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Original Article

SEVERITY OF DEPRESSION AND ANXIETY AMONG CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AND THEIR CORRELATION WITH FUNCTIONAL CAPABILITIES OF THE CHILDREN

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ABSTRACT

Objective: To evaluate the severity of depression and anxiety among caregivers of children having cerebral palsy and correlate severity with the type of cerebral palsy and functional capability of the child.

Study Design: A cross-sectional study.

Place and Duration of Study: Department of Psychiatry and Rehabilitation Medicine, Combined Military Hospital, Gujranwala, from Oct 2015 to Aug 2018.

Methodology: Through consecutive sampling, 186 caregivers diagnosed with anxiety and/or depression based on the diagnostic criteria of International Classification of Diseases version 10, and their cerebral palsy children were recruited. Symptom severity was assessed using Beck Depressive Inventory for depression and Beck Anxiety Inventory for anxiety. The functional capabilities of the children were assessed through gross motor function classification system (GMFCS). For correlation, Pearson's chi square test was used using SPSS version 20.

Results: The mean age was 30 ± 3.3 years. Fourteen (7.5%) were fathers of cerebral palsy children and 172 (92.5%) were mothers of cerebral palsy children. Majority of the cerebral palsy children 74 (39.8%) had spastic diplegia and the functional level I of gross motor function classification system 53 (28.5%). Most of the caregivers had mild anxiety and minimal depression (33.9% and 38.7% respectively). Significant correlation existed among the gross motor functional capability and the level of anxiety but not with depression ($p<0.01$ and $p=0.155$ respectively). No statistical association was found between the type of cerebral palsy and the level of anxiety or depression ($p=0.240$ and $p=0.102$ respectively).

Conclusion: Most caregivers in our study had mild anxiety and minimal depression. Significant positive correlation existed between the level of anxiety and the gross motor functional capability.

Keywords: Anxiety, Caregiver, Cerebral palsy, Depression, Motor function.

INTRODUCTION

Cerebral palsy (CP) is a neuro developmental disorder with major physical and cognitive impairments due to damage to the developing brain during perinatal period or shortly after childbirth[1]. Prevalence of CP is 2.11 per 1000 live births among children born since 1985[2]. Families having children with CP face difficulties as the child is fully or partially dependent on the caregiver, which is mostly the mother[1,3]. Dependency of CP child has direct effects on physical, emotional, social, marital, and financial status of the primary caregiver or the mother[3-6]. These effects are more pronounced on caregiver due to personal closeness to the CP child[7]. Caregiving the child with CP is intense with specific demands like feeding, grooming, and mobility[7]. Graver disability inflicts greater impact on the caregiver.

As a child grows and gains weight, it poses increased strain on the caregiver depending on the level of disability. Family of a child with CP especially mothers, face sense of responsibility and guilt feeling, which causes mothers to adopt behaviors that are directed to counter the disability of the child. Primary caregiver or mother of the CP child is psychologically neglected because she does not get adequate support from the relatives and friends for care of the disabled child[8]. She has trouble in maintaining balance between her abilities and demands for care tendered by the disabled child. This puts primary caregiver or the mother under lots of stress and, consequently, she starts to neglect her own needs leading to psychosocial problems and depression[9]. Studies have shown that primary caregiver or mothers with CP child have four times more incidence of depression as compared to normal population[10]. There is a need to realize more and more about stress and strain faced by the caregivers and mothers of the children affected by CP. In developing countries like Pakistan, the resources are limited and daycare facilities are deficient. The stress and strain are increased manifolds as they are neither recognized nor apprecia-

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ted properly[6]. There have been studies[11,12], to look for the frequency and severity of depression among children with CP and learning disabilities. However, more needs to be explored especially in relation to disability characteristics of the affected child. This study intended to correlate severity of depression and anxiety in primary caregivers of CP children with the type of CP and functional capability of the child.

METHODOLOGY

This cross-sectional study was conducted at the department of Psychiatry, Combined Military Hospital Gujranwala in liaison with the department of Rehabilitation Medicine from October 2015 to August 2018. A sample size of 180 was estimated via Epi Tools Epidemiological Calculator[13], while keeping level of significance 5%, confidence level 90%, estimated true proportion 79%[14], and 5% of absolute precision. We consecutively sampled 186 caregivers of children (age: 2-18 years) with CP who were diagnosed with anxiety and/or depression based on the diagnostic criteria of International Classification of Diseases version 10 after approval from the hospital ethical committee. All inductees were interviewed after the informed written consent and their confidentiality was ensured. Children with other disabling diseases were not included.

