

## Stress and Coping among Caregivers with Cerebral Palsy and ADHD Children

Pushpalatha. R<sup>1\*</sup>, Shivakumara. K<sup>2</sup>

### ABSTRACT

The aim was to study stress and coping between parent caregivers of children with cerebral palsy and ADHD children. 120 parent caregivers, of them 30 male and 30 female parent caregivers having children with cerebral palsy and 30 male and 30 female parent caregivers having children with ADHD were considered for the study. The male parent caregiver's age ranged between 28-40 years and the female parent caregiver's age ranged between 22-30 years. The disabled children age ranged between 7-12 years. 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) 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 and coping between caregivers of cerebral palsy children and caregivers of ADHD children.

**Keywords:** *Stress, Coping, Caregivers, Cerebral Palsy, ADHD*

Children with disabilities comprise nearly 5-8 percent of the Indian population. Children with disabilities are subjected to numerous deprivations and have limited opportunities in most of the areas which make their lives difficult. The parents of such children go through a lot of stress and burden while caring for the disabled child and often face challenges from the other family members. This ultimately affects their physical and mental health and having its impact on their coping and psychological well-being.

Cerebral palsy (CP) is a chronic condition defined as a group of functional limitations due to the damage in the development of central nervous system (Rethlesfsen, et al 2010). The world incidence of CP was estimated between 2 to 2.5 cases per 1000/live births (Blair 2010). Cerebral palsy is characterized by limitations in cognitive, sensory and social development. These

<sup>1</sup> Research Scholar, Department of Psychology, Karnatak University, Dharwad, India

<sup>2</sup> Associate Professor, Department of Psychology, Karnatak University, Dharwad, India

*\*Responding Author*

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limitations have its impact on their self care functions such as eating, attending to their personal hygiene and mobility. Caring for such children requires a lot of attention and long term care. This long lasting care leads to a lot of stress and burden. Excessive responsibility can adversely affect their physical, psychological and social health (Brehout et al, 2009, Desmong and Surrency, 2009). It also affects parent's social, cultural and professional lives (Grootenhuis and Bronner 2009). Mc Cubbin (1989) and O' Neill et al (2001) found a direct relationship between the level of parenting stress experienced and an increased burden of care or severity of cerebral palsy. In their work with mothers of children with cerebral palsy, Glenn and colleagues (2009) found considerably higher levels of maternal stress when compared to mothers of typically developing children, with the highest levels of stress determined by factors such as role restriction, feelings of isolation, insufficient support from their spouse, and demandingness of their child. Sources of stress in parents of children with CP include the child, parent, and family or the social environment. Other child factors thought to be important include communication impairment, the presence of child behavior problems, and intellectual impairment.

Attention deficit hyperactivity disorder (ADHD) is a common childhood disorder (APA, 2000; AACAP, 2002). It is a pervasive and debilitating condition affecting many aspects of the individual's life, namely academic life (DuPaul et al., 2001), social skills (Bagwell et al., 2001) and parent-child relationships (Johnston and Mash, 2001). ADHD is the most commonly diagnosed childhood neurological-behavioral condition, affecting at least 3-7% of school-aged children in Europe and the United States (American Psychiatric Association, 2000). Abidin (1995) emphasizes that parental stress is formed by a combination of child and parent characteristics, the family context and other life stressors. It is necessary to understand that caring for a child with disability or having some behavioral problem is quite difficult for the parents to cope especially when there is inadequate support; parents are at risk for increased health problems, depression or feeling incompetence. Since the behavioral problems of ADHD children are high, their parents have more stress than normal children parents (Anastopoulos, Guevremont, Shelton & Dupaul, 1992). Stress in the family context, especially when stress is chronic and present early in development, has detrimental effects on the well being of parents, children and parent-child relationship (Abidin, 1990; Deater-Deckard, Scarr, 1996).

Beck (1990) analyzed PSI reports from mothers whose boys were hyperactive in certain situations and compared them to reports from parents whose boys' pervasive hyperactive reported significantly more overall stress, compared to mothers of situational hyperactive and no hyperactive children. (Beck, Young & Tarnowski, 1990)

Mesh and Johnston (1983) in their study have found that the parents of smaller children have more parenting stress than the parents of older children and this stress causes child-parent relationship disturbances which is a determining subject for studying ADHD.

