

Caregiver Adherence to A Home Exercise Program for The Care of Children with Cerebral Palsy

Diana S. Lalithabai^{1*}, Wael M Ammar², Khalid S. AlGhamdi³, Manal A AlGhouth⁴, Tariq A Wani⁵

¹*Nursing Education Administration, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

²Nursing Education Administration, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

³Executive Administration of Nursing Affairs, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

⁴Physical Therapy Department, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

⁵Biostatistics Department, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

***Corresponding Author:-** Diana S. Lalithabai

^{*}Nursing Education Administration, King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

Background: Home exercise programs (HEP) are essential in managing cerebral palsy (CP), and caregivers who care for the children at home play a significant role in HEP. But, some factors contribute to adhering to home exercise programs (HEP). It is essential to identify the factors associated with adherence. This research aims to assess caregiver adherence to home exercise programs for children with cerebral palsy and the factors influencing it.

Methods: The research was conducted with 150 participants using a cross-sectional survey design. A previous study's self-reported questionnaire examined the caregivers' adherence to the home exercise program and the factors contributing to adherence by the caregivers.

Results: The study found that most caregivers 129 (89.6%) had a thorough knowledge of the exercise program. However, 92 (63.9%) caregivers were non-adherent, while only 52 (36.1%) were adherent to the exercise program and could not predict any significant association with their sociodemographic characteristics. Both the groups (non-adherent and adherent reported overall satisfaction with the attention from the physiotherapist. Backward step regression also predicted the significant association of non-adherence with the parent as caregiver. The factors that influence adherence to the home exercise program were knowledge about the home exercise program 'confidence in performing the home exercise program and support from the partner.'

Conclusion: The study concludes that the low adherence to the home exercise program was caused by several factors involving the caregiver, the therapist, and the exercise regimen. Exercise therapy knowledge, parents' confidence, and support from the partner enhanced adherence to exercise therapy.

KeyTerms: Cerebral palsy, caregiver, adherence, home exercise programs, rehabilitation

1. Introduction

Children with CP, a neurological disorder, rely almost exclusively on others to do their daily chores (Zanon & Batista, 2012; Davis et al., 2010). The prevalence of CP in Saudi Arabia is 0.41% (Al-Asmari et al., 2006). CP is a non-progressive (static) damage to the developing brain caused by persistent motor dysfunction, which calls for a customized treatment strategy (Jan, 2006). Exercise treatment aids in symptom management despite the poor prognosis of cerebral palsy (Ryan et al., 2017) by improving mobility, boosting muscle strength, and lessening abnormal movement patterns (Arghavan et al., 2014). Exercise treatment works best at home; thus, managing CP requires close coordination between the families and the rehabilitation staff (Jan, 2006).

Exercise treatment is the most efficient or appropriate for all cerebral palsy patients, and the main goals of care are to reduce contractures and manage symptoms (Arghavan et al., 2014). Numerous exercises help care for children with CP (Booth et al., 2018; Bryanton et al., 2006; Damiano, 2009; Chiu, Ada, & Lee, 2018).

Exercise is a crucial part of controlling cerebral palsy; however, there is a lot of non-adherence to these programs. Studies reveal that caregivers have a favorable opinion of physical therapy; they respect and appreciate the advantages; they are willing and able to put the physical therapist's suggestions into practice, and they consistently exhibit concern for the wellbeing of their children. Nevertheless, despite acknowledging the need for exercise therapy, comprehending the reasons for their non-compliance, and offering them guidance, counsel, and assistance to alleviate worries and assist caregivers with issues, there was still a lack of adherence (Domenech et al., 2016).

People with cerebral palsy (CP) are advised to engage in exercise therapy based on their physical capabilities and limitations, with the rehabilitation team, particularly physical therapists, paying less attention to the participation and environment component at home, which is essential to achieving the treatment goal (Anaby et al., 2017; Saleh et al., 2008;

Kavlak et al.,2014). Home exercise programs, usually recommended as part of therapy, should be approached holistically and with the family's preferences in mind(Peplow & Carpenter,(2013).

Rehabilitation should be addressed while considering all aspects of the participant, especially the home environment, to generate numerous advantages and achieve the rehabilitation's aim. This entails fostering trust-based relationships, engaging families, and promoting family involvement in the physiotherapy program (Gibson et al.,2012; Wiart et al.,2010).

Studies have examined how often parents exercise and how difficult it is to maintain a home exercise routine (Rabino et al., 2013; Lillo-Navarro et al.,2015). Surprisingly, there aren't many studies on caregiver compliance, and it is suggested that research studies on the rehabilitation components of CP (Nijhuis et al.,2008). Little is known about caregivers' compliance with exercise therapy in Saudi Arabia. Understanding the factors that affect caregivers' Adherence is necessary for improved Adherence. As a result, research was initiated to measure caregiver adherence to exercise therapy.

1.1. Research objectives

The study aims to assess caregiver adherence to the home exercise program to associate the level of adherence with potential factors.

The study's objectives are to:

- assess caregiver adherence to the home exercise program;
- assess whether caregiver adherence is related to (Individual factors, including caregiver characteristics, factors related to social support, and factors related to illness/treatment)

3. Methods

3.1 Study design

A cross-sectional survey methodology was used for this study. In most instances, the hospital offers treatment for kids with cerebral palsy and their families in the rehabilitation hospital.

