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Anxiety and Depression among Primary Caregivers of Male versus Female Children with Cerebral Palsy: A Cross-Sectional Comparative Study in Karachi, Pakistan

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Author`s Contribution

[1] Substantial contributions to the conception or design of the work for the acquisition, analysis or interpretation of data for the work, [1] Drafting the work or reviewing it critically for important intellectual content, [1] Final approval of the version to be published, Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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ABSTRACT

Background: Cerebral palsy (CP) is a neurological disorder that impacts movement, posture, and muscle tone due to brain damage in fetal development, infancy, or early childhood.

Objective: To compare anxiety and depression among primary caregivers of male versus female children with cerebral palsy.

Methodology: This cross-sectional comparative study was carried out between February 2020 and March 2021 with the caregivers of CP-inflicted children admitted at a rehabilitation center in Karachi, Pakistan. Among 46 approached caregivers, only 30 (75%) voluntarily participated in the study. Group 1 encompassed caregivers of male CP-inflicted patients (n=19) and group 2 encompassed caregivers of female CP-inflicted patients (n=11). Data on physical characteristics and additional impairments accompanying CP was gathered whereas face-to-face meetings were arranged with primary caregivers to gather data for sociodemographic questionnaire and Hospital anxiety depression scale (HADS).

Results: No significant differences were observed in the two groups concerning the physical characteristics of CP cases and sociodemographic characteristics of caregivers. Compared to the caregivers of female CP children, caregivers of male CP children had significantly higher anxiety (7.09±1.64; 8.42±1.6, p=0.044), depression (5.90±1.8; 8.10±1.88, p=0.004) and total HADS scores (6.50±1.79; 8.26±1.75, p=0.006).

Conclusion: Caregivers of male CP children were more prone to anxiety and depression problems. There was no significant correlation found between the sociodemographic profile of the caregivers and the characteristics of CP with the gender of CP children.

Keywords: Anxiety; Caregivers; Cerebral Palsy; Children; Depression; Pakistan

Introduction

Cerebral palsy (CP) is a neurological disorder that impacts movement, posture, and muscle tone due to brain damage in fetal development, infancy, or early childhood.[1] The worldwide incidence of CP is estimated at around 1.6 per 1,000 live births.[2] However, in countries like Pakistan, there is limited specific data on the epidemiology and etiology of CP.[3,4] CP predominantly affects males during the prenatal developmental period.[5,6] Primarily, it manifests poor coordination, stiff or weak muscles, and tremors but can affect abilities to sense, see, hear, or speak. CP can be classified based on muscle tone, topographical distribution, severity, and Gross motor function classification system (GMFCS).[1] Signs and symptoms vary from person to person based on the extent of the brain injury.

Functional limitations in CP-inflicted children are due to emotional, mental, physical, and social disorders[1] which makes them fully or partially dependent on caregivers, especially mothers. They need external assistance for feeding, healthcare, personal care, and mobility. The dependency of a CP-inflicted patient has a direct influence on the economic, emotional, physical, and social wellbeing of the caregivers.[7-9] Sometimes, taking care of disabled patients becomes a full-time occupation for the caregivers which puts them at risk of anxiety and depression.[9] Studies from Brazil,[10] Saudia Arabia,[11] Turkey,[12] and Zimbabwe[13] observed that caregivers of CP children particularly mothers have higher levels of anxiety and depression than caregivers of healthy children. Research from Canada[14] and Ireland[15] has reported inferior physical and psychological well-being in caregivers of CP children.

In Pakistani society, often family members take care of patients by sacrificing their own physical and psychosocial well-being to provide extensive care to the patients. It is stressful for caregivers to balance the inevitable demands of CP-inflicted children and their own social needs which elicits several psychiatric problems. And, if the caregivers are unable to meet the challenges of caretaking due to psychiatric problems, their CP-inflicted child may not attain an optimal level of functioning. Everybody in Pakistan mostly overlooks the psychiatric problems among caregivers. It is important to consider the detrimental effects on the caregivers of CP-inflicted patients. There is a dearth of research in this context, especially in Pakistan. Limited studies have reported depression and anxiety levels among caregivers of children with CP and the results are controversial. The present study aimed to compare anxiety and depression among primary caregivers of male versus female children with cerebral palsy.

Methodology

This cross-sectional comparative study was carried out between February 2020 and March 2021 with the caregivers of CP-inflicted children admitted at Al Umeed Rehabilitation Association, Karachi, Pakistan. Figure 1 shows the study protocol. Study approval was taken from the 'Institutional Bioethics Committee' of the University of Karachi (IBCKU-2017) followed by the permission of rehabilitation center. Written consent was also taken from the primary caregivers of CP children. Participants' identities were kept confidential.

