was cross-sectional in nature. A mixed method design was employed for the data analysis. Quantitative as well as qualitative research design using thematic network analysis was applied.

Measures

The following tools were utilized in the process of data gathering: Data sheet incorporating socio-demographic and clinical details of the child, General Health Questionnaire-28, Parenting Stress Index/short form and lastly, a semi-structured interview schedule.

- 1. Data sheet incorporating socio-demographic and clinical details of the child:** The researcher prepared a semi-structured data sheet was prepared for the study, in order to obtain information about the intellectually deficient child's and parent's socio-demographic variables like age, sex, religion, education, marital status, domicile and occupation, socio-economic status of the household, etc., along with the clinical details of the child.
- 2. General Health Questionnaire-28:** The GHQ-28 was formulated in 1978 by Goldberg and is translated into 38 languages (Hjelle et al. 2019). It is primarily used as a tool for screening to detect those individuals who are prone and susceptible to develop the danger of psychopathology. This test comprises of 28 items of psychological issues predominantly observed in the hospital settings. GHQ-28 is fractioned into four subscales. These are somatic symptoms (ranging from item 1-7), anxiety/insomnia (ranging from items 8 to 14), social dysfunction (ranging from items 15 to 21) and severe depression (ranging from items 22 to 28). Inter-rater and intra-rater reliability ranges from 0.90 to 0.95.
- 3. Parenting Stress Index/Short Form:** The shorter form of PSI has descended from the full length version of the test. All items of the shorter version have been extracted word to word from longer version. This test has been utilized as a sound tool to evaluate the degree of stress between the parent-child dyad, which can be completed within 10 minutes. The shorter form is segregated into three components—parental distress, parent-child dysfunctional interaction and difficult child (Rivas et al. 2020).
- 4. Semi-structured interview schedule:** A semi-structured schedule for conducting the interview, with certain possible prods was created to interview the caregivers who gave consent to take part in the detailed interview. A list of proposed questions, which were developed considering the existing review of literature, was prepared to interview the caregivers/parents. The interview will be directed by the flow of information given by the caregivers. After taking consent the interview was audio recorded, which approximately was wrapped up within an hour. The word-to-word written text was carried on after completion of the interview.

Data Analysis

The present study called for a small group of caregivers having children, from the four groups on the basis of severity of intellectual disability. Parametric statistics was applied. SPSS (version 20) was employed for the analysis on the variables of parenting stress and general health of the caregivers. Analysis of variance test was applied for investigating the severity of divergences in the extent of parenting stress and general health conditions.

Further, the extent and quality of social support was analyzed using the qualitative method of thematic network analysis.

RESULTS AND DISCUSSION

Demographic characteristics

Table 1 depicting social and demographic profiles of the caregivers (N=40)

Variables		Sample (N%)	
Gender	Male	5	12.5%
	Female	35	37.5%
Education	Primary	5	12.5%
	Secondary	6	15.0%
	H. Secondary	13	32.5%
	Graduate	6	15%
	Post-Graduate	1	2.5%
	Illiterate	9	22.5%
Occupation	Farmer	6	15.0%
	Business	4	10.0%
	Professional	1	2.5%
	Housewife	28	70.0%
	Daily labour	1	2.5%
Category	General	13	32.5%
	OBC/MOBC	12	30%
	SC	3	7.5%
	ST	7	17.5%
	Others (Muslim)	5	12.5%
Domicile	Rural	20	50%
	Semi-Urban	10	25%
	Urban	10	25%
Religion	Hindu	28	70%
	Muslim	7	17.5%
	Christian	3	7.5%
	Others	2	5.0%
Family Income (per month)	Less than 5000	4	10.0%
	5000-10000	21	52.5%
	10000-15000	10	25%
	Above 15000	5	12.5%
Mother tongue	Hindi	31	77.5%
	Bengali	2	5.0%
	Others	7	17.5%
Family type	Joint	12	30.0%
	Nuclear	20	50.0%
	Extended	8	20.0%

Table 1 exhibits the social and demographic characteristics of the 40 caregivers selected, hailing from both urban and rural settings. The table is a representation of both men and women caregivers, along with different religions, occupation and income level.

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Table 2: Frequency and percentage of participants reporting physical and psychological issues as per the General Health Questionnaire-28

Level of intellectual disability	No. of caregivers reporting above the cut-off scores	Percentage of the caregivers above the cut-off
Mild	4	40%
Moderate	4	40%
Severe	5	50%
Profound	5	50%

As it can be seen from table 2, four caregivers (40%), having children with intellectual disability, both from the mild and moderate range have reported bodily complaints, stress, disruptions in sleep pattern, inability to perform social activities optimally and marked symptoms of sadness, above the cut-off levels. Half of the caregivers, both from the severe as well as profound ranges have reported somatic, anxiety, sleep, social disturbances along with symptoms of depression above the cut-off scores.

