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# **Research Article**

# LEVEL OF DIFFERENT FAMILY STRESS AND INFLUENCES OF SOCIAL SUPPORT AMONG PARENTS OF MENTALLY RETARDED AND CEREBRAL PALSY CHILDREN

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#### **ARTICLE INFO**

# ABSTRACT

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*Key Words:* Intellectual disability, Cerebral Palsy, Family Stress, Social support **Background:** Parent's reactions, in the moment when they find out that their child is with developmental disabilities, are absolutely individual. A lot of parents need months, while some of them need years to face the fact that their child is with developmental disability. The state and the crisis that arise are very hard to be prevented; however they could be overcome by a good professional help and support. Aim: The aim of the present research study is to examine the family stress level that the parents of these children experience as well as the social support that they receive by the family and the local community. **Methodology:** Three hundred parents of children with Intellectual disability (ID), Cerebral palsy (CP) and normal healthy were taken from Indian institute of Cerebral Palsy and handicapped children, Sigra, Varanasi. Only parents of children between 0-18 years were included in this study. **Result:** Results show that the family stress is much more on parents of ID and CP as compared to healthy children. Another finding also revealed that low level of social support was found among parents of category children as compared to parents of healthy children. **Conclusion:** This result convincingly exhibited that the maximum stress producing events for any parents is that point of time when they realize that their child is disabled.

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### **INTRODUCTION**

When a child is born the life of the family changes significantly and each of its members must adapt to the new situation. However, when the child is born with a disability, in addition to regular adaptation, the family must cope with stress, grief, disappointments, and challenges, which may lead to a serious crisis or even disruption of family life. Parents must coordinate assessments, evaluations and various treatments while maintaining contact with many professionals and numerous institutions or services. They find themselves faced with important decisions on behalf of the child, decisions on management of the child with disability, and economic decisions that will affect the whole family. To sum up, birth of a disabled child or a child with special need becomes an additional source of stress for not only the parents but also for other members of the family. The event of a child born with a disability is always a tragedy for the family, but early intervention and support may help the family to adjust and become positively involved in the care and development of the child, even if that child is different and in need of special treatment. The presence of the child with ID & CP can cause financial hardships for families by increasing the family's consumptive demands and decreasing its productive capacity

(Turnbull et al., 1983) and (Vanketesan and Das, 1994). The child with ID often imposes social restrictions on the family (Goldfarb et al., 1986). The presence of a child with intellectual disability may curtail the recreational needs of the family (Londsdale, 1978). Peshawaria et al., (1994) reported social restrictions, which include non-participation in most social activities, were significantly more in parents having a female child with intellectual disability. The child with ID/CP may also influence the interactions and relationships between the parents. The magnitude of stress of parents of ID and CP child depends on a number of factors including the characteristics of the child as well as parents. For example, Fatheringham et al., (1971) hypothesized that living with a severely retarded child would be difficult to endure and therefore, the family would be subjected to stress, the degree of which would be influenced by the characteristics of the child, the family capacity for coping and the available community support. Baxter (1992) reported that parental stress attributed to care and management of the child with an intellectual disability was found to be related to the extent of the child's dependence and to the extent of the child's behaviour problems. The nature and magnitude of parenting stress has also been found to be moderated by a number of personal characteristics of parents such as, their parenting

style, personality, coping style and availability of coping resources and social support. Another factor that helps the parents of ID and CP to buffer their level of stress is the availability of social support. For example, Moudgil et al., (1985) found that those parents who got maximum social emotional support from spouses, family members, parents, relatives and friends experienced less stress and problems as compared to those parents who were not getting much social and emotional support. Researchers suggest that social support can protect people in crises from a wide variety of pathological states: from low birth weight to death, from arthritis through tuberculosis to depression, alcoholism & the social breakdown syndrome (Cobb, 1976) The preceding review (including the electronic database search e.g., PubMed, and other Internet resources) of the literature dealing with stress of parents, revealed that most of the studies have been conducted on parents of those children who are suffering either from various kinds of medical conditions or diseases (diabetes, cancer, asthma etc.) or psychopathological conditions (e.g. ADHD, autism etc.). Proportionately little attention has been given to explore the nature of stress of parents of children suffering from Cerebral Palsy (CP) and Intellectual disability (ID). Moreover, most of these studies focused on parenting stress and little attention was given to explore the child-related stress. Often a distinction is made between parenting stress and child related stress, the former being related with the additional demands imposed on the parents in providing the needed care to the child while the later deals with the adjustive demands in dealing with the specific problems of the child (e.g., temperament, emotional problems, behavioural problems etc.).