3.2. Sample and sampling

Participants were deemed qualified for the research if they had a child receiving treatment at the institution for at least a year, visited the rehabilitation hospital as caregivers, were open to taking the survey, and were proficient in Arabic.

The sample size was determined using the prevalence factor and high adherence (65.3%) rates among caregivers of children with cerebral palsy from previous research^[21]. The result was calculated using the following formula with a 95% confidence limit and an 8% relative estimation precision. Sample size (N) = $(1.96)^2 * 0.653 * (1 - 0.653) / (0.08)^2 = 137$ caregivers. The participants were thereby randomly picked at the rehabilitation center in King Fahad Medical City (KFMC), Riyadh, Saudi Arabia. Therefore, 150 questionnaires were distributed to get at least 90% of responses in the survey, and 148 (98.7%) participants responded. However, 144 responses were considered for analysis.

3.3. Ethical consideration

The Institutional Review Board at the setting approved this study. The study's approach was thoroughly explained to the careers. The study's goals and the voluntariness of participants were explained to the participants by the researcher. The participants were also aware of anonymity, confidentiality, and the potential of voluntarily quitting anytime.

3.4. Data Collection Tool and Data Collection Procedure

The questionnaire, Care provider's commitment to home exercise programs from the study (Medina-Mirapeix et al.,2017), was used with the author's consent. This study measured Adherence for each exercise component, frequency per week. Currently, how many days a week has your child's physiotherapist recommended doing the exercises at home? (5 always, 4 very often, 3 sometimes, 2 rarely, 1 never) 2. Many parents find it difficult to do the exercises at home on all the recommended days. Over the last week, how many days have you done your exercises with your child? Item 16 (0 means none ...and 7 means seven days).

In this study, we considered potential factors from three areas: 1) individual, 2) social support and resources, and 3) illness/treatment. We examined the association of 3 groups of potential factors: individual, social, and illness factors associated with Adherence to each exercise component using univariate and multivariate analyses. The inferences were drawn at a 95% confidence interval (P<0.05).

Individual factors: for this research, we considered the parents' demographic characteristics, Perceived Barriers to integrating exercise, and Self-Efficacy under individual factors. We considered parents' demographic characteristics as follows: age (years), gender (male/female), educational level), type of family (two parents/one), and the number of children living at home. In addition, the child's age and gender were also considered. The Perceived Barriers to integrating exercise were examined by two items (I understand my child's home program 2. I am skillful in carrying out the home

program). Self-efficacy was determined by one item (How confident are you about performing the home program?) Scoring for these items is (5 strongly agree, 4 agree, 3 undecided, 2 disagree, 1 strongly disagree).

Factors related to social support: One item used to examine the Factor related to social support (My partner supports me at home (5 always, 4 very often, 3 sometimes, 2 rarely, 1 never). Factor related to physical resources examined by one item (I have the equipment required to do the exercises at home (1 yes, 2 no)).

Factors related to illness/treatment: In this study, the factors related to illness were examined by the level of health condition and the duration of caring for the child with cerebral palsy. In the treatment factor, the health professional's involvement during therapeutic sessions was examined by the following seven questions (1. The physiotherapist gives me information regarding my child's progress 2. The physiotherapist justifies the usefulness of the exercises 3. The physiotherapist gives me written instructions explaining the exercises. 4. The physiotherapist explains the exercises using the child as a model 5. The physiotherapist gives me advice on how to include exercises into daily routines 6. The physiotherapist regularly checks my skill at performing the exercises 7. The physiotherapist usually asks me about my Adherence to the exercises at home. All seven questions were assessed by the uniform scoring pattern (5 always, 4 very often, 3 sometimes, 2 rarely, 1 never). In addition, the parents' overall satisfaction was assessed by one item with the physiotherapy care (if you had to mark from 1 to 10 your overall satisfaction with the attention from your physiotherapist, what would your score be? (10 very satisfied - 0 very unsatisfied).

The caregivers received detailed information regarding the study's methodology. The participants' consent was acquired before collecting the data, and the caregivers were encouraged to participate, and the data were collected.

3.5. Statistical analysis

Descriptive statistics using proportions and their 95% confidence interval (CI) were calculated for the description of the sample and adherence rates. To obtain a minimal precision of ±8% on the calculated percentages, irrespective of the value of the percentages, the minimal sample size required was 150. The sociodemographic categorical variables were presented as frequencies with their percentages. We examined the association of the three groups of potential factors: individual, social, and illness with Adherence to each exercise component using univariate and multivariate logistic regression analyses. The univariate associations were tested by χ^2 analysis to determine the relationship ($p < 0.05$) with adherence. The factors with a significant univariate contribution ($P < 0.05$) were included in the multivariate analysis. The process of backward elimination of independent variables produced these final models. This procedure consists of dropping an independent variable using the likelihood ratio test at a significance level of $P = 0.05$. Goodness-of-fit and regression for the reduced model were assessed using the methods described by Hosmer and Lemeshow. Crude Odds Ratio (OR), Adjusted OR, and 95% CI are reported. A pie diagram and multiple bar diagram were used to represent the data. Two-tailed tests were used to test significance, and the inferences were drawn at a 95% confidence interval. Statistical Package for Social Sciences (SPSS, version 22) was used for the statistical analysis.