Demographic details of the caregivers and children were documented. To assess the functional level of the children, Gross motor function classification system (GMFCS) was applied. GMFCS is a system used to categorize children with CP that classifies children younger than 12 years of age into five groups according to gross motor movements: group-I) Walks without limitations; group-II) walks with limitations; group-III) walks using a hand-held mobility device; group-IV) self-mobility with limitations; may use powered mobility; group-V) Transported in a manual wheelchair. Functions are defined according to four different age-groups and lower levels mean better functional capability. Children over 12 years of age were considered and assessed as 12 years old.

Detailed assessment and symptom severity was assessed using beck depressive inventory (BDI) for depression and beck anxiety inventory (BAI) for anxiety. BDI consists of 21 questions, each with four possible answers that are assigned a score ranging from 0-3. Higher scores indicate more severe symptoms. Total score is obtained by adding individual scores of 21 items and total score ranges from 0-63. The cut off score for presence of symptoms is 9. It may be noted that BDI is for detecting depressive symptoms and not for diagnosing depression. Scores of 0-9 indicate minimal depression, 10-18 mild depression, 19-29 moderate depression, and scores of 30-63 indicate severe depressive symptoms. BAI consists of 21 items, scored on likert-type scale from 0-3 where 0 is considered negative, 1 is judged as mild, 2 is deemed moderate, and 3 is considered severe. Total score of 0-7 reflects minimal anxiety and a score of 8-15 points toward mild anxiety. Score of 16-25 correlates with moderate anxiety and score of 26-63 compares with severe anxiety.

Data analysis was performed using Statistical Package for Social Sciences version 20. The data were described as numbers and percentages. For association and comparison pearson's chi square test was used. All the inferences were made at 95% confidence interval and *p*-values of ≤0.05 were considered significant.

RESULTS

A total of 186 caregivers and children were included in the study. The mean age of the children was 5.1 ± 2.4 years (range: 2-12 years) while the mean age of the caregivers was 30 ± 3.3 years (range: 20-43 years). In the study sample, 115 (61.8%) were male children and 71 (38.2%) were female children. Fourteen (7.5%) caregivers were fathers of CP children and 172 (92.5%) caregivers were mothers of CP children. All caregivers were married. Twenty (10.8%) caregivers had to provide care to someone else in the family apart from the child while 166 (89.2%) did not have such compulsion. The number of siblings, educational status of the caregiver, employment status of the caregiver, and financial status of the family are given in table-I.

With regards to the type of CP in children, 74 (39.8%) had spastic diplegia, 56 (30.1%) had spastic quadriplegia, and 45 (24.2%) had spastic hemiplegia. Eleven (5.9%) children had other types of CP. Gross motor functional capability level-I was present in 53 (28.5%) children; 18 (9.7%) children had level-II, 37 (19.9%) children had level-III, 31 (16.7%) children had level-IV, while 47 (25.3%) children had level-V of functional capability. One hundred and twenty-five (67.2%) caregivers had minimal to mild level of anxiety, 47 (25%) had moderate, while 14 (7.5%) had severe anxiety. One hundred and thirty-eight (74.2%) caregivers exhibited minimal to mild depression, 32 (17.2%) had moderate, while 16 (8.6%) had severe depression (table-I).

After evaluating statistical correlation of gross motor functional deficit with the severity of anxiety and depression, a significant correlation was found with the level of anxiety but not with depression (*p*

Table-I: Demographic details of study participants.

Characteristics	n (%)
Number of siblings of the cerebral Palsy child	
None	38 (20.4)
One	92 (49.5)
Two	18 (9.7)
Three	20 (10.8)
Four	11 (5.9)
More than four	7 (3.7)
Educational status of the care giver	
Illiterate	3 (1.6)
Less than primary	14 (7.5)
Primary	134 (72)
Secondary	20(10.8)
High school	14(7.5)
University	1 (0.6)
Employment status of the care giver	
Employed	27 (14.5)
Un-employed	159 (85.5)
Family income	
Poor	27 (14.5)
Middle class	152 (81.7)
High income	7 (3.8)
Level of gross motor function deficit in the cerebral palsy child	
Level-I	53 (28.5)
Level-II	18 (9.7)
Level-III	37 (19.9)
Level-IV	31 (16.7)
Level-V	47 (25.2)
Level of anxiety in the caregiver	
Minimal	62 (33.3)
Mild	63 (33.9)
Moderate	47 (25.3)
Severe	14 (7.5)
Level of depression in the care giver	
Minimal	72 (38.7)
Mild	66 (35.5)
Moderate	32 (17.2)
Severe	16 (8.6)

≤0.01 and *p*=0.155 respectively) (table-II). Similarly, no statistically significant correlation existed with the type of CP for the level of anxiety or depression (*p*=0.240 and *p*=0.102 respectively) (table-III).