#### *Operational definitions of Cerebral palsy (CP) and Intellectual disability*

CP is a diagnostic term used to describe a group of motor syndromes resulting from disorders of early brain development. CP is caused by a broad group of developmental, genetic, metabolic, ischemic, infectious & other acquired etiologies that produce a common group of neurologic phenotypes.

Although CP is often associated with epilepsy & abnormalities of speech, vision & intellect it is the selective vulnerability of the brain's motor system that defines the disorder. (although, it has historically been considered a static encephalopathy, this term is not entirely accurate because of the recognition that no neurologic features of CP often changes or progress overtime).

ID is defined as "significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behaviour & manifested during the developmental period, that adversely affects a child's educational performance" DSM-IV-TR criteria (diagnostic & statistical manual criteria) for intellectual disability was used for this study.

## METHODOLOGY

*Study Deigns:* The design of this study was 3X2 Factorial ANOVA in which the scores of fathers & mothers of both ID & CP children were compared.

*Sample:* The present study was conducted on parents of 300 children. Among them, 100 children were suffering from CP, 100 from ID & 100 healthy children served as control. Parents

either mother or father of these babies were included in the study. Only parents of children between 0-18 yrs were included in this study. Parents of CP, ID children were taken from data base of these children from Indian Institute of Cerebral Palsy & Handicapped Children, Sigra, Varanasi & adjoining areas. Initially, consent of these parents was taken. These parents were interviewed after explaining those regarding typed questionnaires.

### Diagnostic criteria of CP & ID

Cerebral palsy was diagnosed by Pediatrician/Developmental Neurologist

Intellectual disability was diagnosed by Pediatrician/ Developmental Neurologist. Usual criteria for diagnosis are:

- I.Q. below 70
- Significant limitation in two or more areas of adaptive behaviour rating scale.
- Evidence that the limitations became apparent before the age of 18.

It is formally diagnosed by professional assessment of intelligence & adaptive behaviour.

These children were initially diagnosed clinically by Pediatrician/Developmental Neurologist & then sent to Clinical Psychologist for further assessment.

#### *Tools Used to assess Intelligence Quotient and Social Maturity*

- Developmental screening test (DST)
- Binet-Kulshrestha Test
- Raven's Progressive Matrices (RPM) & Colored Raven's Progressive Matrices (CRPM).
- Vineland Social Maturity Scale.

### Measures

- 1. Parental Stress Scale (K. Shanmugavelayutham, 1999): This scale was developed by K. Shanmugavelantham. The test-retest reliability of this scale is 0.85. 4 dimensions were covered in this scale: economic stress, social stress (family), social stress (extra familial), & psychological stress. There are 24 questions in this scale, 6 in each sector.
- 2. Social Support Scale (Madhu Asthana): Social support scale developed by Madhu Asthana was used for measuring social support in these parents. This social support scale measures perceived social support of adult population on a five point response format. This scale covers three aspects of social support (Emotional support, Informational support& Instrumental support) This scale provides a total social support score as well as the score on the above three dimensions. The possible score for social support scale is 140 & the minimum is zero. High score on social support.

### Objectives

1. To assess and compare the level of family stress among parents of ID, CP and healthy children.

2. To assess and compare the social support among parents of ID, CP and healthy children.

#### Hypotheses

- 1. There would be high level of family stress among parents of ID & CP children as compared to parents of healthy children.
- 2. There would be low level of social support among parents of ID & CP children as compared to parents of healthy children.

#### Procedure

The investigator personally visited the parents & explained the purpose of the study to the parents of CP & ID children. Parental Stress Scale and Social Support Scale were individually administered on the parents of CP & ID children. After getting back the filled questionnaires, the investigator examined that respondents have given their answers to each & every question. If any question/item was found unanswered, then the questionnaire was referred back to the respondents with the request to make their answer on the unanswered items. After getting back the completed questionnaires, the responses were scored as per the predetermined standard scoring procedures.

### RESULTS

The present study investigated family stress and social support among parents of CP, ID & healthy children. The mean & SD values for parents of CP, ID & healthy children for each variable were computed & 3 X 2 ANOVA (3 group X 2 gender) was applied to highlight the significant independent & interaction effect of group & gender variables. A close perusal of Table-1 and Table-2 indicate that financial stress in category of child [F (2,294) = 66.12; p < .01] was found to be significant, with a higher mean value for parents of CP (M = 8.60, SD = 4.37) followed by parents of M.R. (M = 8.18, SD = 4.56) and lower mean value for parents of healthy children (M = 3.05, SD = 1.92). There were no significant differences noted in category of parents (F = 1.48) and interaction effect between category of parents & category of children.

