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Depression, Quality of Life, and Quality of Sleep in Mothers of Children with Cerebral Palsy

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Cerebral palsy (CP) is a neurological disorder characterised by impairments of posture and mobility. The caregivers of children with CP experience various physical, emotional, and environmental challenges. This study aimed to determine the level of depression, quality of life, and sleep in mothers of children with CP. This cross-sectional study was conducted at the University of Lahore, and data were collected from paediatric rehabilitation departments in various hospitals of Lahore, Punjab, Pakistan. A sample of 50 mothers of children with CP was obtained, and the severity of depression, quality of life, and sleep were assessed using the *Beck Depression Inventory-II* (Beck et al., 1996), the *World Health Organization Quality of Life-BREF* (WHO, 1998), and the *Pittsburgh Sleep Quality Index* (Buysse et al., 1989), respectively. CP children were of an age range from 4 to 15 years, with a mean of 6.32±2.88 years, and mothers were between 25 and 45 years, with a mean of 35±4.94 years. A considerable proportion of mothers had moderate levels of depression, while their quality of life across physical, psychological, social, and environmental domains was moderate to low. Sleep quality was also poor, representing notable sleep disturbances. The age and gender of the children with CP were also found to be associated with the changes in the mother's social relationships and sleep quality. These findings depict that the mothers providing care to children with CP had a sufficient psychosocial burden that requires appropriate and timely support, counselling, and community-based interventions to help improve their mental health and well-being.

Keywords. Cerebral Palsy, Depression, Mothers, Quality of life, Sleep quality

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Cerebral Palsy (CP) is a non-progressive neurological disorder arising from an injury to the developing brain (Kumar R et al., 2016). It is one of the most common causes of lifelong disability among children, manifested by impaired muscle tone, movement dysfunction, and postural instability (Almeida et al., 2024; Dhondt et al., 2023). The CP is marked by various clinical subtypes, including spastic, athetoid, ataxic, and mixed, with each subtype associated with certain sets of motor issues and challenges, ranging from atypically stiff muscles to involuntary movements, and poor coordination to walking difficulties (Kumar R et al., 2016). Cerebral palsy affects children worldwide, impacting populations across the globe, with a reported prevalence of 2-4 cases per 1,000 live births across a diverse range of populations. (Albayrak et al., 2019; Xia et al., 2023; Malik MS et al., 2016). The long-term disability associated with CP poses a high physical, financial, and caregiving burden on family and society. Moreover, the profound and continuing load on educational, medical, and financial systems, it is considered a significant public health challenge (Dhondt et al., 2023).

The numerous other attributes of CP, including vision loss, seizures, cognitive impairments, abnormalities in sensory processing, and emotional and behavioral disorders, intensify the demands of care and complicate the management (Abd Elmagid & Magdy, 2021). While the impact of cerebral palsy (CP) on children is widely recognized, the challenges faced by mothers who serve as caregivers for CP children are often overlooked. The relentless caregiving responsibilities, which include assisting with daily activities, managing complex medical needs, and meeting the educational and grooming tasks, place mothers at significant risk for a vicious cycle of adverse health-related outcomes (Dlamini et al., 2023; Martin et al., 2023). This burden directly disrupts maternal sleep, as caregivers are often on call throughout the night to attend to their child's needs, leading to chronic sleep deprivation that impairs daytime functioning (Varma et al., 2021; Micsinszki et al., 2018). This physical, emotional, and psychological strain leads to poor mental health that is proportionate to the high prevalence of depression and disruption of physical functioning among these mothers (Kouther et al., 2022; Barutcu et al., 2021). Ultimately, the sleep deprivation, higher levels of depression, and the constant demands of care integrate and reduce the mother's overall quality of life.

The well-being of mothers is a basis and a paramount aspect of effective care for a child with physical challenges. When a mother's own psychological and physical health is compromised by the huge caregiving demands, added to by the social stigma and intense anxiety about the future, her capacity to provide sustainable care is affected (Aman et al., 2021; Barutcu et al., 2021). Despite the clear,

interconnected nature of these challenges, where sleep deprivation, depression, and a diminished quality of life form a vicious cycle, a holistic understanding of this syndemic is often missing. This gap is particularly pronounced in Pakistan, where there is a scarcity of research that simultaneously investigates the mental and physical health burdens on mothers of children with neurological disorders like CP, and hence targeted support strategies. This study, therefore, aims to determine the levels of depression, quality of life, and sleep disturbances in mothers of children with cerebral palsy in Pakistan. By assessing these factors together, the findings will lay a foundation for developing support systems that protect maternal well-being and, by extension, improve outcomes for the entire family.

