

## Parent Stress in Relation to Activities of Daily Living and Gross Motor Impairments in Children with Diplegic Cerebral Palsy

Ahmed F. Salman<sup>\*1</sup>, Khaled A. Mamdouh<sup>2</sup>, Walaa A. Abd El-Nabie<sup>2</sup>, Hoda A. El Talawy<sup>2</sup>

<sup>1</sup>Department of Physical Therapy for Pediatrics, Faculty of Physical Therapy, May University in Cairo.

<sup>2</sup>Department of Physical Therapy for Pediatrics, Faculty of Physical Therapy, Cairo University.

\*Corresponding author: Ahmed F. Salman, Mobile: +201067873174, Email: ahmed.fekry@muc.edu.eg

### ABSTRACT

**Background:** Cerebral palsy is the most common cause of motor disability in children. Parents of children with cerebral palsy experience more stress than parents of typically developed children. The aim of the current study is to find out the relation of parent stress between activities of daily living and gross motor limitation in children with diplegic cerebral palsy; and investigate the relation between parent stress and their quality of life.

**Patients and Methods:** A cross sectional study of 107 children with diplegic cerebral palsy, aged from 2-4.8 years, assigned to two groups; *Group A* included ambulant children on level I, II and III on gross motor function classification system, while *Group B* included non-ambulant children on level IV and V. Parent stress and quality of life was assessed by parenting stress index – short form and pediatric quality of life inventory family impact module respectively, while activities of daily living and gross motor impairment were assessed by Wee functional independency measure and gross motor functional classification system respectively.

**Result:** There was a positive correlation between parent stress and gross motor limitation in Groups A and B ( $r= 0.865$  and  $0.489$ , respectively). In addition, there was a positive correlation between parent stress and quality of life in Groups A and B ( $r= 0.982$  and  $0.785$ , respectively). Negative correlation between parent stress and activities of daily living (required total score) in Groups A and B ( $r= -0.911$  and  $-0.811$ , respectively) also was found.

**Conclusion:** Activities of daily living and gross motor limitation may have an effect on parent stress.

**Keywords:** Activities of daily living, Cerebral palsy, Motor impairment, Parent stress, Quality of life.

### INTRODUCTION

Cerebral palsy (CP) is described as a group of permanent disorders of the development of movement and posture, attributed to non-progressive injury or abnormal development occurring in the fetal or infant brain <sup>(1)</sup>. Spastic diplegia is one of the most common clinical subtypes of CP, where motor impairment and spasticity is more severe in the lower than upper extremities and a significant weakness in the trunk <sup>(2)</sup>. The worldwide incidence of CP is approximately 2 cases per 1000 live births and 44 % of total incidence is spastic diplegic of CP <sup>(3)</sup>.

Gross motor disorders are the main problem in children with CP, seizures, as well as sensory, cognitive, and communication issues, may accompany these disorder <sup>(4)</sup>. Moreover, children with CP always have limitations in self-care functions, such as feeding, dressing, bathing mobility and locomotion. These limitations may lead to long-term care requirements that far exceed the usual needs of children during their development <sup>(5)</sup>.

Functional deficits in children with CP make it difficult for children to fulfill their roles in society and thus affect their quality of life, besides the physical limitations of the child; a life-long treatment process can affect psychosocial development and daily life activities by isolating the child from family and society. The functional level of the child with CP and the level of proficiency in activities of daily life are crucial factors in establishing and tracking rehabilitation goals or in deciding the rehabilitation program's structure <sup>(6)</sup>.

Parent stress (PS) is a negative psychological response to the obligations of being a parent <sup>(7)</sup>, caring for a children with CP entails high physical, financial

and emotional demands and these family functioning variables are strong predictors of overall PS <sup>(8)</sup>.

The stress resulting from dealing with a child with CP is a primary risk factor for the development of psychosocial problems in both the affected child and family members. These stresses may be the result of actual disease parameters, such as severity and as a result of the child functional limitations <sup>(9)</sup>.

Caregivers of children with CP who had a limitation in activities of daily living (ADL) are faced with ongoing difficulties and complications arising from their children's impairment, they are often unable to provide for their own physical and mental needs, and are more likely to experience caregiver stress and low quality of life <sup>(10)</sup>.

Caring for a child, with a limitation in gross motor activities, impacts many aspects of a parent's life including physical, social, and emotional health, wellbeing, marital relationships, employment, and financial status. It requires a considerable amount of physical and mental effort and is associated with physiological and psychological costs <sup>(11)</sup>.