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Coping with the disabled child especially one with behavioral problem and hyperactivity is a herculean task for the parents. Coping skills (Sarafino, 2002) aim to reduce the demands of a stressful situation or to expand one's resources to deal with the situation (i.e. problem-focused coping). Sarafino (2002) argues that problem-focused is considered more adaptive than emotion-focused.

Deisinger et al. (1996) found that using adaptive coping strategies, such as self-reliance or positive comparisons, tended to reduce stress. Nowack (1989) suggests from reviewing the stress and coping literature that coping is a potential moderator of stress and illness.

### ***The Need for the study***

Cerebral Palsy (CP) is the most common physically disabling pediatric condition globally (Gagliardi *et al.* 2008). It is characterized by multiple impairments and functional limitations; essentially, it is a group of disorders that affects the development of movement and posture (Aisen *et al.* 2011). Care-giving is a normal part of being the parent of a young child, but this role takes on an entirely different significance when a child experiences functional limitations and possible long-term dependence. One of the main challenges for parents is to manage the child's chronic health problems effectively in addition to that of coping with the requirements of everyday living. Children with cerebral palsy have also been reported to exhibit psychological problems and this adds to the burden of care. Parents of children with cerebral palsy (CP) often experience higher levels of stress than other parents. Coping with the problems of cerebral palsy children could be very difficult. As children with Cerebral palsy need long term care this will have a long term impact on the parenting stress especially when there is lot of demand from the child. Caring for such children drains out the energy of the caregivers which ultimately leads to parental distress.

ADHD is most commonly used to describe individuals who have difficulty sustaining attention, adjusting activity levels, and regulating impulses over various social contexts (Lange et al., 2005). ADHD children have more educational problems than their peers, and they are rejected from the society and or will have antisocial behaviors during post-school years and they will confront a lot of problems in the coming years (Sonuga, Daley & Thompson, 2001). Baker (1994) compared reports of parenting stress (using the PSI) and child behavior (using the CBCL) between mothers and fathers in 20 sets of parents of children with ADHD. Results showed that mothers perceived their child to be more stressful (on the Child Domain of the PSI) than did fathers and that on the attachment subscale of the Parent Domain of the PSI fathers reported feeling less attached to their children than did mothers. One well-accepted sequel of ADHD in children is increased parenting stress (Johnston and Mash, 2001). Although having some parenting stress is considered normal (Crnic and Greenberg, 1990), parents who experience extreme levels of this stress may suffer psychologically and may be less able to implement interventions to help their children (Kazdin, 1995). Increased parenting stress may also affect the

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parent–child relationship and negatively impact parenting practices (Abidin1992; Rodgers1998). Stress is a part of life but it is how an individual copes with it that determines human functioning. Coping resources can be used to decrease a family's vulnerability to stress. Resources may include health, problem-solving skills, and perceptions of the situation, family relationships, and social support networks. (Lazarus & Folkman, 1984).

In a study by Narkunam et al (2014) have reported that mothers having ADHD children were significantly more stressed than fathers. Stressed parents acknowledged that having a child with ADHD was their biggest worry. In another study by Jennifer et al., (2013) reported that parents of children with ADHD experience more parenting stress than parents of nonclinical controls and that severity of ADHD symptoms was associated with parenting stress. Parents differ in their coping response. McKee et al. (2004) concluded that emotion-focused coping styles (e.g. focusing on or venting emotions) and avoidant-focused styles are associated with greater psychopathology compared to adaptive emotion-focused strategies (e.g. positive reappraisal), problem-focused styles, and seeking social support, all three of which are linked with fewer psychological problems. Carver & Sheier (1994) noted that there was a significant association between maladaptive coping strategies and negative outcomes, rather than between adaptive coping skills and positive outcomes.

Cerebral Palsy describes 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 CP are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder (Rosenbaum et al., 2007).the use of either maladaptive or adaptive coping strategies. Wiegner and Donders (2000) reported that parents of children with CP experience more stress than those of children with spina bifida and limb deficiencies. Wanamaker & Glenwick, 1998; King, King, Rosenbaum, & Goffin, 1999; Mobarak, Khan, Munir, Zaman, & McConachie, (2000) in their studies have concluded that the presence of behavior problems in the child with CP was related to parental stress.

