

PSYCHOSOCIAL STRESSORS, BURNOUT AND MENTAL HEALTH PROBLEMS IN CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY

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ABSTRACT

Objective: To explore the relationship between psychosocial stressors, burnout and mental health problems in caregivers of children with cerebral palsy.

Methodology: Cross sectional research design was used in the current research. The sample comprised of 93 mothers of children with cerebral palsy selected from 3 institutes of special education in Lahore, through purposive sampling strategy. They were given demographic proforma, psychosocial stressors scale, caregiver burnout scale and depression & anxiety stress scale (DASS-21).

Results: There was positive relationship between psychosocial stressors i.e. lack of self-regulation ($p < .001$), lack of social support ($p < .034$), burnout i.e. withdrawal ($p < .007$), somatic problems ($p < .001$), reactivity ($p < .012$) were found to be a significant positive predictor of depression, stress and anxiety in mothers of children with cerebral palsy.

Conclusion: There was a positive relationship between lack of self-regulation, lack of social support, withdrawal, somatic problems, reactivity and depression, stress & anxiety in mothers of children with cerebral palsy.

Key Words: Cerebral palsy, Mental health problems, Caregivers, Psychosocial stressors, Burnout

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INTRODUCTION

Caregiving is very unique responsibility which does not demand in return. When any person face illness and demand constant care, at the same time person who provide care take the role of care taker or caregiver¹. Care is also a part of parenting and the birth of a child includes the new roles and responsibilities for parents. Parenting for normal children is very much difficult but it's more complicated and stressful job when we talk about children with special needs, intellectual and physical disability. It can create burden for parents when they involve in excessive responsibility in the form of children with special needs². Being a parent of child with special needs is very stressful and lifelong responsibility. This kind of responsibility affects the physical and psychological health of parents or caregivers³. Most of the time mothers are forced to stay at home and take care of family and provide care to disabled child as a full time job along with household duties and the role of father is bread earner and provides facilities to his family. One of the most common disabilities is called cerebral palsy (CP) which is associated with sensory, motor and intellectual impairments. CP is characterized by chronic, non-progressive neurological damage that occurred during the development of the central nervous system.

The care of CP children imposed a negative consequence on the health of the parents especially for the mothers because mothers are the primary caregivers of children. Mothering is very stressful responsibility as a primary caregiver of child with cerebral palsy. All problems that child is facing in his life, it affects mother's mental and physical health directly. Different studies indicated that parents of CP children perceive unsatisfactory health especially the issues related to stress, depression, muscular pain, social issues, lack of social support and low quality of life⁶⁻⁷. Mothers play a different role for the child like they have to attend the child and at the same time they have to train their children with different skills like self help, language and social skills.

In Pakistani culture, most of the time mothers face the pressure because they have the main responsibility of the child. Mothers face challenges biologically, psychologically and socially. They felt tiredness and muscular pain when they work all the day with the CP child. Psychologically they felt stress, burnout, lack of motivation and even depression. Moreover, lack of social and family support take them towards severe mental health issues. In one research it was indicated that stress and depression is higher in the caregiver of CP children and caregiver also face poor quality of life¹⁰.

To understand the impact of child's disability on mothers, it is important to understand the issues related to care giving such as burnout or fatigue¹¹. Burnout is a stress response related to the social relationships and distorted image of self and others. There is lot of aspects of burnout. First aspect of emotional response is emotional exhaustion defined as a lack of personal energy to face the responsibilities of next day and this component present the stress of person. Depersonalization is referred to negativity and detachment from others. Usually it developed after emotional exhaustion. Last one is reduced accomplishment or reduced competence which lead to depression and inability to cope with the demands of environment¹². All of these create burden for caregivers. Caregiver stressors are also defined as physical, emotional, social and financial burden placed by disabled member of the family¹³. Burnout and fatigue are associated with daily activities, socioeconomic status, interpersonal and family relationships¹⁴. Studies have shown that continued stress causes many psychological and sleep disturbances in caregivers.

These changes affect the physical health, immune functioning and financial well-being of caregivers¹⁵. At the end this situation leads to physical pains, emotional disturbances, social and financial issues¹⁶. The level of stress increased with low economic issues, physical care, demand of time and thoughts about their child's future. All these stressors lead to social stress, burnout and mental health problems in mothers¹⁷.

