Original Article

Clinical-Demographic Variables and Compliance with Home Programme among Nigerian Informal Caregivers of Children with Cerebral Palsy

T J. Olagunju, M B. Fatudimu, T K. Hamzat

Department of Physiotherapy, College of Medicine, University of Ibadan

Abstract

Background and Purpose of Study: Prescription of home exercise programme is a common component of physiotherapy intervention in managing children with Cerebral Palsy (CP). Home programme has been shown to accelerate the success of rehabilitation intervention and improve motor functions in the patient. Many factors related to the caregiver are thought to influence their compliance with home programmes. Such factors have however not been studied among Nigerian informal caregivers of children with cerebral palsy. Identification of such factors may help clinicians spot patients at risk of non-compliance and suggest methods to reduce the impact of these limiting factors thereby improving compliance with prescribed home programmes. This study was carried out to highlight clinical and demographic factors associated with compliance with home programme among informal caregivers of Nigerian children with cerebral palsy.

Methods: Forty-seven consecutively recruited informal caregivers that had been bringing their children/wards consistently for physiotherapy at selected hospitals in Ibadan for at least 6 months preceding this study constituted the study sample. A validated questionnaire was used to obtain

information on the selected clinico-demographic variables and assess compliance with home programme. Compliance was rated as one of the following: "1-2 times per week", "3-4 times per week", "5-6 times per week" and "Greater than 6 times per week". These figures were then interpreted as "Sometimes", "When time permits", "Always" and "Regularly" respectively. Data were summarised using descriptive statistics while Chisquare test at 0.05 alpha level was used for the inferential statistic.

Results: 51.1% of the caregivers carried out prescribed home programme regularly. There was no significant association between any of the selected clinico-demographic variables and the level of compliance of the caregivers.

Conclusions: About half of the informal caregivers of children with cerebral palsy carried out home programme regularly. This has clinical significance in physiotherapy practice with respect to total management of children with cerebral palsy. It is worthy of note that no clinic-demographic variable of the caregivers determined their compliance. The study sample size calls for cautious in generalisation of the findings from this study.

Corresponding author:

Professor T. K. Hamzat
Department of Physiotherapy, College of Medicine
University of Ibadan PMB 5017 GPO Dugbe Ibadan, Nigeria
Email: tkhamzat@com.ui.edu.ng Tel: +234-7031096849

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INTRODUCTION

Cerebral Palsy (CP) is a group of permanent disorders of the development of motor and posture, causing activity limitation that are attributed to non-progressive disturbances which occurred in the developing foetal or infant brain. Cerebral palsy also refers to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affects body movement and muscle coordination but do not worsen over time. The clinical manifestations of cerebral palsy vary greatly in the type of movement disorder, the degree of functional ability and limitation, and the affected parts of the body.

The disabilities experienced by children with CP make them require both formal and informal caregiving. An informal caregiver is a spouse, parents, children, friends and relations or anyone with significant relationship with a patient and provides care to that patient. According to Hamzat⁴, the impact of a neurological illness such as CP is usually felt by both the victim and their informal caregivers. This is more so that in the management of neurological conditions, Physiotherapist prescribes to the patients' home programmes which are expected to be executed at their respective homes, under the supervision, or with the assistance of their informal caregivers. Informal caregivers therefore play an important role in the management of children with CP, including ensuring compliance with appointment schedules and home programmes that compliment hospital-based physiotherapy intervention.5

Home programme refers to activities that are specially designed for an individual patient and taught to parents or informal caregivers to be carried out at home with the aim of achieving their therapy goals such as improving gross motor skills, self-care abilities, behaviour and communication. The idea of home programmes is to increase the intensity of therapy, either during treatment sessions or during break from therapy ⁶ and in the case of CP, to achieve desired health outcomes in the children.⁷

Home programmes involving the caregivers have been shown to accelerate the success of the rehabilitation goals and to improve motor function of children with cerebral palsy.⁸ Physiotherapy uses physical approaches to promote, maintain and restore physical, psychological and social wellbeing. Therefore, compliance with physiotherapy home programmes by the informal caregiver may accelerate improvement in a child with cerebral palsy. The extent to which caregivers of children with CP comply with home programmes may be a function of many factors including caregiver's factors and patient's health. It is therefore necessary to understand how these clinico-demographic variables relate to compliance with home programme by informal caregivers of children with cerebral palsy. In a study by Rone-Adams⁸ 66% of the caregivers declared varying levels of noncompliance to their programme due to different factors. Some qualitative studies have assessed factors that affect compliance among children with cerebral palsy^{10, 11} in various parts of the world, but there appears to be no similar study published in Nigeria. Yet every community or society has peculiar factors that could influence compliance with home programme. This study was carried out to assess the level of compliance with home programme among Nigerian informal caregivers of children with cerebral palsy. In addition the association between factors such as age of children, type of CP, gender of caregivers, age of caregivers, level of education of caregivers, marital status of caregivers, family setting of caregivers, number of siblings of the children with CP and the compliance of their informal caregivers with home programme was investigated.

