

# Factors Affecting Mother's Adherence towards Cerebral Palsy Home Exercise Program among Children at Hebron and Bethlehem, Palestine

MOHAMMED TAHAYNEH<sup>1\*</sup>, SYEDA HUMAYRA<sup>2</sup>, ABDOUL AZIZ FALL<sup>3</sup>, HANNAH ROSLAND<sup>4</sup>, AKRAM AMRO<sup>5</sup>, ABDELKODOSE MOHAMMED<sup>6\*</sup>, ABD. LATIFF MOHAMED<sup>7</sup>

<sup>1-7</sup>Faculty of Medicine, University of Cyberjaya, Persiaran Bestari, Cyber 11, Cyberjaya, Selangor, Malaysia.

<sup>5</sup>Faculty of Health Professions, Physiotherapy Department, Al Quds- University, Palestine.

\*Corresponding Author

Email ID: matahaini@yahoo.com, latiff@cybermed.edu.my

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## ABSTRACT

The incidence of cerebral palsy is significantly growing in children, especially among specific spasticity C.P children at south west bank (Hebron and Bethlehem) areas in Palestine. This serious health concern disrupts the active daily living (ADL) among C.P children and affects the lives of their families, both socially as well as economically. The aim of this study was to investigate the factors associated with mother's adherence towards cerebral palsy home exercise program among children at Hebron and Bethlehem city. We did a clinical trial among the cerebral palsy children at Al- Caritas hospital and Al- Ihsan rehabilitation centre. The study participants were children with cerebral palsy (mild to moderate spasticity) followed up at Al-Ihsan rehabilitation centre in Hebron city and Al-Caritas hospital in Bethlehem city. The calculated sample size was 48 participants. Data were collected at two different time periods, one at baseline right before implementing the rehabilitation program and another at six-month' time interval after the intervention was carried out. Our results indicated that there was no significant association between mother's age and adherence towards home exercise program ( $p=0.946$ ). Furthermore, there were no significant differences among mothers' adherence to rehabilitation program in relation to socioeconomic status ( $p= 0.415$ ), work ( $p= 0.704$ ) and their level of education ( $p= 0.265$ ). This study deduced that all mothers with C.P children were strongly committed towards the implementation of home exercise program regardless of their age, work, education level and financial background.

**Keywords:** Cerebral Palsy, Home Exercise Programs, Hebron and Bethlehem.

## INTRODUCTION

Cerebral palsy (C.P) defines a group of continuous motion and posture developmental disorders that cause restriction of activity attributable to non-progressive disorders in the growth of lethal or infant brain (Rajesh, Li, & Kong, 2015). It is often described as cognition, communication, feeling, behaviour and perception disturbances associated with musculoskeletal as well as epileptic issues (Bax et al., 2005). Since mid-1940s, founders of the American Academy of C.P and Developmental Medicine- Carlson, Crothers, Deaver, Fay, Perlstein, and Phelps (U.S); and the Little Club's Mac Keith, Polani, Bax, and Ingram (U.K) were among the finest leaders who introduced basic concepts of C.P and lead its path towards treatment, advocacy and resistance (Rosenbaum et al., 2007). Spastic Cerebral Paralysis is the most common form of C.P, where damage to the motor cortex causes spasticity in the muscles, joints as well as tendons, and the pyramidal tract damage has a similar effect to damaged motor

cortex (Miller & Bachrach, 2017). Spasticity is the most prevalent movement disorder in C.P, caused due to inadequate release of gamma amino butyric acid (GABA) in the spinal cord. The objectives of spasticity therapy may differ based on severity and magnitude of the muscles involved, so should be defined before initiating therapy (Albright et al., 2003). Several classifications exist based on neurological signs and topography, on motor function loss, on associated disabilities, on severity of the clinical pattern and on the neuro imaging findings. The prevalence of C.P is around 2 per 1000 live births in developed and developing countries, with a direction leading towards reduction over the last ten years, at least for the severe subgroups and in very small babies. More attention is required on interpreting these changes in prevalence rates as several factors may influence these estimates. (Blair, Cans, & Sellier, 2018). In Palestine, births have risen from 55673 in 2012 to 65997 in 2014 (PCBS, 2015), and the incidence of cerebral

palsy represents nearly about 3.6 percent of the entire disabled population (PCBS, 2000).

Home exercise programs (HEP) are basically lifelong activities that are facilitated for better functioning in children with cerebral palsy (Basaran et al., 2013). Lack of adherence towards treatment can lead to unfavourable outcome and excessive healthcare cost. Identification of these factors would minimize non-adherence and produce better results in overall treatment (Jack et al., 2010). Family is the main factor to be responsible for the child's growth and development. All family members are affected when there is an individual with special needs (Fewell & Vadasy, 1986), and face distinctive stressors in providing C.P child with lifetime care (M. A. Mc Cubbin & Huang, 1989).

