

CAREGIVERS' BURDEN AMONG PARENTS OF CHILDREN WITH CEREBRAL PALSYHumaira Shamim Kiani¹, Anam Aftab¹, Saima Waqar², Syed Alamdar Hussain³, Qudsia Naqvi⁴, Waqar Ahmed Awan¹**Submitted:** November 14, 2020**Accepted:** December 31, 2020**Published:** June 30, 2021

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ABSTRACT

Introduction: Caregivers help a person in those actions which cannot be performed by an individual independently; a person's personal needs, environmental barriers that hinders an individual's abilities etc. This ultimately puts an increased burden on the caregiver. This study was conducted to determine the levels of caregivers' burden among the parents of children with cerebral palsy.**Material & Methods:** A cross-sectional survey was conducted on 298 parents of children with cerebral palsy. Non-probability convenience sampling technique was used to collect data from the parents coming to the National Institute of Rehabilitation Medicine, Islamabad. The parents of children with cerebral palsy who were having auditory, cognitive or visual impairment were excluded from this study. Demographic information form and Caregiver Burden Inventory were used for the data collection. The data was analysed through IBM SPSS version 21 and results were presented in the form of frequency, percentages and mean \pm sd with p-value wherever needed.**Results:** the result of this study showed a greater need for respite and other services for caregivers of children with cerebral palsy. The overall Caregiver Burden Inventory score was 45.19 ± 11.9 . Out of the total included participants, 163 (54.33%) participants sometimes needed relief, 116 (36.67%) needed frequent need for relief and other services while 19 (6.33%) of the included parents rarely needed relief and other services.**Conclusion:** Majority of the caregivers of children with cerebral palsy needed relief and other services (compromise the growth, physical and emotional health and social relationship) to manage caregivers' burden.**Key Words:** cerebral palsy, caregiver burden, emotional health, physical health, social participation, stress

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INTRODUCTION

Caregivers help a person in those actions which cannot be done by an individual including one's personal needs and some of the environmental barrier.¹ Parents are performing such activities for their children and it seems an obligation for parents to fulfil the health care needs and other daily requirements of their children.² It is obvious that a child with a long-term disease is more dependent on his/her parents for the better physical condition and good social interaction. Surrounding in the house have a good effect on the health of a child and helps to decrease the negative impact. Children with Cerebral Palsy (CP) need long-term support which may cause problems to the caregivers. Parents or caregivers of such children focus on the care of these children which ultimately result in a low rate of work and a potential decrease in the income of caregivers or parents of these children.³ Moreover, it has been reported that caregivers or parents of such children need extra time to spend with their children and sometimes, they may lose their jobs which again affects the financial status of these parents.⁴ In developing countries, the economic burden of caring for a disabled child has a great impact on the financial status of caregivers as a majority of these people belong to poor families. In addition, many parents devote enormous emotional resources and time to planning,

finding and maintaining services for their children with disabilities.⁵ It has been reported that a CP child increases the severity and duration of their parenting tasks, and needs sufficient time for supervision of their normal activities of daily livings performed in a tailor-made way.⁶

It is important to note that majority of the parents of children with CP are not satisfied by the care services provided and that's one of the reasons that these parents are closely involved providing care to these children. Care of these children is a demanding job and it is clear from the literature that very few families have the ability to cope with such children.⁷ Despite the later fact, some caregivers have reported reasonable or less burden while managing these children.⁸ Literature suggests favorable effects on parents of CP children if they are provided with some types of interventions or trainings.⁹ For this purpose, it is recommended to know about the experiences of caregivers and to know about the facilities that help to improve the quality of life of these caregivers.¹⁰

It is estimated that 1/1000 children in district Swabi, Khyber Pakhtunkhwa Pakistan are born with CP. The parents of disabled children of either intellectually challenged or hearing impaired children have a

substantial liabilities.¹¹ Therefore, children with any sort of disability born in developing countries like Pakistan will have a significant impact on their parents. The level of caregivers' burden may be different in developing countries from that of developed countries due to the unavailability of resources and unavailability of support services for CP children in the former countries. There is paucity in the literature regarding the burden on caregivers of CP children in our country, therefore, this study was designed with the aim to assess the levels of burden among caregivers of CP children.

