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COMPARISON OF STRESS LEVELS IN THE PARENTS OF CHILDREN WITH CEREBRAL PALSY AND PARENTS OF NORMAL CHILDREN IN VADODARA REGION OF GUJARAT

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ABSTRACT

Background: Parenting is inherently stressful at times and several studies have shown that being a caregiver of a child who is disabled is even more stressful. A number of studies have identified the factors which exacerbate or mediate parenting stress in caregivers of children who are disabled. The aim of this study was to assess the parenting stress levels in parents of children who have cerebral palsy as compared to parents of normal children. Further objectives were to ascertain variables predictive of parenting stress levels.

Methods: The Gujarati translated version of Parenting Stress Index/Short Form was first validated and was given to 49 parents of children with cerebral palsy (Group-A) who were attending Varun Mahajan Apang Shishu Mandal, Vadodara and to the 50 parents of normal children (Group-B). Caregivers also completed a demographic questionnaire. 43 questionnaires from Group-A and 45 from Group-B were returned to the researcher. Means and frequencies were used to summarise the demographic data. T-tests were performed to establish whether there was any significant difference between the parenting stress levels in Group-A and Group-B.

Results: The parents in Group-A showed clinically significant, and in many cases, pathological levels of parenting stress as compared to the parents in Group-B.

Conclusions: The results of this study confirm that parenting stress is complex matter and it is important to predict the parenting stress levels of caregivers of disabled children. Therapists should evaluate the needs of each family individually and follow a family centred approach when managing children with cerebral palsy.

Key words: Cerebral Palsy, Parenting Stress, Care giving, Parenting Stress Index.

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INTRODUCTION

Cerebral palsy (CP) is primarily a disorder of movement and posture. It is defined as an “umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development”.¹

According to World Health Organization (WHO) estimation, 10% of the global population has some form of disability due to different causes; in India, it is 3.8% of the population. Nearly 15-20% of the total physically handicapped children suffer from CP.² The estimated incidence of CP is 2-2.5 per 1000 live births in developed countries whereas in India it is around 3/1000 live births; however, being a developing country, the expected actual figure may be much higher.³ There are about 25 lakh CP children in India as per the last statistical information.⁴

Children with CP have significant limitations in the activities of daily living because of motor, sensory, cognitive and verbal impairments in addition to learning difficulties and behavioural problem.^{5, 6} Limitations can result in need for long term care that far exceeds the usual needs of children as they develop.⁷ Parenting take an entirely different significance when child experiences functional limitations and possible long term dependence.⁸ Caring for a child with health problems can entail greater than average time demands, medical costs, employment constraints and childcare challenges.⁹⁻¹⁶ Acceptances of the child with cerebral palsy within the family and of the family within the society is still a matter of discussion. Mothers worry about their children's future and acceptance in its social environment, these maternal emotions can cause the risk of suffering from an anxiety disorder.⁶

Parents shoulder the principal role in multifaceted responsibilities of long term disability management. These families are required to deal with an alteration in the family dynamic which requires a modification of their activities with the increased burden of caring for a child who cannot adequately care for itself. There is also considerable stress associated with their concern for their child's future potential, prognosis, and financial burden and the time constraints placed on them by the need for specialised equipment and compliance with medical regimens. Service providers need therefore, to consider both the potential negative and the positive effects of their intervention in order to minimise the stress experienced by the parents.¹⁷ The burden of child's

disability on the family, therefore, needs to be examined in an effort to identify and minimise the main causal factors. Parental involvement and compliance with the intervention is required for the carry-over of the intervention into the child's daily life and subsequent successful outcomes.¹⁸

In recent years, there has been a shift in the delivery of healthcare services away from child-centred models toward a family-centred model. This family centred approach encompasses a philosophy of care in which the pivotal role of the parent is respected in the lives of children with special needs, and in which the family's strengths, needs and hopes determine the service plan. Further, the success of any intervention relies on a positive, supportive relationship between members of the intervention team and the caregivers and therefore, that services that include the whole family may be more successful in effecting change in a cerebral palsy child's functional development.¹⁹ Identifying and acknowledging these needs increases the parents' confidence and makes them more able to cope in their role as caregivers. Empowered parents will also better be able to teach their disabled children to advocate for themselves and to take control of their own lives.²⁰

To achieve success in such a situation and really make a difference in a family's ability to cope effectively with their disabled child requires a greater knowledge of possible family stressors and coping strategies, so that we can focus our energies in the appropriate direction and provide more appropriate, consumer-driven services. This study aims to establish stress levels in parents of children with cerebral palsy as compared to the stress levels of parents of normal children.

