

Maternal Stress in Mothers of Children with Cerebral Palsy

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Abstract:

The aim of the present project was to study the maternal stress in mothers of children with cerebral palsy and also to compare the maternal stress between mothers of children with cerebral palsy and autism, to determine if stress is caused more by physical problem or by behavioral problem in children. The Parental Stress Scale was used in both cases. Data was collected from 30 mothers of children with CP and 28 mothers of children with autism, in the age group 2-12 years. It was found that maternal stress of mothers of children with cerebral palsy lies on the "moderate" level of PSS norms, while within group comparison resulted in 18 out of 30 cases of mothers of CP children lying above average stress level. Further it was found that there was no significant difference in the stress level of mothers of children with CP and those with autism.

Key words: Cerebral Palsy, Autism, Maternal Stress, Development Disorders.

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Introduction:

Neurodevelopmental disorders are disabilities associated primarily with the functioning of the neurological system and brain. Examples of neurodevelopmental disorders in children include intellectual disability (also known as mental retardation), attention-deficit/hyperactivity disorder (ADHD), autism, and learning disabilities. Children with neurodevelopmental disorders experience difficulties with language and speech, motor skills, behavior, memory, learning, or other neurological functions.

While the symptoms and behaviors of neurodevelopmental disabilities often changes as a person ages, some individuals with neurodevelopmental disabilities in childhood do have permanent disabilities. Diagnosis and treatment of these disorders can be difficult; treatment often involves a combination of professional therapy, pharmaceuticals, and home- and school-based programs.

Based on parental response to survey questions, approximately 12% of children in the United States ages 3 to 17 years are affected by neurodevelopmental disorders such as ADHD, learning disorders, or intellectual disability. Many of these children have more than one of these conditions. Some researchers have stated that the prevalence of certain neurodevelopmental disorders, specifically autism and ADHD, has been increasing over the last four decades.

Genetics can play an important role in many neurodevelopmental disorders, and some cases of certain conditions such as intellectual disability are associated with specific genes. However, most neurodevelopmental disorders have complex and multiple contributors rather than any one clear cause.

A child's brain and nervous system are vulnerable to adverse impacts from pollutants because they go through a long developmental process beginning shortly after conception and

continuing through adolescence. This complex developmental process requires the precise coordination of cell growth and movement, and may be disrupted by even short-term exposures to environmental contaminants if they occur at critical stages of development.

A precise definition of cerebral palsy has remained elusive because cerebral palsy is not a single diagnosis but an "umbrella" term describing non-progressive brain lesions involving motor or postural abnormalities that are noted during early development.

"Cerebral" means *"brain"* and *"palsy"* means *"a physical disorder"*. Loosely translated, it means *"brain paralysis."*

Cerebral palsy has been described as follows:

"A group of disorders of the development of movement and posture causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior and/or a seizure disorder." Cerebral palsy is known to occur 2-2.5/1000 births in developed countries. However in India, it is reported to occur 1/50 births.

An Indian study reported the cases of 1000 children with CP, who were seen at the Rehabilitation Centre for Disabled Children, Chandigarh from 1985-1993, were reviewed to study their clinical profile, etiological factors and associated problems. The age at the time of presentation ranged from 2-16 years of age. Results showed that Spastic quadriplegia formed the dominant group (61%), followed by spastic diplegia (22%). Dyskinetic CP was present in 7.8 cases. Mental retardation was the most common associated problem. (*Dr. Pratibha D. Singhi, et al. 2002*).

Brain lesions of cerebral palsy occur from the fetal to the neo-natal period up to 3 years of age. The symptoms are usually seen before a child is 2 years old, sometimes they are seen as

early as 3 months old.

Autism is known as a complex developmental disability. Experts believe that Autism presents itself during the first 3 years of a person's life. The condition is the result of a neurological disorder that has an effect on normal brain function, affecting development of the person's communication and social interaction skills. People with autism have issues with non-verbal communication, a wide range of social interactions, and activities that include an element of play and/or banter.

Autism (or ASD) is a wide-spectrum disorder. This means that no two people with autism will have exactly the same symptoms. As well as experiencing varying combinations of symptoms, some people will have mild symptoms while others will have severe ones. Most parents of autistic children suspect that something is wrong by the time the child is 18 months old and seek help by the time the child is age 2. Children with autism typically have difficulties in:

- Pretend play
- Social interactions
- Verbal and nonverbal communication

In a study of the stress experienced by mothers of children with cerebral palsy attending special schools in Kerala State, India. P.V. Vijesh and Sukurmaran (2007). Stress level was assessed using the local language version of the Questionnaire on Resources and Stress and the data were analyzed 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.