Participants

This was a descriptive cross-sectional survey which involved 47 participants who were recruited over a 3- month period using a consecutive sampling technique. The participants were informal caregivers of children with CP, who regularly brought their children for physiotherapy treatment at

the Physiotherapy out-patient clinics of the University College Hospital, Adeoyo Maternity Teaching Hospital and Oni Memorial Children's Hospital and have been directly involved in caring for these children at home. Only informal caregivers, those who had been receiving physiotherapy for a minimum of 6 months prior to the study and could comprehend and speak either English or Yoruba language were recruited in this study.

Procedure

The University of Ibadan/University College Hospital (UI/UCH) Health Research Ethics Committee approved the procedure for the study. All the participants gave informed consent.

The instrument was researcher-administered. Each consenting participant was interviewed based strictly on the questionnaire using either the English or Yoruba questionnaire, as appropriate. The 40-item questionnaire purposely designed for data collection in this study was used to gather information on socio-demographic characteristics of informal caregivers of children with cerebral palsy and clinico-demographic characteristics of children with cerebral palsy. Content and face validity were established by 6 Physiotherapists who were versed in caring for children with CP and research methodology.

The questionnaire comprised three sections; the first section was used to gather clinic-demographic data on the child, the second section comprised of questions aimed at collecting information on the caregiver's socio-demographic characteristics and the third section consisted of questions that were used to determine their level of compliance to home programme. Participants were asked to indicate one of these as representing their compliance to home programme: "1-2 times per week", "3-4 times per week", "5-6 times per week" and "Greater than 6 times per week". These figures were then interpreted as "Sometimes", "When time permits", "Always" and "Regularly" respectively.

Selected factors like the age of the children, type of CP, gender of caregivers, age of caregivers, level of education of caregivers, marital status of caregivers, family setting of caregivers, and number of siblings of the children with cerebral palsy were also documented. The questionnaire was translated to Yoruba language by a Yoruba expert and backtranslated for the benefit of those who could not comprehend English Language. Both the English version and Yoruba version were used as appropriate.

Data Analysis

Data were summarised using descriptive statistics of mean, mode, frequency percentage and standard deviation. Chi-square test was used to explore the association between clinico-demographic variables and compliance of informal caregivers of children with cerebral pals

Result

Forty seven individuals who were caregivers of 47 children with cerebral palsy comprising 24 (51.1%) males and 23 (48.9%) females constituted the sample in this study. The incident children with CP were aged between 8 and 156 months with a mean age of 38.47 ± 30.57 months. A larger proportion 24 (51.1%) of the children were delivered in a private hospital while only one (2.1%) was delivered at a traditional birth attendant's place. Most of the children, 35 (74.5%) had spastic cerebral palsy and only one (2.1%) had mixed cerebral palsy. Also a larger proportion (78.7%) of the children presented with quadriplegic affectation as shown in Table 1. Results showed that 22 (46.8%) of the children had no associated conditions while 25 (53.2%) had presence of associated conditions with speech impairment affecting 16 (34%); while one each (2.1% respectively) had sensory deficits and intellectual deficits. Fifteen children (31.9%) were an only child as shown in Table 2 and 11 (33.3%) of them were a 2nd child (Table 2). Most 27 (57.4%) of the children were not attending school as shown in Table 2.

Table 1: Clinical information of children with Cerebral palsy (N=47)

Variables	n	%
Type of CP		
Spastic	35	74.5
Choreo-athetoid	9	19.1
Ataxic	2	4.3
Mixed	1	2.1
Topography		
Quadriplegia	37	78.7
Diplegia	7	14.9
Hemiplegia	3	6.4
Presence of		
associated conditions		
None	22	46.8
Present	25	53.2

KEY: CP-Cerebral Palsy

Table 2: Socio-demographic information of children with cerebral palsy (N=47)

Variables	n	%
Number of siblings		
child has		
0	15	31.9
1	13	27.7
2	10	21.3
3	3	6.4
4	4	8.5
5	2	4.3
Position of child		
among siblings		
1 st	5	18.2
2 nd	11	33.3
3 rd	10	30.3
4 th	3	9.1
5 th	2	6.1
6 th	1	3.0
If child attends		
school		
Yes	20	42.6
No	27	57.4

Socio-demographic Characteristics of the Caregivers

The caregivers of children with cerebral palsy comprised 43 (91.5%) females and 4 (8.5%) males with a mean age of 36.00 ± 10.00 years (Table 3).