## MATERIAL AND METHODS

A randomized-controlled trial (RCT) was used for study design while a randomization sampling procedure was applied to recruit the study participants. The study was conducted at the southern west bank area in Palestine; it mainly involved two reputed healthcare services that were Al-Ihsan rehabilitation centre and Caritas hospital. Our study aimed to assess the factors such as mother's age, level of education, job and socioeconomic status in relation to her adherence towards C.P children home exercise program.

We recruited a total of 48 study participants, mainly mothers having a child with cerebral palsy followed up until a period of 6-months.

The study population involved all cerebral palsy children both male and female, between 1 to 3 years of age with mild to moderate spasticity C.P among Caritas hospital and Al Ihsan rehabilitation centre. While all children below one year and above three years, with or without C.P and/or with severe spasticity were excluded from the study. Mothers interested to participate in the study, were enrolled at two health-care centres, Caritas Hospital for rehabilitation of the disabled in Bethlehem (n=24) and Al-Ihsan rehabilitation centre in Hebron city (n=24) through convenience sampling method. Home exercise program was conducted to improve the functional level of C.P children and facilitate mothers in a systematic approach. Data were collected using questionnaire and interview-based design utilized on a small cohort of 48 mothers who performed home program exercises and physiotherapy sessions with C.P children. Self-reported questionnaires were administered to assess the mothers' adherence towards rehabilitation

program at home, and scoring was done on a 5-point Likert scale (5 strongly agree, 4 agree, 3 moderate, 2 disagree, 1 strongly disagree) based on their commitment towards implementation, relationship with family and society. The validity and reliability of questionnaire, and the required filling time were measured. The Gross Motor Function Measure (GMFM) was used to evaluate changes in gross motor function among children with cerebral palsy, while Ashworth Scale was used to measure the level of spasticity for cerebral palsy. Data analysis was carried out using Statistical Package for Social Sciences (SPSS) software version 23.0. Frequencies and percentages were calculated for all categorical variables according to the study demographic variables. Ethical clearance was obtained from the higher authorities at Palestinian Ministry of Health before initiating this study. Written consent was taken from all participants and they were at liberty to withdraw any time during the study period and without giving a reason. Collected data were safely stored by strictly maintaining participants' anonymity and confidentiality.

## RESULTS

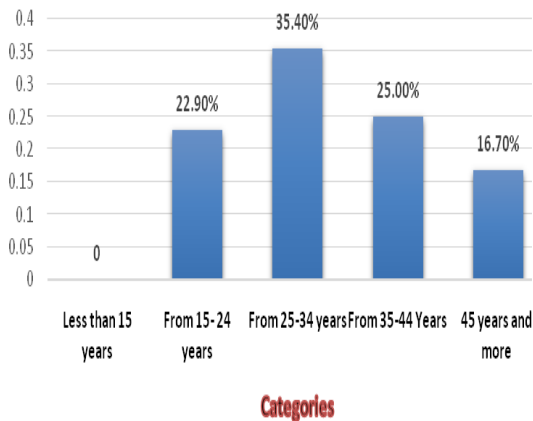
The results showed that 62.5% mothers were housewives and 37.5% were working. About 35.4% mothers were aged between 25-34 years, 22.9 % between 15-24 years, 25% were 35-44 years old, and 16.7% of them were above 45 years old (Table I and Figure 1).

Based on their academic qualifications, 20% of mothers had diploma degree, 20% had high school certificate, 26.7 % had bachelor's degree, whereas 6.7% of them master's degree, and 6.7% had PhD degree (Table I and Figure 1).

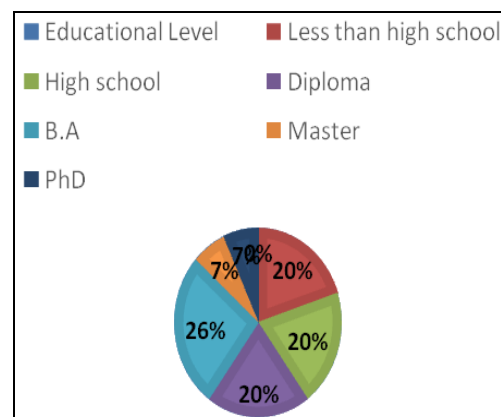
The analysis showed that 43.8% of the children were from cities, 27.1% from town, 18.8% village and 10.4% were from rural area. Also, 50% of the children were treated at the Caritas hospital and 50% at the Al-Ihsan rehabilitation centre (Table I). The results also showed that the average number of family members were 5, and the number of children presented with cerebral palsy in all families were 1 (n= 48, 100%). Furthermore, 47.9% of the families had income between \$401-999 per month and 37.5% had income above \$1000 per month (Figure 1). In addition, the analysis also revealed that 75% of the families lived in their own houses while 25% lived in rented homes. All of the study participants' families had one child with cerebral palsy (Table I).