In a study to assess the importance of disability severity and child functional status as predictors of maternal depressive symptoms and the moderating effects of maternal appraisal, social support, and family income on the relationship between disability factors (severity and functional status) and maternal depressive symptoms. Janeen Manuel et al (2003). Mothers of 270 children with cerebral palsy completed surveys on their appraisal of the child's disability, social support, and family demographics. Physicians assessed the severity of the disability and the child's functional status. Results showed 30% of the mothers had depressive symptoms above the cutoff on a depression screening instrument. Disability severity and child's functional status did not predict maternal depression. Perceived social support moderated the relationship between the child's functional status and maternal depressive symptoms. Concluding that mothers of children with cerebral palsy may be at risk for depression. Interventions that take into account the moderating effects of social support may increase maternal adaptation.

In a study to identify the stress experienced by mothers of young children with cerebral palsy in Bangladesh and to determine the predictive factors, 91 mothers of CP children aged 1.5-5 years were recruited as they sought services at an urban and a rural centre for children. Mobarak et al (2000). Mothers were interviewed with Self-Report Questionnaire and other family background and child behavior measures. Out of 91, 38 (41.8 %) mothers were at risk for psychiatric morbidity. Significantly associated factors included living in the rural areas within poor family and a relatively older child. The strongest predictor of maternal stress in multivariate analysis was child behavior problems, especially those related to burden of caring.

In a comparison study of parents of children with other disabilities (Down syndrome, fragile-syndrome, undifferentiated developmental disability, and cerebral palsy),

mothers of individuals with ASD report more negative impact and poorer well-being during their children's preschool years and adulthood. Abbeduto et al. (2004); Blacher and McIntyre (2006).

It is well established that mothers of children with developmental and psychiatric difficulties are at risk for experiencing greater distress than mothers of typically developing children (Baker, Blacher, Crnic, & Edelbrock, 2002; Dumas, Wolf, Fisman, & Culligan, 1991; Hauser-Cram et al., 2001; Hodapp, Ricci, Ly, & Fidler, 2003; Johnston et al., 2003; Rodrigue, Morgan, & Geffken, 1990). Several studies suggest mothers of children with autism spectrum disorders (ASD) may experience higher levels of distress than mothers of children with other disabilities (e.g., Gallagher & Bristol 1989). For example, mothers of children with ASD have demonstrated lower psychological well-being and coping compared with mothers of children with Down Syndrome, Fragile X and cerebral palsy (Abbeduto et al. 2004; Blacher & McIntyre 2006; Eisenhower, Baker, & Blacher 2005; Kasari & Sigman 1997). Mothers of children with ASD also report higher stress and depressive symptoms compared with mothers of children with broadly defined developmental delay (Dumas et al. 1991).

Methodology:

Objectives:

- 1) To study the maternal stress level of mothers of children with cerebral palsy.
- 2) To study maternal stress level of mothers of children with autism and cerebral palsy.

Hypothesis:

- 1) There will be a moderate or significant amount of maternal stress of mothers of children with cerebral palsy.

- 2) There will be a difference in the maternal stress levels of mothers of children with autism and cerebral palsy.

Sample:

Data was collected from 30 mothers of children with Cerebral Palsy and 28 mothers of children with autism, who sought treatment at the General OPD in the Child Guidance Clinic, Sir Ganga Ram Hospital.

Instrument used:

Basic developmental case history forms (refer to Appendix 1) and Parental Stress Scale. The *Parental Stress Scale* is a self-report scale that contains 18 items representing pleasure or positive themes of parenthood (emotional benefits, self-enrichment, personal development) and negative components (demands on resources, opportunity costs and restrictions). Respondents are asked to agree or disagree with items in terms of their typical relationship with their child or children and to rate each item on a five-point scale: strongly disagree (1), disagree (2), undecided (3), agree (4), and strongly agree (5). The 8 positive items are reverse scored so that possible scores on the scale can range between 18 and 90. Higher scores on the scale indicate greater stress. The scale is intended to be used for the assessment of parental stress for both mothers and fathers and for parents of children with and without clinical problems.

Results:

The results are shown in Table 1 and Table 2. The average of maternal stress scores of mothers of children with cerebral palsy was calculated at 47.76 and the SD at 7.79. *t* score for the maternal stress of mothers of children with autism and cerebral palsy was derived which was $+1.13$ at $df=56$.