Due to lacking of the research on measuring PS and its relation to ADL and gross motor limitation in children with diplegic CP, therefore the purpose of this study is to explore the relation between these variables.

### PATIENTS AND METHODS

#### Patients:

The current study was registered on one hundred and seven children with diplegic CP aged from 2 years to 4.8 years old. All children were medically and clinically stable and represent all level of Gross Motor Function Classification System (GMFCS), children

were assigned in two groups, group A (sixty seven ambulant children on level I, II, III on GMFCS) and group B (forty non-ambulant children on level IV, V on GMFCS). They were recruited from the Physical Therapy Department of the National Institute of Neuromotor Disorders, the Outpatient Clinic of the Faculty of Physical Therapy at Cairo University and Abu El-Reesh Hospital, in the periods from January 2021 to May 2021.

Children were excluded if they had one or more of the following: behavioral issues, a history of persistent heart or chest disease, significant visual or auditory impairment, botulinum toxin injection at last six months prior to the study and those whose parents were illiterate.

### **Sample size estimation:**

A pilot study involving 37 kids served as the basis for conducting sample size estimation. A sample size of 107 parents of children with diplegic CP would be achieved 80% power and correlation coefficient (r): -0.226 and coefficient of determination (r<sup>2</sup>):0.072, with significance level of 0.05 using a tow-tail exact correlation bivariate normal model.

### **Outcome measures:**

#### ***1- Parent stress:***

It was measured by utilizing the Arabic version of parent stress index–short form (PSI-SF), which is a valid and reliable questionnaire and could be integrated as a part of screening and intake assessment of PS <sup>(12)</sup>. Parent stress index–short form consists of 36-item, self-reported questionnaire; the range of total scores varies from 36 to 180. Parents were instructed to carefully read each statement, concentrate on it, and circle the appropriate response that best suited their psychological situation concerning their child. Participants answers according to a 5-point likert scale 1 (strongly agree), 2 (agree), 3 (not sure), 4 (disagree) and 5 (strongly disagree). Parents had chosen only one response per item. Parents, who had score of 85 or more, were categorized as stressed parents according to **Abidin and Brunner** <sup>(13)</sup>.

#### ***2- Gross motor impairments:***

It was measured by Gross motor function classification system. It is a valid and reliable scale in clinical practice and research <sup>(14)</sup>. It consists of 5-levels of gross motor function based on self-initiated movement, with emphasis on sitting, transfers, walking and wheeled mobility <sup>(15)</sup>.

The optimum level of the child was selected by monitoring the child motor activities in a calm and suitable environment to the child. The scoring of each child was as the following according to **Wood and Rosenbaum** <sup>(16)</sup>:

- Level I: represents walking without restrictions with limitations in more advanced gross motor skills.
- Level II indicates walking without assistive devices with limitations, walking outdoors and in the community.
- Level III: indicates walking with assistive mobility devices with limitations, walking outdoors and in the community.

#### **Non ambulant child (level IV, V):**

- Level IV indicates self-mobility with limitations; the patient is transported or uses power mobility outdoors and in the community.
- Level V indicates that self-mobility is severely limited even with assistive technology.

#### ***3- Activities of daily living:***

It was measured by Wee functional independency measurement (WeeFIM), validity and reliability of WeeFIM were verified for children with CP <sup>(17)</sup>. It consists of six subsets with a total of 18 measurement items. The subsets are categorized as self-care (six items), sphincter control (two items), transfers (three items), locomotion (two items), communication (two items) and social cognition (three items). In the present study only self-care, transfer and locomotion domains were measured. Assessment had been performed by direct observation of the child in a quit and calm environment. However, interviewing parents who are familiar with the child's daily activities is vital when direct observation was not available <sup>(18)</sup>. Each item of the subsets is scored on a scale of 1 - 7, where 1 indicates total assistance and 7 shows complete independence. The minimum total score is 11 (total dependence in all skills) and the maximum required score is 77 (complete independence in all skills) <sup>(19)</sup>.