METHODS

Study Setup

This study was conducted at Varun Mahajan Apang Shishu Mandal run by Kashiben G. Patel Children Hospital at Vadodara.

Sample Selection

All parents of children with CP who were attending Varun Mahajan Apang Shishu Mandal and were between the ages of 6 and 12 years were identified. They were given the information sheet and their participation in the study was requested. Those agreeing to take part in the study were required to sign consent.

Inclusion Criteria

Group-A: All subjects were parents of children who were:

- Between the ages of 6 and 12 years.

- Diagnosed as having cerebral palsy by a paediatric neurologist.
- Attending Varun Mahajan Apang Shishu Mandal.

Group-B: All subjects were parents of children who were:

- Between the ages of 6 and 12 years.
- Not having any kind of disorder or disability.

Exclusion Criteria

Parents were excluded from the study if:

- Unwilling to participate in study.
- Child was diagnosed as having other neurological conditions such as autism, myopathy, muscle dystrophy etc.
- Parents were diagnosed with psychological and cognitive-behavioural illness and are not able to understand and co-operate for the study.
- Parents who had long history of diagnosed diabetes, hypertension, cardio-pulmonary or renal illness.
- The child was no longer domicile with at least one of his/her biological parents.
- The questionnaires were returned incomplete or if they were incorrectly filled out.

Procedure and Outcome Measures

An examination of records allowed the identification of 49 children attending the centre that met the study criteria. A numerical code was assigned to each of these children. A parent of each child was then approached by the researcher and verbally informed about the study. They were at the same time supplied with a data collection sheet which included the details of the study, a consent form, a demographic questionnaire and a Parenting Stress Index- Short Form in Gujarati language. The parents were asked to sign their consent if they agree to participate and to return completed data sheet in the sealed envelope to the physiotherapy department. The coding system was used to ensure that only the researcher would have access to the data thus preserving the parents' confidentiality. Written and telephonic reminders were given to the subjects who didn't respond after

2 weeks and 2 months. The data sheet contained all information in Gujarati as primary language of population is Gujarati in this region. The subjects were informed to contact the researcher if they experience any difficulty in interpreting the contents of the data sheet or questionnaire, which was not necessary in any of the cases.

Parenting Stress Index- Short Form (Gujarati)

Parenting Stress Index-Short Form (PSI-SF) was developed as a direct derivative of the full length Parenting Stress Index (PSI) and included total the 36 item divided into 3 major domains 1. Parental Distress (PD), 2. Parent Child Dysfunctional Interaction (PCDI) and 3. Difficult Child (DC).^{21, 22} The PSI-SF questionnaire was translated into the Gujarati language as the guidelines of American Association of Orthopaedic Surgeons.²³

Scores were calculated for each of the subscales of the index (PD, PCDI, DC) respectively, by summing the values scored for each of their 12 items. By adding these three subscale scores, a total parenting stress value (PSI-SF Total) could then be calculated for each respondent. The scores above the 90th percentile i.e. raw scores of above 90 for the PSI-SF Total, could be regarded as indicative of clinically significant stress within the parent-child dyad and as requiring professional intervention.^{21, 22}

Demographic Questionnaire

It included the details regarding the sample families' makeup for example number of siblings, socio-economic status, educational levels of parent, as well as the degree of support, both tangible and emotional experienced by each different caregiver whilst fulfilling their child-rearing task.

Data analysis and results

Group- A included 43 children between the ages of 6 and 12 years (Mean age: 8 years and 5 months) and their parents where as Group-B included 45 children (Mean age: 8 years and 9 months) with their parents. The sample included a mixture of all the different types of cerebral palsy. The children's diagnoses and mean ages are presented in Table-1.

TABLE -1: CHATRACTERISTICS OF CHILDREN

GROUP A	TOTAL NO. OF CHILDREN	MEAN AGE
	43	8 Years 5 months
QUADRIPLÉGIC	8	8 years 2 months
DIPLEGIC	15	9 Years
HEMIPLEGIC	9	8 Years 8 Months
DYSKINETIC	7	9 years
MIXED	4	7 Years 6 Months
GROUP B: Total No. of Children	45	8 Years 9 months

Majority of the primary caretakers interviewed were mothers of male children from Hindu households, with primary school education, living in joint families, and following labour or clerical occupations (Table-2).

Stress Levels

Mean scores in each sub scales and total stress levels were calculated using IBM SPSS Statistics 20.