4. Results

Table 1: Demographic Profile of the Caregiver and Children

Table 1: Adherence with respect to Demography (Between-group comparison)							
Characteristic	Description	Non-adherence	Adherence	Total	p-value	Binary Logistic Regression analysis	
		N=92 (63.9%)	N=52 (36.1%)	N=144 (100.0%)		OR [95% CI (LL - UL)]	P-value
Relation with the child	Parent	86 (93.5)	50 (96.2)	136 (94.4)	0.711	1.38 [0.24 - 8.04]	0.721
	Relative/Sibling (reference)	6 (6.5)	2 (3.8)	8 (5.6)			
Age (year)	≤ 25	27 (29.3)	15 (28.8)	42 (29.2)	0.949	0.65 [0.25 - 1.66]	0.367
	26 - 40 (reference)	65 (70.7)	37 (71.2)	102 (70.8)			
Gender	Male	27 (29.3)	15 (28.8)	42 (29.2)	0.949	[-]	
	Female	65 (70.7)	37 (71.2)	102 (70.8)			
Professional qualification	No qualification	6 (6.5)	1 (1.9)	7 (4.9)	0.458	0.26 [0.02 - 4.16]	0.341
	Primary school	4 (4.3)	0 (0)	4 (2.8)		0 [0 -]	0.999
	High school	30 (32.6)	20 (38.5)	50 (34.7)		0.54 [0.09 - 3.18]	0.499
	Graduate or postgraduate	48 (52.2)	28 (53.8)	76 (52.8)		0.45 [0.08 - 2.6]	0.370
	Med school (reference)	4 (4.3)	3 (5.8)	7 (4.9)			0.868
Taking care of this child with cerebral palsy (year)	< 1	13 (14.1)	11 (21.6)	24 (16.8)	0.155	2.02 [0.38 - 10.89]	0.412
	1 - 5	42 (45.7)	28 (54.9)	70 (49.0)		1.77 [0.37 - 8.43]	0.471
	> 5 (reference)	37 (40.2)	12 (23.5)	49 (34.3)			0.705
Another child with cerebral palsy in the family	Yes	13 (14.1)	6 (11.5)	19 (13.2)	0.659	1.18 [0.37 - 3.81]	0.777
	No (reference)	79 (85.9)	46 (88.5)	125 (86.8)			

Thorough knowledge of the exercise program	Yes	81 (88.0)	48 (92.3)	129 (89.6)	0.421	1.52 [0.4 - 5.81]	0.537
	No (reference)	11 (12.0)	4 (7.7)	15 (10.4)			
Type of family	Supported by one parent	71 (77.2)	35 (67.3)	106 (73.6)	0.197	0.48 [0.2 - 1.17]	0.106
	Supported by both parents (reference)	21 (22.8)	17 (32.7)	38 (26.4)			
Number of children in the family	Median (min, max)	3 (1, 12)	3 (1, 10)	3 (1, 12)	0.422	[-]	
Number of children in the family	1	11 (12.1)	8 (15.7)	19 (13.4)	0.687	0.99 [0.32 - 3.05]	0.987
	2	20 (22.0)	13 (25.5)	33 (23.2)			
	≥3 (reference)	60 (65.9)	30 (58.8)	90 (63.4)			
Gender of the child	Male	49 (53.3)	29 (55.8)	78 (54.2)	0.772	1.24 [0.54 - 2.84]	0.614
	Female	43 (46.7)	23 (44.2)	66 (45.8)			
Age of the child (year)	< 1	14 (15.9)	12 (23.1)	26 (18.6)	0.452	1.15 [0.22 - 5.99]	0.867
	1 to 5	37 (42.0)	24 (46.2)	61 (43.6)			
	6 to 8	8 (9.1)	5 (9.6)	13 (9.3)			
	9 to 12 (reference)	29 (33.0)	11 (21.2)	40 (28.6)			
Diagnosis	CP	65 (70.7)	36 (69.2)	101 (70.1)	0.982	0.78 [0.3 - 2.06]	0.622
	Congenital illness	7 (7.6)	4 (7.7)	11 (7.6)			
	Others (reference)	20 (21.7)	12 (23.1)	32 (22.2)			

4.1. Sample characteristics

We identified 393 eligible parents, among which 150 consented to the study. Incomplete responses were identified in were 2 Questionnaires. Of the 144 caregivers,' the majority (93.92%), 136 (94.4), were parents of the children. Most of the parents86 (63.2) were non adherent, and 50 (36.8) were adherent to the exercise program. Concerning other caregivers (relative or sibling) majority, 6 (75.0) were non-adherent, and 2 (25.0) were adherent to the exercise program. The majority of the caregivers102 (70.8) were in the age group of 26 – 40 years, while 102 (70.8) were female. More than half of the caregivers, 76 (52.8), were graduates and above. Nearly 70 (49.0) cared for the child diagnosed with cerebral palsy for 1- 5 years. One parent supported the Majority106 (73.6) of the children. Besides the majority, 129 (89.6) caregivers thoroughly knew the exercise program. All of the demographic characteristics had an insignificant association with adherence. The backward step binary logistic regression also could not predict any significance for the sociodemographic characteristics with adherence. The characteristics of the participants and the children with cerebral palsy are shown in Table 1

4.2. Adherence Behaviors and associated factors

Though Adherence is a derivative of the ratio between Q16-number of days doing exercises in the previous week to Q15-number of recommended days per week, the percentage ratio of ≥66% is considered Adherence to the Home Exercise Program [21].