Table 3: Socio-demographic characteristics of the caregiver (N=47)

Variables	n	%
Age		
18-27	6	12.8
28-37	22	46.8
38-47	13	27.7
48-57	3	6.4
58-67	3	6.4
Family setting		
Monogamous	42	89.4
Polygamous	2	4.3
Single	3	6.4
Relationship with child		
Mother	33	70.2
Father	5	10.6
Grandmother	5	10.6
Others	4	8.5
Average hours spent		
at home daily		
0-8	1	2.1
9-16	29	61.7
17-24	12	25.5
Undisclosed	5	10.6
Occupation		
Unemployed	3	6.4
Non-skilled	17	36.2
Semi-skilled	11	23.4
Skilled	14	29.8
Undisclosed	2	4.3
Average Income of		
caregiver		
Less than 50000	24	51.1
50000-100000	8	1.7
200000-250000	1	2.1
Undisclosed	14	29.8

A total of 42 (89.4%) had at least a secondary school leaving certificate, most 42 (89.4%) were married with 40 (95.2%) of them being in a monogamous setting and 2 (4.1%) of the caregivers were pregnant at the time of the study. In terms of relationship with the children with CP, 33 (70.2%) of the caregivers were mothers, with fathers representing only 5 (10.6%) as shown in Table 3. Many 17; (36.2%) of

the caregivers had unskilled occupation and 14 (29.9%) had skilled job. Table 3 shows the average number of hours spent at home daily by the caregivers having a mean of 17.00 ± 5.00 hours. Only one of the caregivers reported having someone else (father-in-law) at home in need of special care asides the child with CP and none of the caregivers had any associated musculoskeletal conditions.

Level of Compliance

All 47 caregivers reported that their child/ward was following a home programme and majority 45 (95.7%) of them reported to carry out all the exercises that made up the home programme prescribed to them by the Physiotherapist while 2 (4.3%) of the caregivers reported to carry out all except one as shown in Table 4. Although all the caregivers reported to have been instructed to perform the home programme more than 6 times per week with only 24 (51.1%) of them reporting to have performed the home programme more than 6 times per week as instructed, 6 (12.8%) of them reported 5-6 times per week, 10 (21.3%) reported 3-4 times per week while 7 (14.9%) reported 1-2times per week (Table 4).

Table 4: Physiotherapy Attendance of Caregivers (N=47)

Variables	n	%
If child is following any		
home programme		
Yes	47	100
Number of exercises		
performed		
A11	45	95.7
All except one	2	4.3
Duration of physiotherapy		
treatment		
Below 12months	9	19.1
13-36months	29	61.7
37-60months	4	8.5
61-84months	3	6.4
85-108months	1	2.1
Above 133months	1	2.1

Most (48.9%) of the caregivers reported that the child was diagnosed with CP between the ages of 13 and 36 months with a mean of 30.30±29.10 months while 23 (48.9%) of the children started receiving physiotherapy between the ages of 13 and 36months (Table 4). Nearly half (48.9%) of children had been consistently receiving treatment at the current physiotherapy centre for a duration of 0-12months with a mean of 19.30±21.90 months while majority 40 (85.1%) of caregivers had been consistently taking their children/ward for physiotherapy for a period of 0-24 months with a mean of 17.30 ± 14.30 months. The motivating factor for carrying out home programme for a significant proportion (78.7%) of caregivers is the need for improvement while (57.4%) reported that one of the factors that prevents them from complying regularly with the prescribed home programmes is their busy schedule and 4 (8.5%) of the caregivers had no reason for not complying regularly.

Association between selected clinicodemographic variables and compliance with home programme by Nigerian informal caregivers of children with cerebral palsy

There was no significant association between selected clinico-demographic factors such as age of children (x^2 =14.5; p=0.70), type of CP (x^2 =3.86; p=0.92), gender of caregivers(x^2 =4.79; p=0.19), age of caregivers(x^2 =6.98; p=0.86), level of education of caregivers(x^2 =8.21; p=0.44), marital status of caregivers(x^2 =4.03; p=0.67); family setting of caregivers (x^2 =4.48; p=0.21); number of siblings of the children with CP (x^2 =18.24; x=0.25) and the compliance of Nigerian informal caregivers of children with cerebral palsy with home programme.

