

## **Stress, Burden and Coping between Caregivers of Cerebral Palsy and Autism Children**

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### **ABSTRACT**

The objective of the study was to find the difference in stress, burden and coping between caregivers with cerebral palsy and autism children. 30 caregivers having children with cerebral palsy and 30 caregivers having children with autism were part of the study. The age of the caregivers ranged between 23-40 years. For the study caregivers of children aged between 7-12 years were considered. A between group research design with purposive sampling technique was opted for the study. After obtaining socio-demographic details the caregivers were administered Parenting Stress Index (Short Form), Schedule to Assess Burden and Coping Checklist. The data was subjected to 't' test to find the significant difference between the two sample groups. Results revealed that there was significant difference in stress, burden and coping between caregivers of cerebral palsy children and caregivers of autistic children.

**Keywords:** *Stress, Burden, Coping, Caregivers, Cerebral Palsy, Autism*

Cerebral palsy is a group of neurological disorders that appear in infancy or early childhood and permanently affect body movement, muscle coordination, and balance. Cerebral palsy affects the part of the brain that controls muscle movements. Other neurological symptoms include seizures, hearing loss and impaired vision, bladder and bowel control issues, pain and abnormal sensations. Parents of such children are at distress when they realize that their little one is diagnosed with cerebral palsy. The unknown journey of stress and burden begins here which continues throughout their life. Caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability (Brehaut et al., 2004). Children with cerebral palsy have also been reported to exhibit psychological problems and this adds to the burden of care (Parkes et al. 2008). It is estimated that the incidence of this disorder worldwide is between 2 to 2.5 cases per 1,000 births (Blair, 2010; Odding, Roebroek, & Stam, 2006). The stresses and hardships faced by families with a disabled child are well documented (Hirose & Ueda, 1990; Jones-Jessop & Stein, 1991;

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Lambrenos et al, 1996; Law et al, 1998; Mc Conachie et al, 2000; Mc Cubbin, 1989; Mobarak et al, 2000; O'Neill et al, 2001; Ong et al, 1998; Viscardis 1998). 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.

Parents of children with cerebral palsy (CP) often experience higher levels of stress than other parents. The cerebral palsy children are highly dependent on mothers for their day to day activities due to which the mothers experience psychological distress. This excessive responsibility may adversely affect the physical and the psychological health of caregivers (Brehaut & Tucker, et al., 2009), affecting their social, cultural and professional lives (Grootenhuis & Bronner, 2009). Caring for a cerebral palsy child is a lifelong task. Loco motor malformation is the main limitation of CP, it is also characterized by the cognitive, sensory and social developmental limitations. These limitations lead to significant influence on self-care activities like eating, mobility, clothing, and personal hygiene. Therefore, Raina (2005) described in his study that CP can be considered as a unique type of disability in childhood. Care of these children require more attention and longer duration of care compared to the care of normal children. It results in burden on parents and family. Excessive responsibility can adversely affect their physical, psychological and social health (Brehout et al, 2009). Coping with all this distress is a challenge for the parents. The parents of such children do have difficulties coping with the stress and burden and need a helping hand to deal with their life situation.

Autism is a neurodevelopment disorder characterized by impaired social interaction, verbal and non-verbal communication, and restricted and repetitive behavior. Autistic children have motor signs that include poor muscle tone, poor motor planning, and toe walking and deficits in motor coordination. Autism has its roots in early brain development. The parents notice the signs and symptoms of autism at a very early age of 2-3 years. Globally, autism is estimated to affect 21.7 million people as of 2013.

Autism is more seen in boys than in girls. It has been found that severity of the autism is strongly associated with behavioral problems (Stanley, 2004). The strong behavior problems usually put these children into trouble. Autistic children usually are aggressive, exhibit socially maladaptive and destructive behavior. Society usually fails to understand the problems of such children and isolate such children. Parents of such children are at high risk of being stressed. Like cerebral palsy, autism also affects the family atmosphere. The parents may feel helpless, overwhelmed and frightened by this kind of behavior and often begin to question their parental ability and will have guilt feelings associated with their inability (Hoch et al, 2008). Several studies have put forward that 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).

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Many parents of children with pervasive developmental disorders reported experienced feelings of intense anger, guilt, depression or anxiety most of the time. (Allik, et al, 2006). Apart from that, having a child with autism can drain a family's resources due to expenses such as evaluations, home programs, and various therapies (Mc Cubbin, et al, 1982).