Method

Study Design

It was a cross-sectional survey that was carried out following the guidelines of Strengthening the Reporting of Observational Studies in Epidemiology (STROBE), where the data were collected at a single point in time.

Time and Location

This study was conducted at the University of Lahore from February to May 2024. Data were collected from various outpatient Paediatric Rehabilitation departments for cerebral palsy in hospitals in Lahore.

Sample Size and Characteristics

A sample of 50 mothers of children with cerebral palsy (CP) was collected through a convenient sampling. The sample size was calculated by using an online sample size calculator, Epitool, using the assumed standard deviation = σ = 5.33 (Goheir et al., 2022), confidence interval = $Za/2$ = 1.96, and margin of error = E = 2. The minimum required sample size was 28, but to empower this study, we included 50 participants.

The children with CP ranged in age from 4 to 15 years. The majority of children were in the youngest age group of 4-7 years (72.0%, n = 36), followed by 8-11 years (18.0%, n = 9) and 12-15 years (10.0%, n = 5). The sample was comprised of 27 female children (54.0%) and 23 male children (46.0%). Regarding clinical presentation, the spastic subtype was the most common diagnosis (90.0%, n = 45),

with the remaining children having the athetoid subtype (10.0%, *n* = 5). All children were receiving rehabilitation services, with 27 children (54.0%) having received services for more than six months and 23 children (46.0%) for a duration of six months or less.

The mothers, who served as the primary respondents, were between 25 and 45 years of age. The largest proportion was between 32-38 years old (38.0%, *n* = 19), with the remainder being 39-45 years (32.0%, *n* = 16) and 25-31 years (30.0%, *n* = 15). The majority of mothers identified as housewives (76.0%, *n* = 38), while 12 mothers (24.0%) were employed outside the home. Based on family income and education, the sample was predominantly from middle-class households (64.0%, *n* = 32), with equal proportions from low (18.0%, *n* = 9) and high (18.0%, *n* = 9) socio-economic status backgrounds.

The mothers of children with CP were screened for general health-related conditions such as diabetes mellitus, hypertension, liver dysfunction, or chronic obstructive pulmonary disease (Lee et al., 2019), and those who reported advanced levels of comorbidities were excluded from participation, as it may have had a confounding effect with the study variables independently affecting mental health, quality of life and sleep outcomes.

Outcome Measures

Severity of depression, quality of life (QoL), and quality of sleep were outcome variables assessed by using the standardised tools such as the *Beck Depression Inventory-II* (*BDI-II*) scale, the *World Health Organization Quality of Life* (*WHOQOL-BREF*) scale, and the *Pittsburgh Sleep Quality Index* (PSQI) scale, respectively. The English version of the tools was administered via a face-to-face interview method, and when the participants had difficulty understanding the items, they were translated into simple Urdu.

Beck Depression Inventory-II (BDI-II)

The Beck Depression Inventory-II scale was used to measure the severity of depression. It was developed by Aaron T. Beck and colleagues. (Beck et al., 1996) This scale is a questionnaire based on twenty-one questions, and each question has four responses that are scored from 0-3. The total score was calculated by simply adding up the scores. The scores range from 0 to 63, classified as minimal (0-13), mild (14-19), moderate (20-28), and severe depression (29-63) (Wang & Gorenstein, 2013).

World Health Organization Quality of Life (WHOQOL-BREF)

The World Health Organization Quality of Life scale brief version (WHOQOL-BREF) was used to measure the quality of life, developed by the WHOQOL Group. (WHO, 1998) This scale is a self-report questionnaire that evaluates the four QOL dimensions and comprises 26 items. It covers social interactions (3 items), environment (8 items), psychological health (6 items), physical health (7 items), overall health (1 item), and overall QOL (1 item). Each domain is rated on a 5-point Likert scale. The sum of the scores of each domain was calculated, and then raw scores were transformed into a 0-100 scale for each domain, where higher scores denote a higher quality of life (Skevington et al., 2004).