DISCUSSION

The mean age witnessed for the sampled children in our study was 5.1 ± 2.4 years. A very similar mean age of 5.6 ± 2.25 years was observed in a Pakistani study carried out by Khan and colleagues[15], in Rawalpindi. Another Pakistani study from Karachi has noted a slightly higher mean age of 6.57 ± 1.9 years[11]. An Indian study carried out by Mehar *et al*[3], in New Delhi had observed a nearer mean age of 4.6 years. The other demographic data in our study showed that most of the involved children were male and most of the primary caregivers were mothers belonging to the middle-class income group and had primary education. These outcomes and family characteristics show similarities in one or more aspects with the results of other studies organized by Masulani-Mwali *et al*[16]. Mehar and Tripathi[3], and Basaran *et al*[9]. The majority of the participants (90.1%) in the study by Mwali *et al*[16], were mothers and 55.7% of them had secondary education only, while the largest representation (44.6%) was from the lower socioeconomic group. Mothers represented 63% of the caregivers included by Mehar *et al*[3], and male children constituted 57% of the sampled children. Basaran *et al*[9], reported that 55.9% of the CP children taken account of were male. Most caregivers were mothers (55.9%) and had merely the primary education (57.3%). Most of the caregivers are expected to be mothers as per our cultural trends because mothers are considered primarily responsible for the care of children while fathers are considered breadwinners for the whole family and, therefore, pass their most time in the outdoors. All the caregivers in our study were married, which is also consistent with the cultural norms of our country as children out of wedlock are very rare and considered a shame and sin in the Islamic and eastern society.

Table-II: Level of anxiety and depression in care givers with relation to level of gross motor function deficit of child.

		Level-I n (%)	Level-II n (%)	Level-III n (%)	Level-IV n (%)	Level-V n (%)	*p*-value
Level of Anxiety in care giver	Minimal	20 (32.3)	8 (12.9)	11(17.7)	12 (19.4)	11 (17.7)	<0.01
	Mild	19 (30.2)	3 (4.8)	11 (17.5)	13 (20.6)	17 (27)	
	Moderate	12 (25.5)	7 (14.9)	14 (29.8)	5 (10.6)	9 (19.1)	
	Severe	2 (14.3)	-	1 (7.1)	1 (7.1)	10 (71.4)	
	Total	53 (28.5)	18 (9.7)	37 (19.9)	31 (16.7)	47 (25.3)	
Level of Depression in care giver	Minimal	22 (30.6)	10 (13.9)	16 (22.2)	14 (19.4)	10 (13.9)	0.155
	Mild	20 (30.3)	2 (3)	11 (16.7)	13 (19.7)	20 (30.3)	
	Moderate	9 (28.1)	4 (12.5)	6 (18.8)	3 (9.4)	10 (31.2)	
	Severe	2 (12.5)	2 (12.5)	4 (25)	1 (6.2)	7 (43.8)	
	Total	53 (28.5)	18 (9.7)	37 (19.9)	31 (16.7)	47 (25.3)	

Table-III: Level of anxiety and depression in care givers with relation to the type of cerebral palsy.

Characteristics		**Diplegic Cerebral Palsy n (%)**	**Hemiplegic cerebral Palsy n (%)**	**Quadriplegic Cerebral Palsy n (%)**	**Others Cerebral Palsy n (%)**	***p*-value**
Level of Anxiety in care giver	Minimal	29 (46.8)	11 (17.7)	17 (27.4)	5 (8.1)	0.240
	Mild	28 (44.4)	15 (23.8)	18 (28.6)	2 (3.2)	
	Moderate	14 (29.8)	13 (27.7)	18 (38.3)	2 (4.3)	
	Severe	3 (21.4)	6 (42.9)	3 (21.4)	2 (14.3)	
Level of Depression in care giver	Minimal	28 (38.9)	14 (19.4)	24 (33.3)	6 (8.3)	0.102
	Mild	33 (50)	16 (24.2)	15 (22.7)	2 (3)	
	Moderate	9 (28.1)	7 (21.9)	14 (43.8)	2 (6.2)	
	Severe	4 (25)	8 (50)	3 (18.8)	1(6.2)	

Regarding type of CP, we found that maximum number of the children had spastic diplegia (39.8%). Khan *et al* also observed spastic diplegia as the most prevalent (33.3%) type of CP in their study[15]. Altindag *et al*[5], and Yilmaz *et al*[8], in two Turkish studies, and Nazi *et al*[17], in an Iranian study, confirmed above findings by reporting spastic diplegia in the maximum number (40%, 39.7%, and 50% respectively) of recruited children. On the other hand, two Korean studies by Yun[18], and Yoo[19], had observed spastic quadriplegia to be the most commonly identified type of CP (49.1% & 52.5% respectively). This variation probably results from the genetic preferences or the environmental factors.

