Original Research Article

A study on the prevalence of perceived stress and coping strategies in parents of intellectually disabled children

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Abstract

Background: Children with intellectual disabilities are common and are increasing in number as more children survive globally. Raising a child with intellectual disability (ID) can add to parenting stress significantly. High perceived stress levels and lack of effective coping skills could be a barrier to achieve the challenges of parenting process. **Objective:** To study the perceived stress, mediators of stress or coping strategies in parents of intellectually disabled children and correlation between perceived stress in parents having children with intellectual disability and behavioral problems in comparison with intellectual disability alone. **Design:** This was a Descriptive Cross Sectional study. **Duration: Setting: Participants:** 50 parents of children with intellectual disability, attending the Psychiatry Out Patient Department of for disability certification **Methods:** The children were initially assessed. IQ test was conducted for each child; subsequent to it children were assessed for behavioral problems. A semi structured proforma was used to collect the socio demographic data of the subjects, after which they were assessed with Modified Kuppuswamy Scale to measure the socioeconomic status followed by the family interview for stress and coping in mental retardation (FISC-MR). Analysis of data was conducted using the SPSS 19.0 software. Correlations were carried out with Pearson's rank correlation coefficient. Two tailed P values ≤0.05 was considered as statistically significant. **Results:** Most of the attending parents were females. Majority of the parents had more than high school education and were from upper lower class and middle class. Living with and caring for persons with Mental Retardation(MR) is very stressful and burdensome. In this study, it was maximum in caregivers of persons with severe to profound intellectual disability. The perceived stress score 33 was maximum which indicates high score, but the mean score was around 12 which indicates mild level of perceived stress over all. The mean total BPI score was 15. Behavioral problems in the child led to high levels of stress and poor adaptation strategies in parents. Perceived stress was not affected by parents' education and economic status but directly proportional to mechanisms involved in coping. However higher education of parents and high income groups have significantly better coping strategies. **Conclusion:** Increased level of disability is associated with high level of stress and burden, it being the maximum in the care givers of persons with severe to profound MR. The study highlights the need for psychological assessment in caregivers and to create the awareness and dispense adequate information to parents.

Key Words: Intellectually Disabled Children, Psychological Distress, Parent, Prevalence, Coping.

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Intellectual disability in a child provokes a period of disequilibrium in the parents, followed eventually by an adjustment to life with or without undue stress. There are various stress which emerge and re-emerge over time. A discrepancy between expectations and the performance of the developmentally disabled child continues bringing feelings of grief[1]. Poor performance by the person with disability, be it physical, psychological or social, needs to be compensated by the caregivers. This leads to unavoidable stress and psychological trauma among the families. In India care provided for MR is mainly home based and alternate support systems such as day care

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centers, weekend care and special schools are meager hence the burden of care can be enormous. Socio-economic level of the parents, seem to contribute to the creation of stress[2], have an impact on the diagnosis of the child's disability. The presence of a member with mental retardation irrevocably changes the family unit and affects all individual members[3]. Many areas may be affected, including family relationships, finances and recreational life, house hold functioning, care giving demands and siblings. The physical, social and emotional functioning of the family members is profoundly interdependent, with changes in one part of the system reverberating in other parts of the system. Families which are capable of coping with having a mentally retarded child are able to mobilize their internal and external means of support to deal effectively with special needs of their child. The ability of the family to cope with any situation will often depend on their strengths and resources. In this study the coping strategies and mediating factors studied were awareness about the child's problem, expectations and attitudes, child rearing practices, social support and global family adaptation. Parents of disabled children in public serve to compound their own sense of embarrassment and adopt stances of defiance, curtness or sometimes are apologetic[4]. The burden of care taking is often increased and more prolonged in a child with a mental handicap. There may be secondary problems associated with the mental handicap which increases the workload of the parents. Anyone who provides care for another person will find their life is altered due to responsibilities they have assumed. Physical exhaustion can be a real problem for caregivers, especially if they are not in good health. In comparison with parents of normal children, parents with mentally retarded children experience more stress[5,6,7,8]. Social isolation can also be a problem for primary carers when the conflicting demands of their families and the cared for person mean that their time is carefully allocated between the two groups, leaving little spare time for making contact with people outside the family boundaries[9]. Caregivers need a comprehensive system of care, complete information that can facilitate the process of family adaptation, social support which includes the nuclear family, the extended family, friends and acquaintances, neighbors, co-workers, families who have children with similar disabilities and skills for coping with the mental disorder.