In a study conducted by Saddler, Hillman, & Benjamins, (1993); Molteno & Lachman, (1996) the researchers did not find differences in stress levels of mothers of children with different kinds of disabilities.

Cheshire et al (2010) examined coping strategies among parents of children with cerebral palsy children. The research findings revealed that positive reinterpretation was positively correlated with self-efficacy and negatively correlated with depression and stress. In India study carried out by Pal & Choudhury, (1998) have noted that in conditions of poverty, a child with a disability is regarded as a burden, an evil spirit, and an object of charity without rights, rather than as an unfortunate child. There is no dearth in the treatment that is available in our country but every

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treatment is a costly affair for the parents that lead to stress of raising children with disabilities. Gupta (2007) reported that behavioral and developmental disability was associated with higher parenting stress than medical disability. Parents need to cope with the day to day stressors. The coping resources include “faith in God, energy, self-determination and perception of the situation, and the external resources such as support from family members, relatives, friends, neighbors, professionals, community and Governmental policies and programs” (Peshawaria et al, 1998).

Caring for a child with disability/having some sort of behavioral problem is difficult for many parents and is quite taxing especially if support and resources are inadequate, parents are at risk for increased health problems and feeling of incompetence. The increased stress and poor coping with stressful situations will have a negative impact on the well-being of the caregivers. Hence the need was felt to find if there was any difference in the stress and coping between parents with cerebral palsy and parents with ADHD children.

### METHODOLOGY

The aim was to study stress and coping between parent caregivers of children with cerebral palsy and ADHD children.

The objective was to study the difference in stress and coping between parent caregivers of children with cerebral palsy and ADHD. To study the difference in stress and coping between male and female parent caregivers of children with cerebral palsy and ADHD.

*The following were the hypothesis of the study,*

1. There will be no significant difference in the stress among parent caregivers of children with cerebral palsy and ADHD children.
2. There will be no significant difference in the coping among parent caregivers of children with cerebral palsy and ADHD children.
3. There will be no significant difference in stress among male and female parent caregivers with cerebral palsy children
4. There will be no significant difference in coping among male and female parent caregivers with cerebral palsy children
5. There will be no significant difference in stress among male and female parent caregivers with ADHD children
6. There will be no significant difference in coping among male and female parent caregivers with ADHD children
7. There will be correlation between stress and coping among caregivers of cerebral palsy children
8. There will be correlation between stress and coping among caregivers of ADHD children

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### *Participants*

The participants for the present study consisted of 120 parent caregivers, of them 30 male and 30 female parent caregivers having children with cerebral palsy and 30 male and 30 female parent caregivers having children with ADHD. 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 crucial phase when the children dependence on parents will be higher. (2) Only those parent caregivers who were accompanying their children to the school were selected for administration of the tests.

The exclusion criteria were (1) Parents of any other differently abled children (2) Parents who were not accompanying their children 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) and Coping Checklist. The details of the tests are as below.

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

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. 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.

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*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>			
Male	Age	30	100
	28-31	6	20.0
	32-35	16	53.3
	36-40	8	26.6
Female	Age	30	100
	22-24	14	46.6
	25-27	8	26.6
	28-30	8	26.6
<b>Caregivers of ADHD</b>	Age	30	100
Male	28-31	14	46.6
	32-35	10	33.3
	36-40	6	20.0
Female	Age	30	100
	22-24	16	53.3
	25-27	8	26.6
	28-30	6	33.3

*Table 02: Mean, SD and 't' values for caregivers of cerebral palsy and ADHD children on stress and coping.*

Variables	Care Givers of Children	N	Mean	SD	't'
<b>Stress</b>	Cerebral palsy	60	18.16	2.49	3.35**
	ADHD	60	16.82	2.00	
<b>Coping</b>	Cerebral palsy	60	15.89	1.92	3.80**
	ADHD	60	17.26	2.14	

\*\* = p <.01 level

Table 02 shows the Mean, SD and 't' value obtained on stress and coping between parent caregivers of cerebral palsy and ADHD children. The mean score obtained on stress for parent caregivers of cerebral palsy and ADHD children are 18.16 and 16.82 respectively. The SD obtained is 2.49 for parent caregivers with cerebral palsy children and 2.00 for caregivers with ADHD children. The 't' value is 3.35, 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 ADHD children. When compared with caregivers having children with ADHD stress is found be higher among the parent caregivers of cerebral palsy children.