In Pakistan there are very few researches on primary caregivers, so the focus of current research is the mothers/ primary caregivers of children who are diagnosed with cerebral palsy and intellectual impairment. The mothers of children were selected as it was observed in studies that mothers are the primary caregivers and face more psychosocial stressors and other mental health issues¹⁸. It was therefore, deemed necessary to find out the relationship between psychosocial stressors, burnout and mental health problems in caregivers of children with cerebral palsy. This research would provide awareness to the mothers of children with cerebral palsy about their own psychological and physical problems they are facing while handling the children with cerebral palsy. Workshops and groups would be conducted to provide them guidance and coping strategies. Individual counseling sessions would be offered to work on issues related to mental health problems. Once problems will be identified it would help in developing multidisciplinary approach for management of the problem and providing timely intervention before the problem get worse. This research would help in providing awareness at government level, mental health practitioners and medical fraternity, to pay heed, towards the sufferings of females, identification of the risk factors, taking preventative measures and manage-

ment of problems which would alleviate the stressors and improve their quality of caregiving.

METHODOLOGY

A cross sectional study was conducted on 93 mothers of children with cerebral palsy selected from 3 institutes of special education in Lahore. The study was carried out from February to June 2017. The criteria of participant selection were: diagnosed CP children (boys and girls) up to 3 years; those who can't walk independently and unable to fulfill their basic needs (toilet and drinking). Mothers were selected for the current research. Children with mild disability and who are self dependent (who could perform self help such as walking independently) were excluded from the study. Children with other physical problems such as visual problems, dysphagia and digestive problems were not included in the study. Purposive sampling technique was used for the primary caregiver of children with cerebral palsy. Sample size was determined based on factor analysis, a statistical analysis used for scale development. The most widely used rule uses the ratio of the number of subjects (n) to the number of items (p), and this varies from three to five subjects per item¹⁹. In the current research, there were 31 items of the psychosocial stressor scale and per item 3 subjects were selected so the total number of participants were 93.

All ethical issues were addressed like obtaining official permission from the Institute of Clinical Psychology. Research topic was approved by institute graduate committee. Afterwards school authorities were contacted with the permission letter. The family who does not belong to any school, the informed consent was individually obtained from them. Debriefing was provided to the participants about the research. Confidentiality and anonymity were also assured to the participants. The participants were then given questionnaire individually and instructions were given to each participant. After collecting the data, code was assigned to each form and the incomplete form were excluded from the sample.

In the current research, three scales depression anxiety and stress scale-21 (DASS-21), psychosocial stressor scale and burnout scale were used. Psychosocial stressors of mothers scale²⁰ is an indigenous scale developed to assess the psychosocial reactions of mothers of children with cerebral palsy (CP). The questionnaire consisted of 31 items with 2 sub factors (lack of self regulation and lack of social support). A 4 point rating scale was used to rate each problem; options included "never, rarely, often and always". The cronbach alpha of the scale was .82. Caregiver burnout scale²¹ is an indigenous scale developed to assess the symptoms of burnout in mothers of children with CP. The questionnaire consisted of 31 items with 3 sub factors (withdrawal, somatic and emotional reactivity). A 4 point rating

scale was used to rate each problem; options included "never, rarely, often, and always". The cronbach alpha of the scale was .95. Depression anxiety stress scale (DASS-21)²² is a self-report questionnaire designed to measure the symptoms of depression and anxiety. It contains 21 items with three sub factors. This scale was used in Urdu language to assess the mental health problems of mothers of children with CP. Individual marks the presence of symptoms of anxiety and depression according to the items; the response options of this measure are; (0) not at all, (1) occasionally, (2) often and (3) always.

Data analysis was carried out using SPSS (v.21). Psychosocial stressor was an independent variable, burnout was the mediating variable and mental health problems was dependent variable in the current research. To find out the relationship of psychosocial stressors, burnout and mental health problems, correlation analysis was carried out. To find out the predictor of mental health problems, regression analysis was carried out. To find out mean difference between mother's educational level, analysis of variance (ANOVA) was carried out.

