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Caregivers Perceived Enhancers and Barriers to Home Exercise Programme of Children with Cerebral Palsy

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Abstract

Home exercise programme (HEP) is a vital component of physical therapy procedures for patients with cerebral palsy (CP). Cerebral palsy is a movement and postural disorder which occurs as a result of brain injury or injury to a developing brain. One of the complementary ways of giving physical therapy is by prescribing home exercise programme (HEP). However, there is paucity of information on adherence to home programmes among caregivers of children with cerebral palsy hence the need for this study. 30% of the respondents adhered to the HEP. A closer look at their activities, 27(56.3% of them performed the HEP for 30minutes- 1 hour, 15(31.3%) performed for less than 30 minutes while 6(12.5%) performed the HEP for greater than 1 hour. Majority 48% of the people that perform the HEP were the mothers. 71.4% of the respondents perceived lack of time as the greatest barrier to their adherence to prescribed HEP while they perceived emphasis by the therapist 63.3%, obvious improvement of their child/wards condition (77.6%), the desire for their Childs' wellbeing (77.6%), and encouragement from the therapist as the major ehancers/motivators to their performing the prescribed HEP. The caregivers recommended that there is need for partners/ family support 57.1%, give time to practice and investigate HEP 57.1% and educate parents/ caregivers to provide emotional and physical support 73.5% to improve performance of HEPs. At the end of this study, it's been discovered that there is low adherence to HEP among caregivers of children with cerebral palsy. Recommendations are made towards the use of family centered approach, counselling, and adoption of certain strategies to improve the performance of HEP. Further studies are also required with a larger sample size.

Keywords: Cerebral Palsy; Children; Parents; Caregivers; Home Exercise Programme; Enhancers; Enablers; Barriers; Strategies; Recommendations

Abbreviations: HEP: Home Exercise Programme; CP: Cerebral Palsy.

Introduction

Cerebral palsy is a non-progressive injury to the brain that causes movement and postural disorder which occurs at infancy or early childhood as a result of brain damage or to a developing brain whose affectation varies considerably as no two individuals are exactly the same [1]. Children with cerebral palsy need intensive therapy or exercise activity to raise the impact of positive adjustments created by neuroplasticity [2]. These exercises, when delivered in the home environment add up to complement the intervention giving directly by the therapist to effect treatment outcome [3,4]. However, the rates at which the caregivers adhere to these exercises are barely known. Hence the need for this study.

HEP has been said to account for 50% to 80% of total therapy time but a number of challenges has been identified to hinder the efficient use of home exercise programmes [3,5]. Among children with cerebral palsy, caregivers participation is important for regular and proper HEP. Rehabilitation specialists agree that the involvement of caregivers is cost effective for a more concise rehabilitation program [6]. Accelerated success of rehabilitation goals with improved motor function in children living with disability has been recorded due to the role played by caregivers in performing home programmes. It is also important to know that adherence could be enhanced by increasing the attractiveness of exercise programs thereby improving patient performance (following a model or providing feedback), having feeling of being supported by both care providers and the patients [7].

Generally, various estimates from different works showed very low adherence to home program by patients [8]. Non-adherence to HEP, has been estimated to be as high as 50%, whereas causes of poor adherence has not been well understood nor documented. This study therefore aimed at determining the characteristics of HEP prescribed, caregivers or parents adherence to HEP, the enablers and barriers of performance of HEP, caregivers recommendation on strategies to improve HEP prescription and adherence of children with cerebral palsy to children with cerebral palsy attending physiotherapy in ESUTH park lane Enugu.

Purpose of Study

General Objective

The aim of this study is to assess the adherence rate to HEP among caregivers of children with cerebral palsy and determine factors that motivate its adherence or hinder it, as well as obtain recommended strategies to improve adherence to HEP [9].

