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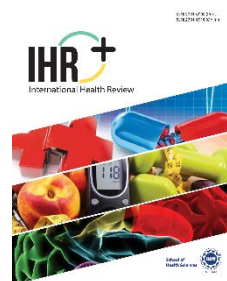
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Title: Association of Cerebral Palsy (CP) Child Behavior with Caregiver Stress Level

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Association of Cerebral Palsy (CP) Child Behavior with Caregiver Stress Level

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Abstract

The disability which occurs frequently in children is known as cerebral palsy (CP). Its prevalence in Pakistan is much higher and about 2 to 3 out of every 1000 children are diagnosed with CP, which affects their functional status of life to a greater extent. The objective of the current study was to determine the association of CP child's behavior with caregiver's stress level. The current study was based on a cross sectional design and it comprised 159 caregivers of CP child. Among them 100 were males and 59 were females. The study was conducted within the time period from December 2016 to May 2017. A convenience sampling technique was used and subjects were selected from different hospitals and rehabilitation centers of Lahore, Pakistan on the basis of inclusion and exclusion criteria after taking informed consent. The two standardized "parental stress scale" and "strength difficulty questionnaire" helped to determine the level of stress and caregiver's burden. The data was analyzed using SPSS v20. The frequency was calculated to obtain mean values of caregiver stress and behavior of CP child using PSS and SDQ. P value $\leq .05$ was considered statistically significant. The Pearson correlation (r) between PSS and SDQ data was $r = 0.63$, which showed a strong positive linear correlation between the two variables, that is, CP child behavior & caregiver stress level. It indicated that both variables increased or decreased together. The behavior of CP child affects the quality of life of parents and caregivers. The study concluded that there is a strong relationship between the CP child's behavior with the caregiver's stress level.

Keywords: cerebral palsy (CP), CP child behavior, health status, Parental Stress Scale (PSS), Strength Difficulty Questionnaire (SDQ)

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Introduction

In childhood, the most frequent disability disorder that occurs among children is cerebral palsy (CP), in which motor impairments occur due to lesion in brain during early development [1–3].

This disorder of movement abnormalities in posture causes activity constraint, credited to the no progressive disturbances that occur during development of child's brain. In CP, patients with motor abnormality are often accompanied by the disturbance of communication, behavioral disorder, sensation, perception, and cognition [4–6].

The occurrence of CP ranges from 1.4 to 4 per 1000 live births. Mother, as the primary caregiver of CP child, is afflicted with more depression and stress as compared to other mothers of normal children [7–9].

Giving care to the children with motor functional limitation is the basic right of being parents. One of the major challenges that caregivers face include managing their child's medical issues along with their requirements of daily living at home [10–12].

The family issues in CP child include financial burdens, such as, out of pocket cost and members who are unemployed. It also affects their health and daily activities, for instance jobs and they need additional income for medical and personal expenses of CP child [2, 3, 14].

It is a difficult task for caregivers to accomplish physical and psychological emotional demands of CP patients. Moreover, it also changes the social life of caregivers. The caregivers face financial, physical, psychological, and emotional stressors. It may be due to low quality of care [15, 16].

The caregivers of CP child often experience behavioral difficulties and limitation in functional skills. The basic idea of the current study was to discover the relation between aspects of parental distress in the parental task due to CP child behavioral issues [17, 18].

The perception of the caregiver or parents of CP child is related to factors, such as, occupation, education, and number of children resources. All these mentioned factors play an important role to develop perception related to CP child's care [19, 20].

A descriptive study was conducted in physical medicine and rehabilitation department in New Delhi, India. The data from 65 caregivers of CP patients

was collected through questionnaires pertaining to physical and mental health from family burden scale. For data analysis, multiple regressions and descriptive statistics were also used. At the end of study, it was determined that both mental and physical health were affected. Moreover, their three domains, such as, 1) family activities, 2) family leisure, and 3) family interaction were also found to be disrupted in caregivers of CP patients [21, 22].