Table 2: Adherence with respect to Home Exercise Program (Between-group comparison)

Characteristic	Description	Non-adherence	Adherence	Total	p-value	Binary Logistic Regression analysis	
		N=92 (63.9%)	N=52 (36.1%)	N=144 (100.0%)		OR [95% CI (LL - UL)]	p-value
Does the home program fit your daily routine?	Never	5 (5.4)	1 (1.9)	6 (4.2)	0.005	0.33 [0.02 - 5.91]	0.451
	Rarely	4 (4.3)	1 (1.9)	5 (3.5)			
	Sometimes	45 (48.9)	14 (26.9)	59 (41.0)			
	Very often	13 (14.1)	14 (26.9)	27 (18.8)			
	Always (reference)	25 (27.2)	22 (42.3)	47 (32.6)			
I understand my child's home program	Strongly disagree	2 (2.2)	0 (.0)	2 (1.4)	0.017	0.38 [0 -]	1
	Disagree	7 (7.8)	2 (3.8)	9 (6.3)			
	Undecided	9 (10.0)	1 (1.9)	10 (7.0)			
	Agree	48 (53.3)	28 (53.8)	76 (53.5)			
	Strongly agree (reference)	24 (26.7)	21 (40.4)	45 (31.7)			
I am skillful in carrying out the home program	Strongly disagree	3 (3.4)	0 (.0)	3 (2.1)	0.14	0 [0 -]	1
	Disagree	5 (5.6)	8 (15.7)	13 (9.3)			
	Undecided	22 (24.7)	2 (3.9)	24 (17.1)			
	Agree	48 (53.9)	28 (54.9)	76 (54.3)			
	Strongly agree (reference)	11 (12.4)	13 (25.5)	24 (17.1)			
How confident are you about performing the home program?	Median (min, max)	5 (0, 10)	8 (1, 10)	6 (0, 10)	0.001	1.13 [0.94 - 1.36]	0.191
My partner supports me at home	Never	36 (39.1)	9 (17.3)	45 (31.3)	0.005	0.37 [0.1 - 1.34]	0.13
	Rarely	8 (8.7)	7 (13.5)	15 (10.4)			
	Sometimes	28 (30.4)	16 (30.8)	44 (30.6)			
	Very often	9 (9.8)	6 (11.5)	15 (10.4)			

	Always (reference)	11 (12.0)	14 (26.9)	25 (17.4)			0.529
I have the equipment required to do the exercises at home	Yes	36 (39.6)	22 (42.3)	58 (40.6)	0.748	1.35 [0.58 - 3.18]	0.486
	No (reference)	55 (60.4)	30 (57.7)	85 (59.4)			
I am skillful in carrying out the home program	Strongly disagree	Backward step regression				0 [0 -]	0.999
	Disagree					2.2 [0.5 - 9.68]	0.298
	Undecided					0.13 [0.02 - 0.69]	0.017
	Agree					0.76 [0.28 - 2.06]	0.586
	Strongly agree (reference)						0.054
How confident are you about performing the home program?						1.24 [1.05 - 1.45]	0.009

The association of adherence concerning the Home Exercise Program is elicited in Table 2, which was significantly associated with how the home program fits into the daily routine, understanding my child's home program, understanding of the home exercise program, confidence in performing the home exercise program and receiving support from the partner. Bivariate regression analysis was carried out concerning the caregiver characteristics, child characteristics, and the six components related to adherence. Adherence group median score 8 (1, 10) for confidence in performing the exercise was significantly more than the non-adherence group median score of 5 (0, 10).

Backward step regression analysis showed the statistical significance of the caregiver's adherence to the Undecided features of the in-home exercise program. Besides, confidence in performing the home exercise program was also significant.

Table 3: Adherence with respect to Therapist's Involvement (Between-group comparison)