Specific objectives

- To establish demographic profile of caregivers of children with cerebral palsy
- To establish that caregivers are given HEP and the characteristics of the prescribed HEP
- To establish caregivers' adherence to HEP and factors contributing to adherence to HEP
- To establish caregivers perceived barriers and enhancers to HEP and determine strategies proffered by caregivers to improve HEP performance.

Study Hypothesis

From anecdotal clinical experience, we hypothesize that personal factors will constitute the majority of caregivers' barriers and enhancers of adherence to HEP.

Methods

Study Design

A cross sectional descriptive survey was utilized for this study.

Area of Study

Setting: This study was carried out in the Department of physiotherapy, Enugu State University teaching Hospital Park Lane, Enugu (ESUTHP).

Location of Study: The study location is the Department of Medical Rehabilitation, University of Nigeria, Enugu campus.

Study Sample

Purposive sampling technique was utilized to recruit participants in this study The caregivers who responded to the invitation and were willing to participate in the study after full explanation were administered the questionnaire [10].

Selection Criteria

- **Inclusion:** The population of this study included caregivers of children who are living with cerebral palsy, irrespective of the type of cerebral palsy. Caregivers of children with delayed developmental milestone or loss of developmental milestone that were at risk of cerebral palsy. Caregivers of the children within the age range of 6 months to 17 years.
- **Exclusion Criteria:** This study however excluded Caregivers of children with musculoskeletal conditions. Caregivers of children with other neurodevelopmental or hereditary disorders such as down syndrome and

patients with cerebral palsy [11].

Study Instrument

The instrument used for data collection is a 29 items structured questionnaire developed to obtain the demographic details of the participants, the HEP characteristics, the level of adherence to HEP, the barriers and enhancers of adherence to HEP including recommendations for strategy to improve on adherence, some of the question were open ended while majority were closed ended [12]. The questionnaire was sent to two renowned Pediatric Physiotherapists and to the deputy director of physiotherapy in Nigeria where this study was carried out for face and content validity and their contribution helped in rephrasing the questions for more clarity [13].

Data Collection

The caregivers of children with cerebral palsy who attended or are still attending physical therapy at ESUT Teaching Hospital park lane Enugu, Nigeria and met the inclusion criteria were invited. Data collection was carried out at the physiotherapy department, ESUTH, Park lane using a structured self-administered questionnaire, after which the responses were gathered by the researcher for data analysis.

Data Analysis

Data analysis was carried out using Statistical Package for Social Sciences Software (version 20, SPSS, Inc. Chicago, Illinois). Data were summarized using descriptive statistics. Frequency and percentage distribution was used to analyze the participants' responses to the four sections [14].

Results

The findings of this study include the Socio-demographic characteristics of the participants, the home exercise programme characteristics, their adherence to home exercise programme, their perceived barriers and enhancers to HEP with their recommended strategies to improve adherence.

Socio-Demographics and Home Exercise Programme (HEP) Characteristics

Majority of the caregivers fell within the age range of 35-44 years (45.1%). Most of the participants were females at 82.4% while a majority, 49% had first degree education with 41.2% self-employed and 33.3% civil servants. Table 1 also shows that 72.5% of the respondents were the mothers of children who were mostly children between the ages of 1-5 (47.1%) with mean age of 2.39±0.896 years. However most of the participants had other children at 68.6% with (25.5%) having no other child, 23.5% having three other children and 94.1 % not having any other physically challenged children.

Variable	Frequency (n=51)	Percent
Age group (years)		
15-24	4	7.8
25-34	9	17.6
35-44	23	45.1
45-54	13	25.5
55 and above	2	3.9
Sex		
Male	9	17.6
Female	42	82.4
Educational Level		
Primary education	5	9.8
Secondary education	12	23.5
First degree	25	49
Post graduate	9	17.6
Occupation		
Civil servant	17	33.3
Self Employed	21	41.2
Unemployed	13	25.5
Relationship with the child		
Father	7	13.7
Mother	37	72.5
Extended family	3	5.9
Friend	1	2
Nanny	3	5.9
Age of Child		
<12 months	7	13.7
1-5 years	24	47.1
>5 years	13	25.5
11-17years	7	13.7
Other Children		
Yes	35	68.6
No	16	31.4
PCI		
Yes	3	5.9
No	48	94.1

Table 1: Socio-demographics.
Key: PCI= Number of other physically challenged children.