Sl. No	AGE	SEX	PSS Score
1	4.5	M	54
2	2	F	36
3	3	M	42
4	12	M	51
5	3	F	47
6	4.5	M	49
7	7	M	66
8	12	M	48
9	4	M	56
10	3	M	53
11	3	F	38
12	8	M	52
13	1.5	M	49
14	4.5	F	48
15	2.5	F	27
16	1.5	M	54
17	4	M	52
18	4	M	42
19	3.5	M	51
20	2	M	52
21	4	F	41
22	3	F	56
23	2	M	58
24	5	M	51
25	2	F	38
26	11	F	43
27	6	M	47
28	4.5	M	42
29	3	M	50
30	7	M	40
TOTAL			1433
Mean			47.76667
SD			7.79

Table1. Maternal stress score of mothers of children with Cerebral Palsy on the Parental Stress Scale

SL No	CP	AUTISM
1	54	33
2	36	67
3	42	36
4	51	42
5	47	37
6	49	35
7	66	48

8	48	42
9	56	41
10	53	52
11	38	40
12	52	38
13	49	40
14	48	48
15	27	39
16	54	35
17	52	58
18	42	69
19	51	48
20	52	53
21	41	45
22	56	47
23	58	47
24	51	38
25	38	65
26	43	46
27	47	39
28	42	36
29	50	
30	40	
TOTAL	1433	1264
MEAN	47.76667	45.14286

Table 2. Scores of maternal stress of mothers of children with CP and Autism.

Data Summary			
	A	B	Total
n	30	28	56
$\sum X$	1433	1264	2697
$\sum X^2$	70211	59622	12933
SS	1761.36	2601.43	4362.79
mean	47.76	45.14	92.9

Results

Mean _a —Mean _b	t	df		
2.62	+1.13	56	two-tailed	2.00

Table 3. t test for the significance of the means of maternal stress of CP and Autism children.

Interpretation and Discussion:

Referring to Table 1 (Maternal stress scores of mothers of children with Cerebral palsy on the PSS), it is observed that all the cases lie on the “Moderate” level of stress as referred to the norms of the PSS.

The average of the group is 47.76. On assessing the mean of the group with individual scores at SD= 7.79, it is found that 18 of the mothers lie above average stress level, while 12 of the mothers lie below average in their stress level. This could be supported by the finding that most of the 18 mothers who lie above average stress level had reported either ‘3-undecided’ or ‘2-disagree’ on items like “Having children gives me a more certain and optimistic view for the future.”; “I am satisfied as a parent.” While for mothers who lie below average stress level had more positive responses on such items. This may conclude that thinking or looking ahead to the future may be the most stressful issue for mothers of children with cerebral palsy. Also there is the possibility that most parents who come for the first time for treatment do not report any stress as they may not be aware of the many complications and comorbid factors of cerebral palsy.

Hence, these findings confirm the first hypothesis that there will be a moderate/significant level of maternal stress in mothers of children with cerebral palsy. Also supporting the finding of the study that stress experienced by mothers of

children with cerebral palsy 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. (Vijesh and Sukurmaran 2007)

Also, all mothers were housewives who were from lower socio-economic status which could further substantiate the study that mothers of children with cerebral palsy were at a higher risk of psychiatric morbidity and the significantly associated factors included living in the rural areas within poor family. (Mobarak et al. 2000).

Referring to Table 3, it is observed that $t = +1.13$. Referring the calculated value of t to the tables of critical value of t , at $df=56$, $\alpha = 0.05$, it found to be *non-significant*. This means that there is no significant difference between the maternal stress level of mothers of children with cerebral palsy and with autism, hence failing to prove the second hypothesis that there will be a difference in the maternal stress level of mothers of children with cerebral palsy and with autism, also failing to substantiate earlier studies that mothers of children with ASD have demonstrated lower psychological well-being and coping compared with mothers of children with Down Syndrome, Fragile X and cerebral palsy (Abbeduto et al. 2004; Blacher & McIntyre 2006; Eisenhower, Baker, & Blacher 2005; Kasari & Sigman 1997). Mothers of children with ASD also report higher stress and depressive symptoms compared with mothers of children with broadly defined developmental delay (Dumas et al. 1991)

Maternal stress occurs irrespective of whether the disability is caused by behavioral or physical problem. In fact, maternal role in itself is a big challenge and stressful, despite the absence of any disorder.

However, there could also be certain limitations of the present study such as language problems in administering the questionnaires and collecting data. Also other limitations include environmental conditions such that interview was done

in the Child Guidance Centre and data was obtained as such not in the best noise-distraction free environmental situations, as desired for any clinical interview.

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