Researchers reported that the development impairment, presented by children with autism spectrum disorders, may have several implications for the family dynamics (Dardas, et al, 2013, Gardiner et al, 2012, Burgees, et al, 2010, Shu, 2009) from the physical and mental burden arising from daily life assignments (Burgees, et al, 2010, Shu, 2009) high levels of stress and low levels of quality of life for the family members (Zablotsky, et al, 2013) to the possibility of developing adaptability and resilience (Gardiner, et al 2012). Changes are reported in daily activities and psychological functioning of its members, heavy workloads and specific demands (Fávero et al, 2005). These aspects may interfere in aspects referring to family, work, social and personal life and may predispose the caregiver to conflicts (Martins, et al 2003 & Ghanizadeh, et al, 2009).

### ***The Need for the Study:***

Cerebral palsy and Autism are neurological disorders which have adverse impact on the caregivers' physical and psychological health. Many parents experience feeling of guilt, anger, helplessness, and depression. The disability of the child exhausts the resource of the family. In caring for such children the relation of the family is strained and at the same time the relationship between the siblings is also affected. Parents have to sacrifice their career aspirations and limit their social activities. The society's attitude towards such children is quite unfriendly and the parents are always under the constant fear of stigmatization. Even among parents of children with autism report significantly higher levels of stress (Dumas, et al., 1991, Sanders, & Morgan, 1997). Likewise studies conducted on caregivers of cerebral palsy also have shown that the diagnosis of the problem, behavior difficulty, and functioning lead to mental stress and burden in caregivers while raising a child with disability (Murphy et al., 2007 ).

The difficulties of care giving differ depending upon the type of disability of the child. Kimura and Yamazaki (2013) examined that the level of difficulties of parents are different depending on the difference of their children disabilities. Parents of children with autism and parents of children with cerebral palsy experience difficulties while caring for the disabled child. The study becomes important to understand if there is significant difference in stress and burden experienced by parent caregivers of cerebral palsy and autistic children and if there is difference in coping strategies adopted by the parents to cope with the day to day difficulties.

Autism is characterized by abnormalities in social interaction and communication, as well as unusual interests and behaviours. (American Psychiatric Association, 1994). Children with ASD initiate few social behaviors and their social expressiveness and sensitivity to others' social cues

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are limited (Mash & Wolfe, 1999). Language delay and speech problems are also salient among children with ASD (De Giacomo & Fombonne, 1998). These behavioral symptoms have been associated with high levels of anxiety, depression and everyday stress in parents (DeMeyer, 1979; Harris, 1984).

In a study by Ma (2012) the results indicated that there were no significant differences in parental stress between parents of children with ASD in Taiwan and America. In another study by Fitzgerald and colleagues (2002), as they reported that mothers of older children with ASD had lower levels of subjective care giving burden and mental health problems than mothers of younger children with ASD. Furthermore, another study also found that the well-being of mothers with adolescent and young adult children with ASD was improving with time (Lounds et al., 2007).

Cerebral palsy on the other hand is characterized by motor malfunction associated with sensory, cognitive and social impairments due to which the child becomes totally dependent on parents for their self-care functions including activities of daily living. Caring for such children usually leads to significant burden especially when the requirements are long lasting.

Researchers found parents of the children with disabilities likely to experience more burdens (Olsson and Hwang 2001) compared to the parents of normal children. (Button et al, 2001).

Glenn, Cunningham, Poole, Reeves, and Weindling (2009) found that mothers of children with CP who exhibited the highest levels of stress were those who perceived their child as needy and unable to adapt; they also felt strong social isolation and received little support from a partner. Distressed parents of children with CP are characterized by limited or even ineffective coping strategies (Knussen & Sloper, 1992). Moreover, passive coping strategies can further increase the stress level among caregivers of children with disabilities (Sloper & Turner, 1993).

In one study, no differences were found between mothers and fathers of children with CP with respect to experienced levels of stress, but mothers experience more parent-related stress, while fathers experience more child-related stress (Wanamaker & Glenwick, 1998).

In Indian context the mothers take the sole responsibility for raising and caring the child with disability. This is characterized by various socio- economic responsibility and the stigma people attach to the disabilities. There has been extensive research associating stress with raising children with developmental disabilities. These studies suggest that the mothers of children with disabilities experience greater stress than other mothers due to the extra daily tasks that take their time away from adequately taking care of themselves (Leonard, Johnson, & Brust, 1993). Dunst, Trivette, and Cross (1986) also found that mothers of children with disabilities reported poorer

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emotional and physical health and that they felt that there were greater demands on their time from the child.