**Table I: Socio-Demographic Characteristics of Participants**

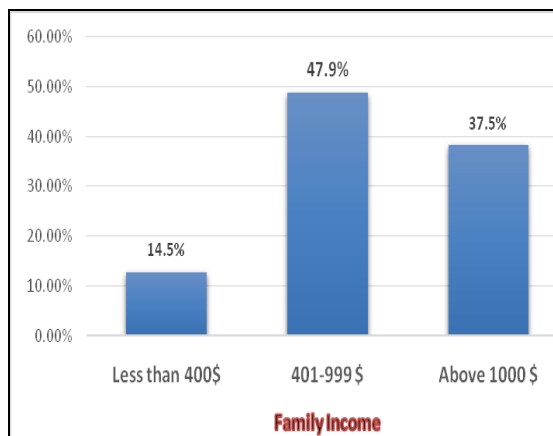
Variable	Classifications	Frequency (%) N=48
	From 15- 24 years	11(22.9%)
	From 25-34 years	17 (35.4%)
	From 35-44 Years	12 (25.0%)
	45 years and more	8(16.7%)
District	Hebron	24(50%)
	Bethlehem	24 (50%)
Address	City	21 (43.8%)
	Town	13 (27.1%)
	Village	9 (18.8%)
	Rural	5 (10.4%)
Are you a house-wife?	Yes	30 (62.5%)
	No	18 (37.5%)
Number of years of work	Did not work	30 (62.5%)
	Less than 1 Year	8 (16.7%)
	From 1-5 Years	7(14.6%)
	From 6-10Years	3 (6.3%)
Educational Level	Less than high school	9 (20.0%)
	High school	9 (20.0%)
	Diploma	9 (20.0%)
	B.A	12 (26.7%)
	Master	3 (6.7%)
	PhD	3 (6.7%)
Number of family members	5 ± 2.3	
Family income per month(dollars)	Less than 400\$	7 (14.6%)
	401-999 \$	23 (47.9%)
	Above 1000 \$	18 (37.5%)
Home	Owned	36 (75.0%)
	Rented	12(25.0%)
Number of floors of the house	Ground floor	17 (35.4%)
	One floor	17(35.4%)
	2 or above	14 (29.2%)
Age of children with cerebral palsy	1-2 Years	20 (42.6%)
	2-3 Years	13 (27.7%)
	3 Years	14 (29.8%)
Hospital	Caritas Hospital	24 (50%)
	Al-Ihsan rehabilitation	24 (50%)



**Fig.1: Sample Distribution According to Mother's Age**



**Fig.2: Sample Distribution According to Educational Level**



**Fig.3: Sample Distribution According to Socioeconomic Status**

We further conducted a one-way ANOVA test to determine the association between mothers' age and their adherence to rehabilitation program. Our analysis showed that there were no significant differences observed in mother's adherence towards rehabilitation program in relation to age,  $p = 0.946$ ; which means that mothers have the same commitment of applying home exercise program regardless their age. (Table II)

**Table 2: Means and Std. Deviation of mother's adherence to rehabilitation program in relation to mother's age**

Age Category	N	Mean	Std. Deviation
From 14-24 years	10	4.0	0.40637
From 25-34 years	17	4.0	0.29130
From 35-44 years	12	4.0	0.40590
45 years and more	8	3.9	0.27386
Total	48	4.0	0.33704

One-way Anova test was done to assess the relationship between socioeconomic status and mother's adherence to rehabilitation program. The analysis showed that there were no significant differences for mothers' adherence to rehabilitation program with socioeconomic status, as  $p = 0.415$ . We deduced that mothers have the

**Table 5: Results of Independent Sample t-test to compare mother's adherence and work**

	Mother work	N	Mean	Std. Deviation	t-value	DF	Sig. (2-tailed)
Adherence to rehabilitation program	Yes	30	4.0	0.36964	-0.383	45	0.704
	No	17	4.0	0.27908			

## DISCUSSION

The establishment of Home Exercise Programs (HEPs) for children with disabilities has been considered as a worldwide resource that leads to

an increase in practical functioning (Myrhaug et al., 2014). The HEPs prescribed for children are mostly individualised, depending on family goals and necessities, thereby include different

same level of commitment towards applying home exercise program regardless of socioeconomic status as shown in Table III, below.

**Table 3: Means and Std.Deviation of the Mother's Adherence to Rehabilitation in Relation to Socioeconomic Status**

Income Category	N	Mean	Std. Deviation
Less than 400\$	6	4.1	0.34448
From 401-999 \$	22	3.9	0.33514
1000 \$ and above	18	4.0	0.34008
Total	46	4.0	0.33743

We also evaluated the association between educational level and mother's adherence to rehabilitation program by using one-way Anova test. The analysis revealed that there was no statistical significance in mother's adherence and level of education (as  $p = 0.265$ ), Table IV.