Table 3: Descriptive statistics (mean and S.D.) on various domains of Parental Stress Index (Short Form) at four levels of intellectual disability

	Parental distress		Parent-Child Dysfunctional Interaction		Difficult Child		Total	
	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
Mild	44.8	6.57	43.50	6.96	47.50	6.38	1.36	1.68
Moderate	44.90	9.06	41.90	7.17	43.60	6.81	1.30	1.60
Severe	51.60	6.32	44.20	6.10	44.60	4.83	1.40	1.42
Profound	52.80	4.02	45.90	7.44	50.10	6.29	1.48	1.47

Table 3 shows the mean and standard deviation on various domains at various levels of intellectual disability. When seen on the domain of parental stress it was found that caregivers having children with profound level of intellectual disability had the highest mean on PSI/SF (Mean=52.80) and in terms of S.D. amongst the four levels of intellectual disability, caregivers having children with moderate level of intellectual disability had the greatest spread (S.D.=9.06). On the domain of parent-child dysfunctional interaction, mean scores were highest in the profound level (Mean=45.90) and lowest in the moderate level (Mean=41.90) and standard deviation was observed to be highest in the profound level (S.D.=7.44) and lowest in the severe level (S.D.=6.10). On the domain of difficult child, highest mean score was observed in the profound level (Mean=50.10) and lowest in the moderate level (Mean=43.60). Standard deviation was observed to be greatest in the domain of moderate level (S.D.=6.81) and lowest in the domain of severe level (S.D.=4.83).

Table 4: Showing summary table of Analysis of Variance on PSI/SF

		Sum of squares	df	Mean Square	F
Parental distress	Between Groups	547.47	3	182.49	4.01*
	Within Groups	1634.50	36	45.40	
	Total	2181.97	39		
Parent-Child Dysfunctional interaction	Between Groups	82.47	3	27.49	0.57
	Within Groups	1733.90	36	48.16	
	Total	1816.37	39		

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		Sum of squares	df	Mean Square	F
Difficult Child	Between Groups	259.70	3	86.56	2.30
	Within Groups	1352.20	36	37.56	
	Total	1611.90	39		
Total	Between Groups	1786.50	3	595.50	2.47
	Within Groups	8651.40	36	240.31	
	Total	10437.90	39		

*Significance level=0.05

Table 4 shows the summary table of ANOVA of the scores incurred by the caregivers having children with intellectual disability on four domains of PSI/SF. There is significant difference found at the domain of parental distress (F= 4.01) significant at 0.05 level. On all of the other domains, scores were observed to have no significant difference. Similar findings have also been observed in the past studies conducted by Staunton et al. 2020; Park & Lee, 2022; Karni-Visel, 2023. This could be possibly due to the pervasive nature of arduous caring of a child with ‘special needs’. Such parents and caregivers are many a time found to take care of the child singlehandedly, which greatly inhibits their social and recreational life, thereby negatively affecting their quality of life. On top of that, many of the participants in the present study reported of limited social support networks, which might have moderated their levels of stress. Therefore, it is desirable to include various formal as well as informal support groups to assist the caregivers who have been rearing children with intellectual disability.

Table 5: Descriptive statistics (mean and S.D.) on various domains of General Health Questionnaire-28 at four levels of intellectual disability

	Somatic Symptoms		Anxiety/Insomnia		Social Dysfunction		Severe Depression		Total	
	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
Mild	14.0	3.43	15.3	3.88	15.4	4.22	12.1	5.25	56.8	1.54
Moderate	14.1	5.78	14.6	5.60	14.3	6.99	10.4	5.37	53.40	2.21
Severe	11.8	3.22	14.0	4.10	12.9	2.84	10.7	4.37	47.9	1.06
Profound	13.8	4.56	15.90	4.60	14.4	3.92	11.8	4.23	55.40	1.63

Table 5 exhibits the mean score and standard deviation on all 5 domains of GHQ, at four domains of intellectual disability. When we see the domain of somatic symptoms of GHQ-28, highest mean score was evident on moderate level (Mean= 14.1) and lowest was observed at severe level (Mean= 11.8). Standard deviation was observed to be highest at the moderate level (S.D.= 5.78) and lowest at the severe level (S.D.= 3.22). on the domain of anxiety/insomnia, highest mean score was found at profound level and lowest was evident at severe level (Mean= 14.0), while standard deviation was observed to be highest at moderate level (S.D.=5.60) and lowest at severe level of ID. Further, on the domain of social dysfunction highest mean score was observed to be at mild level while lowest was observed at severe level of intellectual disability. Standard score was highest at moderate level (S.D.= 6.99) and lowest at severe level. Mean score was observed to be highest on the domain of severe depression at mild level (Mean= 12.1) and lowest at the moderate level (Mean= 10.4). Standard deviation was highest at moderate level and lowest at the profound level.