Primary caregivers living with CP child were included in the study. However, participants using any antidepressant or anxiolytic drugs and the absence of a history of psychological disorders were excluded

It was a 1st phase clinical study for which the sample size could be lower than twenty.[16] The focus group was the caregivers of CP children. The caregivers were contacted by the rehabilitation center and their interviews were conducted in the presence of a psychologist within the premises of rehabilitation center. Among 46 approached caregivers, only 30 (75%) voluntarily participated in the present study. Group 1 encompassed caregivers of male (n=19) and group 2 encompassed caregivers of female CP-inflicted patients (n=11).

The present study involved 3 instruments including

1. **Characteristics of CP children:** Age, gender, GMFCS, mobility, muscle tone, severity, topographical distribution, and presence of any additional impairments were recorded from the medical records at the center. Muscle tone was assessed using Modified Ashworth Scale (MAS) scale.
2. **Sociodemographic questionnaire for primary caregivers:** 14-item questionnaire encompassing age, absence from work/commitments, blaming by people for a disabled child, district of residence, education, gender, income level, marital status, occupation, relationship with the child, religion, social support, and a total number of normal and disabled children.
3. **Anxiety and depression assessment among the primary caregivers**: The Hospital Anxiety and Depression Scale (HADS) was designed by two scientists namely Snaith and Zigmond to provide clinicians with an adequate, valid, easily accessible, and reliable tool to assess anxiety and depression.[17] HADS consists of fourteen questions with four response choices grouped into two subscales, anxiety (odd numbers) and depression (even numbers). The choices for each item are scored from zero to three for a total of twenty-one on each subscale. The cut-off point is the same for both anxiety and depression and is normal '0–7'; borderline abnormal '8–10'; or abnormal case '11 or more'. HADS has high reliability with a '0.84–0.87' Cronbach alpha value and validity (p<0.05).[17]

Descriptive statistics were used to determine the frequencies, ratios, mean, and standard deviation of the acquired data. An independent t-test was employed to compare between-group differences for the primary caregivers of the male and female CP patients.

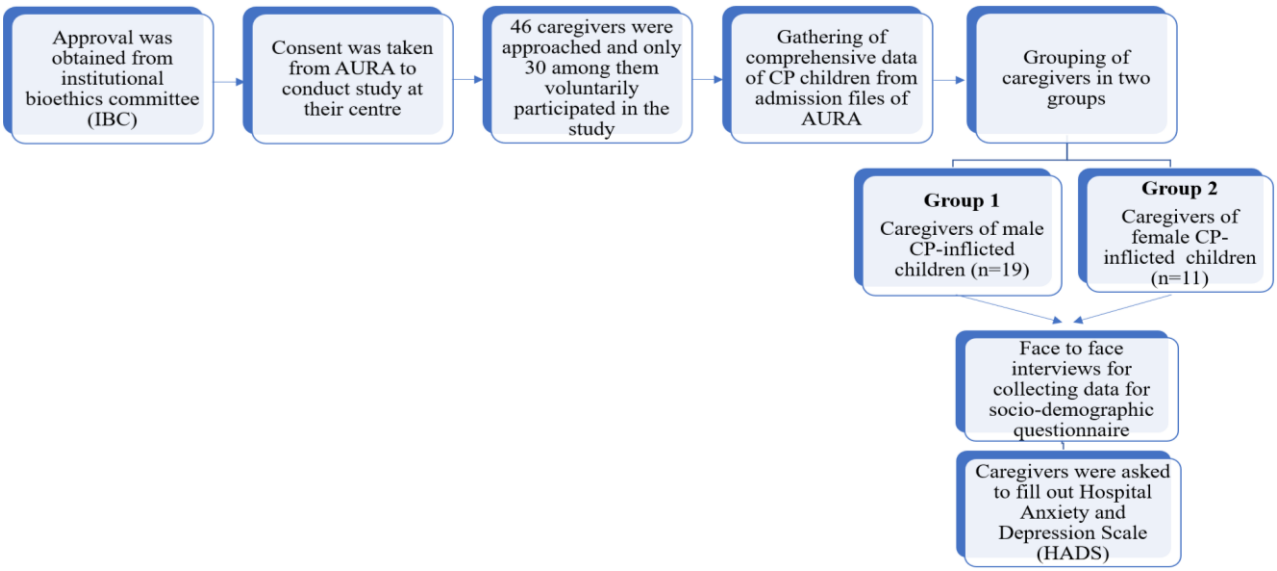

Figure 1: Flow chart for the study

Figure 2: CP Child gender and anxiety, depression, and total HADS score of caregivers. Caregivers of male CP children compared with caregivers of female CP children. Values are significant at *p<0.05, **p<0.01, and ***p<0.001 (t-test). Error bars are Standard deviations.