**Table 4: Means and Std. Deviation of the Mother's Adherence to Rehabilitation Regarding to Educational Level**

Educational Level Category	N	Mean	Std. Deviation
Less than high school	9	4.0	0.28223
High school Diploma	8	3.9	0.36130
B.A	9	4.2	0.25712
Master	12	3.9	0.34143
PhD	3	3.8	0.23629
Total	3	4.2	0.27538
Total	44	4.0	0.31511

An independent sample t-test was conducted to see the differences observed for mother's adherence to rehabilitation program in comparison to work. The results showed that there was no significant association between adherence to rehabilitation program and mother's work, as  $p = 0.704$  (Table V).

an increase in practical functioning (Myrhaug et al., 2014). The HEPs prescribed for children are mostly individualised, depending on family goals and necessities, thereby include different

mechanisms or types of therapeutic exercises and interventions (Novak and Berry, 2014). Adherence can be defined as active, voluntary participation of the patient for collaborative and productive therapeutic results (Ho, Bryson and Rumsfeld, 2009). The adherence related to rehabilitation program that includes physiotherapy and occupational therapy, depends on home-based patient behaviour and clinical adherence (S Frances Bassett, 2003). It is well-established in existing literature that adherence is a desirable behaviour; which is essential for achieving the goals of an HEP. However, in most HEP setups for children, the parental adherence is less than 50% (Lillo-Navarro et al., 2019). Mothers play a significant role in the process of rehabilitation and implementation of home exercise programs for cerebral palsy children. Despite being highly organized in taking care of C.P child, most mothers often face difficulties in finding an affordable rehabilitation centre that can enhance their child's active daily life (ADL) and train them properly. In such circumstances, it's essential to create awareness among mothers, facilitate and encourage them to practice home exercise program for better quality of life among C.P children. Factors such as mother's age, work, educational qualification and financial background may affect the expected outcome in terms of adherence towards home exercise programs. Mother is the foremost person accountable for the development of a child; hence her commitment during home therapy sessions and her relationship with family and society can also have an effect upon the implementation of rehabilitation program. Therefore, our study aimed to identify those factors and promote better adherence among mothers with C.P children.

Socioeconomic status (SES) is a major health determinant among all age groups, especially in children. In comparison to peers with higher SES, children from impoverished homes are more prone to developing acute and chronic illnesses such as obesity and asthma (Ruijsbroek et al., 2011), mental disorders (Goodman, 1999) and developmental disabilities. (Najman, Bor, Morrison, Andersen, & Williams, 1992). However, strong evidence lacks regarding the effectiveness of HEP in relation to SES as it's not been identified as a significant predictor for adherence. But another research stated that patients with higher SES may have higher adherence rates (Gajdosik and Campbell 1991; Nuccio and Milstein 2019). Previously some studies were conducted to determine the factors that influenced HEP adherence. Some study had similar findings like ours whereby factors such as age, socioeconomic

status, educational status and employment of the caregiver, were all found to be non-predictive of adherence (Rone-Adams et al., 2004; Basaran et al., 2013).

Our analysis showed that the level of mother's commitment towards implementation of home therapy exercises for children with cerebral palsy was high with mean value of 3.96. All mothers regardless of their age, work, level of education and living standards committed to the HEP with the same amount of dedication.

## CONCLUSION

In order to enhance patient compliance, several strategies may be employed. First, offering specific verbal directions, assessing the patient's recall and promoting it with extra written instructions may be efficient in emphasizing adherence to exercises (McLean et al., 2010).

It may also be beneficial to use motivational methods such as counselling sessions, positive feedback, rewarding, written therapy contracts and exercise diaries, to set objectives and draw up action plans as well as coping plans that have been agreed collaboratively between the clinician and the patient or with clients who intend to participate (Sandra F Bassett & Petrie, 1999). Using approaches such as agreeing to realistic expectations, setting forth objectives for therapy, coping action planning, and positive reinforcements can lead to patient self-efficacy and adherence (Göhner & Schlicht, 2006).

We conducted this study to enhance the functional level in C.P children and implemented home program exercises to train their mothers through a more holistic approach. This practice among mothers will provide better quality of life for C.P children and comfort for the entire family.

This study will help to demonstrate the importance of adherence and implementation of home program exercises in improving the functional level of C.P children in south West Bank. It will also contribute in the development of home therapy exercises and help to improve the current situation of cerebral palsy in Palestine.

Home program exercises for C.P may lead to cost reduction and support families to overcome the socioeconomic burden. Therefore, the utilization of home exercise programs in training mothers with cerebral palsy children should be strongly encouraged in both local and international hospitals and rehabilitation centres.

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