Characteristic	Description	Non-adherence	Adherence	Total	p-value	Binary Logistic Regression analysis	
		N=92 (63.9%)	N=52 (36.1%)	N=144 (100.0%)		OR [95% CI (LL - UL)]	p-value
The physiotherapist gives me information regarding my child's progress	Never	3 (3.4)	1 (2.0)	4 (2.9)	0.776	0 [0 -]	0.999
	Rarely	0 (0)	0 (0)	0 (0)			
	Sometimes	4 (4.6)	4 (8.2)	8 (5.9)		2.83 [0.16 - 51.11]	0.481
	Very often	3 (3.4)	3 (6.1)	6 (4.4)		5.74 [0.05 - 639]	0.468
	Always (reference)	77 (88.5)	41 (83.7)	118 (86.8)			0.823
The physiotherapist justifies the usefulness of the exercises	Never	2 (2.2)	1 (2.0)	3 (2.2)	0.349	9.1E+10 [0 -]	0.999
	Rarely	0 (0)	0 (0)	0 (0)			
	Sometimes	5 (5.6)	4 (8.0)	9 (6.5)		14.49 [0.17 - 1230]	0.238
	Very often	1 (1.1)	5 (10.0)	6 (4.3)		0.29 [0.01 - 16.73]	0.551
	Always (reference)	81 (91.0)	40 (80.0)	121 (87.1)			0.646
The physiotherapist gives me written instructions explaining the exercises	Never	27 (30.7)	10 (20.0)	37 (26.8)	0.328	0.3 [0.05 - 1.8]	0.186
	Rarely	9 (10.2)	6 (12.0)	15 (10.9)		91.09 [1.13 - 7340]	0.044
	Sometimes	6 (6.8)	4 (8.0)	10 (7.2)		0.02 [0 - 2.65]	0.119
	Very often	3 (3.4)	4 (8.0)	7 (5.1)		0.21 [0 - 15.09]	0.47
	Always (reference)	43 (48.9)	26 (52.0)	69 (50.0)			0.128
The physiotherapist explains the exercises to me using the child as a model	Never	2 (2.3)	2 (3.8)	4 (2.9)	0.283	1.4E+14 [0 -]	0.999
	Rarely	0 (0)	1 (1.9)	1 (0.7)			
	Sometimes	0 (0)	0 (0)	0 (0)			
	Very often	2 (2.3)	2 (3.8)	4 (2.9)		0.69 [0.01 - 82.59]	0.88
	Always (reference)	84 (95.5)	47 (90.4)	131 (93.6)			0.989
The physiotherapist gives me advice on how to include exercises into daily routines	Never	35 (42.7)	15 (28.8)	50 (37.3)	0.053	7.22 [1.34 - 38.96]	0.021
	Rarely	8 (9.8)	3 (5.8)	11 (8.2)		0 [0 - 0.4]	0.02
	Sometimes	5 (6.1)	4 (7.7)	9 (6.7)		3.01 [0.16 - 57.39]	0.463
	Very often	6 (7.3)	5 (9.6)	11 (8.2)		0.1 [0 - 9.21]	0.316
	Always (reference)	28 (34.1)	25 (48.1)	53 (39.6)			0.049
The physiotherapist regularly checks my skill at performing the exercises	Never	17 (18.9)	3 (6.0)	20 (14.3)	0.006	0.6 [0.08 - 4.38]	0.617
	Rarely	5 (5.6)	1 (2.0)	6 (4.3)		0 [0 -]	0.998
	Sometimes	10 (11.1)	2 (4.0)	12 (8.6)		0.03 [0 - 1.52]	0.079
	Very often	2 (2.2)	3 (6.0)	5 (3.6)		95.47 [1.91 - 4780]	0.022
	Always (reference)	56 (62.2)	41 (82.0)	97 (69.3)			0.084
The physiotherapist usually asks me about my adherence to the exercises at home	Never	6 (6.7)	4 (7.7)	10 (7.0)	0.381	107.73 [0.92 - 12600]	0.054
	Rarely	0 (0)	1 (1.9)	1 (0.7)		4.0E+08 [0 -]	1
	Sometimes	2 (2.2)	2 (3.8)	4 (2.8)		2.5E+10 [0 -]	0.997
	Very often	2 (2.2)	3 (5.8)	5 (3.5)		4.78 [0.15 - 149]	0.372
	Always (reference)	80 (88.9)	42 (80.8)	122 (85.9)			0.391
If you had to mark from 1 to 10 your overall satisfaction with the attention from your	Median (min, max)	9 (0, 10)	10 (4, 10)	10 (0, 10)	0.027	1.14 [0.72 - 1.79]	0.583

physiotherapist, what would your score be?							
Many parents find it difficult to do the exercises with the number of repetitions or the amount of time the physiotherapist has recommended. In your case, how often do you generally accomplish the time or number of repetitions that the physiotherapy	Never	19 (20.9)	0 (.0)	19 (13.3)	<0.001	0 [0 -]	0.996
	Rarely	15 (16.5)	4 (7.7)	19 (13.3)		0.06 [0.01 - 0.5]	0.01
	Sometimes	33 (36.3)	15 (28.8)	48 (33.6)		0.1 [0.02 - 0.59]	0.011
	Very often	10 (11.0)	13 (25.0)	23 (16.1)		0.74 [0.15 - 3.53]	0.704
	Always (reference)	14 (15.4)	20 (38.5)	34 (23.8)			0.042
Many parents find it difficult to do the exercises with the number of repetitions	Never	Backward step regression			0 [0 -]	0.998	
	Rarely				0.16 [0.04 - 0.65]	0.01	
	Sometimes				0.24 [0.08 - 0.7]	0.009	
	Very often				0.79 [0.24 - 2.65]	0.708	
	Always (reference)					0.021	

Table 3 describes the caregivers' adherence to the home exercise program concerning the therapist's involvement. Nine variables were included in this model, of which six components were related to physiotherapist involvement, including communicating progress while defending the use of exercises, routine follow-up, and parents' satisfaction with care were the remaining three components.

