

**STRESS AMONG MOTHERS OF CHILDREN
WITH CEREBRAL PALSY ATTENDING
SPECIAL SCHOOLS**

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ABSTRACT

This paper draws attention to the stress experienced by mothers of children with cerebral palsy attending special schools in Kerala State, India. Stress level was assessed using the local language version of the Questionnaire on Resources and Stress and the data were analysed with respect to certain child related and mother related variables. The study reveals that stress experienced by mothers of these children is at a moderate level and the pessimism expressed regarding the child's ability towards achieving self sufficiency, is found to be most stress producing factor. Among the child related and mother related variables, only multiple disability along with cerebral palsy is a significant variable in deciding the difference in the severity of stress among the mothers. This article also gives suggestions on how the stress levels can be minimised among the mothers.

INTRODUCTION

Cerebral palsy is a term used to describe a broad spectrum of motor disability, which is non-progressive and is caused by damage to the brain, at or around birth. Although the damage is nonprogressive, the clinical picture changes as the nervous system develops and the child grows. There are usually associated disabilities like mental retardation or hearing impairment.

The birth of a child with cerebral palsy places the family in a dilemma. Society views parenthood positively, but it views the birth of a disabled child negatively. Awareness of society's ambivalence, adds to the stress the family feels within themselves.

The stress factors accompanying the birth of a normal child are intensified when the child is disabled. The marital relationship may suffer unduly from the added stresses of blame, guilt and anxiety. A child's disability attacks the fabric of marriage in different ways. It excites

powerful emotions in both parents. It reshapes the organisation of the family. It creates a fertile ground for conflict (1).

The economic stress may be multiplied by additional hospital and medical costs. The parents' social life may become non-existent. They may be fearful of rejection by their friends and relatives. Additional stress is likely to occur in families of disabled infants, depending on each family's unique characteristics, like number of members in the family, presence of other chronic illness, disabilities and so on. However, the psychological impact experienced by these families are common-shock, denial and grief.

Generally, parents of a disabled child progress through six emotional stages upon discovering their child's disability: disbelief, guilt, rejection, shame, denial and a feeling of helplessness. Though reactions to the birth or diagnosis of a disabled child may vary from parent to parent, or family to family, people seem to share common elements. Frequently, the parents' initial feelings are shock and numbness; parents may experience periods of panic, anxiety and helplessness, as well as periods of indifference and anger, at which time they face nearly overwhelming depression, apathy and bitterness (2).

As normal children progress from one developmental stage to the next, their parents observe them with pride, anxiety and alarm. Parents have expectations of them based on social, family and experimental standards. When the children's behaviour deviates from the established standards, family crisis may develop.

Every child affects his/her family in the process of growing up based on the characteristics of the child and characteristics of the family. Transitions from infancy to early childhood, to late childhood and to adolescence, affect the family and the child. Crises and triumphs present in every child's life affect the family too. In addition to the pressures and demands that all parents experience, parents of disabled children must learn to deal with the exceptionality of various natures, some times for a life time.

Parents become aware of their child's exceptionality at birth, or shortly thereafter during the pre-school years, or after the child enters school. If they recognise the child's exceptionality before school entry, they have time to adjust to the child's condition and can accept the need for special education and related services. If they become aware upon or after school entry, they may need time to adjust to the diagnosis, thereby delaying implementation of the needed interventions.

The prevalence of cerebral palsy is gauged by the number of cases present during a specific time and is usually calculated as age-specific prevalence rate (3). A reasonable estimate of the prevalence of cerebral palsy at school age is 3 to 4 per 1000 live births in industrialised nations (4). Unfortunately, in Kerala, special schools and rehabilitation centres exclusively for children with cerebral palsy are very few in number. Children with cerebral palsy are in most cases, clubbed along with mentally retarded children. Teachers' training institutes for the care of children with cerebral palsy are less in number in Kerala state and research work is also not undertaken in the field of cerebral palsy and related areas. Until now, no studies were reported on the stress of mothers of children with cerebral palsy from this southern state of India.