High levels of stress were seen in all subscales of PSI – SF. As shown in Table-3 mean scores in each subscale and total stress level were above the 90th percentile of the standardisation sample in both the groups. Results show more stress levels in both Group A and Group B when the scores of subscales and total stress were compared to standardisation sample which is depicted in Graph 1.

TABLE 2: DEMOGRAPHICS OF THE STUDY POPULATION

CHARACTERISTICS	RESULTS	
	GROUP A (n = /43)	GROUP B (n = /45)
RELIGION		
Hindu	48.84% (21)	55.55% (25)
Muslim	20.93% (9)	15.55% (7)
Jain	16.28% (7)	22.22% (10)
Others	13.95% (6)	6.66% (3)
EDUCATION		
Primary	20.93% (9)	22.22% (10)
Secondary –Higher secondary	39.53% (17)	42.22% (19)
Graduation	25.58% (11)	26.66% (12)
Post Graduation	4.65% (2)	6.66% (3)
Professional	6.98% (3)	2.22% (1)
Unknown	2.33% (1)	0% (0)
1° CAREGIVER OF THE CHILD		
Mother	90.70% (39)	86.66% (39)
Father	2.33% (1)	4.44% (2)
Others	6.98% (3)	8.88% (4)
FAMILY STRUCTURE		
Joint	46.51% (20)	48.88% (22)
Nuclear	48.84% (21)	44.44% (20)
Unknown	4.65% (2)	6.66% (3)
OCCUPATION		
Labour Manual/Skilled	34.88% (15)	35.55% (16)
Clerical	25.58% (11)	26.66% (12)
Managerial/Business/Professional	32.56% (14)	33.33% (15)
Others	6.98% (3)	4.44% (2)
SEX OF THE CHILD		
Male	72.09% (31)	73.33% (33)
Female	27.91% (12)	26.67% (12)

t- test were performed for comparison of the means of independent sample and to establish if there was

any significant difference between the stress levels in Group A and Group B.

TABLE 3: PARENTAL STRESS

STRESS DOMAIN	MEAN (SD)		90TH PERCENTILE	
	GROUP A (n = 43)	GROUP B (n = 45)	ABIDIN	ABIDIN MEAN + 1.2 SD
PARENTAL DISTRESS(PD)	39.79 (3.576)	29.07 (4.624)	26.4 (7.2)	36
PARENT-CHILD DYSFUNCTIONAL INTERACTION (PCDI)	35.02 (3.391)	31.29 (3.733)	18.7 (4.8)	27
DIFFICULT CHILD (DC)	38.74 (3.540)	32.82 (4.064)	26.0 (6.7)	36
TOTAL STRESS	113.56 (9.963)	93.18 (8.515)	72.0 (15.4)	91

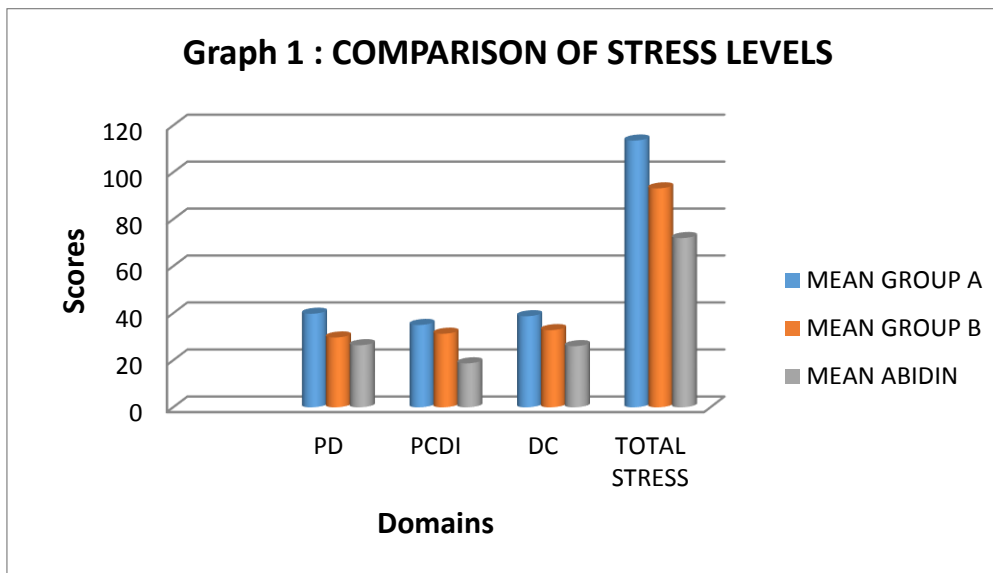


TABLE 4: COMPARISON OF STRESS LEVELS IN GROUP A AND GROUP B

STRESS DOMAIN	t- Value	DOF	Level of significance
PARENTAL DISTRESS(PD)	12.131	86	0.0001
PARENT-CHILD DYSFUNCTIONAL INTERACTION (PCDI)	4.905	86	0.0001
DIFFICULT CHILD (DC)	7.276	86	0.0001
TOTAL STRESS	10.331	86	0.0001