Both the groups (non-adherent and adherent reported overall satisfaction with the attention from the physiotherapist with a median score of 9 (0, 10) and 10 (4, 10), respectively. Overall, 118 (86.8%) agreed that "the physiotherapist gives the information regarding my child's progress, and 121 (87.1%) revealed that they justified the usefulness of the exercises. Though a significant number, 131 (93.6%), agreed that the physiotherapists explain the exercise using the child as a model, only 69 (50.0%) agreed that the physiotherapist gives me written instructions explaining the exercises. Among the caregivers with a high frequency, 97 (69.3) agreed that the physiotherapist regularly checks the skill at performing the exercises and asks about the adherence to the exercises at home 122 (85.9%). However, the non-adherence group concludes that many parents find it difficult to exercise with the number of repetitions for the time the physiotherapist has recommended. The response was never 19 (20.9), rarely 15 (16.5), sometimes 33 (36.3), very often, 10 (11.0), and always 14 (15.4), and the difference was significant in comparison to the adherent group. Backward step regression also predicted the significant association of non-adherence with the parent-caregiver statement only.

Characteristic	Description	Non-adherence	Adherence	Total	p-value
		N(%)	N(%)	N(%)	
Many parents find it difficult to do the exercises with the number of repetitions or the amount of time the physiotherapist has recommended. In your case, how often do you generally accomplish the time or number of repetitions that the physiotherapist recommended?	Never	19 (100.0)	0 (.0)	19 (13.3)	<0.001
	Rarely	15 (78.9)	4 (21.1)	19 (13.3)	
	Sometimes	33 (68.8)	15 (31.3)	48 (33.6)	
	Very often	10 (43.5)	13 (56.5)	23 (16.1)	
	Always	14 (41.2)	20 (58.8)	34 (23.8)	

Table 4 represents the adherence to the home exercise program concerning parent involvement. The non-adherent group was complacent to the extent that those did never 19 (100.0), rarely 15 (78.9), sometimes 33 (68.8), very often 10 (43.5), and always 14 (41.2) would respectively participate with the physiotherapist, which significantly opposed to the adherence.

5. Discussion

In the current study, caregivers' adherence to HEP was low, supported by an International study finding that the parents' adherence to exercise regimens was low (Medina-Mirapeix et al.,2017). A Saudi Arabian study supported this finding and documented that most mothers (66.1%) did not follow the HEP (Alwhaibi, Omer, & Khan, 2022). On the other hand, some International studies reported that the parents' adherence to exercise regimens ranged from moderate to high (Beckers et al.,2020; Olagunju et al.,2017).

A randomized trial has pointed out that home-based therapy was ineffective in children with cerebral palsy, even with adherence to training sessions (Van Wely et al.,2014).

The current study revealed that adherence to exercise treatment was influenced by the caregiver's understanding and confidence in performing the home exercise program. The findings align with a study that informed parents' adherence was stronger when they perceived few obstacles and felt self-sufficient. In support of this conclusion, a study (Gmmash et al.,2021) documented that the parents' adherence to home activities is also influenced by factors such as the appropriateness of the home activities to daily routines and the home environment, the availability of activities children enjoys, and parent self-efficacy. The study showed receiving support from the partner significantly influenced the adherence to the home exercise program. This aligns with a study that reported several factors influencing parents' commitment to exercise programs, including support (Peplow & Carpenter, (2013).

The study reported that the caregivers in both groups (non-adherent and adherent reported overall satisfaction with the attention from the physiotherapist. A study highlighted that the parents were more likely to adhere to the program when they had a positive experience with the physiotherapist's style and content (Lillo-Navarro et al.,2015). This study reported that educating patients about exercise and providing written instructions outlining the exercises did not influence adherence. The finding corroborates a study that claimed that interventions combining exercise programs with information and novel delivery strategies for exercise programs did not significantly affect adherence (Johnson et al.,2020). The study found that physiotherapists' behaviors during encounters did not increase exercise adherence at home, and this contradicts the findings from the literature, which revealed that with the healthcare professional's help (Medina-Mirapeix et al.,2017) and the conduct of health providers (Lillo-Navarro et al.,2019). parents adhered to HEP to a high degree Adherence to various workouts was significantly influenced by the conduct of health providers. We might speculate from the literature that the rehabilitation team, especially the physical therapist involved in the program, plays a vital role in enhancing adherence to the exercise programs.

It is interesting to note that the demographic characteristics of the caregivers did not influence adherence, according to this study. This aligns with a study that reported no significant association between the mother's age, socioeconomic status, work, and level of education and Adherence to a home exercise program (Tahayneh et al.,2020). Another similar study revealed no significant association between any of the selected clinico-demographic variables and the level of compliance of the caregivers (Olagunju, Fatudimu, & Hamzat, 2017). Another study's findings contradicted this study's findings. It showed that the demographic characteristics of the caregivers, such as socioeconomic class, education degree, marital status, and understanding of the illnesses, significantly impacted caregiver adherence (Usman et al.,2017). This study's finding contradicts a study in Saudi Arabia (showing that the caregivers' demographic characteristics and the mother's age influence adherence, and mothers aged 20–25 were more adherent than the other age groups(Alwhaibi, Omer & Khan, 2022).

6. Limitations

The study was conducted in a single location, which gave sample selection bias. The sample size may have impacted some elements, such as participant selection. Additionally, the statistical analysis included only the variables the research predicted would be Adherence predictors.