MATERIAL AND METHODS

A cross-sectional survey was conducted to explore caregivers' burden of CP children. The sample size was calculated through the open epi tool where the CP children population was set at 100000, hypothesize frequency of response rate of 75% with 95% confidence interval. A total of 289 sample size was calculated. The author collected the sample size of 300 to avoid any loss from the sample. A total of 2 respondents were excluded due to incomplete responses and data of 298 participants was reported in this study.

Non-probability convenience sampling technique was used to collect the data. The data was collected from the National Institute of Rehabilitation Medicine, Islamabad. The duration of the study was six months. Parents of CP children were included in the study. Parents of CP children with hearing, cognitive or visual impairment were excluded from the study. The Demographic Information Form and Caregiver Burden Inventory were used to collect the data. Results of the study were presented in the form of frequencies, percentages, mean \pm SD. SPSS 21 was used to data analysis.

RESULTS

A total of 298 caregiver participated in this survey. Out of the total, 269 (90.3%) were female and 29 (9.7%) were male's caregivers. Findings of this trial showed that the minimum age of children whose parents' data was collected, was 1 year and the maximum age was 14 years. The mean age of these children was 4.46 ± 2.50 years. The minimum age of parents of these children was 19 years and the maximum age was 53 years. The mean age of these parents was 32.25 ± 7.19 years.

The result showed a greater need for relief and other services in caregivers of CP children. The overall caregiver burden inventory score was 45.19 ± 11.9 which showed $n=163$ (54.33%) participants sometimes need relief and other services to manage caregiver burden. A total of 116 (36.67%) parents of CP children reported that they frequently need relief and other services, 19 (6.33%) reported rarely need for relief and other services. The responses of study participants about individual items of CBI are given in table 1.

DISCUSSION

The objective of the study was to explore caregivers' burden among parents of CP children. Majority of the caregivers needed relief and other services to manage caregivers' burden. Inadequate public-services design and effects of negative behaviours of others can result in the withdrawal of children and caregivers of CP children from community engagement.¹² Accessible transportation services enable a person to travel or participate in work and social activities that's ultimately inspire one to explore and live a health life.¹³ There are cars that are equipped to transport non-ambulant people

which might be one of the solutions to limited moment in these children.¹⁴ Moreover, going outside may be correlated with a decrease in burden on the caregivers.

The current study showed that caring the CP child is time consuming activity as such children are fully dependent on their caregiver for activities of living and compromise the growth, physical and emotional health and social relationship of caregivers. Studies suggested that mostly time of caregivers is taken by these children's duties like medicine management, physical therapies, helping with mobility and arranging appointments and equipment for them.^{15,16} If a caregiver has some sort of disorders and also managing a CP child then this will lead to greater effort to manage such children. The children who have any disability or disorder are relaxed but the family members or caregivers who are responsible for their activities' management are very stressful.^{15, 17, 18}

The results of our study showed that social relationships of caregiver with their friend and family members were compromised due to less time available for such activities. There is a dilemma whether relief is or not provided by friends, family and loved ones. It has been reported that caregivers were rarely helped by their extended family and friends. One of the reasons for this could be lack knowledge to care for these children as these children have special needs and dealing them is not an easy task. In few cases, the mother and the father are looked after by their child and share or alternate the task. When both parents are active guardians, their primary goal is child care and this can reduce the chances of spending time alone for such couples. In addition, respite care is often difficult in other cases and mothers assume the role of primary caregiver, while many fathers accept responsibility for bread earning for the family.^{18, 19}

In current study caregivers also reported that CP children might increase the severity and duration of the their parenting tasks, such as providing supervision, tailor-made activities and activities to meet these children's needs.²⁰ The sleep of the caregivers is also affected due to the child extra care and caregivers are advised to take proper rest at night.¹⁰ Fatigue prevent caregivers from even thinking about leaving home that accompanies these caregiver activities and long periods of sleep deprivation.^{10,21-23} This is not easy for parents of CP children to maintain their relationships with their friends due to their commitment to manage their CP child which lead the parents to think that their lives became different compared to their friends.^{21, 22}

The parents of the children with CP indicated that they cannot share their feelings with others who have not experienced to be parents for a CP child. These parents. Sometimes, can be socially and mentally isolated. The possibility of changes in family relationships of caregivers is experienced. It has been reported that the families of children with CP experienced unwelcoming marital affairs and sometimes having a CP child could be a source of divorce among couples.¹³ The birth of the disabled child cause extra stress on family and also put pressure on marital relationships.²⁴⁻²⁶