MATERIALS AND METHODS

Place Of Study :

Type Of Study : This was a Descriptive Cross Sectional study.

Sample Collection : Sample size: 50 subjects

Sampling Methods : Non probability convenient purposive sampling

Inclusion Criteria :

1. Age of Parent : 18-65 years.
2. Age of Child : 2- 18 years.
3. Parents having children with IQ<70.
4. Language compatibility with Hindi-Marathi-English and Gujrati.

Exclusion Criteria :

1. Any major medical/surgical illness.
2. Unwilling parents.

Statistical Methods : Analysis of data was conducted using the SPSS 19.0 software. Correlations were carried out with Pearson's rank correlation coefficient. Two tailed P values ≤0.05 was considered as statistically significant.

Ethical Approval : Approval was taken from the Institutional Ethics Committee prior to commencement of the study.

OBSERVATIONS AND RESULTS

There were 50 children having mental retardation ranging from 5-18 years of age. The mean age was 11.58 years and standard deviation was 3.5. More males than females were affected, 24% were lowest in birth order, and 25% had IQ between 70-50. All most half the children were last born (48 %) followed by 36 % of first born and 16 % born in between. Maximum children (50 %) had mild level of mental retardation, closely followed by 44% having moderate level and 4% and 2 % having severe and profound mental retardation respectively. Majority of children were 36 (72%) Hindu by religion and 13 (26%) were Muslims. 10 (20 %) were born of a consanguineous marriage and 40 (80%) were born from a non consanguineous union. All most 2/3rd (74%) children were attending a special school for mentally handicapped whereas only 4 (8%) were attending a general school, and 9 (18%) children were found to have no schooling at all.

Table 1: Socio-Demographic Profile of Intellectually Disabled Children

Variable	N	Min	Max	Mean	SD
Age	50	5	18	11.58	3.50
IQ	50	17	69	50.00	12.20
Variable				N	Percent

Sex	Male	42	84
	Female	8	16
Birth Order	First	18	36
	Between	8	16
	Last	24	48
MR Grade	Mild(50-70)	25	50
	Moderate(3550)	22	44
	Sever(20-25)	2	4
	Profound(<20)	1	2
Religion	Hindu	36	72
	Ariable Muslim	13	26
	Other	1	2
Consanguinity	Consanguineous	10	20
	Non-Consanguineous	40	80
School of child	Hindu	36	72
	Ariable Muslim	13	26
	Other	1	2

Table 2: Socio-Demographic Profile of Parents

Variable	N	Min	Max	Mean	SD
Age	50	26	61	40.44	7.62
Time Spent	50	2	24	12.18	8.09
Variable				N	Percent
Gender	Male			18	36
	Female			32	64
Education	Illiterate			5	10
	Primary			15	30
	High school and more			30	60
Income per month	Rs <5000			5	10
	Rs 5000-10000			21	42
	Rs >10000			24	48
Occupation	Unemployed			29	58
	Semiskilled			9	18
	Skilled			12	24
Living status	Married			49	98
	Widow			1	2
Type of Family	Nuclear			29	58
	Extended			21	42
Modified Kuppuswamy scale	Upper26-29			3	6
	Upper middle class16-25			14	28
	Lower middle class11-15			15	30
	Upper lower class5-10			18	36

The mean age of parents was 40.4 years with standard deviation of 7.62 and ranged from 26 to 61 years. The average time spent with child was 12 +/- 8 hours/day and ranged from a minimum of 2 hours/day to a whole day taking care of the child. The samples were predominantly females i.e.; 62 %(32) mothers and only 36 %(18) fathers. Almost all 98% (49) were living together with both parents and only one child had a single mother. 58% (29) were living in nuclear families and 42%(21) were from joint/extended families. This is because of the prevalent Indian culture of living with parents even after marriage. 60% (30) were educated up to high school and more, whereas 30%(15) were having only primary education and 10 % were illiterate. 58% (29) parents were unemployed, 18%(9) had self-skilled jobs and 34%(12) of them were in skilled jobs. According to Modified Kuppuswamy socio-economic class 36% belonged to lower class, 30% parents belonging to lower middle class and 28% in upper middle class. Only 3 parents belonged to upper class. This finding is indicative of the population group visiting a Government Hospital Unit.IQ scores of mentally retarded children range from 17-69 with mean IQ as 50 and standard deviation as 12.2.