METHODOLOGY

A descriptive method was used to achieve the objectives of the study (5). The tools used included Case Sheet Record and Questionnaire on Resources and Stress.

The Case Sheet Record is prepared to collect general information about the child with cerebral palsy and his/her family from the mother of the child. This includes information such as the child's name, sex, age, birth order, type of cerebral palsy, religion, presence of multiple disability, name of the school that the child is attending, locality of residence. In addition, details of mother such as age, educational status, occupation, monthly income, type of family, are also collected.

The Questionnaire on Resources and Stress (QRS) is the local language version of the short form of the Questionnaire on Resources and Stress modified by Freidrich, Greenberg and Crnic in 1983 (5). It measures the impact of a developmentally delayed, or chronically ill child, on other family members. The tool measures the four broad categories (1) parent and family problems (2) pessimism (3) child characteristics and (4) physical incapacitation. The instrument requires respondents to provide 'true' or 'false' answers concerning their children and family. QRS-F gives a total stress score and separate scores on the four independent factors of stress. A total of higher value in the scale indicates severe stress and lower value indicates lower stress. A range of score 0-17 indicates minimum stress; 18-34 indicates moderate stress and 35-52 indicates severe stress.

This four category structure suggests that the problems facing the families of disabled children are clearly multi-dimensional and that the score on a given dimension cannot predict or be predicted from knowledge of the score of the remaining dimensional factors. The KR-20 reliability coefficient for this short form is determined to be 0.95. Validation study of QRS-F is determined to be 0.93 by its authors. Also, correlations between QRS-F factors and other independent measures of depression, problem checklist and social desirability are indicative of the concurrent validity of the QRS-F.

Since this tool was originally developed in English, a vernacular translation carried out by Mathew and Asha (6) was used for the study. The test retest coefficient of reliability of the whole test estimated by using Spearman-Brown Prophecy formula, was 0.92. The scores obtained from this version were correlated with the English version and it was 0.78.

The reliability and validity coefficients indicate that the vernacular version of QRS-F used, is reasonably dependable and can be used to assess the stress experienced by mothers of children with cerebral palsy.

Classification of Data

The data were classified according to the different variables studied viz., age, sex, birth order, type of cerebral palsy, mobility factor, multiple disability, religion, location of residence, age, education and occupation of mother, type of family and husband's stay and support. Instead of considering the socio-economic status as a single variable, education, occupational status of the mother and monthly income of the family were taken separately as it would specify more clearly the relation of the variables with the maternal stress.

The educational level of mothers was categorised into three groups as follows:-

- Low education group:- Up to class 9.
- Middle education group:- Class 10 to Bachelor Degree.
- High education group:- Post Graduation and Professional Degree.

Similarly, the occupational level of the mother was categorised into 4 groups as follows:

- Group I : Daily wages, fisher woman, agricultural labour, petty shop business.
- Group II : Clerk, accountant, retired people, laboratory assistant, junior nurse, health inspector
- Group III : Office superintendent, gazetted officer, teacher, engineer, doctor, senior nurse

- Group IV: Unemployed

Monthly income of family was categorised into three groups of low income group, middle income group and high income group; based on monthly incomes.

The birth order of the children with cerebral palsy were classified as first, middle and last born. If the child with cerebral palsy is the elder one in the family or if there is only one child, then he/she is considered as the first born. Those children with cerebral palsy who were born between the first and the last child are considered as middle born. If the child with cerebral palsy is the youngest one among two or more number of children, he/she is considered as the last born category.

Mobility of the children with cerebral palsy was classified as group I, II, III and IV. Children with cerebral palsy who are independent in mobility are referred to as group I. Children with cerebral palsy who are independent with devices, are referred to as group II. Those children with cerebral palsy who are dependent on wheelchairs, are considered as group III. Children with cerebral palsy who are dependent on caregivers, are considered as group IV.