Pittsburgh Sleep Quality Index (PSQI)

The Pittsburgh Sleep Quality Index (PSQI) was used to measure the quality of sleep, which was developed by Buysse and colleagues. (Buysse et al., 1989) It has 19 items that are grouped into 7 components/domains of sleep; the duration of sleep (3 items), sleep disruption (5 items), sleep-onset delay(2 items), daytime dysfunction due to tiredness (7 items), the efficiency of sleep (4 items), the requirement for medicine to fall asleep (6 items), and overall quality of sleep (1 item). The score of each domain ranges from 0-3. For some items, reverse scoring is used to convert more positive answers into higher scores, indicating the worst sleep quality. The total score was calculated by summing up the scores of all 7 domains, which ranged from 0 to 21; a greater score represents poor sleep quality, and a score greater than 5 suggests significant sleep difficulties (Fabbri et al., 2021).

Procedure

The study follows the guidelines outlined by the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE). Ethical approval for the study was obtained from the Research Ethical Committee of The University of Lahore (Ref no. REC-UOL-/254/08/24). Informed consent was obtained from the participating mothers of children with cerebral palsy. The study's objectives were explained to them. The anonymity of the personal details and confidentiality of the data were ensured. The right to withdraw from the study was maintained. Given the sensitivity of the topic, the interview session was conducted in a respectful and empathic manner. The participants were continuously reminded that they could skip the

question or pause the interview if they felt distressed. Secondly, the demographic data was taken, followed by the outcome variables through standardised outcome measure tools. At the end of the interview session, emotional closure was offered through debriefing and reassurance.

Results

The data was analysed using SPSS version 26. The Chi-square analysis was used to find the association between age and gender of children with depression. The independent t-test was used to compare the mean score of quality of life and sleep among the genders of CP children and the working status of mothers, while one-way ANOVA was used to compute the mean difference in the mean score of quality of life and sleep among the age groups of children and mothers and their socioeconomic status. A p-value less than 0.05 was set as significant.

Table 1: *Levels of Depression, Quality of Life, and Sleep in Mothers of CP Children (N = 50)*

Variables and Measures	Category or Domain	*N*	*%*	*M*	*SD*
Depression (BDI-II)	Minimal	9	18.0	-	-
	Mild	12	24.0	-	-
	Moderate	17	34.0	-	-
	Severe	12	24.0	-	-
Quality of Life (WHOQOL-BREF)	Physical health	-	-	58.21	15.84
	Psychological health	-	-	52.41	13.54
	Social relations	-	-	62.83	10.80
	Environment	-	-	54.68	10.10
Sleep Quality (PSQI)	Subjective sleep quality	-	-	1.26	.77
	Sleep latency	-	-	1.64	.94
	Sleep duration	-	-	.64	.87
	Sleep efficiency	-	-	1.48	.78
	Sleep disturbance	-	-	1.36	.52
	Use of sleep medication	-	-	.00	.00
	Daytime dysfunction	-	-	1.30	.70
	Overall Sleep	-	-	7.68	2.05

Note. *N* = number, *M* = Mean, *SD* = Standard Deviation.

Table 1 depicts the summary scores of study variables. The results showed that around 34% of mothers had moderate depression. The mean score of domains of WHOQOL-BREF, such as physical health, was 58.21 ± 15.84, psychological health was 52.41 ± 13.54, health of social relationships was 62.83 ± 10.80, and environment was 54.58 ± 10.10, representing moderate to low quality of life. The mean score of PSQI was 7.68 ± 2.05, indicating poor sleep quality.

***Relationship of Maternal and Children's Demographic Variables With* Depression**

The relationship between children's age and gender, and the mother's age, occupation, and socio-economic status, with depression was analyzed using chi-square tests. The results indicated no significant associations between these variables. However, cross-tabulation revealed that moderate depression was present in 15 (30%) mothers of children with cerebral palsy aged 4-7 years and in 9 (18%) mothers of female children (χ^2 = 5.671, p = .461) Depression was more prevalent among mothers aged 32-38 and 39-45 years (χ^2 = 6.025, p = .420), housewives (χ^2 = 4.044, p = .257), and those from middle-class backgrounds (χ^2 = 6.657, p = .354) as illustrated in Table 2.