Following hypotheses were made in the current research: 1). there will be a positive relationship between psychosocial stressors, burnout and mental health problems of mothers of children with CP; 2). mother's educated till primary level experience more psychosocial stressors, burnout and mental health problems as compared to mothers having education till intermediate, bachelors and master level.

RESULTS

For the current research 93 mother's of children with cerebral palsy with the age range of 20-50 (mean 34.39 ±9.08 years) were selected. The results showed that there was a positive relationship between lack of self-regulation, lack of social support, withdrawal, somatic problems, reactivity and depression, stress &

anxiety in mothers of children with cerebral palsy. The results supports the hypothesis that higher the psychosocial stressors, higher will be burnout out and mental health problems in mothers of children with cerebral palsy. The details are given in Table 1.

In order to identify the significant positive predictors of mental health problems in caregivers of children with cerebral palsy, hierarchical regression analysis was carried out. In Step 1, demographic variables of the participants like age, gender and education were taken into account. In step 2 and 3 psychosocial stressors scale and caregiver burnout scale were entered. The results showed that psychosocial stressors, lack of self-regulation and lack of social support, burnout withdrawal, somatic and reactivity were found to be significant predictors of mental health problems in caregivers of children with CP. The details are given in Table 2.

The results showed that mothers who had education till primary level have greater difficulties in self-regulation, experience more somatic complaints and were more emotionally reactive as compared to mothers having education till intermediate, bachelors and master level. The details are given in Table 3.

DISCUSSION

Caregiving of chronically ill children is a source of constant stress²³. The finding of our research study indicates that there was a positive relationship between psychosocial stressors (lack of self-regulation & lack of social support), burnout (withdrawal, somatic problems & reactivity) and depression, stress and anxiety in mothers of children with cerebral palsy. We can find similar research findings of Freitas et al⁶ and Brittain et al²⁴ which stated that the stress associated with caring cause physical and mental strain which makes them vulnerable for physical, social and emotional breakdown, leading to feelings of drain out. Another study also

Table 1: Summary of inter-factor correlation, means, standard deviations of the participants (n=93) on CGS, PSSM and DASS-21

Factors	PSSMS-F1	PSSMS-F2	CBS-F1	CBS-F2	CBS-F3	DASS-21
PSSMS-F144***	.64***	.50***	.36***	.60***
PSSMS-F245***	.29**	.50***	.46***
CBS-F172***	.69***	.84***
Somatic57***	.74***
Reactivity68***
DASS-21
M	23.48	9.67	14.92	11.61	4.89	25.01
SD	6.23	5.35	8.30	4.86	3.35	10.29

Note. df =92, ***p <.001, PSSMS= Psychosocial stressors of mothers scale, PSSMS-F1= Lack of self-regulation, PSSMS-F2= Lack of Social support, CBS= Care giver burnout scale, CBS-F1 Withdrawal, CBS-F2= Somatic, CBS-F3= Reactivity, DASS-21= Depression anxiety stress scale

supported the fact that parents of CP children perceive stress, causing depression, muscular pain, social issues, lack of social support and low quality of life⁷.

To understand the impact of child’s disability on mothers, it is important to understand the underlying issues related to care giving¹². The plausible explanation could be the role of collectivistic culture, where mothers are considered as primary source of attachment for children. Role of mothers are perceived as nurtur-

ing, upbringing, binding the family, maintain balance and equilibrium within the family with loyalty, affection, dedication, and reverence, where the family is the most important social institution, the mother occupies the central role and family members are mutually dependent²⁴. To live up to the expectations and maintain their social and perceived role, puts them under a lot of stress. Secondly in a family where children had disability instead of providing social support, the mother is

Table 2: Hierarchical regression analysis of depression anxiety and stress scale (n=93)

Model	SEB	B	t	P
Step 1 (R=.36, R ² =.35)				
Gender	-.13	-2.91	1.29	.198 (ns)
Mother Education	-.07	-.78	.74	.457 (ns)
Family System	-.16	-3.38	1.53	.128 (ns)
Number of Disable Children	.11	3.71	1.08	.279 (ns)
Duration of Care	.21	.43	1.15	.251 (ns)
Step 2 (R=.68, R ² =.40)				
PSSMS-F1	.50	.83	5.12	.001***
PSSMS-F2	.21	.40	2.15	.034*
Step 3 (R=.89, R ² =.76)				
CBS-F1	.44	.55	4.42	.001***
CBS-F2	.21	.46	2.75	.007**
CBS-F3	.20	.62	2.55	.012**

Note: Only significant results are display in the step 2 & step 3.

