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ORIGINAL ARTICLE

RELATION BETWEEN MATERNAL QUALITY OF LIFE WITH MOTOR FUNCTIONING OF CEREBRAL PALSY CHILDREN AFTER PHYSIOTHERAPY REHABILITATION

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ABSTRACT

OBJECTIVE: To find the relationship between quality of life of mothers of cerebral palsy children and child's motor functioning after at least 3 months of rehabilitation.

METHODS: This cross-sectional study was conducted at Liaquat National Hospital, Karachi, Pakistan from August to November 2019. Total 35 cerebral palsy (CP) children and their mothers were involved. Assessment of mother's health done through Medical Outcomes Study Questionnaire Short Form 36 Health Survey (SF-36) and children's motor functioning through Gross Motor Function Measure (GMFM-88).

RESULTS: While comparing the results of SF-36 in GMFM-88, we found that children's mothers with low GMFM score had a general health deterioration compared to children with higher GMFM score. Mothers who are having a child with cerebral palsy, with GMFM between 1-80 had to cut down the amount of time spend on work while mothers whose child's GMFM was between 1-20 were limited in kind of work and other activities as well as they accomplished less than she would like, and they didn't do their work as carefully as usual. Due to low GMFM (1-20) of kids' mothers even suffered from moderate level of body ache. Likewise, in children's mothers with lower GMFM ratings (1-20 & 21-40) have disturbed work intervention due to affected physical and emotional health. Similarly, social interaction has also been affected.

CONCLUSION: This study illustrates that mother of cerebral palsy patient deal with severe physical and mental fatigue. While paying attention only to children's issues, the health of caregiver mothers also needs special considerations.

KEYWORDS: Cerebral Palsy (MeSH); Gross motor function measure (GMFM) -88 (non-MeSH); SF-36 (non-MeSH); Quality of Life (MeSH); Motor functioning (non-MeSH).

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INTRODUCTION

The growth and development of children relates to the series of physical, linguistic, thinking, and emotional modifications occurring in them from birth to adulthood. A kid progresses from dependence on their parents/guardians to increased independence during this phase. Genetic factors and occurrences during prenatal life heavily influence child development.[1] Cerebral palsy (CP) is one such developmental disorder that starts in early adolescence as a set of functional constraints resulting from central nervous system developmental disorders.[2] The present estimated prevalence of CP in advanced countries is 2.0 to 2.5 per 1000 live births.[3]

The word 'Cerebral palsy' used for static brain abnormality during maturation of brain, affects body's motor function. Various etiological factors are responsible for CP like infections, jaundice in infants, hypoxic brain injury during birth.[4] There are four main types of CP including Spastic CP (70-80%), Dyskinetic CP (10-20%), Ataxic CP (5-10%) or combination of these types.[5-8]

Quality-of-life is the perception of individuals place in life in the factors of their cultures and values in which they reside and in regard to their objectives, belief, norms as well as issues. Poor caregiver fitness has adverse consequences for the kid, the family, and the society, leading to lower productivity of work and enhanced health care expenses for the caregiver as well as enhanced facilities and expenses for a child.[9] Taking care of a child with CP may be devastating, resulting in stress and grief as the reality of hopelessness becomes obvious. It has been proclaimed that, along with the emotional disturbance parents have to fight with, they also have to deal with the negative attitudes of friends, relatives and the community. These experiences have been described by mothers of disabled children in advanced nations as well as under developing countries including Asia and Africa.[10] Most of the societies put more responsibilities on mother for bringing up their kids and are the lead supporter of disable ones; so mothers suffer more than fathers by the problems of these children.[11] Mothers often feel guilty and feeling of accountability more than the other family members because of their personality characteristics; thus, they engage in compensation approaches to overcome the disability of their children.[12]

Fatigue is very common among mothers of children with CP and is associated with higher depression rates and lower quality of life (QOL).[13] In reality exhaustion has affected QOL. The presence of pain, physical agility, strength, sleep, social isolation, and emotional reactions among CP child mothers.

In Pakistan, research on QOL of caregivers is very limited. Kumar R, et al showed a very high incidence (49.4%) of depression among mothers of CP

TABLE I: EFFECT OF CHILDREN WITH CEREBRAL PALSY GROSS MOTOR FUNCTION MEASURE ON ACTIVITIES OF MOTHERS

Study Questionnaire Short form 36 (SF-36)		Gross Motor Function Measure (GMFM-88)									
		1 – 20		21 – 40		41 – 60		61 – 80		81 – 100	
		f	%	f	%	f	%	f	%	f	%
Cut down the amount of time spend on work by mothers of children with Cerebral Palsy	Yes	3	8.57	4	11.42	4	11.42	4	11.42	2	5.71
	No	4	11.42	7	57.14	1	2.85	6	17.14	0	0
Mothers were limited in kind of work and other activities	Yes	5	14.28	4	11.42	2	5.71	4	11.42	2	5.71
	No	2	5.71	7	57.14	3	8.57	6	17.14	0	0
Mothers faced difficulty in performing the work or other activities	Yes	5	14.28	8	22.8	4	11.42	4	11.42	2	5.71
	No	2	5.71	3	8.57	1	2.85	6	17.14	0	0
Accomplished less than she would like	Yes	5	14.28	8	22.85	2	5.71	4	11.42	2	5.71
	No	2	5.71	3	8.57	3	8.57	6	17.14	0	0
She didn't do work or other activities as carefully as usual	Yes	7	57.14	8	22.85	3	8.57	4	11.42	2	5.71
	No	0	0	3	8.57	2	5.71	6	17.14	0	0