#### ***4- Quality of life:***

It was measured by quality of life inventory, family impact module (PedsQL) <sup>(20)</sup>. It consists of 36 items across 8 dimensions, it includes 6 subscales measuring parents' self-reported functioning: physical functioning (6 items), emotional functioning (5 items), social functioning (4 items), cognitive functioning (5 items), communication (3 items) and worry (5 items); as well as 2 subscales measuring parent- reported family functioning: daily activities (3 items) and family relationships (5 items) <sup>(21)</sup>. Assessment was applied by asking the parent to read each statement carefully. Parent was asked to focus on each sentence and circle the number that had best suits him/her, a 5-point response scale was utilized (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem), lower scores had reflected better health related quality problems <sup>(22)</sup>. To calculate the total score of the questionnaire, all scores of each item in the scale 8 domains were added <sup>(23)</sup>.

#### **Ethical approval:**

### **Ambulant child (level I, II, III)**

This cross-sectional study was approved by the Ethical Committee of the Faculty of Physical Therapy, Cairo University. Agreement (NO:P.T.REC/012/003167) was obtained before starting the procedure of the study.

The current study was registered on clinicaltrials.gov (ID: NCT04938063). In addition, participation in the current study had been authorized by asking the parents to sign a consent form prior to data collection. This work has been carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for studies involving humans.

**Statistical analysis**

SPSS for Windows, version 26, was used to conduct the statistical analysis (SPSS, Inc., Chicago, IL). Data were checked for the normality assumption, homogeneity of variance, and the existence of extreme scores before final analysis. This exploration was done as a pre-requisite for parametric calculations of the analysis of difference. Preliminary assumption checking revealed that data was not normally distributed for all measured variables, as assessed by Shapiro-Wilk test ( $p \leq 0.05$ ).

The levene's test of homogeneity of variances indicated that there was homogeneity of variances ( $p > 0.05$ ) and covariances ( $p > 0.05$ ). Accordingly, non-parametric statistics were used. The Spearman rank correlation coefficient was used to investigate the relationship between the PS, WeeFIM domains (Selfcare, Transfer, Locomotion and total score), and GMFCS level. The alpha level was set at 0.05 and the correlation coefficients were interpreted as 0-0.1 = very low, 0.10-0.30 = low, 0.30-0.50 = moderate, 0.50-0.70 = high, 0.70-0.90 = very high, and 0.90-1.0 = strong.

**RESULTS**

As showed in **Table (1)** the demographical data of both groups including participant: GMFCS levels, gender, consanguinity and birth order distribution. Regarding Group A, 67 ambulant children with diplegic CP participated in the present study.

There were 29 girls and 37 boys, number of children was assigned to GMFCS level I, II and III was 15, 21, and 31, respectively, number of children with 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>, 4<sup>th</sup> and 5<sup>th</sup> birth order was 27, 13, 17, 8, 2, respectively. Regarding their parents, there were 17 parents was in a positive consanguinity and 50 were in a negative consanguinity. Regarding Group B, 40 non-ambulant children with diplegic CP and their parents had participated in the present study.

There were 16 girl and 24 boys, 39 children were assigned to GMFCS level IV, 1 to level V, number of children with 1<sup>st</sup>, 2<sup>nd</sup>, 3<sup>rd</sup>, 4<sup>th</sup> and 5<sup>th</sup> birth order was 16, 9, 10, 4 and 1, respectively. Regarding their parents, there were 10 parents were in a positive consanguinity and 30 were in a negative consanguinity.

**Table (1): Characteristics of participants in both groups.**

Variable		Group A (ambulant child) N=67 (%)	Group B (non- ambulant child) N=40 (%)
Sex distribution	Girls	29 (43.28%)	16 (40%)
	Boys	38 (56.7%)	24 (60%)
Parent Consanguinity	Positive	17 (25.37%)	10 (25 %)
	Negative	50 (76.62%)	30 (75%)
GMFCS distribution	Level I	15 (22.38%)	0
	Level II	21 (31.34%)	0
	Level III	31 (46.26%)	0
	Level IV	0	39 (97.5%)
	Level V	0	1 (2.5%)
Child's birth order distribution	Frist	27 (40.2%)	16 (40%)
	Second	13 (19.4%)	9 (22.5%)
	Third	17 (25.3%)	10 (25%)
	Fourth	8 (11.9%)	4 (10%)
	Fifth	2 (2.9%)	1 (2.5%)

As showed in **Table 2**, in Group A, there was a strong negative correlation between PSI and Wee FIM (Self-care, transfer, locomotion and total score) ( $r = -0.871, -0.809, -0.903, \text{ and } -0.911$ , respectively). There was a strong positive correlation between PSI to GMFCS and PedsQL as ( $r = 0.865, \text{ and } 0.982$ , respectively).