Variable	Frequency (n=51)	Percent (%)
Prescription HEP		
Yes	48	94.1
No	3	5.9
Proper handling/ positioning/postural awareness		
Yes	32	65.3
No	17	34.7
Mobilization/ Flexibility Exercises		
Yes	36	73.5
No	13	26.5
Functional training		
Yes	31	63.3
No	18	36.7
Time asked to do HEP		
<30mins	10	20.4
30mins-1 hour	30	61.2
>1 hour	9	18.4
Time to do HEP daily		
Once	10	20
2 times	6	12.2
3 times	7	14.3
4 times	5	10.2
2 hourly	19	38.8
1 hourly	2	4.1
Level of Good understanding of HEP		
2	2	4
3	9	18
4	7	14
5	31	62
Level of Aware of HEP Benefit		
0	1	2
1	1	2
3	5	8
4	3	14
5	40	74
Level of emphasis laid on HEP		
0	1	2
2	1	2
3	4	8
4	7	14
5	34	74
How HEP are given		
Oral instruction	*8*	16.3

Practical demonstration	9	18.4
Written prescription	4	8.2
Combination 1 & 2	25	51
Combination 1, 2 & 3	3	6.1
Given opport. To demons		
Yes	42	85.7
No	6	12.2

Table 2: Home Exercise Programme (HEP) Characteristics.
(Grading of understanding, HEP benefit and emphasis laid on HEP).
0= None, 1= minimum. 2= little, 3= moderate, 4= enough, 5= maximum.

As shown in (Tables 1 & 2) shows that 94% of respondents affirmed that HEP is being prescribed for the children through the caregivers. 65.3% were given proper handling/positioning/postural awareness programs, 73.5% were given mobilization/ flexibility exercises while 63.3% were given functional training. In majority 61.2% of the HEPs the time given for the performance of the HEP was 30minutes – 1 hour and to be performed 2 hourly (38.8%) daily. Respondents were also ask to grade their understanding of the HEP, their awareness of the HEP the benefit of the HEP and the level of emphasis which the therapist lay on performance of the HEPs. 62% had very good understanding of the HEP, 74% were well aware of the benefit of the HEP and on the other hand 74% acknowledged that their therapist gave great emphasis to the performance of the HEPs. Assessing the way by which the HEPs were given, 16.3% were by oral instruction, 18.4% were by practical demonstration, 8.2% were written prescription, 51% were a combination oral instruction and practical demonstration whereas 61% combined the three means (oral, written and practical demonstration). Furthermore 85.7% showed that caregivers were given opportunity to demonstrate the given HEPS.

Adherence to Home Exercise Programme (HEP)

Caregivers adherence to the given HEP, as they were asked to grade their strict adherence to the HEPs given. 30% of the respondents adhered to the HEP. A closer look at their activities, 27(56.3% of them performed the HEP for 30minutes- 1 hour, 15(31.3%) performed for less than 30 minutes while 6(12.5%) perform the HEP for greater than 1 hour. An aggregation of their weekly performance of the HEP showed, 1-2times (18.8%), 3-4times (33.3%) and 5 times and above (47.7%). Majority 48% of the people that perform the HEP were the mothers. In 79.2% of the treatment session, their therapist spends time investigating the performance of the HEPs given. This is done by oral assessment/ questioning (29.2%), by practical demonstration (20.8%) while in 45.8% of the cases both oral and practical demonstration were utilized as shown in Table 3.