child.[4] We planned this study to find the association between QOL of mother with CP child and his/her motor functioning after three months of rehabilitation. It will help clinicians and guardians in identifying the most common reasons which could impact the QOL of mothers with CP child.

METHODS

This was a cross-sectional study conducted in Liaqat National Hospital, Karachi, Pakistan from August 2019 to November2019. Total 35 children with CP were recruited through convenience-based sampling of both the genders along with their mothers.

As per the inclusion criteria the age of children with CP considered was between 3 months to 13 years. All the mothers aged between 20-55 years who know diagnosis of CP for their children and participating in their rehabilitation program from at least 3 months were included in the study. Mothers aging less than 20 years and more than 55 years were not included and patients who could not rehabilitate for 3 months were excluded from the study.

Written, informed consent was taken from mothers before inclusion in the study. Demographic details were obtained through a self-administered proforma while to evaluate the overall health status of mothers, Medical Outcomes Study Questionnaire Short form 36 (SF36) was used.

This questionnaire consists of total 11 questions ranging from limited daily activities and household chores of mothers to rating their overall health status. SF-36 has eight scales scores which are basically the weighted sums of the questions in each section. Sections covered in this questionnaire were vitality, physical functioning, bodily pain, general health status, general health perceptions, emotional role functioning, social role functioning and mental health. Total score ranges from 0-100. Lower score means more disability while the higher scores mean less disability.

Moreover, to evaluate the motor function of CP Children with the respective months of rehabilitation, Gross Motor Function Measure (GMFM 88) score sheet was used.

GMFM 88 questionnaire starts with the basic demographic details along with GMFCS level and testing condition. Furthermore, it consists of total 88 questions divided among the categories of: A: Lying and rolling B: Sitting C: Crawling and Kneeling D. Standing E: Walking, running and jumping. At the end of each category questions the calculated scores must need to be mentioned refer to as dimension. The scoring key consist of the following scores: 0 = does not initiate, 1 = initiates, 2 = Partially completed, 3 = Completes, 9 (or leave blank) = not tested (NT). At the end of the form calculation of total dimensions must need to be done.

Another interesting thing in this GMFM88 questionnaire was mentioning the specific aid the child use for ambulatory purpose or for support.[14] Furthermore, the analysis was done using SPSS 21.0 version.

RESULTS

A total of 35 caregiver mothers aware of diagnosis of CP for their children undergoing rehabilitation for last 3 months at least were included in study. Children who were included in study were in between ages of 3 months to 14 years. We evaluate the QOL of mothers with the comparison of current GMFM scores of their children.

While comparing the results of SF-36 in GMFM-88, we found that children's mothers with low GMFM score had a general health deterioration compared to children with higher GMFM score (Table 1). Mothers who are having a child with cerebral palsy, with GMFM between 1-80 had to cut down the amount of time spend on work while mothers whose child's GMFM was between 1-20 were limited in kind of work and other activities as well as they accomplished less than she would like,

TABLE II: ANALYSIS OF COMPLAIN OF BODY PAIN TO MOTHERS DURING PAST FOUR WEEKS IN RELATION TO THE GMFM SCORING OF THEIR CHILDREN WITH CEREBRAL PALSY

Body pain	Gross Motor Function Measure (GMFM-88)									
	1 – 20		21 – 40		41 – 60		61 – 80		81 – 100	
	f	%	f	%	f	%	f	%	f	%
None	0	0	0	0	1	2.85	0	0	2	5.71
Very mild	2	5.71	0	0	0	0	2	5.71	0	0
Mild	0	0	3	8.57	2	5.71	4	11.42	0	0
Moderate	5	14.28	0	0	0	0	4	11.42	0	0
Severe	0	0	6	17.14	1	2.85	0	0	0	0
Very severe	0	0	2	5.71	1	2.85	0	0	0	0

TABLE III: ANALYSIS OF PAIN INTERFERENCE WITH NORMAL ACTIVITY OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY

Interference with Normal activity	Gross Motor Function Measure (GMFM-88)									
	1 – 20		21 – 40		41 – 60		61 – 80		81 – 100	
	f	%	f	%	f	%	f	%	f	%
Not at all	2	5.71	0	0	1	2.85	2	5.71	2	5.71
A little bit	4	11.42	0	0	1	2.85	6	17.14	0	0
Moderate	1	2.85	4	11.42	0	0	0	0	0	0
Quite a bit	0	0	6	17.14	3	8.57	0	0	0	0
Extremely	0	0	0	0	0	0	0	0	0	0

and they didn't do their work as carefully as usual. Due to low GMFM (1-20) of kids' mothers even suffered from moderate level of bodyache (Table II). Likewise, in children's mothers with lower GMFM ratings (1-20 & 21-40) have disturbed normal activity (Table III), social interaction (table VI) & general health (Table V).