Table 3: Scoring of the scales

		Min	Max	Mean	SD
FISR_MR Section I					
Care Stress		0	14	5.12	3.84
Emotional Stress		0	9	3.78	2.26
Social Stress		0	7	2.34	2.10
Financial Stress		0	4	0.80	1.14
Perceived stress in families of MR		0	33	11.98	7.99
FISC-MR Section II					
Awareness of misconception		3	7	5.12	1.00
Expectation and Attitude		3	9	6.72	1.25
Child Rearing		3	7	4.66	0.77
Social support		1	3	2.32	0.55
Global Adaptation		1	4	2.28	0.61
Coping Strategies		12	28	21.02	3.47
Behavior problem Inventory					
Self-injurious behavior	Frequency	0	13	1.70	2.93
	Severity	0	13	1.66	2.86
Stereotyped behavior	Frequency	0	28	2.70	6.10
	Severity	0	18	1.70	3.97
Aggressive behavior	Frequency	0	24	4.40	6.38
	Severity	0	20	3.68	5.63
BPI Total score		0	94	15.84	21.94

Living with and caring for persons with Mental Retardation(MR) is very stressful and burdensome. In this study, it was maximum in caregivers of persons with severe to profound intellectual disability. The perceived stress score 33 was maximum which indicates high score, but the mean score was around 12 which indicates mild level of perceived stress over all. The mean total BPI score was 15.84. Behavioral problems in the child led to high levels of stress and poor adaptation strategies in parents.

DISCUSSION

In the present study, parents of children with intellectual disability experience significant amount of perceived stress. A combination of factors appears to predict the likelihood of stress experienced by caregivers. Parents of children with severe to profound MR had very high level of stress and burden. Many different studies worldwide and in India have demonstrated that the parents of intellectually disabled children face many special stresses[10,11,12]. Studies by Ghosh[13] and Piscula and Gorska[14] noticed that parents of severe and profoundly retarded children have higher stress. Children with lower IQ have increased demands of energy and time input from parents on a daily basis with less of leisure time available to parents. They are also more difficult to manage in social settings and lead to feelings of embarrassment and humiliation in parents. Many studies replicate this finding, however financial or emotional stress was not found to have significant correlation with intellectual disability in present study. Majority of the sample was from lower socio-economic strata and availed of public special schools for their intellectually disabled child's education and faced no additional cost as compared to a normal child. Gender of the mentally challenged individual has not shown any influence on parental stress in the present study. Tangi and Verma[15] report higher stress in parents of female retarded children. No significant difference in perceived stress amongst mothers and fathers was noted in the study. Heller[16] found that in comparison with fathers of intellectually disabled children mothers spend more time providing care, offered more types of support and perceived more care-giving burden. The behavior and health of the children had a greater impact on mothers than on fathers. Socio-economic level of parents i.e.; the level of parental education and family income has an impact on the perceived stress, but in this study parents education and economic status of the family did have statistical significance to the perceived stress and burden. Behavioral problems in children led to significantly high perceived stress in all sub-groups of daily care, emotional social and financial stress. Problematic behavior of the child includes matters concerning the inability of the child to integrate into the family structure and routine[17], the time demanded for everyday care of the child[18]. This is a likely explanation for increased stress levels in parents, as they have to deal with disturbed behavior on daily basis and in social settings. Parents in higher levels of family functioning used better types of stress coping method than those in lower levels. Mentally retarded child's age, sex and parent's education had no significant role in determining level of coping in the present study. Perceived stress and caregiver burden was directly related

to child specific variables like severity of mental retardation, gender of child and behavior problems in child, where as coping strategies and resilience were more dependent on parent specific variables like income and education rather than level of intellectual disability in the child. Families can do adapt resiliently to high levels of demand; and that the focus should now be on family-centered practices of care, natural teaching strategies and cooperative family teaching.

CONCLUSIONS

Living with MR person and caring them is very stressful and burdensome. level of disability is associated with high levels of stress and burden, it being the maximum in the caregivers of persons with severe to profound MR. There are no significant gender differences in perceived stress and burden of caring for a child with MR. Parents education and economic status of the family do not significantly affect the perceived stress and burden but is directly proportional to mechanisms involved in coping. Behavioral problems in the child lead to high levels of stress and poor adaptation strategies in the parents. Consanguinity failed to achieve significant association with severity of intellectual disability. Perceived stress is influenced by severity of MR and behavioral problems in child but not by socio-economic group of parents. This study highlights the need for psychological assessment in caregivers and the need to create awareness and dispense adequate information to parents.

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