Variables	Frequencies (n=51)	Percentage
Level of Strict Adherence		
0	2	4
1	2	4
2	9	18
3	14	28
4	8	16
5	15	30
Time spent on HEP/ session daily		
>30mins	15	31.3
30mins	27	56.3
<1 hour	6	12.5
Weekly HEP		
1-2times	9	18.8
3-4times	16	33.3

5times and above	23	47.7
Who carries out HEP		
Father	4	8
Mother	24	48
Both parent	9	18
Nanny	3	6
Mother and nanny	4	8
Mother and sibling	1	2
Mother, sibling & nanny	1	2
Both parent and sibling	1	2
Investigate how often		
Each treatment session	38	79.2
Occasionally	6	12.5
Rarely	2	4.2
None	2	4.2
How Therapist investigate		
Oral assessment	14	29.2
Practical	10	20.8
Both	22	45.8
None	2	4.2

Table 3: Adherence to Home Exercise Programme (HEP).

Barriers to Home Exercise Programme (HEP), Enhancers/ Motivators of Home Exercise Programme (HEP) and Recommended Strategies to Improve Home Exercise Programme (HEP)

Majority (71.4%) of the respondents perceived lack of time as the greatest barrier to their adherence to prescribed HEP as shown in Table 4. On the other hand, they perceived emphasis by the therapist 63.3%, obvious improvement of their child/wards condition (77.6%), the desire for their Childs' wellbeing (77.6%), and encouragement from the therapist as the major ehancers/motivators to their performing the prescribed HEP as shown in Table 5. Finally, Table 6 showed that strategies recommended by the caregivers to improve performance of HEPs were, partners/ family support 57.1%, give time to practice and investigate HEP 57.1% and educate parents/ caregivers to provide emotional and physical support 73.5%.

Variables	Class	Frequency (n =51)	Percentage(%)
Lack of time	Yes	35	71.4
	No	14	28.6
Depression	Yes	7	14.3
	No	42	85.7
Discussion with other care givers	Yes	3	6.1
	No	46	93.9
Lack of support	Yes	13	26.5
	No	36	73.5
Lack of emphasis	Yes	1	2
	No	48	98

Don't know how to do HEP	Yes	3	6.1
	No	46	93.9
Emotions	Yes	12	12
	No	37	37
Interruption from partner/family members	Yes	12	24.5
	No	37	75.5
Overwhelmed by the condition	Yes	5	10.2
	No	44	89.8
Forgetful	Yes	9	18.4
	No	40	81.6
Stress	Yes	21	42.9
	No	28	57.1
Difficulty in performing HEP singlehandedly	Yes	16	32.7
	No	33	67.3
Energy and time consuming	Yes	11	22.4
	No	38	77.6
Resist of HEP by Child	Yes	18	36.7
	No	31	63.3
Seizure occurring during HEP	Yes	3	6.1
	No	46	93.9
Tired of proper positioning	Yes	10	20.4
	No	39	79.6

Table 4: Barriers to Home Exercise Programme (HEP).

Variables	Class	Frequency(n =51)	Percentage (%)
Use of exercise log book	Yes	7	14.3
	No	42	85.7
Emphasis by child/wards Therapist	Yes	31	63.3
	No	18	36.7
Discussion with other caregivers	Yes	22	44.9
	No	27	55.1
Obvious improvements of my child/ward	Yes	38	77.6
	No	11	22.4
Family assistance in performance of HEP	Yes	17	34.7
	No	32	65.3
Use of time table	Yes	6	12.2
	No	43	87.8
Availability of video/audio clips	Yes	8	16.3
	No	41	83.7
Desire for child's wellbeing	Yes	38	77.6
	No	11	22.4

SMS from Therapist	Yes	6	12.2
	No	43	87.8
Telephone calls from Therapists	Yes	7	14.3
	No	42	85.7
Investigations by Therapists	Yes	13	26.5
	No	36	73.5
Encouragement from Therapist	Yes	37	73.5
	No	12	26.5

Table 5: Enhancers/ motivators of Home Exercise Programme (HEP).