The mothers of the children with cerebral palsy are grouped into the younger group in which the age is less than 35 years, middle group where the age ranges between 36-50 years and older group in which the age is more than 50 years.

The types of families of children with cerebral palsy are grouped into nuclear family and joint family. The status of husbands living with the family is classified under four groups I - husbands who are staying with the family a minimum of 5 days or more per week. Group II- husbands who are staying away from the family for 5 days or more per week. Group III indicates divorced cases, and Group IV are widows. The husbands' support in bringing up the children with cerebral palsy are categorised under Group I- physical support only, Group II-financial support only, Group III-both physical and financial support and Group IV-no support at all.

RESULTS

The mean stress experienced by 50 mothers of children with cerebral palsy is 22.8, which is at moderate level. Out of 50 mothers, 16 mothers expressed mild stress, 23 mothers showed moderate stress and 11 mothers expressed severe stress. A section-wise analysis showed that Factor II that concerns pessimism regarding the child's ability with cerebral palsy towards

self sufficiency; was found to be more stress producing. Factor I related to parent and family problems was found to be the least stress producing.

The mean stress experienced by mothers of cerebral palsied children aged between 3-6 years was 22.94 and that of 7-11 aged group was 22.46. Independent “t” test showed that there was no statistically significant difference in the severity of stress experienced by mothers of these two groups.

The mean stress experienced by mothers of boys with cerebral palsy was 23.4 and that of girls with cerebral palsy was 21.90. Independent “t” test showed that there was no significant difference in the severity of stress experienced by these mothers.

With respect to the birth order of the child with cerebral palsy the mean stress experienced by mothers of first born children was 25.78, that of middle born children was 19.0 and that of last born was 21.83. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

The mean stress experienced by mothers of spastic children was 22.65, that of ataxic children was 23.42, that of choreo-athetoid was 19.44, that of floppy type was 23.33 and of mixed group was 28.75. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

Mothers of children with cerebral palsy and multiple disability showed a mean stress of 25.37 and those of children without multiple disability had a score of 15.46. Independent “t” test revealed that there was significant difference in the severity of stress experienced by mothers of these two groups ($t= 10.32, df 48, p<0.01$). On comparison of mean values, it was found that mothers of children with multiple disability experienced significantly more stress.

With respect to the mobility of the children, mothers of children with cerebral palsy who were independent in mobility showed a mean stress of 18.90, those children who were independent with devices showed a mean stress of 18.00, those children who were dependent on wheel chair had a score of 25.78 and those of children who were dependent on care givers showed a mean stress of 25.56. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

The mean stress experienced by mothers in the younger age group was 22.90 and that of the middle age group was 22.33. Independent “t” test indicated that there was no significant difference in the severity of stress experience by these mothers.

Hindu mothers showed a mean stress of 23.00, Christian mothers showed a mean stress of 22.42 and Muslim mothers showed a mean stress of 26.60. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

Mothers from a low education group showed a mean stress of 27.75, those from the middle education group showed a mean stress of 21.62 and those from a high education group showed a mean stress of 26. ANOVA indicated that there was no significant difference in the severity of stress experienced by these mothers.

The mean stress experienced by mothers belonging to rural area was 22.05 and that of urban area was 23.30. Independent “t” test revealed that there was no significant difference in the severity of stress experienced by mothers of these two groups.

The mothers from a low monthly income group showed a mean stress of 23.11, those from a middle income family showed a mean stress of 21.73 and that of high family income showed a mean stress of 26.5. ANOVA revealed that there was no significant difference in the severity of stress experienced by mothers from different income groups.

The mean stress experienced by the unemployed mothers was 22.30, that of group I (daily wages etc) was 40.00, that of group II (clerks etc) was 23.50 and that of group III (gazetted officers etc) was 8.66. Since 88% of mothers belonged to the unemployed category, no further statistical analysis was done in determining the effect of occupation in difference in the severity of stress experienced by mothers.