As the requirement and demands of the disabilities and disabled children differ the parent caregivers have to cater to the needs of the disability accordingly. The literature shows that some parent caregivers experience stress, burden and have difficulties in coping while catering to the needs of the disabled child, while some parent caregivers are able to cope with stress and burden while caring to the disabled child. The need was felt to find if there was any difference in stress, burden and coping between parents with cerebral palsy and parents with autistic children.

### **METHODOLOGY**

The aim was to study stress, burden and coping between parent caregivers of children with cerebral palsy and autistic children. The objective was to study the difference in stress, burden and coping between parent caregivers of children with cerebral palsy and autism.

The following were the hypothesis of the study

1. There will be no significant difference in the stress between parents of children with cerebral palsy and autistic children.
2. There will be no significant difference in the burden between parents of children with cerebral palsy and autistic children.
3. There will be no significant difference in the coping between parents of children with cerebral palsy and autistic children.

### ***Participants***

The participants for the present study consisted of 60 female parents, of them 30 parent caregivers having children with cerebral palsy and 30 parent caregivers having children with autism. The following inclusion criteria were used (1) Parent caregivers of those children belonging to the age group of 7- 12 years were considered for the study since this is the period when the children dependence on parents will be higher.(2) Only those parent caregivers who were accompanying their wards to the school were selected for administration of the tests. The exclusion criteria were (1) Parents of any other differently enabled children (2) Parents who were not accompanying their wards to the school (3) Parents with major psychiatric/psychological problem.

### ***Research Design:***

A between group research design with purposive sampling was adopted for the study.

### ***Tools:***

The participants were administered with the Parenting Stress Index (short form), Schedule to Assess Burden and Coping Checklist. The details of the tests are as below.

1. **Abdins Parenting Stress Index – Short Form by Abidin (1986).**

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The questionnaire consists of 36 statements which has two domains - the child domain and the parent domain. It has five options—strongly agree, agree, neutral, disagree and strongly disagree. Likert's 5 point rating is used to score the items ranging from 1-5. A higher score will indicate higher stress. It has good internal consistency reliability that ranges between 0.70 and 0.79 for the scale.

2. **Schedule to Assess Burden by Pai and Kapur (1981):** It has 24 items and the scale assesses burden in four areas - financial, disruption of routine family activities, disruption of family interaction and family health. The Burden Scale has three options – Severe, Moderate and No burden. Severe is given a score of 2, Moderate 1 and No burden 0. It has reliability above 90% for 20 items and between 87 to 89% for the other 4 items. Validity of the scale is 0.72.

3. **Coping Checklist by Rao, Subbakrishna and Prabhu (1989):** Coping check list has 70 items, which covers a wide range of behavioral, cognitive and emotional responses to handle stress. Items are scored dichotomously in a yes/no format, the responses indicating presence or absence of a particular coping behavior. The test retest reliability (over a month) is 0.74, indicating adequate reliability and the internal consistency is 0.86.

### *Statistical Techniques:*

The mean, SD and t-test were used to analyze if there was significant difference between the caregivers of cerebral palsy and autistic children.

*Table 1 shows the demographic details of parents of cerebral palsy and autistic children*

Variables	Characteristics	Frequency (n)	Percentage
<b>Caregivers of Cerebral Palsy</b>			
Gender	Females	30	100
Age	23-26	8	26.6
	27-30	11	36.6
	31-35	7	23.3
	36-40	4	13.3
Housing	Urban	30	100
Occupation	Housewife	17	56.6
	Private Sector	8	26.6
	Government	5	16.6
Level of Education	Secondary	16	53.3
	Tertiary	14	46.6
<b>Caregivers of Autism</b>			
Gender	Females	30	100
Age	24-27	7	23.3
	28-31	5	16.6
	32-35	7	23.3
	36-40	11	36.6
Housing	Urban	30	100
Occupation	Housewife	21	70
	Private	9	30
	Government	0	00
Level of Education	Primary	9	30
	Secondary	13	43.3
	Tertiary	8	26.6

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**Table 2: Mean, SD and 't' values for caregivers of cerebral palsy and autistic children on stress, burden and coping.**