Likewise the obtained mean results for coping for parent caregivers with cerebral palsy and ADHD children are 15.89 for cerebral palsy and 17.26 for parent caregivers with ADHD children. The SD scores are 1.92 for parent caregivers with cerebral palsy and 2.14 for parent caregivers with ADHD children. The 't' value is 3.80, which is significant at 0.01 level. This

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clearly indicates that there is significant difference in coping between parent caregivers with cerebral palsy and parent caregivers with ADHD children. When compared with caregivers having children with cerebral palsy coping is better among the parent caregivers of ADHD cerebral palsy children.

The present study mainly focused on the difference in stress and coping of the parent caregivers of children with cerebral palsy and ADHD. There are several factors that lead to stress in caregivers. The findings of the present study show that caregivers having cerebral palsy children experience more stress. The results supports the earlier findings that 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 behavioral problem (Erkin G, et al & Ones K, 2005). Parents of children with developmental disability have reported greater stress than parents of typically developing children (Baker BL, & Harrison C et al 2002). The changes in behavior, the psychological and emotional disturbances of the children, and the need for continuing and specialized care are factors associated with higher levels of stress. (Raina P, et al 2005& Sipal RF, et al 2010). Some studies indicate a relationship between motor impairment level of the children and stress experienced by the parents. (Raina P, et al 2005& Butcher PR, et al 2008).

The findings of present study have shown that the parents of cerebral palsy children cope less than parents having ADHD children. The result has been supported by earlier studies that 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).

The result in the table of the present study indicates that the parent caregivers of ADHD children experience less stress compared to parent caregivers with cerebral palsy children. The result of the present study has been supported by earlier study. (Cadman et al., 2012; Lee, Harrington, Louie, & Newschaffer, 2008) in their study have found that parenting stress was found to be less in families of children with ADHD. Mash and Johnston (1983a) in their study found that fathers, tended to view their child's problem behavior as less severe. It is possible, that by viewing their child's behavior as less problematic, fathers also experience less stress.

The obtained results in the table indicate that the parents with ADHD children cope better than parents having cerebral palsy children. The present findings have been supported by the earlier studies. The qualitative study by Kendall (1998), on coping in parents of children with ADHD, found that parents were able to cope with ADHD by use of three processes of reinvesting. Making sense is the first process followed by recasting biography and by relinquishing the good ending.



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**Table 3 shows the Mean, SD and 't' values for male and female parent caregivers having cerebral palsy children on stress and coping.**

variables	Caregivers of children	N	Mean	SD	't'
Stress	Male	60	18.63	2.08	3.65**
	Female		20.82	2.61	
Coping	Male	60	17.12	2.40	4.23**
	Female		15.68	2.00	

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

Table 3 shows the mean, SD and 't' values for male and female parent caregivers having cerebral palsy children on stress and coping. The mean score obtained on stress for male parent caregivers is 18.63 and 20.82 for female caregivers. The SD for male parent caregivers being 2.08 and 2.61 for female parent caregivers. The obtained 't' value is 3.65 which is significant at 0.01 level which indicates that there is significant difference in stress experienced by male and female parent caregivers. This clearly shows that the female parent caregivers experience more stress than male parent caregivers.

The mean score obtained on coping for male parent caregivers is 17.12 and 15.68 for female parent caregivers. The SD being 2.40 for male parent caregivers and 2.00 for female parent caregivers. The obtained 't' value is 4.23 which is significant at 0.01 level which indicates that there is significant difference in coping by male and female parent caregivers. This clearly shows that the male parent caregivers have better coping than female parent caregivers.

The obtained results in the table indicate that the female parent caregivers experience more stress than male parent caregivers having cerebral palsy children. The present finding has been supported by the previous research findings. A study conducted by (Rashida Begum & Ona Desai 2010) has found that the mothers of cerebral palsy suffered from more psychological distress than mothers with normal children. Ong et al (1998) in their study have reported that mothers with cerebral palsy children experienced significantly more stress.