In context of Social stress-family results show that social stress (family) in the category of child [F (2,294)=77.10; p < .01] was found to be significant, with a higher mean value in parents of CP (M=8.05, SD = 3.36) followed by parents of MR (M=7.70, SD=3.55) and lower mean value for parents of healthy children (M = 3.19, SD = 2.73). There were no significant differences noted in category of parents (F = .85) and interaction effect between category of parents & category of children. The Social Stress Extra familial in the category of child [F (2,294) = 64.85; p < .01] with a higher mean value for parents of CP & MR (M = 9.98, SD = 3.41; M = 9.77, SD = 3.23) and lower mean value in parents of healthy children (M = 4.63, SD = 3.15). There were no significant differences noted in category of parents (F =1.97) and interaction effect between category of parents & category of children. Results denote that total family stress was found to be significant in category of child [F (2,294) = 120.82; p<.01] with a higher mean value in parents of CP (M = 34.44, SD = 11.27) followed by parents of MR (M = 33.80, SD = 10.60) and lower mean value for parents of healthy children (M = 14.22, SD=9.48).

Table 1 Means and SDs of various dimensions of family stress as function of category of child and gender of parents

Dimensions of Family Stress		СР			ID				HEALTY			TOTAL		
		F	М	Т	F	М	Т	F	М	Т	F	М	Т	
Financial	Mean	8.61	8.59	8.60	8.73	7.67	8.18	3.30	2.77	3.05	6.80	6.42	6.61	
Stress	SD	4.47	4.31	4.37	4.43	4.65	4.56	2.45	1.00	1.92	4.62	4.50	4.56	
Social Stress-	Mean	8.08	8.02	8.05	7.63	7.77	7.70	3.72	2.60	3.19	6.41	6.21	6.31	
Intra familial	SD	3.24	3.52	3.36	3.58	3.56	3.55	3.55	1.04	2.73	3.97	3.86	3.91	
Social Stress-	Mean	7.55	8.08	7.81	8.06	8.23	8.15	3.47	3.21	3.35	6.29	6.59	6.44	
Extra familial	SD	3.96	3.53	3.75	3.51	3.44	3.46	3.35	1.50	2.64	4.15	3.77	3.96	
Emotional	Mean	10.14	9.82	9.98	9.94	9.62	9.77	5.08	4.13	4.63	8.31	7.94	8.13	
Stress	SD	3.41	3.44	3.41	2.96	3.48	3.23	3.91	1.90	3.15	4.18	4.00	4.09	
Total Family	Mean	34.37	34.51	34.44	34.35	33.29	33.80	15.57	12.70	14.22	27.81	27.16	27.49	
Stress	SD	11.68	10.95	11.27	9.80	11.36	10.60	12.33	4.13	9.48	14.43	13.69	14.05	

Dimensions of Family Stress	Source of Variance	Sum of Squares	df	Mean Square	F
	Cat.Child	1922.77	2	961.39	66.12**
Financial Stress	Gend.Parents	21.51	1	21.51	1.48
Financial Stress	Cat.Child x Gend.Parents	13.51	2	6.75	.47
	Within	4274.51	294	14.54	
	Cat.Child	1485.49	2	742.74	71.10**
Social Stress-Intra	Gend.Parents	8.91	1	8.91	.85
familial	Cat.Child x Gend.Parents	23.04	2	11.52	1.10
	Within	3071.22	294	10.45	
	Cat.Child	1436.03	2	718.02	64.85**
Social Stress-Extra	Gend.Parents	21.05	1	21.05	1.97
familial	Cat.Child x Gend.Parents	6.52	2	3.26	.31
	Within	3135.44	294	10.67	
	Cat.Child	26606.16	2	13303.08	120.82*
	Gend.Parents	119.60	1	119.60	1.09
Family Stress	Cat.Child x Gend.Parents	113.84	2	56.92	.52
	Within	32370.67	294	110.10	

There were no significant differences noted in category of parents (F = 1.09) and interaction effect between category of parents & category of children groups.

There are no significant differences noted in any dimension of family stress between mother & father of these children. It means that parents of CP & MR children were more stressed on financial aspect, family level, outside family & emotionally in comparison to parents of healthy children. These findings accept our hypothesis 1 that parents of CP & MR children were more stressed as compared to parents of healthy children. However, no difference was found between parents of CP & MR children, because these chronic conditions affect similarly in both groups. Dyson LL, Faculty of Education, University of Victoria, British Columbia, Canada, in his article "Fathers & Mother's of school age children with developmental disabilities: parental stress, family functioning, and social support" found that fathers & mothers of children with developmental disabilities did not differ from each other. However, parents of children with disabilities experienced a disproportionately greater level of stress relating to their children than did those of children without disabilities.