Type of family was not found to be a significant variable in deciding the difference in the severity of maternal stress. The mean stress experienced by mothers from a nuclear family was 21.00 and that of other type of family (joint family etc). was 24.21. Independent “t” test showed that there was no significant difference in the severity of stress experienced by mothers from these two groups.

The mean stress experienced by those mothers whose husbands stayed with them was 22.43 and that of those mothers whose husbands stayed away from the family was 23.84. Independent “t” test showed that there was no significant difference in the severity of stress experienced by mothers of these two groups. All the 50 mothers reported that they were getting physical and financial support from their husbands in bringing up their children. All the 50 children were undergoing physiotherapy, regularly.

Table 1. Mean, standard deviation and percentage of total stress experienced by mothers of children with cerebral palsy attending special schools

Variable	Mean	SD
Total maternal stress	22.8	9.56

Table 2. Frequencies, percentages, means and standard deviations of different categories of stress experienced by mothers of children with cerebral palsy attending special schools

Category(stress score)	Number	Mean	SD
Mild (0-17)	16	11.25	3.98
Moderate (18-34)	23	23.34	3.58
Severe (35-52)	11	37.00	1.95

Table 3. Means, standard deviations and percentages of maternal stress with respect to factor I, II, III, and IV

Stress factors (max. Score)	Mean	S.D	% in relation to max. score
Factor I (20)	7.00	4.32	35.00
Factor II (11)	6.64	2.45	60.00
Factor III (15)	6.06	4.02	40.40
Factor IV (6)	3.18	1.61	53.00

Table 4. Means, standard deviations and t value of maternal stress with respect to age of the children with cerebral palsy

Age groups	N	Mean	SD	t value
3-6 yrs	35	22.94	10.54	<1
7-11 yrs	15	22.46	6.81	

Table 5. Means, standard deviations and t value of maternal stress with respect to the sex of the children with cerebral palsy

Groups	N	Mean	SD	t value
Male	30	23.40	10.14	<1
Female	20	21.90	8.59	

Table 6. Means and standard deviations of maternal stress with respect to birth order of the children with cerebral palsy

Birth Order	N	Mean	SD
First	23	25.78	9.41
Middle	15	19.00	9.84
Last	12	21.83	7.39

Table 7. Summary of ANOVA for the difference in maternal stress with respect to birth order of the children with cerebral palsy

Source	sum of squares	df	mean square	F ratio
Between groups	432.41	2	216.20	2.44
Within groups	4157.59	47	88.45	
Total	4590.00	49		

Table 8. Means and standard deviations of maternal stress with respect to the type of cerebral palsy

Type	N	Mean	SD
Spastic	20	22.65	8.99
Ataxic	7	23.42	11.00
Choreo-athetoid	9	19.44	5.43
Floppy	10	23.33	6.04
Mixed	4	28.75	8.55

Table 9. Summary of ANOVA for difference in maternal stress with respect to the type of cerebral palsy

Source	Sum of squares	df	Mean Square	F ratio
Between group	248.65	4	62.16	<1
Within group	4341.45	45	96.47	
Total	4590.10	49		

Table 10. Means, standard deviations and t value for maternal stress with respect to multiple disability of the children with cerebral palsy

Group	N	Mean	SD	t value
Multiply disabled	39	25.37	9.09	10.32**
Non-multiply disabled	11	15.46	6.69	

** Significant at 1% level

Table 11. Means and standard deviation of maternal stress with respect to the mobility factor of children with cerebral palsy

Group	N	Mean	SD
I (Independent)	11	18.90	10.37
II (Independent with crutches)	9	18.00	8.35
III (Dependent on wheelchairs)	14	25.78	8.76
IV (Dependent on care givers)	16	25.56	8.21

Table 12. Summary of ANOVA for maternal stress with respect to mobility factor of the children with cerebral palsy

Source	Sum of squares	df	Mean Square	F ratio
Between group	620.79	3	206.93	2.39
Within group	3969.21	46	86.28	
Total	4590.00	49		