A study conducted in Pakistani population where the level of stress and caregiver burden among caregivers of CP children in Lahore was evaluated reported moderate level of stress in all caregivers. The satisfaction related to their emotional health, physical health and social

relationship was significantly compromised by being a caregivers of CP children.²⁷

CONCLUSION

The study concluded that majority of caregiver needed relief and other services to manage caregivers' burden. The caring of a CP child is time consuming as such children are dependent on their caregiver for activities of daily livings. These things may compromise the growth, physical and emotional health and social relationship of these caregivers.

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Table 1: Caregiver Burden Inventory Responses

		Never	Rarely	Sometimes	Quite frequently	Nearly always
Time Dependency item	He/she needs my help to perform many daily tasks	0(0.0%)	8(2.3%)	94(31.5%)	145(48.7%)	91(17%)
	He/she is dependent on me.	0(0.0%)	5(1.7%)	85(28.5%)	154(51.7%)	54(18.1%)
	I have to watch him/her constantly	0(0.0%)	13(4.4%)	91(30.5%)	138(46.3%)	56(18.8%)
	I have to help him/her with many basic functions	0(0.0%)	15(5%)	95(31.9%)	136(45.6%)	52(17.4%)
	I don't have a minute break from his /her chores.	4(1.3%)	48(16.1%)	109(36.6%)	102(34.2%)	35(11.7%)
	I feel that I am missing out on life	28(9.4%)	83(27.5%)	141(47.3%)	41(13.8%)	5(1.7%)
Development Items	I wish I could escape from this situation	33(11.1%)	104(34.9%)	105(35.2%)	52(17.4%)	4(1.3%)
	My social life has suffered.	19(3.0%)	67(22.5%)	126(42.3%)	85(28.5%)	11(3.7%)
	I feel emotionally drained due to caring for him/her.	6(2.0%)	41(13.8%)	163(54.7%)	81(27.2%)	6(2.0%)
	I expected that things would be different at this point in my life.	18(6.0%)	81(27.2%)	142(47.7%)	51(17.1%)	6(2.0%)
Physical Health Items	I'm not getting enough sleep	13(4.4%)	41(13.8%)	136(45.6%)	81(27.2%)	27(9.1%)
	My health has suffered.	14(4.7%)	49(16.4 %)	114(38.3%)	93(31.2%)	28(9.4%)
	caregiving has made me physically sick	12(4.0%)	51 (17.1%)	104(34.9%)	103(34.6%)	28(9.4%)
	I'm physically tired.	8(2.7%)	47(15.8%)	113(37.9%)	100(33.6%)	30(10.1%)
	I feel embarrassed over his/her behaviour	95(31.9%)	136(45.6%)	56(18.8%)	10(3.4%)	1(3%)
Emotional Health Items	I feel ashamed of him/her.	119(39.9%)	118(39.6%)	54(18.1%)	27(2.3%)	0 (0%)
	I resent him/her.	72(24.2%)	113(37.9%)	98(32.9%)	14(4.7%)	1(3%)
	I feel uncomfortable when I have friends over.	35(11.7%)	86(28.9%)	144(48.3%)	31(10.4%)	1(3%)
	I feel angry about my interactions with him/her.	44(14.8%)	109(36.6%)	129(43.3%)	16(5.4%)	0(0.0%)
	I don't get along with other family members as well as I used to with others	55(18.5%)	130(43.6%)	98(32.9%)	13(4.4%)	2(.7%)
Social Relationships Item	My caregiving efforts aren't appreciated by others in my family.	26(8.7%)	121(40.6%)	119(39.9%)	26 (8.7%)	6(2 0%)
	I've had problems with my marriage (or other significant relationship).	94(31.5%)	85(28.5%)	87(29.2%)	27(9.11%)	5(1.7%)
	I don't get along as well as I used to with others	55(18.5%)	85(28.5%)	116(38.9%)	37(12.4%)	5(1.7%)
	I feel resentful of other relatives who could but do not help	20(6.7%)	79(26.5%)	144(48.3%)	50(16.8%)	5(1.7%)