Table-4 revealed that emotional support was found significant in category of child [F (2,294) = 69.02, P < .01], with a higher mean value in parents of healthy children (M = 51.41, SD =10.61) followed by parents of MR (M = 40.60, SD = 7.09) and lower mean value for parents of CP children (M = 38.80, SD =6.17). There were no significant differences noted in category of parents (F = .09) and interaction effect between category of parents & category of children. Similarly, informational support was also found significant in category of child [F (2,294) = 54.21, P < .01], with a higher mean value in parents of healthy children (M = 16.06, SD = 3.61) followed by parents of MR (M = 13.09, SD = 2.45) and lower mean value for parents of CP children (M = 12.41, SD = 1.41). There were no significant differences noted in category of parents (F = 1.33) and interaction effect between category of parents & category of children.

Instrumental support was found to be significant in category of child [F (2,294) = 139.64, P <.01], with a higher mean value in parents of healthy children (M = 22.14, SD = 6.39) followed by parents of MR (M = 14.29, SD = 4.34) and lower mean value for parents of CP children (M =12.58, SD = 2.76).

Table 3 Means and SDs of various dimensions of Social Support as function of category of child and gender of parents

Dimensions of Social Support		СР			MR			Healthy			Total		
		Father	Mother	Total	Father	Mother	Total	Father	Mother	Total	Father	Mother	Total
Emotional	М	39.37	38.20	38.80	40.73	40.48	40.60	51.15	51.70	51.41	43.91	43.29	43.60
Support	SD	6.28	6.05	6.17	6.93	7.31	7.09	11.58	9.50	10.61	10.14	9.63	9.88
Informati-	Μ	12.39	12.43	12.41	12.94	13.23	13.09	15.72	16.45	16.06	13.72	13.99	13.85
Onal Support	SD	1.48	1.35	1.41	2.48	2.43	2.45	3.92	3.23	3.61	3.18	2.98	3.08
Instrume	Μ	12.63	12.53	12.58	14.40	14.19	14.29	21.83	22.49	22.14	16.39	16.28	16.34
- ntal Support	SD	2.70	2.84	2.76	4.16	4.53	4.34	5.87	4.84	5.39	6.01	5.97	5.98
Total Social Support	М	64.41	63.16	63.80	68.21	68.19	68.20	87.79	88.60	88.17	73.76	73.01	73.39
	SD	7.24	7.03	7.13	10.44	11.69	11.05	19.87	17.62	18.75	17.19	16.70	16.93

Table 3 presents Means & SDs of various dimensions of social support as function of category of child and gender of parents. As table indicated that various categories of parents differed on various dimensions of social support. Furthermore, to ascertain the impact of various dimensions of social support on different categories of parents, a 3 X 2 factorial analysis of social support & results are displayed in table-4. Social support includes emotional support, informational support & instrumental support. As table indicates that category of child differed on various dimensions of social support.

There were no significant differences noted in category of parents (F = .06) and interaction effect between category of parents & category of children. Similarly, total social support was also found significant in category of child [F (2,294) = 95.59, P < .01], with a higher mean value in parents of healthy children (M = 88.17, SD = 18.75) followed by parents of MR (M = 68.20, SD = 11.05) and lower mean value for parents of CP children (M = 63.80, SD = 7.13). There were no significant differences noted in category of parents (F = .01) and interaction effect between category of

Table 4 Summary of 3 x 2 ANOVA (Three categories of children x two genders of parents) of Social Support

Dimensions of Social Support	Source of Variance	Sum of Squares	df	Mean Square	F
	Catchild	9313.31	2	4656.65	69.02**
Emotional	Catparen	6.23	1	6.23	.09
Support	Catchild * catparen	36.95	2	18.48	.27
	Within	19834.96	294	67.47	
	Catchild	762.06	2	381.03	54.21**
Informational	Catparen	9.34	1	9.34	1.33
Support	Catchild * catparen	6.13	2	3.07	.44
	Within	2066.57	294	7.03	
	Catchild	5206.62	2	5206.62	139.64**
Instrumental	Catparen	1.07	1	1.07	.06
Support	Catchild * catparen	11.03	2	5.52	.30
**	Within	5480.90	294	18.64	
	Catchild	33743.26	2	16871.63	95.59**
Total Social	Catparen	1.77	1	1.77	.01
Support	Catchild * catparen	53.24	2	26.62	.15
	Within	51889.08	294	176.49	

parents & category of children. These findings confirm the second hypothesis that there would be low level of social support among parents of MR, CP children as compared to parents of healthy children. But there were no significant differences noted in social support of mothers & fathers of MR, CP & healthy children.