As it is shown in table 4, calculated 't' values were higher as compared to the table values at 95% confidence intervals. This suggests that there is highly significant difference in the stress scores between both the groups. The level of overall stress was found to be higher in Group A i.e. Parents of children with CP as compared to Group B i.e. Parents of normal children.

DISCUSSION

Parents in both the groups included in the study experienced very high levels of stress in all domains. Parenting is having inherently stressful character as the roles and responsibilities are at completely different levels than other roles in the society. As per the use of Abidin's construct, stress is generated in the parents when their capacity to fulfil their parenting role is exceeded by the demands made on them by their child.²² The level of stress on the parents depends upon the interaction between the child's and parents' characteristics, major and minor life stress events (such as serious illness, socio-economic concerns), daily care taking demands (such as feeding, sleeping and behavioural problems) and other child, parent and family associated variables (such as child temperament; caregiver's age, education level and marital status; family income and presence of social support).^{24,25,26,27}

In the present study, our results indicated mother as a primary care giver of the child in both the groups. It is similar to most published reports, where the burden of caring for a child with disability was shown to be borne primarily by the mother.^{28,29,30} This may be because woman is traditionally accepted to be having the role of bearing and care giving of the children in Indian culture as compared to the male, who is responsible for the financial support to the family. Some of the previous studies have reported that the mothers show higher levels of distress and stress in her role as a primary caregiver of a CP child.³¹

Indian socio-cultural scenario shows presence of high proportions of joint families in society. As it was observed the parents having child with CP were living more in nuclear family as compared to parents of normal children. This may add up to the levels of distress and parenting burden in the group A. But as long term care giving is needed for the rehabilitation of the children with cerebral palsy, it can be hypothesised that this process can be devastating to the finance, employment and quality of life for parents as well as it may affect whole family.^{31,32} This can be easily stated from the results of our study showing almost equally significant levels of stress in both groups.

Group B consisted of the parents who were mostly involved in the clerical and managerial kind of

work or owned small business which is supposed to be financially strong as compared to other occupation subtypes. Still as it is observed that there is minor difference of stress levels in both groups, this can be due to many reasons including impaired sense of competence, restrictions placed on other life roles, lack of social support and depression. This finding is in contrast to most published studies which report higher stress among parents of low socioeconomic status. Higher stress among parents who are engaged in a prestigious occupation may be due to their higher expectations from their children, higher perception of shame, frustration at not being able to restore the condition of the child and more restrictions on their social and professional activities.²⁸

Thus parents with or without children with CP feel same levels of stress irrespective of their family structure, financial status, or sex of the children. Our study enlightens the inherently stressful nature of parenting in Indian socio-cultural background. Having a child with CP increases the levels of burden and hardens the task of parenting and caring for families and especially parents. The high amount of stress and the lack of support measures in the family may in turn affect not only the condition of the child, but the family as a whole. Healthcare providers need to be aware of the various coping mechanisms which could impact the management of the child's disability. The healthcare providers, especially the physiotherapists should be trained to provide pastoral counselling to help families cope with the condition of disability.

The specific sources of parenting stress among parents of different socioeconomic status and levels of available supporting and coping strategies for them should be explored in future studies so that appropriate interventions can be planned.

CONCLUSION

The study was undertaken to compare the levels of stress in the parents of children with two completely different levels of physical and/or mental abilities. The study also tried to identify additional demographic stressors which need to be taken into account by therapists when attempting to develop more effective and appropriate treatment strategies.

The results of the study allow the following conclusions to be drawn:

1. The parenting stress levels (measured using the PSI-SF) amongst parents with cerebral palsied children were generally higher as compared to the parents with normal children.

2. The level of parenting stress experienced by the parents of cerebral palsied children was found to be associated with levels of education, job status of the parents and type of the family structure. But the interaction of other socio-demographic variables was also found to affect the levels of stress in both groups.

The results of this study confirm that parenting stress is complex and that it is not a simple matter to predict the parenting stress levels of caregivers of disabled children. Therapists should evaluate the needs of each family individually and follow a family centred approach when managing children with cerebral palsy

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