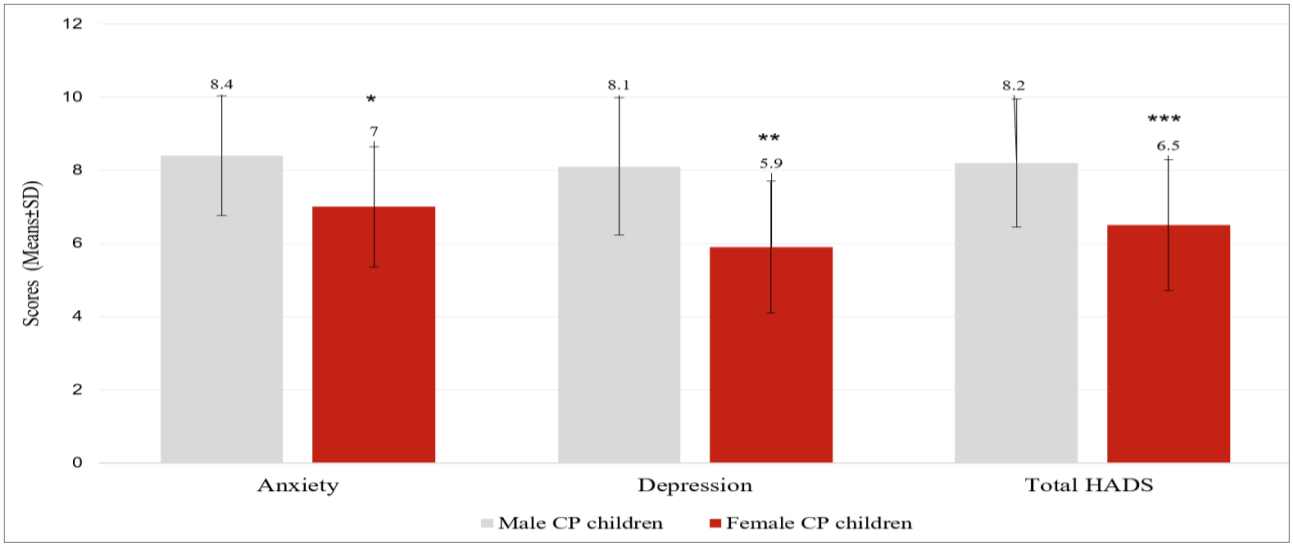

Figure 2: Between Group Analysis among Male and Female CP Children

Results

Characteristics of CP children: Table 1 presents the characteristics of CP children which encompassed 36.6% of females and 63.3% of males. The mean ages of male and female CP children were similar (14±4 years, and 14±4.6 years respectively). No significant differences were found between the two groups (p>0.05) (Table 1).

Sociodemographic questionnaire for primary caregivers: The mean age of primary caregivers in group 1 was 34.3±6.70 years and in group 2 was 34.2±6.57 years. Detailed sociodemographic data about the caregivers of both groups are given in Table 2.

Anxiety and depression assessment among the primary caregivers: Both groups showed anxiety and depression in the caregivers. Compared to the caregivers of female CP children, caregivers of male CP children had significantly higher anxiety (7.09±1.64; 8.42±1.6, p=0.044), depression (5.90±1.8; 8.10±1.88, p=0.004) and total HADS scores (6.50±1.79; 8.26±1.75, p=0.0006) (Figure 2).

A statistically significant difference was observed in the presence of additional impairments between the groups (p < 0.05) (Table 1). However, no significant differences were identified in the sociodemographic data of the caregivers between the two groups of children with cerebral palsy (p > 0.05) (Table 2).