Another cross sectional study was conducted in which data was collected from 424 Irani mothers of CP patients. The association of quality of life was assessed in primary caregivers. The data was collected from different rehabilitation centers. The results showed that the caregiver of CP patients, especially mothers suffer from poor physical and mental health [23, 24].

Another cross sectional study was conducted in which data was collected through (SSDS), a tool to identify the mother depression from Neurology OPD, Karachi, and Rehabilitation Centre DUHS Karachi. The data was collected from 81 mothers of the CP children. Out of 40 primary caregiver (mothers) with depression, 30% got mild depression, 60% moderate, and 10% severe depression [7].

Material and Methods

The current study was based on a cross sectional design. Physical therapy department of Children's hospital, Gulab Devi hospital Lahore, PSRD, and Social Security hospital Ferozepur road, Lahore were the places from which data was collected. Caregivers of CP children were the source of data collection. This study was completed in three months after the approval of synopsis. The non-probability convenient sampling technique was used. The sample size was 196 after calculation from "Rao soft". Caregivers, for instance, mothers, fathers or any other relation who spend minimum 6 to 1 hours with CP child were included in this study. Caregivers with diagnosed chronic illness and caregivers who were not willing to participate were excluded from this study. The data was collected from caregivers of CP children after getting consent from ethical review board committee of the related organization. The parent or caregiver of CP children gave the informed consent. The data collection tools included PSS and SDQ Scale. The questionnaire was fully elaborated and explained by the researcher to CP child parents and caregivers. SPSS version 20 was used to analyze the data.

Results

Table 1. Descriptive Statistics of Age

	Minimum	Maximum	Mean \pm SD
Age	4	13	6.51 \pm 2.56

Out of 159 sample, mean age of the CP child was 6.51(2.56)

Table 2. Frequencies

Gender	Frequency (n=159)	Percentage
Male	100	62.9
Female	59	37.1

Out of sample 159, male 100 (frequency, 100 percent, 62.9) and female 59 (frequency 59 percent 37.1) of CP child.

Table 3. Correlation of Parental Stress and Behavior of child / (Strength difficulty questionnaire)

	R	P –value
Parental stress scale and Strength difficulty scale	.631	.000
	.631	.000

A strong positive significant correlation was found between parental stress scale and strength difficulties questionnaire, because (P value .000, r value .631).

Discussion

In childhood the most frequent disability disorder is cerebral palsy in which motor impairments occur due to lesion in brain during early development [1]. The purpose of the current research was to determine the association of CP child with caregiver stress level. In order to determine the effects of CP child behavior with the health status of his/her caregivers, such as, mother, father or any other relation, it is necessary to spend a minimum of 6 to 10 hours or less than half a day with the CP child.

By coping with the behavioral issues of CP children, caregiver stress could be reduced, which help them having better social life and job status of the caregiver.

The psychological changes of CP child cause mental and physical stress in their caregivers. The previous studies focused on the behavior of CP caregivers and distress, however, this study would determine the association of CP child behavior on caregivers' health status.

The results of the current study proved the alternate hypothesis that there are significant effects on the parental health status due to CP child behavior. The results of other studies supported this statement.

A previous study in 2004 was designed to compare the health of caregivers of CP children with other general population caregivers on the basis of physical and psychological health status.

It was proved that the caregivers of CP children had less income as compared to other general population of caregivers [25]. This study also showed the same results that the CP child tends to impose a financial burden for caregivers. Another descriptive study was conducted in New Delhi, India 2016, in which both mental and physical health were found to be affected and their three domains for instance, family activities, family leisure, and family interaction were also found to be disrupted in caregivers of CP patients [21]. This study also showed the 4 domains of SDQ which somewhat affected the caregiver health status.

A recent study was found to be differing from other similar studies because of the use of observation tools and amount of study population.

The existing significant findings showed that the health of the parents is much affected by the behavior of their CP child. The parents face many problems regarding their child and it made them guilty that their stress reason was due to their child.

Conclusion

CP child behavior affects the parent and caregiver's quality of life. The study concluded that there is a strong relationship between the CP child's behaviors with the caregiver's stress level. Therefore, it could be said that the parent's life gets much affected due to their CP child's behavior.

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