## DISCUSSION

This study was conducted amongst a sample of parents of 300 children (100 of CP, 100 of MR & 100 controls). The sample were included from all strata of society. Most of the studies done on these children were very small studies (Sheshadri 1983) (30 patients).

The magnitude of stress of parents depends on a number of factors including the characteristics of the child as well as parents. Fatheringham et al., (1971) hypothesized that living with a severely retarded child would be difficult to endure & therefore, the family would be subjected to stress, the degree of which would be influenced by the characteristics of the child, the family capacity for coping & the available community support. The correlation between social support and family stress are found to be negatively co-related. Researchers (Abbott & Meredith, 1986; Friedrich et al., 1981) have found that having a strong parental coalition is a high predictor of parental adjustment and reduced amounts of stress associated with caring for a child with disability. Single parents are at a greater risk for experiencing higher amounts of stress (Beckman, 1983; Vadasy, 1986).

Various dimensions of family stress were calculated on these parents. Dimensions were financial stress, social stress (intrafamilial), social stress - extra familial, emotional stress & total family stress. The results indicate that the parents of CP & MR children reported significant stress on financial aspects (F=66.12), social stress intra-familial (F=71.10), social stress extra-familial (F=64.85), emotional stress (F=86.83). The Scheffe's test for multiple comparisons was applied in order to find out significant differences among means of different groups. Results revealed that the mean difference was significant in parents of CP & MR as compared to parents of healthy children. It means that parents of physically & mentally challenged children were more stressed as compared to parents of healthy children. Stresses were significant on all aspects eg. Financial, social, familial & emotional aspects. Many studies support this fact that parents of disabled children are more stressed as compared to healthy children. A number of studies have supported the notion that the stresses associated with parenting a child with a handicap are even greater (Pearson & Chan, 1993; Brehaut et al., 2004; O' Neill et al. 2001; Mobarak et al 2000). Study by Upadhyay GR, Haralappanavar NB (2008) in their article "stress in parents of mentally challenged children" also noted that most of the mothers & fathers have reported mild & moderate levels of stress. As a group, parents who have children with cerebral palsy & mental retardation reported higher amount of stress as compared to families who do not have children with special needs (Gallagher et al., 1983; Kazak & Marvin, 1984).

The maximum stress producing event for any parent is that point of time, when they realize that their child is disabled. Narayan (1978) studied the social problem of families with mentally retarded children and he was of the opinion that the

presence of mentally retarded children often hindered the social and routine activities of fathers. Studies have been extrapolated over the risk status from a variety of factors that caused parental stress such as based parental attention, familial resources, family isolation and stigmatization, decreased social and recreational opportunities in families with mentally retarded children (Begun, 1989; Featherstone, 1980; Levigne & Ryan, 1979).

Findings suggested that no significant differences were found between fathers & mothers of CP & MR children because these chronic conditions affect similarly in both groups. Similar finding was reported by Dyson LL, (1997) Faculty of Education, University of Victoria, British Columbia, Canada, in his article "Fathers & Mothers of school age children with developmental disabilities; parental stress, family functioning & social support" found that fathers & mothers of children with developmental disabilities did not differ from each others. However, parents of children with disabilities experienced a disproportionately greater level of stress relating to their children than did those of children without disabilities.

However, few of the researches have suggested a difference in the quality of stress experienced by fathers & mothers. Upadhyay GR & Havalappanvar NB in their study felt that the mothers experienced higher stress than fathers. Heller, Hgeich & Rowitz (1997) also reported higher stress in mothers, but this study clearly showed no significant difference between mothers & fathers. In modern era, fathers & mothers are equally involved in the care of their children, so, stressors are almost similar for both fathers & mothers. Sloper F, Turner S (1993) in their study showed that fathers of children with physical disabilities experienced little psychological distress compared with mothers. Most studies have focused only on maternal mental health (Wallander H et al., 1990; Florian V, 2001; Lambrenos K et al., 1996). It is increasingly being recognized that the functioning of families requires contributions from both parents. As more families are depending on two incomes to maintain their standard of living, fathers will contribute more to child-care than before. Although, typically the mothers were the primary caregivers of children with physical disabilities, in this study, we did not find any difference in psychiatric morbidity between fathers & mothers. Therefore, health professionals working in this area should consider the psychological status of both parents.

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