Table 1: Characteristics of CP children					
Category	**Sub-category**	**Group 1 (n=19)**	**Group 2 (n=11)**	**Total (n=30)**	**p-value**
Age (years)	Below 10	4 (21.0%)	4 (36.3%)	8 (26.6%)	0.17
	10–19	8 (42.1%)	4 (36.3%)	12 (40%)	
	20–29	6 (31.5%)	2 (18.1%)	8 (26.6%)	
	30–39	1 (5.26%)	1 (9.09%)	2 (6.66%)	
	≥ 40	0	0	0	
GMFCS	Level I	5 (26.3%)	1 (9.09%)	6 (20%)	0.19
	Level II	4 (21.0%)	2 (18.1%)	6 (20%)	
	Level III	3 (15.7%)	2 (18.1%)	5 (16.6%)	
	Level IV	7 (36.8%)	4 (36.3%)	11 (36.6%)	
	Level V	0	2 (18.1%)	2 (6.66%)	
Muscle tone	Spastic	11 (57.8%)	4 (36.3%)	15 (50%)	0.40
	Hypotonic	8 (42.1%)	7 (63.6%)	15 (50%)	
Mobility	Independent	5 (26.3%)	1 (9.09%)	6 (20%)	0.18
	Walker	5 (26.3%)	1 (9.09%)	6 (20%)	
	Wheelchair dependency	9 (47.3%)	9 (81.8%)	18 (60%)	
Severity	Mild	5 (26.3%)	1 (9.09%)	6 (20%)	0.09
	Moderate	10 (52.6%)	7 (63.6%)	17 (56.6%)	
	Severe	4 (21.0%)	3 (27.2%)	7 (23.3%)	
Topographical distribution	Diplegia	9 (47.3%)	5 (45.4%)	14 (46.6%)	0.19
	Athetoid	2 (10.5%)	3 (27.2%)	5 (16.6%)	
	Hemiplegia	5 (26.3%)	1 (9.09%)	6 (20%)	
	Quadriplegia	2 (10.5%)	1 (9.09%)	3 (10%)	
	Dystonia	1 (5.26%)	1 (9.09%)	2 (6.66%)	
Additional impairments	ADHD	1 (5.26%)	1 (9.09%)	2 (6.66%)	0.04
	Epilepsy	3 (15.7%)	1 (9.09%)	4 (13.3%)	
	Intellectual disability	2 (10.5%)	2 (18.1%)	4 (13.3%)	
	Poor attention	5 (26.3%)	2 (18.1%)	7 (23.3%)	
	Incontinence	4 (21.0%)	3 (27.2%)	7 (23.3%)	
	None	4 (21.0%)	2 (18.1%)	6 (20%)	
Values are frequencies and percentages. [ADHD; Attention Deficient Hyperactivity Disorder]					

Table 2: Sociodemographic data of each group of caregivers (n=30)					
Category	**Sub-category**	**Group 1 (n=19)**	**Group 2 (n=11)**	**Total (n=30)**	**p-value**
Age (Years)	Below 18	0	0	0	0.09
	18-29	4 (21.0%)	2 (18.1%)	6 (20%)	
	30-39	7 (36.8%)	5 (45.4%)	12 (40%)	
	40-49	8 (42.1%)	4 (36.3%)	12 (40%)	
	≥ 50	0	0	0	
Marital status	Never married	1 (5.26%)	0	1 (3.33%)	0.38
	Married	18 (94.7%)	10 (90.9%)	28 (93.3%)	
	Divorced	0	0	0	
	Separation	0	0	0	
	Widowed	0	1 (9.09%)	1 (3.33%)	
Relationship of caregiver with the child	Father	0	0	0	0.34
	Mother	18 (94.7%)	11 (100%)	29 (96.6%)	
	Others	1 (5.26%)	0	10 (33.3%)	
Religion	Islam	18 (94.7%)	11 (100%)	29 (96.6%)	0.34
	Christianity	1 (5.26%)	0	1 (3.33%)	
	Others	0	0	0	
Education	None	3 (15.7%)	1 (9.09%)	4 (13.3%)	0.06