Table 2: *Association of CP Children and Maternal Characteristics with Depression in Mothers (N = 50)*

Demographic Characteristics	Category	Severity of Depression *n* (%)				Test Statistics	
		Minimal	Mild	Moderate	Severe	χ^2	*p*
Age of the child	4-7	7 (14)	7 (14)	15 (30)	7 (14)	5.671	.461
	8-11	1 (2)	3 (6)	1 (2)	4 (8)		
	12-15	1 (2)	2 (4)	1 (2)	1 (2)		
Gender of child	Male	6 (12)	3 (6)	8 (16)	6 (12)	3.763	.288
	Female	3 (6)	9 (18)	9 (18)	6 (12)		
Age of Mother	25-31	3 (6)	3 (6)	4 (8)	5 (10)	6.025	.420
	32-38	5 (10)	3 (6)	6 (12)	5 (10)		
	39-45	1 (2)	6 (12)	7 (14)	2 (4)		
Occupation	Working	0 (0)	3 (6)	6 (12)	3 (6)	4.044	.257
	Housewives	9 (18)	9 (18)	11 (22)	9 (18)		
Socio-economic-status	Low	0 (0)	4 (8)	2 (4)	3 (6)	6.657	.354
	Middle	8 (16)	7 (14)	11 (22)	6 (12)		
	High	1 (2)	1 (2)	4 (8)	3 (6)		

Table 3: *Association between Children and Maternal Factors and Mother's QoL and Sleep Quality (N = 50)*

Demographic Characteristics	Category	Quality of Life *M* (*SD*)				Sleep Quality
		Physical	Psychological	Social	Environment	*M* (*SD*)
Age of Child	4-7	58.63 (15.47)	52.31 (13.67)	64.58 (10.03)	54.86 (9.89)	8.25 (2.68)
	8-11	55.15 (19.73)	50.46 (14.79)	63.88 (7.21)	52.08 (10.59)	9.66 (2.50)
	12-15	60.71 (13.12)	56.66 (12.00)	48.33 (12.36)	58.12 (11.81)	11.20 (3.56)
	F statistics	0.234	0.331	6.048	0.583	3.087
	p-value	.792	.720	.005	.562	.055
Gender of Child	Male	56.83 (16.92)	53.62 (15.80)	65.57 (8.81)	56.11 (10.25)	7.82 (2.46)
	Female	59.39 (15.09)	51.38 (11.49)	60.49 (11.91)	53.47 (10.00)	9.62 (2.95)
	t statistics	0.565	0.577	1.689	0.920	-2.356
	p-value	.575	.567	.037	.777	.023
Age of Parent	25-31	61.66 (12.33)	54.44 (15.94)	67.77 (8.83)	54.16 (11.43)	8.00 (2.50)
	32-38	57.70 (18.22)	51.31 (14.03)	64.91 (10.23)	55.09 (9.67)	8.89 (3.28)
	39-45	55.58 (16.12)	51.82 (10.96)	55.72 (9.96)	54.68 (9.94)	9.43 (2.60)
	F Statistics	0.577	0.238	6.609	0.034	0.997
	p-value	.566	.789	.003	.966	.377
Occupation	Working	58.03 (16.69)	50.34 (9.64)	60.41 (8.04)	53.90 (7.66)	8.91 (2.57)
	Housewife	58.27 (15.80)	53.07 (14.61)	63.59 (11.53)	54.93 (10.84)	8.76 (2.97)
	T Statistics	-0.044	-0.965	-0.887	-0.304	0.161
	p-value	.603	.549	.380	.762	.873
Socio-economic-status	Low	54.36 (18.01)	46.75 (9.02)	62.96 (9.41)	51.38 (7.51)	8.33 (3.31)
	Middle	63.05 (11.63)	55.72 (14.07)	63.54 (10.53)	56.83 (9.89)	8.81 (2.72)
	High	44.84 (19.40)	46.29 (12.40)	60.18 (13.67)	50.34 (11.73)	9.22 (3.11)
	F Statistics	5.974	2.861	0.330	2.126	0.212,
	p-value	.005	.067	.720	.131	.810

Quality of Life and Sleep

The relationship between the age of the child and mother, socio-economic status, and their impact on quality of life and sleep was assessed using one-way ANOVA. The results in Table 3 indicate that both the child's (F = 6.048, p < 0.001) and mother's ages (F = 6.609, p < 0.001) are associated with the mother's social life, representing that with increased age of children requiring more social contacts to manage the needs of caregiving, whereas, the increased age of mother being more likely to disrupt the social aspects of their lives. However, physical functioning was more markedly impacted in mothers of the high class (F = 5.974, p < 0.001) owing to higher expectations and social comparisons. Moreover, with the increased age of children, the sleep quality of mothers is more disturbed (F = 3.087, p = 0.05) due to the high burden of care.