7. Conclusion

This study informs therapists and caregivers about patients' exercise therapy compliance. We could hypothesize that the low adherence to the home exercise program was caused by several factors involving the caregiver, the therapist, and the exercise regimen. According to this research, adopting new teaching strategies and receiving follow-up care from the rehabilitation team may not aid carers and their families in enhancing adherence to the understanding and 'confidence in performing the home exercise program and receiving support from the partner. Hence, the rehabilitation team should focus on improving the knowledge about the exercise program and building the caregiver's confidence in performing the home exercise program. The physical therapist must take into account the Perceived Barriers, e.g., forgetting the exercises)(HEP), not having the time because it is too much or too difficult to fit into their daily routine, and provide a treatment plan (HEP) based on the responsibilities of the caregiver and their social conditions and their daily obligations and routine and their appropriate time to do the exercise. The results may impact initiatives designed to educate caregivers about the advantages of at-home physical therapy and make modifications in the home rehabilitation programs for children with cerebral palsy.

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Conflict Of Interest

The authors declare no conflict of interest, financial or otherwise.

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References

1. Zanon, M. A., & Batista, N. A. (2012). Qualidade de vida e grau de ansiedade e depressão em cuidadores de crianças com paralisia cerebral. *Revista Paulista de Pediatria*, 30, 392-396. <https://doi.org/10.1590/S0103-05822012000300013>
2. Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child: care, health and development*, 36(1), 63-73. doi:10.1111/j.1365-2214.2009.00989.x
3. Al-Asmari, A., Al Moutaery, K., Akhdar, F., & Al Jadid, M. (2006). Cerebral palsy: incidence and clinical features in Saudi Arabia. *Disability and Rehabilitation*, 28(22), 1373-1377. DOI: 10.1080/09638280600638083
4. Jan, M. M. (2006). Cerebral palsy: comprehensive review and update. *Annals of Saudi Medicine*, 26(2), 123-132. <https://doi.org/10.5144/0256-4947.2006.123>
5. Ryan, J. M., Cassidy, E. E., Noorduyn, S. G., & O'Connell, N. E. (2017). Exercise interventions for cerebral palsy. *Cochrane Database of Systematic Reviews*, (6). DOI: 10.1002/14651858.CD011660.pub2.
6. Arghavan, S., Ardalan, S., Ahmad, A., & Tamrin, B. S. M. (2014). Physical activity as a prescription for the children with cerebral palsy. *Russian Open Medical Journal*, 3(1), 108.
7. Rabino, S. R., Peretz, S. R., Kastel-Deutch, T., & Tirosh, E. (2013). Factors affecting parental adherence to an intervention program for congenital torticollis. *Pediatric physical therapy*, 25(3), 298-303. DOI: 10.1097/PEP.0b013e318298eb92
8. Lillo-Navarro, C., Medina-Mirapeix, F., Escolar-Reina, P., Montilla-Herrador, J., Gomez-Arnaldos, F., & Oliveira-Sousa, S. L. (2015). Parents of children with physical disabilities perceive that characteristics of home exercise programs and physiotherapists' teaching styles influence adherence: a qualitative study. *Journal of physiotherapy*, 61(2), 81-86. <https://doi.org/10.1016/j.jphys.2015.02.014>
9. Nijhuis, B. J., Reinders-Messelink, H. A., de Blécourt, A. C., Ties, J. G., Boonstra, A. M., Groothoff, J. W., ... & Postema, K. (2008). Needs, problems, and rehabilitation goals of young children with cerebral palsy as formulated in the rehabilitation activities profile for children. *Journal of Rehabilitation Medicine*, 40(5), 347-354. DOI: 10.2340/16501977-0182.
10. Booth, A. T., Buizer, A. I., Meyns, P., Oude Lansink, I. L., Steenbrink, F., & van der Krogt, M. M. (2018). The efficacy of functional gait training in children and young adults with cerebral palsy: a systematic review and meta-analysis. *Developmental Medicine & Child Neurology*, 60(9), 866-883. doi: 10.1111/dmcn.13708.
11. Bryanton, C., Bosse, J., Brien, M., Mclean, J., McCormick, A., & Sveistrup, H. (2006). Feasibility, motivation, and selective motor control: virtual reality compared to conventional home exercise in children with cerebral palsy. *Cyberpsychology & behavior*, 9(2), 123-128. <https://doi.org/10.1089/cpb.2006.9.123>
12. Damiano, D. L. (2009). Rehabilitative therapies in cerebral palsy: the good, the not as good, and the possible. *Journal of child neurology*, 24(9), 1200-1204. doi: 10.1177/0883073809337919
13. Chiu, H. C., Ada, L., & Lee, S. D. (2018). Balance and mobility training at home using Wii Fit in children with cerebral palsy: a feasibility study. *BMJ open*, 8(5), e019624. DOI: 10.1136/bmjopen-2017-019624.
14. Domenech, A. C. P., Tavares, K. O., Ruedell, A. M., & Nobre, J. R. D. S. (2016). Paralisia cerebral: o significado da fisioterapia na visão de mães cuidadoras. *Fisioterapia em Movimento*, 29, 757-766. <https://doi.org/10.1590/1980-5918.029.004.AO12>
15. Anaby, D., Korner-Bitensky, N., Steven, E., Tremblay, S., Snider, L., Avery, L., & Law, M. (2017). Current rehabilitation practices for children with cerebral palsy: focus and gaps. *Physical & occupational therapy in pediatrics*, 37(1), 1-15. doi: 10.3109/01942638.2015.1126880.
16. Saleh, M. N., Korner-Bitensky, N., Snider, L., Malouin, F., Mazer, B., Kennedy, E., & Roy, M. A. (2008). Actual vs. best practices for young children with cerebral palsy: a survey of paediatric occupational therapists and physical therapists in Quebec, Canada. *Developmental Neurorehabilitation*, 11(1), 60-80. <https://doi.org/10.1080/17518420701544230>
17. Kavlak, E., Altuğ, F., Cavlak, U., Kavlak, H. A., & Şenol, H. (2014). Expectations from rehabilitation of children with Cerebral Palsy: the agreement between the physiotherapists and mothers. *Journal of Physical Therapy Science*, 26(8), 1209-1213. doi: 10.1589/jpts.26.1209.