Table 13. Means, standard deviations and t value of maternal stress with respect to the age of mothers

Group	N	Mean	SD	t value
Younger (below 35)	41	22.90	9.91	<1
Middle (36-50)	9	22.33	7.88	

Table 14. Means and Standard deviations of maternal stress with respect to religion

Religion	N	Mean	SD
Hindu	31	23.00	9.18
Christian	14	22.42	9.44
Muslim	5	26.60	11.35

Table 15. Summary of ANOVA for maternal stress with respect to religion

Source	Sum of squares	df	mean squares	F ratio
Between group	67.37	2	33.68	<1
Within group	3602.63	47	76.65	
Total	3670.00	49		

Table 16. Means and standard deviations of maternal stress with respect to the education of the mother

Group	N	Mean	SD
Low group (0-IX)	8	27.75	11.64
Middle (X-degree)	32	21.62	7.88
High (P.G./ Professional)	10	26.00	12.29

Table 17. Summary of ANOVA for maternal stress with respect to education of mother

Source	sum of squares	df	Mean Square	F ratio
Between group	319.48	2	159.74	2.78
Within group	2697.00	47	57.38	
Total	3016.48	49		

Table 18. Means, standard deviations and t value of maternal stress with respect to the location of residence

Group	N	Mean	SD	t value
Rural	20	22.05	10.74	<1
Urban	30	23.30	9.11	

Table 19. Means and standard deviations of maternal stress with respect to family income

Group	N	Mean	SD
Low (upto 3000/-)	18	23.11	10.01
Middle (3001 to 8000)	26	21.73	9.76
High (above 8001)	6	26.50	5.67

Table 20. Summary of ANOVA for maternal stress with respect to monthly income

Source	Sum of squares	df	mean square	F ratio
Between group	113.60	2	56.80	<1
Within group	4476.40	47	95.24	
Total	4590.00	49		

Table 21. Means, standard deviations and t value for maternal stress with respect to the type of family

Group	N	Mean	SD	t value
Nuclear	22	21.00	9.37	1.17
Others	28	24.21	9.50	

Table 22. Means, standard deviations and t value for maternal stress with respect to the husband's stay with family

Group	N	Mean	SD	t value
Stayed with the family	37	22.43	10.34	<1
Stayed away from family	13	23.84	6.95	

DISCUSSION

This study points towards the fact that irrespective of the differences in child related and mother related variables, the level of stress in mothers of children with cerebral palsy is almost the same, and is of a moderate level. This may be due to the non-progressive nature of the condition. Another reason for this can be that all the children studied attend special schools and the mothers think positively in the hope that their children will attain some level of independence. For any parent the maximum stress producing event in their life is that point in time when they realise that their child is disabled. For all the mothers who participated in this study, this realisation had happened long ago. It is striking that the study reveals a significant difference in the stress level between mothers of children with multiple disability. The presence of multiple disability is a significant variable that decides the level of stress experienced by mothers of children with cerebral palsy. Cerebral palsy in itself is adequate enough to create stress among mothers and it is worse if the children have other difficulties. The different categories of associated disabilities were mental retardation, learning problems, speech and hearing problems, visual problems, behavioural problems and epilepsy. 97% of multiply disabled children showed features of mental retardation and speech problems. The cumulative effect of these problems might have produced a significantly high amount of stress in mothers of multiply disabled children. This indicates a need for a more comprehensive assessment of children with cerebral palsy by which the severity of the associated problems as well as the possible impact on mothers could be predicted.

Analysis of stress experienced by mothers of children with cerebral palsy showed that Factor II which deals with the pessimism regarding the child's ability to reach self sufficiency was the most stress producing factor for the mothers. For any parent of a disabled child, the most stress producing factor is the child's dependence for daily living activities. Once the child attains independence in these activities, the dependence on the mother is reduced, and naturally it will reduce the stress level. This gives an important point in managing the disabled child, where the emphasis has to be on attaining independence in daily activities.