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Table 6: Showing summary table of Analysis of Variance on GHQ-28

		Sum of squares	df	Mean Square	F
Somatic Symptoms	Between Groups	129.12	3	43.04	3.62*
	Within Groups	428.04	36	11.89	
	Total	557.16	39		
Anxiety/Insomnia	Between Groups	20.50	3	6.83	0.32
	Within Groups	761.40	36	21.15	
	Total	781.90	39		
Social Dysfunction	Between Groups	31.70	3	10.56	0.46
	Within Groups	811.80	36	22.55	
	Total	843.50	39		
Severe Depression	Between Groups	87.9	3	29.30	4.29*
	Within Groups	245.88	36	6.83	
	Total	333.78	39		
Total	Between Groups	458.07	3	152.69	0.55
	Within Groups	9955.3	36	276.53	
	Total	10413.37	39		

*Significance level=0.05

Table 6 shows the summary table of ANOVA of the scores incurred by the caregivers having children with ID on five domains of GHQ. Significant difference amongst the four levels was observed to be on the domains of somatic symptoms (F= 3.622) and severe depression (F= 4.29). On all of the other domains, scores were revealed to be insignificant.

Significant difference was obtained in the domain of somatic symptoms. On the domains of severe depression and somatic symptoms, there has been evidence that significant difference among the four levels of intellectually deficient exists. There are many similar findings from past studies exhibiting that caregiving a child with intellectual deficiency has significantly affected a caregiver’s physical and mental health, as has been illustrated in the past studies by Bourke-Taylor et al. (2010), Nimbalkar et al. (2014) and Lobato et al. (2022). It was observed (while qualitative interview was taken), that the caregivers having children with profound level of intellectual disability had been mostly presenting symptoms of disturbed sleep, worrying, feeling that they were burnt out by the ‘caregiving role’ and had also been taking medicines for themselves, as they used to get frequently ill. The extended family support of such caregivers was also limited, which strained their mobility for self and leisure outside. Sometimes the caregivers felt so worn out and helpless, that their stress gradually manifests as clinical depression.

Table 7: Themes extracted during thematic analysis

GLOBAL THEME	SUB-THEMES	Frequency of occurrence of sub-themes
“My positive experiences of caregiving”	Sense of bringing broader understanding	3
	Happiness	5
	Acceptance	
“My unpleasant times during caregiving”	Emotional unpleasantness	7
	Feeling ‘pained’	

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GLOBAL THEME	SUB-THEMES	Frequency of occurrence of sub-themes
	Source of hurt	7
	A 'heavy' weight to carry	9
	Symbol of 'disgrace'	12
Commonalities in the issues jointly shared	Difficulties that the child exhibits	
	Aggressiveness	6
	Co-occurring problems	5
	“Child is dependent and helpless!”	8
		9
	Societal attitude	10
	The act of 'marking'	9
	Ignorance	11
	Experiences with the extended relatives	12
	Distorted relationships	7
	'Nobody to support!'	7
	Inability to take part in social gatherings	5
	Experiences pertaining to services and organizations	
Monetary resource		
Medical resource		
Support systems		
“How I am grappling with the negativities”	Spiritual-religious coping	
	Prayer	5
	Taking responsibility	6

From the above table, four global themes were identified from the present research. These themes illustrated the complex psychological and social issues shared by the caregivers continually rearing the intellectually deficient children. The themes were: “my positive experiences of caregiving”, “my unpleasant times during caregiving”, “commonalities in the issues jointly shared” and lastly “how I am grappling with the negativities”.

CONCLUSION

In this present study, there is no doubt parents as well as the other primary caregivers have to go through confusions and frustrations due to the limited understanding of the problem of what the child has been going through. The study also came to the conclusion that, although parents and caregivers felt lack of support, depression and feelings of burden due to their 'caring role', they also could undergo feelings of positive emotions of their atypical child through acceptance of their role as a significant family member, who brought smile to their face. The most commonly occurring quoted common unpleasant experience that the present study revealed is that caregivers were 'pained'. This is also aligning with other past researches. As has been depicted in the previous researches, caregivers have been neglected and disrespected by the relatives, due to them holding biases and poor attitude. This, in turn, has resulted in skewing between the families. Most significantly, many female primary care providers reported they no longer felt the same way about getting ready for attending social functions and parties, as they were solely responsible to care for the dependent child. They

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worried about being humiliated or ridiculed in front of the relatives, if the child acted defiantly. The primary care providers mostly came from the rural, remote and belonged to the underserved sections. Hence, they reported considerable scarcity in the support systems and medical facilities for the children with intellectual dysfunction. The grave issue of financial constraints adds more complexity to the picture. However, even though the caregivers were going through such difficult experiences every moment, they had learnt to bounce back. They spent their quality time by being religious, devoting themselves into hymns and prayers chants and believing optimistically that they could overcome challenges in their future paths.

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Conflict of Interest

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