The commonest functional level of GMFCS detected by us was level-I (28.5%). Türkoğlu *et al*[20], labelled level-II as the most frequent (29.9%) functional level. Altindag *et al*[5], described level-III to be the most common. Yun[18], and Yoo[19], stated that level-IV of GMFCS was the most frequent level. Nazi *et al*[17], had observed level-IV as the most repeated functional level in children with CP, while Yilmaz and colleagues[8], reported Level-V as the most common functional level.

Basaran *et al*[9], demonstrated that level of education, financial constraints, lack of recreation, and social isolation are related to stress, exhaustion, and development of mental health problems in caregivers of CP children. Mothers of CP children mainly bear the burden of care giving, which leads to deterioration of psychosocial wellbeing and has ill effects on children too. Though we included only the caregivers already diagnosed with anxiety and/or depression, the incidence of anxiety and depression seems quite high among caregivers of disabled children in the medical literature. Fahim *et al*[12], reported an incidence of 89.6% while Mbugua *et al*[14], and Dambi *et al*[6], reported incidences of 79% and 78% in caregivers of the children with disabilities, which were attributed to long term stress.

Majority of the caregivers had minimal to mild level of anxiety and depression and very few exhibited severe levels of anxiety and depression. These results indicate that anxiety and depression in caregivers of CP child might have relation to the type of CP. Results of our study though, do not demonstrate any relationship between anxiety and depression and the type of CP. Türkoğlu *et al*[20], on the contrary, noted that intellectual impairment and type of CP were correlated with the mental health of caregiver of the CP child. Terzi *et al*[1] also, demonstrated that mental health of the caregiver of CP child might have correlation with the type of CP.

We found a significant effect of severity of gross motor functional deficit on the development of anxiety but not on the depressive symptoms. Tuzun *et al*[21]. Chen *et al*[22], and Unsal-Delialioglu *et al*[4], also noted that there was no correlation between severity of anxiety and depressive symptoms and quality of care given by the caregiver of CP child. We found that anxiety and depression were higher in level I gross motor functional deficit which is contrary to the logical interaction i.e. anxiety and depressive symptoms are expected to be more in caregivers of the children with worse functional capability. On the other hand, Basaran *et al*[9], in his study, noted that anxiety and depression were marked in the caregivers of CP child who had level IV and level V gross motor functional deficit indicating that severity of impairment predisposes caregiver to the development of anxiety and depression. Yoo[19], endorsed results of Basaran *et al*[9], and concluded that caregivers' quality of life (QoL) was worse and their depression scores were significantly higher as the children's motor functioning was impaired more severely. Yun[18], also mentioned similar conclusion and stated that children's motor function affects caregivers' QoL in not only physical but also psychological sides. Thus, if parents are not able to meet the challenges of providing care for their CP child due to psychiatric disorders, the required level of child functioning will not be achieved and the QoL of the child shall be reduced[23].

Focusing on the general and holistic medical paradigms, more attention needs to be given to the environments of patients and caregivers along with their health status, duration of care, and economic status. Caring training for caregivers of children with CP has a positive effect on caregiver's mental health and the participation of children in activities of daily living and their fine and gross motor function[24]. In addition, planned care for children with CP involving psychotherapists in a team-based rehabilitation can improve caregivers' QoL and mental health. It is important to keep in mind that our cross-sectional study has not established this causal relationship.

This study had a couple of limitations. As this was a descriptive cross-sectional study, therefore, causal relationship could not be established. Furthermore, other confounding factors to the development of anxiety and depression could not be accounted for.

RECOMMENDATIONS

Psychological needs of caregivers of functionally impaired children should be given due attention as they are more vulnerable and predisposed to develop mental health problems. Improvement in the psychological support of caregivers along with addressing comprehensive rehabilitation needs of children with CP can ensure good QoL for the child and caregiver collectively.

CONCLUSION

Most caregivers in our cohort had mild anxiety and minimal depression. Significant positive correlation existed between the level of anxiety and the gross motor functional capability.

CONFLICT OF INTEREST

This study has no conflict of interest to be declared by any author.

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