Additionally, an independent sample t-test was used to compare the mean quality of life and sleep between the genders of the children and the working status of the mothers. The results indicated a significant association between the sleep quality of mothers and the gender of their children with cerebral palsy (t = -2.356, p < 0.001). However, no such association was found concerning the mother's occupation.

Discussion

This study aimed to determine the psychological well-being, quality of life, and sleep quality among mothers of CP children. The findings revealed that the majority of mothers had moderate levels of depression and faced challenges in psychological health and environmental well-being; however, their social relationships and physical health were relatively better. Sleep quality was also compromised, indicating that mothers had poor sleep patterns. While no significant association was observed between the children’s age and maternal depression, the children’s age was associated with mothers’ disrupted sleep quality and increased social relationships, highlighting the social impact of caregiving. Additionally, the children’s age and gender were significantly associated with maternal sleep quality, suggesting that caregiving demands may vary based on age and gender.

These results are similar to the findings of a study by Maham Shabbir et al. on the frequency of depression among caregivers, which showed that 56.1% of parents had clinical depression. Around 25% of parents presented with a moderate level of depression, while mothers

experienced higher rates of severe depression compared to fathers (Malik MS et al., 2016). This is attributable to the fact that in Pakistan, mothers serving as a primary caregiver who shares the major physical and psychological responsibility of child care and lacks social and institutional support, which may intensify the depressive symptoms.

Another study by Dina Gamal on the quality of life of mothers of children with CP reported that mothers' QoL is related to their education level, socioeconomic status, and knowledge of their child's health care needs. Mothers with low levels of education and financial constraints have to struggle with accessing the rehabilitation services and understanding the treatment plans, resulting in frustration and lower QoL (Gamal Mohammed Desoky et al., 2021). The same trend was evident in the present study, where most mothers belonged to middle or lower-income groups. However, with time, mothers often adapt to the caregiving role and develop social networks through hospitals, therapy centers, or parent groups to help them share experiences and seek practical advice from others in a similar situation, as seen according to the results of the current study.

Moreover, it was observed through the findings of the current study that mothers of female children reported poorer sleep quality may reflect cultural concerns about daughters' future independence and social acceptance in societies where disability and gender both influence life opportunities. This culturally embedded anxiety may contribute to greater emotional arousal and sleep disturbance.

In parallel, a study by Demet Karabulut also presented that the mothers of CP children had a worse quality of life compared to developing children of the same age, owing to the increased burden of responsibilities of child health care (Karabulut & Avci, 2020). Likewise, the study of Ilknur Albayrak et al. on the burden of care and quality of life in mothers of children with cerebral palsy demonstrated that the mothers had poor health status in all the domains compared to the mothers of healthy children (Albayrak et al., 2019). Similarly, Cathryne P. Lang concluded that poor sleep quality, psychological health, and physical well-being in caregivers of children with CP, it was worse in parents with older children (Lang et al., 2021). The findings are consistent with the findings of the current study, where moderate depression, compromised QoL, and sleep disruption were found in mothers of CP children. This is probably because, as the child grows, the physical care and related healthcare needs proportionately increase, leading to increased fatigue and stress on the caregivers, especially mothers.

Limitations

The cross-sectional design of the study limits the ability to establish cause-and-effect relationships among study variables. Furthermore, the sample was recruited from an urban area, which may affect the generalizability of the findings to other areas with more restricted facilities and support or different cultural contexts.

Recommendations

It is recommended that clinicians should educate mothers about cerebral palsy, as improved awareness can help manage anxiety and cope with the management and caregiving needs. Multidisciplinary clinics should be established to allow mothers to visit related healthcare services in one visit to reduce time and conserve energy. Additionally, online forums should be created for mothers to share experiences and receive emotional support. It is also recommended that future research should examine the support provided by spouses and the mental health of family members of children with cerebral palsy to understand the broader family impact of caregiving.

Implications

The findings imply to healthcare providers and policy makers and highlight the need for psychological counseling, mental health support, and tailored healthcare intervention for caregivers, especially mothers, to improve their physical, emotional, and social well-being and overall quality of life, which subsequently helps to overcome the burden of lifelong disability of children with CP.

Conclusions

Based on the findings of this study, it is concluded that mothers of children with cerebral palsy had moderate levels of depression, moderate to low quality of life, and disturbed sleep quality. The increasing age of the children greatly affects the mother's social life and sleep quality. Moreover, the female gender of CP children leads to more sleep disturbances among mothers compared to male children.

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