Note: PSSMS= Psychosocial stressors of mothers scale, PSSMS-F1= Lack of self-regulation, PSSMS-F2= Lack of Social support, CBS= Care giver burnout scale, CBS-F1 Withdrawal, CBS-F2= Somatic, CBS-F3= Reactivity, DASS-21= Depression anxiety stress scale

Note: Step 1, ns= p >0.05, F (8, 92) =1.62., Step 2, *p <0.05, **p <0.01, ***p <0.001, F (10, 92) =7.18., Step 3, *p <0.05, ***p <0.001, F (13, 92) = 23.69.

Table 3: One way analysis of variance of education years of mothers and three factors of CBS, two factors of PSSMS and total score of DASS-21

Factors	Education Level of Mothers								F	P
	Primary (n=27)		Middle-Matric (n=27)		Intermediate-Bachelor (n=27)		Masters (n=12)			
	M	SD	M	SD	M	SD	M	SD		
PSSMS-F1	25.74	5.01	23.22	5.65	23.62	5.77	18.66	8.52	3.93	.011**
PSSMS-F2	10.18	4.78	8.18	5.81	11.59	5.41	7.58	4.05	2.68	.051 (ns)
DASS-21 total	25.00	8.75	25.07	8.75	27.66	11.62	18.91	12.43	2.06	.110 (ns)
Withdrawal	16.07	6.71	14.03	7.23	16.59	9.52	10.58	10.00	1.77	.158 (ns)
Somatic	12.44	3.85	11.55	4.26	12.77	5.34	7.25	5.13	4.45	.006**
Reactivity	5.66	3.64	4.11	2.75	5.85	3.26	2.75	3.04	3.62	.016**

Note: df between groups= 3, df within group= 89, dfgroups total = 92, *p <0.05, **p <0.01, ***p <0.001, ns= > .05, Note: PSSMS= Psychosocial stressors of mothers scale, PSSMS-F1= Lack of self-regulation, PSSMS-F2= Lack of social support, DASS-21= Depression anxiety stress scale

blamed and it is perceived that disability occurred as a result of fate or ill deeds. She had to face the discrimination within and outside the family leading towards social segregation and isolation from the community and worrying about the marriage prospects of other family members, especially daughters. A study carried out in Pakistani cultural context also reported the fact that females have no freedom to express their emotions. They suppress their emotions which later on convert into somatic complaints²⁵. However, the underlying causes of these complaints are depression, anxiety and other mental health problems of women in Pakistani culture²⁶.

Our results also indicated that mothers who have primary level of education they scored significantly high on lack of self-regulation, somatic and reactivity across class groups of mothers who have children with cerebral palsy. These findings are consistent with the study showing that the primary education level mother's have lack of awareness, training and exposure of outer world so they have more mental health issues²⁷. From the above discussion it is evident that mothers are silent sufferers who are left unheard which affect their physical, social and emotional functioning. They are put under constant stress and left with the feelings of emotional exhaustion and drain out.

LIMITATIONS

Some limitations of this research were that it was done only on urbanized population. Moreover, disabilities other than CP were ignored and the fathers of the children were not included in the current research.

CONCLUSION

There was a positive relationship between lack of self-regulation, lack of social support, withdrawal, somatic problems, reactivity and depression, stress & anxiety in mothers of children with cerebral palsy. Lack of self-regulation and lack of social support were significant contributing factors in aggravating the mental health problems in caregivers. Female caregiver's prolonged exposure to psychosocial stressors causes burn out which in turn affects their mental health functioning. Early and timely identification will help in enhancing their physical, social and emotional functioning and improve their quality of caregiving.

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CONTRIBUTORS

FN conceived the idea, planned the study and drafted the manuscript. SA, AA and ZM helped acquisition of data, did statistical analysis and critically revised the manuscript. All authors contributed significantly to the submitted manuscript.