Factor IV which expresses the physical incapacities of a child is second to Factor II, in causing stress, while Factor III which assesses the behavioural and attitudinal problems is next. Interestingly Factor I, which assesses parent and family problems is the least stress producing factor for mothers. Generally, it is assumed that this factor would be the most

stressful for mothers as it can alter interpersonal and marital relationships. The present findings show these as least stress producing to mothers. The age of the children with cerebral palsy selected for this study is an important factor in determining this finding. All the children were in the range of 6-11 years. At this age level, the problems associated with giving birth to a disabled child would have been settled in the family and thus Factor I causes the least stress to mother.

Child related variables such as age, sex, birth order, type of cerebral palsy and mobility of the child with cerebral palsy are found to be non-significant variables in determining severity of stress among mothers of these children. Mother related variables such as age, religion, educational level, location of residence, monthly income, employment status, type of family, husband's stay with family etc were found to be non significant variables in determining stress levels of mothers.

CONCLUSION

The present study shows the extent of stress experienced by mothers of children with cerebral palsy attending special schools. Based upon the findings of this study, the following suggestions are made.

- A concerted effort must be made to prepare and train mothers of children with cerebral palsy in handling the needs of their children. This efforts should start from the stage of identification of the disability of the children.
- Formulation of small mothers' groups in the special schools, will provide the mothers a needed platform for expressing their difficulties, sharing their experiences, solving their problems and more importantly, to develop a mutual help system.
- The Parent Teacher Association (PTA) should be strengthened and function as a link between the special school and the community. PTAs should be the link to make the community aware about various aspects of cerebral palsy and should take necessary steps to promote proper education, vocational training and placement.
- Organisations of parents should be formed to fight for the rights of persons with cerebral palsy and their families and to persuade the government to take action for the implementation of various rehabilitative measures.
- Special teachers and school authorities should recognise the important role of mothers in the whole process of special education and should keep on motivating the parents for their active participation.

- The services of professionally qualified counselors should be available in the special schools so that active involvement of mothers could be enhanced.
- Siblings and other family members should be encouraged and equipped to participate in the training and educational process of children with cerebral palsy. This will help the mothers to relax and to reduce their anxiety about the future of the children. This will also help in developing optimism among the mothers.
- Steps should be taken to produce books and other reading materials regarding the causes, types of cerebral palsy, training and education of children with cerebral palsy at community level in regional languages and make them available to all mothers and family members, which will be of utmost utility to them.
- Special teacher training programmes should be given due importance to develop skills in the special teacher trainees, for effectively working with mothers. This will help the teachers to keep a healthy relationship with the mothers.
- Representatives of mothers should be included in all the administrative as well as academic committees of the school. This is very important for increasing mother participation and satisfaction.
- Physical therapists of the special schools should be given more role in explaining about the causes, features, types, prognosis of cerebral palsy to the mothers. This will help in the development of awareness and realistic outlook regarding cerebral palsy.
- The special schools should also conduct periodic orientation programs for parents and community.

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REFERENCES

1. Feather stone H, **A Difference in Family** New York: Baic Books, 1980.
2. Mc Dowell G, Shea TM, and Bouer AM **Parents and Teachers of exceptional students. A Hand book for involvements.** Boston : Allyn and Bacon Inc. 1985.
3. Abberman E. **Describing the cerebral palsies : methods of classifying and counting spastics.** London: William Heineman Medical Books Ltd. 1984.
4. Paneth N, Kiely JL, Susser M, and Stein N. Cerebral palsy and New born care. **Developmental medicine and child neurology**, 1981; Vol.23: 801-817.
5. Friedrich W N, Greenbrg MP and Crnic K. A short form of the Questionnaire on resources and stress. **American Journal of Mental Deficiency** 1983: Vol 88(1); 41-48.
6. Mathew A and Asha CB. **Stress and coping among the parents of mentally retarded.** Unpublished Doctoral Dissertation, University of Calicut (1999).