18. Peplow, U. C., & Carpenter, C. (2013). Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: a qualitative study. *Physical & occupational therapy in pediatrics*, 33(3), 285-299. DOI: 10.3109/01942638.2013.773954.
19. Gibson, B. E., Teachman, G., Wright, V., Fehlings, D., Young, N. L., & McKeever, P. (2012). Children's and parents' beliefs regarding the value of walking: rehabilitation implications for children with cerebral palsy. *Child: care, health and development*, 38(1), 61-69. <https://doi.org/10.1111/j.1365-2214.2011.01271.x>
20. Wiart, L., Ray, L., Darrah, J., & Magill-Evans, J. (2010). Parents' perspectives on occupational therapy and physical therapy goals for children with cerebral palsy. *Disability and rehabilitation*, 32(3), 248-258. doi: 10.3109/09638280903095890.
21. Medina-Mirapeix, F., Lillo-Navarro, C., Montilla-Herrador, J., Gacto-Sánchez, M., Franco-Sierra, M. A., & Escolar-Reina, P. (2017). Predictors of parents' adherence to home exercise programs for children with developmental disabilities, regarding both exercise frequency and duration: A survey design. *Eur J Phys Rehabil Med*, 53(4), 545-55. DOI: 10.23736/S19 201773-9087.17.04464-1
22. Alwhaibi, R. M., Omer, A. B., & Khan, R. (2022). Factors Affecting Mothers' Adherence to Home Exercise Programs Designed for Their Children with Cerebral Palsy. *International Journal of Environmental Research and Public Health*, 19(17), 10792. <https://doi.org/10.3390/ijerph191710792>
23. Beckers, L. W., Geijen, M. M., Kleijnen, J., Rameckers, E. A., Schnackers, M. L., Smeets, R. J., & Janssen-Potten, Y. J. (2020). Feasibility and effectiveness of home-based therapy programmes for children with cerebral palsy: A systematic review. *BMJ open*, 10(10), e035454. <http://dx.doi.org/10.1136/bmjopen-2019-035454>
24. Olagunju, T. J., Fatudimu, M. B., & Hamzat, T. K. (2017). Clinical-demographic variables and compliance with home Programme among Nigerian informal caregivers of children with cerebral palsy. *Medical Journal of Zambia*, 44(3), 157-165.
25. Van Wely, L., Balemans, A. C., Becher, J. G., & Dallmeijer, A. J. (2014). Physical activity stimulation program for children with cerebral palsy did not improve physical activity: a randomised trial. *Journal of physiotherapy*, 60(1), 40-49. <https://doi.org/10.1016/j.jphys.2013.12.007>
26. Gmmash, A. S., Effgen, S. K., Skubik-Peplaski, C., & Lane, J. D. (2021). Parental adherence to home activities in early intervention for young children with delayed motor development. *Physical Therapy*, 101(4), pzab023. <https://doi.org/10.1093/ptj/pzab023>
27. Johnson, R. W., Williams, S. A., Gucciardi, D. F., Bear, N., & Gibson, N. (2020). Can an online exercise prescription tool improve adherence to home exercise programmes in children with cerebral palsy and other neurodevelopmental disabilities? A randomised controlled trial. *BMJ open*, 10(12), e040108. <http://dx.doi.org/10.1136/bmjopen-2020-040108>
28. Lillo-Navarro, C., Montilla-Herrador, J., Escolar-Reina, P., Oliveira-Sousa, S. L., García-Vidal, J. A., & Medina-Mirapeix, F. (2019). Factors associated with parents' adherence to different types of exercises in home programs for children with disabilities. *Journal of clinical medicine*, 8(4), 456. doi: 10.3390/jcm8040456
29. Tahayneh, M., Humayra, S., Fall, A. A., Rosland, H., Amro, A., Mohammed, A., & Mohamed, A. L. (2020). Factors affecting mother's adherence towards cerebral palsy home exercise program among children at Hebron and Bethlehem, Palestine. *Int. J. Pharm. Res*, 12, 1019-1024.
30. Usman, M. Y., Abdulmanaf, A., Abba, M. A., & Kani, M. Z. (2017). Factors affecting adherence to physiotherapy appointments for caregivers of children with cerebral palsy in Kano metropolis. *Archives of Physiotherapy & Global Researches*, 21(2).