DISCUSSION

CP is very common now-a-days in our society and a common cause of childhood disability. Caregivers especially mothers, play a vital role in CP management and their rehabilitation. Due to which they are highly vulnerable to mental, physical and emotional stress.[14] In our study mothers were limited in kind of work and other activities due to stress therefore, sufficient attention must be given to the health of mothers also along with rehabilitation of CP children. In one research a general incidence of anxiety and depressive disorders was recorded in the community population as 34%. Globally, including, Pakistan, surveys revealed an extremely variable incidence of depression among mothers of CP child, ranging from 49.38%[4] and it supports our study because analysis of interference in social activities of mothers due to physical and emotional health showed that mothers faced the interference some of the time in their routine work.

In 2016 one study illustrated that mothers of children with cerebral palsy are at greater risk for having musculoskeletal problems which can cause pain and depression similarly, our study also proved that severity of musculoskeletal pathologies in these mothers, especially those with lower functional level, should be considered.[15]

In our study age range of CP children were very wide-ranging from 3 months to 14 years. While research conducted by Rajesh Kumar et al.[4] selected the age criteria between 3-10 years. Moreover, they used Siddiqui Shah Depression Scale (SSDS) to assess the mental health of disabled children's mothers. whereas we were focused on mother's mental as well as physical and emotional health with social participation so we choose SF-36 Questionnaire for the assessment of these domains. Duration of rehabilitation of CP child wasn't discussed in the previously mentioned study but we included CP child with at least 3 months of rehabilitation. We have also assessed the motor functioning of CP child through GMFM-88, which was not seen in the study discussed above.

Another interesting thing we found was that although mothers found fatigued and tired according to our results but contrary to this their happiness scale was still high and their motivation level was high enough for the rehabilitation of their children. This finding is contrary to previous study that said mothers of children with CP have increased fatigue rates in terms of fatigue severity, fatigue period and QOL intervention.[13] Children's mothers with distinct disability rates tolerate elevated stress levels. Circumstances trigger depression, mental and behavioral issues in CP children's mothers.[12]

Therefore, it is very necessary to optimize the mothers' health by giving them training to cope up with stress, time management and suggesting them appropriate treatment of mental health problems.

Limitations of the study

The limitations of our study were small sample size and difficulty in collecting data because mothers were reluctant to express their original feelings and looked like in a denial phase of grief.

CONCLUSION

This study indicated substantial physical and mental exhaustion by mothers of children with CP. Besides paying attention only to children's problems, there is also need of paying special considerations to the health of care giver mothers.

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TABLE IV: ANALYSIS OF INTERFERENCE IN SOCIAL ACTIVITIES OF MOTHERS DUE TO PHYSICAL AND EMOTIONAL HEALTH

Interference in social activities of mothers	Gross Motor Function Measure (GMFM-88)									
	1 – 20		21 – 40		41 – 60		61 – 80		81 – 100	
	f	%	f	%	f	%	f	%	f	%
All of the time	0	0	0	0	1	2.85	2	5.71	0	0
Most of the time	0	0	4	11.42	2	5.71	0	0	0	0
Some of the time	3	8.57	6	17.14	0	0	2	5.71	0	0
A little of the time	2	5.71	1	2.85	1	2.85	4	11.42	2	5.71
None of the time	2	5.71	0	0	1	2.85	2	5.71	0	0

TABLE V: ANALYSIS OF GENERAL HEALTH OF MOTHERS OF CHILDREN WITH CEREBRAL PALSY WITH DIFFERENT GMFM SCORE

General health of mothers		Gross Motor Function Measure (GMFM-88)									
		1 – 20		21 – 40		41 – 60		61 – 80		81 – 100	
		f	%	f	%	f	%	f	%	f	%
My General Health Is Excellent	Definitely true	0	0	0	0	0	0	2	5.71	0	0
	Mostly true	0	0	1	2.85	3	8.57	2	5.71	2	5.71
	Don't know	4	11.42	0	0	0	0	2	5.71	0	0
	Mostly false	3	8.57	8	22.85	0	0	4	11.42	0	0
	Definitely false	0	0	2	5.71	2	5.71	0	0	0	0

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AUTHOR'S CONTRIBUTION

Following authors have made substantial contributions to the manuscript as under:

NF: Acquisition of data, drafting the manuscript, critical review, approval of the final version to be published

SHAR & NP: Analysis and interpretation of data, drafting the manuscript, approval of the final version to be published

ZJ: Conception and study design, Acquisition of data, drafting the manuscript, approval of the final version to be published

SB: Acquisition, analysis and interpretation of data, critical review, approval of the final version to be published

Authors agree 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.

CONFLICT OF INTEREST

Authors declared no conflict of interest

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DATA SHARING STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.