	Primary	3 (15.7%)	2 (18.1%)	5 (16.6%)	
	Secondary	6 (31.5%)	5 (45.4%)	11 (36.6%)	
	Higher	7 (36.8%)	3 (27.2%)	10 (33.3%)	
District of residence	East	2 (10.5%)	1 (9.09%)	3 (10%)	0.23
	West	1 (5.26%)	0	1 (3.33%)	
	South	1 (5.26%)	1 (9.09%)	2 (6.66%)	
	Central	13 (68.4%)	7 (63.6%)	20 (66.6%)	
	Malir	0	1 (9.09%)	1 (3.33%)	
	Korangi	2 (10.5%)	1 (9.09%)	3 (10%)	
Occupation	Housekeeping	17 (89.4%)	9 (81.8%)	26 (86.6%)	0.50
	Job	2 (10.5%)	2 (18.1%)	4 (13.3%)	
Income level of the family	Low	0	0	0	0.42
	Middle	19 (100%)	11 (100%)	30 (100%)	
	High	0	0	0	
Presence of other child/children	Yes	18 (94.7%)	11 (100%)	29 (96.6%)	0.40
	No	1 (5.26%)	0	1 (3.33%)	
Presence of any other disabled child	Yes	0	0	0	0.50
	No	19 (100%)	11 (100%)	30 (100%)	
Social support to the caregiver	Yes	15 (78.9%)	9 (81.8%)	24 (80%)	0.29
	No	4 (21.0%)	2 (18.1%)	6 (20%)	
Absence from work/commitments due to caregiving	Yes	2 (10.5%)	2 (18.1%)	4 (13.3%)	0.50
	No	17 (89.4%)	9 (81.8%)	26 (86.6%)	
Been blamed for disabled child/children?	Yes	1 (5.26%)	1 (9.09%)	2 (6.66%)	0.50
	No	18 (94.7%)	10 (90.9%)	28 (93.3%)	
If blamed then, by whom?	Spouse	0	0	0	0.39
	Immediate family	1 (5.26%)	0	0	
	Others	0	1 (9.09%)	2 (6.66%)	
	None	18 (94.7%)	10 (90.9%)	28 (93.3%)	
Values are frequencies and percentages.					

Discussion

Findings demonstrated that the caregivers of male CP-inflicted children had significantly higher anxiety, depression, and total HADS scores as compared to the caregivers of female CP-inflicted children. Generally, the caregivers of children with disabilities experience greater anxiety and depression. In our comparative study, more serious cases of CP were observed in group 1 which might be the reason of 57.8% anxiety and 52.6% depression reported by the caregivers of the group. Wijesinghe et al. reported that male CP-inflicted children, with lower functional capacity, and lower socioeconomic level may increase the burden on the caregivers.[18] In the present study, the children in Group 1 had 78.9% additional impairments which encompassed ADHD, epilepsy, intellectual disability, incontinence, and poor attention except for movement, and they may present in 25-80% of cases.[19] Children with additional impairments are even more dependent on caregivers which may be one of the reasons for the higher reporting of anxiety and depression in the primary caregivers inducted in the present study. Seeking psychosocial interventions may reduce the burden on caregivers.[20]

Current findings indicate that anxiety, depression, and total HADS scores of male caregivers were significantly higher which is concordant with the findings of Al-Eithan and co-authors.[11] The present study also showed that the primary caregivers were mothers of the children in both groups i.e., 29 (96.6%). Yilmaz and co-authors reported that mothers of CP-inflicted children have higher anxiety and depression which is concordant with the findings of the present study.[12] There may be several reasons associated with the higher levels of anxiety and depression including lack of social support, low-income status, gender of primary caregiver, and the child's intellectual disability as indicated in the present study.

The function of parents has a direct influence on the function of their CP-inflicted children.[21] Several interventions can enhance functions in CP-inflicted patients including acupuncture, assistive devices, aqua therapy, behavior therapy, castings, chiropractic treatment, cognitive rehabilitation therapy, counseling, environmental enrichment techniques, hippotherapy, home programs, massage, medications, occupational therapy, parent training, physiotherapy, religion-based therapies, selective dorsal

rhizotomy, sensory interventions, speech therapy, or even joint surgeries in extreme cases.[22,23] To ensure the efficacy of interventions and to achieve the goals of maximizing child function, clinicians should also consider interventions to improve and support parent function, particularly their mental health.[24] It has been reported that interventions likely cognitive-behavioral and psychoeducation are effective for the improvement of mental health in the caregivers of disabled children.[25] The quality of life was not assessed in the present study, but caregiving has a significant impact on the quality of life of the mothers.[26]

The present study is the first in the literature that diagnosed and compared the levels of anxiety and depression among the caregivers of male and female CP-inflicted children in Karachi, Pakistan. The limitation of the study was the small sample size as a few caregivers gave consent. Another limitation of the study was the acquisition of data from a single rehabilitation center. More research with sufficient samples in multi-centers will further validate reported findings. However, further clinical studies with a larger sample size are required to identify anxiety and depression in the caregivers of CP children. More research on the identification and management of anxiety and depression in the caregivers of CP-inflicted children on a mass scale is necessary for Pakistan. It is essential to diagnose and develop adequate interventions as the foremost objective for minimizing the anxiety and depression problems of caregiving in Pakistan.

Conclusion

It is concluded that caregivers of male CP children were more prone to anxiety, depression and total HADS. There was no significant correlation found between the sociodemographic profile of the caregivers and the characteristics of CP with the gender of CP children. Moreover, the present study indicated that caregivers of both groups had anxiety and depression.

Disclaimer

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