The results in the table show that the female parent caregivers cope less when compared to male parent caregivers with cerebral palsy children. The findings of the present study have been supported by earlier findings. Twoy R, et al 2007 & Mitić M. (1997) have confirmed the frequent use of passive appraisal among the mothers whose children have not only CP but other developmental disorders as well. Christine M. et al (2013) have found in their study that mothers who experience more stress in the parenting role are more likely to engage in higher levels of avoidant coping when faced with parenting problems.

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*Table 4 shows the Mean, SD and 't' values for male and female parent caregivers having ADHD children on stress and coping.*

variables	Caregivers of children	N	Mean	SD	't'
Stress	Male	60	17.34	2.13	3.01**
	Female		19.12	2.43	
Coping	Male	60	18.26	2.39	3.34**
	Female		16.32	2.11	

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

Table 4 shows the mean, SD and 't' values for male and female parent caregivers having ADHD children on stress and coping. The mean score obtained on stress for male parent caregivers is 17.34 and 19.12 for female caregivers. The SD for male parent caregivers being 2.13 and 2.43 for female parent caregivers. The obtained 't' value is 3.01 which is significant at 0.01 level which indicates that there is significant difference in stress experienced by male and female parent caregivers. This clearly shows that the female parent caregivers experience more stress than male parent caregivers.

The mean score obtained on coping for male parent caregivers is 18.26 and 16.26 for female parent caregivers. The SD being 2.39 for male parent caregivers and 2.11 for female parent caregivers. The obtained 't' value is 3.34 which is significant at 0.01 level which indicates that there is significant difference in coping by male and female parent caregivers. This clearly shows that the male parent caregivers have better coping than female parent caregivers.

The obtained results in the table indicate that the female parent caregivers experience more stress than male parent caregivers having ADHD children. The present finding has been supported by the previous research findings. There is evidence that mothers of children with ADHD report greater global psychological distress as well as greater role specific distress, in addition to less parenting competence (Podolski & Nigg, 2001). In another study, mothers of hyperactive sons reported significantly greater amounts of stress than parents of normal children (Mash & Johnston, 1983).

The obtained results in the table indicate that the female parent caregivers cope less when compared to male parent caregivers having ADHD children. The finding of the present has been supported by previous research. In a Pearlin & Schooler (1978) study, women were worse copers than men were, indicating that women reported significantly more stress as a result of coping strategies than men did. McKee et al. (2004) found in their study that mothers of ADHD children who reported being depressed were more likely to use avoidant-focused coping styles, less adaptive-focused coping styles, and sought social support less often.

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*Table 5 shows the correlation of stress and coping among parent caregivers with cerebral palsy and ADHD children*

Variable	Coping	
Stress	Cerebral palsy	ADHD
	0.52	0.36

The obtained result in the table shows that there is substantial correlation between stress experienced by parent caregivers of cerebral palsy and ADHD children. A research study conducted by Mitchell M, M (2006) has reported that stress scores were highly correlated for parents having ADHD children.

The results of the present study indicate that there is low correlation between coping by parent caregivers of cerebral palsy and ADHD children. Ramesh Kumari, &Supriya Palwinder Singh (2013) in their study have reported a negative correlation between stress and coping among mothers. The mother who had higher level of stress in caring their children with cerebral palsy was not following adequate coping strategy.

### CONCLUSION

The obtained results indicate that the parent caregivers having cerebral palsy children experience more stress than that of parent caregivers having ADHD children. The result of the present study has shown that parent caregivers with cerebral palsy children cope less compared to parent caregivers of ADHD children. Female parent caregivers experience more stress compared to male parent caregivers which is indicated by the obtained result of the present study. Likewise previous studies have revealed that female parent caregivers having cerebral palsy children have difficulties in coping compared to male parent caregivers which is as well indicated by the results of the present study.

Results in the present study indicate that the female parent caregivers experience more stress compared to male parent caregivers with ADHD children. The female parent caregivers of ADHD children have difficulties in coping compared to male parent caregivers which is indicated by the results of the present study

The obtained results indicate that there is association between stress and coping among parent caregivers with cerebral palsy children. The obtained results indicate that there relation between stress and coping among parent caregivers with ADHD children.

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