Variables	Class	Frequency (n =51)	Percentage(%)
Use of exercise log book	No	31	63.3
	Yes	18	36.7
Use of video and audio clips	Yes	24	49
	No	25	51
SMS sent as reminders	Yes	19	38.8
	No	30	61.2
Telephone calls by Therapist	Yes	18	36.7
	No	31	63.3
Partner and Family support	Yes	28	57.1
	No	21	42.9
Giving time to teach, practice and investigate HEPs	Yes	28	57.1
	No	21	42.9
Prescribing a small number of exercises	Yes	20	40.8
	No	29	59.2
Developing individualized exercise programme	Yes	24	49
	No	25	51
Educating parents/caregivers and providing emotional and physical support	Yes	36	73.5
	No	13	26.5

Table 6: Recommended strategies to improve Home Exercise Programme (HEP).

Discussion

Approximately 82% of the caregivers in this study were females. This supports earlier study by Olagunju, et al. 2017 which reported similar pattern. This suggests that caring for children with disability lies largely with women. This study also showed that a greater number of those that perform the HEP were mothers and most times share the caregiving responsibility with others in the family. Whereas many of the participants agreed that HEP were given, the result obtained in this study showed that a few percentage of participants showed strict adherence to HEP. Majority of the caregivers showed good understanding of HEP yet there is poor adherence.

The caregivers were also aware of the benefit of HEP yet poor adherence. The study also showed that the therapist laid emphasis on the performance of HEP by majority of the participants and make effort to enquire about the performance of the prescribed exercise at each treatment session using both oral and practical demonstration. While majority of the caregivers were given opportunity to demonstrate the exercises. This supports the work of Lillo, et al. where it was stated that the physiotherapists teaching style / ways the physiotherapist taught parents to acquire skills for their child's treatment influenced adherence to HEP.

The poor adherence recorded in this could be traced to lack of time as majority of the caregiver claims that lack of time was a major barrier to performance of HEP. This is no wonder as most of them were middle age/ working class population either self-employed or civil servants while few were unemployed and more than half of them have other children to take care of greater percentages of the participants agreed that emphasis on the performance of the HEP by the therapist, obvious improvement of the child's functional abilities, the desire for child wellbeing and encouragement from the child' therapist were the motivating factors that kept them going despite the obvious challenges facing the parents of children living with cerebral palsy.

This is contrary to the work of Basaran, et al. [6] where severity of the functional limitation of children with cerebral palsy enhanced adherence of caregivers to HEP. On the other hand, several professional behaviours were identified as significant factors of adherence. These varied across different types of exercises. An association was found between the adherence to flexibility exercises and 'giving information about evolution', 'justifying usefulness of treatments', 'using the child as a model during instruction of exercises' and 'high satisfaction.

Only two strategies which are use of log book and educating parent/ caregivers, in addition proving emotional and physical support gained recommendation as strategies to help improve adherence to HEP. This agreed with the study by Lilo, et al. [9] and Peplow, et al. [10] and Taylor, et al. [11] on educating parents/ caregivers, in addition proving emotional and physical support while Jonhnson, et al. [12] recognized the use of exercise log book but seek other preferred means of ensuring adherence. This is also supported by Palazzo, et al. [7] who advocates the use of dedicated strategies to improve performance of HEP.

Conclusion

In conclusion, most of the caregivers of children with cerebral palsy were women/ mothers, who have the responsibility to take care of other children in addition to their daily activities and occupation. There is poor adherence to home exercise programme among caregivers of children living with cerebral palsy. The caregivers have good understanding of the home exercise programme because of the child's therapist take measures to explain then and lay emphasis on them. The caregivers are well aware of the benefit of HEP for their child.

There are barriers to the performance of the HEP despite being aware of the advantanges of performing them. There is need to seek strategies to help improve the performance of HEP. Family centered care or approach is recommended to be utilized from the first day of presentation to the clinic. Counselling session can be organized for the caregivers and their families. Strategies to improve performance of HEP should be adopted by therapists. Sample size for further studies should be increased. Further study should be done utilizing strategies to improve performance of HEP.

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