**Table (2) Correlation between PSI to WeeFIM and GMFCS level in Group A:**

Variable		WeeFIM (self-care)	WeeFIM (Transfer)	WeeFIM (Locomotion)	WeeFIM (Total score)	GMFCS	PedsQL
PSI	r value	-0.871	-0.809	-0.903	-0.911	0.865	0.982
	p value	0.0001	0.0001	0.0001	0.0001	0.0001	0.0001

R value= Pearson correlation coefficient

P > 0.05 = significant

As shown in **Table 3**, in Group B, there was a strong negative correlation between PSI and WeeFIM (Self-care, transfer, locomotion and total Score) ( $r = -0.690, -0.795, -0.729, -0.811$ ), respectively. There was a moderate positive correlation between PSI and GMFCS ( $r = 0.489$ ). Finally there was a strong positive correlation between PSI and PedsQL as ( $r = 0.785$ ).

**Table (3): Correlation between PSI to WeeFIM and GMFCS level in Group B:**

Variable		WeeFIM (self-care)	WeeFIM (Transfer)	WeeFIM (Locomotion)	WeeFIM (Total score)	GMFCS	PedsQL
PSI	r value	-0.690	-0.795	-0.729	-0.811	0.489	0.785
	p value	0.0001	0.0001	0.0001	0.0001	0.0001	0.0001

R value= Pearson correlation coefficient

P > 0.05 = significant

## DISCUSSION

The present study was carried out to investigate the relation between both of ADL impairment and gross motor limitation in diplegic CP children and the level of their parents' stress, and to detect the impact of PS on the Quality of their life.

The age range of 2 to 4.8 years was selected because it was thought that the greatest increase in functional abilities and gross motor development in children with CP occurs between these age ranges (24).

The results of the current study showed that there was a positive correlation between PS and gross motor limitation in children with diplegic CP in both groups, these findings showed that gross motor disabilities in those children affected significantly the psychological status of their parents, while there was a negative correlation between PS to their QoL and ADL limitation of children in both groups, which revealed that the functional independence limitations those children were inversely proportional to parent stress, and experiencing stress of parents would negatively affect their quality of life. The positive relation between PS and gross motor limitation may be due to that parents spent a substantial amount of time in managing their CP child's gross motor limitation as chronic health problems and perform this role along with the requirements of everyday living. Thus, the parents caring for their child with CP may impair their own life while attempting to improve that of their child.

This positive correlation come in agreement with the findings of **Guard et al.** (25) and **Fritz and Roberts** (26) who had reported that parent stress was significantly affected by limitation in the gross motor activities in the children with CP.

The negative relation between PS and ADL may be because of the caregiving process was carried on an entirely different significance when a child experiences functional limitations and possible long-term dependence which make additional responsibilities for parents and additional stress. Moreover, the CP diagnosis changes the family routine as it requires a number of behavioral changes to meet the child's needs. Depending on the severity of ADL limitation which leads to constant care (food, clothing, consultations, and rehabilitation) for longer periods reduces the caregiver's time for themselves and their

professional activities, making them feel physically and psychologically overloaded (27-29).

Despite the direct negative impact of ADL and gross motor limitation on PS, **Skok et al.** (30) and **Ho et al.** (31) mentioned that the severity of disability was not significantly related to maternal wellbeing and stress, which could be due to the buffering effect of the social and financial support that found to have a slight to moderate role in mediating the impact of stress on these parents and improve their wellbeing.

Regarding the negative relation between PS and their QoL, these results may be because of the main challenges for parents to manage their child's chronic health problems effectively while maintaining the requirements of everyday living, therefore, mothers who reported higher levels of both marital QoL have described less parental distress (32-33). Moreover, parent stress is not only affect the QoL of the parents but also affect the QoL of their children (34).

The main limitations of the present study were: (1) there wasn't age strata for each age group in WeeFIM. (2) Some items in WeeFIM (dressing upper and lower body) cannot be conducted completely by the evaluators because of culture and religious issues.

Future studies should highlight the relation between PS to the severity of ADL and gross motor limitation in other deferent age group, different types of CP, different child characteristics (behavioral and cognitive level abnormality), and other ADL domains (sphincter control, communication and social cognition).

**In conclusion**, activities of daily living and gross motor limitation may have an effect on parent stress.

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