Variables	Care Givers of Children	N	Mean	SD	't'
<b>Stress</b>	Cerebral palsy	30	18.66	2.10	4.98**
	Autism	30	21.50	2.32	
<b>Burden</b>	Cerebral Palsy	30	10.80	2.37	4.06**
	Autism	30	8.40	2.21	
<b>Coping</b>	Cerebral palsy	30	17.50	2.57	4.61**
	Autism	30	20.73	2.82	

\*\* =  $p < .01$  level

Table 02 shows the Mean, SD and 't' value obtained on stress, burden and coping between parent caregivers of cerebral palsy and autistic children. The mean score obtained on stress for parent caregivers of cerebral palsy and autistic children are 18.66 and 21.5 respectively. The SD obtained is 2.10 for parent caregivers with cerebral palsy children and 2.32 for caregivers with autistic children. The 't' value is 4.98, which is significant at 0.01 level. This implies that there is significant difference in stress level between parent caregivers with cerebral palsy and parent caregivers with autistic children. When compared with caregivers having children with cerebral palsy stress is found be higher among the parent caregivers of autistic children.

Similarly, the mean score obtained on burden for parent caregivers of cerebral palsy and autistic children are 10.80 and 8.40 respectively. The SD scores obtained are 2.37 for parent caregivers with cerebral palsy children and 2.21 for caregivers with autistic children. The 't' value 4.06, which is significant at 0.01 level. This shows there is significant difference in burden of parent caregivers with cerebral palsy and parent caregivers with autistic children. When compared with caregivers having children with autism burden is found to be higher among the parent caregivers of cerebral palsy children.

The obtained mean results for coping for parent caregivers with cerebral palsy and autistic children are 17.5 for cerebral palsy and 20.73 for parent caregivers with autistic children. The SD scores are 2.57 for parent caregivers with cerebral palsy and 2.82 for parent caregivers with autistic children. The 't' value is 4.61, which is significant at 0.01 level. This clearly indicates that there is significant difference in coping between parent caregivers with cerebral palsy and parent caregivers with autistic children. When compared with caregivers having children with autism coping is better among the parent caregivers of cerebral palsy children.

The present study mainly focused on the difference in stress, burden and coping of the parent caregivers of children with cerebral palsy and autism. There are several factors that lead to stress and burden and caregivers use different coping strategies to cope with the grim situation of the

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family especially when they have a disabled child. The findings of the present study shows that parent caregivers having children with cerebral palsy have less stress. This results support the earlier findings that many such families having children with cerebral palsy were able to rise above the challenges they were facing without becoming dysfunctional (Cadman et al, 1991). Mobarak et al (2000) in their study have reported that there was no such relationship between severity of cerebral palsy children and parental stress.

The obtained findings of the present study indicate that the parent caregivers with cerebral palsy experience more burden. The significant predictor of caregiver's burden was degree of disability/dependence of children (Marrón et al, 2013). Numerous studies have shown that there are several factors that contribute to the onset of burden and stress in caregivers of children with disabilities (Barlow, Cullen-Powell, & Cheshire, 2006; Button, Pianta, & Marvin, 2001; Mobarak et al., 2000; Wang & Jong, 2004).

Studies conducted earlier on coping have shown that the parent caregivers having children with cerebral palsy use less coping strategies. While coping with child's disability is important for the parents. Whereas, a study by (Krstić & Oros, 2012) has shown that parents used reframing strategy as it helps the parents to cope with the grave situations

The findings of the present study reveal that parents with autistic children experience more stress. Studies have shown that parents of autistic children experience stress and burden that has harmful effects on their career (Morrell & Palmer, 2006). The findings of the present study has been supported by the study conducted by Nagaraju and Wilson, (2013), they have found that more than half of the respondents having autistic children perceived moderate burden and nearly half of them had mild to moderate stress. Taanila et al., (2002) have found that parents of physically or intellectually disabled children use social support as coping strategy. Study conducted by Nisha Vidyasagar and Susan Koshy (2010) have found that caregivers with autistic children frequently use coping strategies like social support, escaping/avoiding or by positively reappraising the situation more.

## **CONCLUSIONS**

- The obtained results indicate that the parent caregivers having autistic children experience more stress than that of parent caregivers having cerebral palsy children.
- With regard to burden, the parent caregivers having cerebral palsy children experience more burden than that of parent caregivers having autistic children.
- Depending on circumstances parent caregivers use different coping ways to cope with their day to day problems.

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**Conflict of Interests**

The author declared no conflict of interests.

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