DISCUSSION

Approximately half of the children with cerebral palsy in this study were males. Earlier studies on prevalence of CP from different parts of the world reported similar trend ^{5, 12, 13, 14, 15} which may suggest that male gender is a risk factor for CP. The age of

the children was between 6 and 156 months, indicating the age range when children with CP present for physiotherapy management. This finding is in line with a study by Pfeifer et al ¹⁶ which reported age range between 5 and 154 months. Three-quarters of the children had the spastic type of CP and a slightly higher proportion was quadriplegic. This finding is in line with previous studies ^{17, 18} reporting the spastic quadriplegic type of cerebral palsy to be the commonest. About one-third of the children with CP in this study had speech impairment and this finding is similar to that reported by Anderson et al ¹⁹ although another study reported 74% of children with CP having speech impairment.²⁰

Socio-demographic Characteristics of the Participants

Mothers made up 91.5% of the caregivers in this study. Earlier studies involving caregivers 21, 22 carried out in the same part of Nigeria as well as studies from other parts of the world ^{23,24} had reported a similar pattern. This suggests that caring for children with disabilities is largely carried out largely by women, although Basaran et al 11 reported more male caregivers than female caregivers. The ages of the caregivers were between 18 and 67 years with nearly half aged between 28 and 37 years. This could be because most of the caregivers were mothers in their child bearing age. The observation in this study that more than half of them had at least a university degree or a diploma and many are skilled labourers is possibly because this study was conducted in an urban area.

Level of Compliance

The results obtained in this study showed that about half (51.1%) of informal caregivers performed the prescribed home programme regularly. This finding is in agreement with the report of Basaran et al "which noted that 65.3% of caregivers performed their home programme at least once daily. This result may be attributed in part to the fact that many of the participants in this study had tertiary

education and live in the urban area. This would influence their awareness level regarding the cause and management of the cerebral palsy and appreciate the importance of adhering to the home programmes as explained by the physiotherapist while prescribing the home programme to the children.

Nearly half of the children were diagnosed with CP between the ages of 13 and 36 months. Kakooza-Mwesige et al 25 had reported similar age range at diagnosis in their studied sample. This is the age range when a typically developing child is expected to have attained most developmental milestones including walking. Earlier reports had indicated that an average child with cerebral palsy is not diagnosed until approximately 12 months of age when developmental milestones are undeniably noticed to be delayed. ^{26, 27, 28} Our findings therefore invariably suggests that majority of the children were taken to the hospital as soon as they noticed delay their children achieving age-appropriate developmental milestone. This also coincides with the duration of time majority of the children have been receiving physiotherapy.

Association between selected clinicodemographic variables and compliance with home programme by Nigerian informal caregivers of children with cerebral palsy

The age of the child did not significantly associate with level of compliance of informal caregivers. The possible reasons for this could be that the caregivers became resigned to the fact that their child with CP would not improve as the child grew older. About 51.1% of the caregivers with children/ward from all the age groups complied regularly with home programme.

Although a non-significant association was obtained between the type of cerebral palsy and compliance of the caregiver with home programme, a large proportion of the children involved in this study had the spastic type of cerebral palsy which is similar to the previous findings. ^{16, 29} Furthermore, out of the approximately half of caregivers who reportedly

carried out the home programme regularly, more than one-third are caregivers whose children have spastic cerebral palsy. The gender of the caregivers showed no significant association with their compliance with home programme for their children with CP. It is noteworthy a significant proportion (91.5%) of the caregivers were females and it is not unusual that the highest level of compliance was found in this gender. Furthermore, only about onequarter of the males that participated in this study performed the home programme "regularly". Although our results showed no significant association between the age of the caregiver and their level of compliance, this trend is similar to that earlier reported.¹¹ The caregivers that participated in this study were aged between 18 and 67 years; and those in the 28 and 37 years age group constituted the modal group of caregivers who reported to be carrying out the home programme regularly. Level of education of the caregivers had no significant association with their compliance level with home programmes. This means that whatever the level of academic attainment an individual might attain did not influence their execution of the home programme. However, more than half of the caregivers reported to perform the home programme at least 5-6 times per week, and were therefore adjudged to always carry out the home programme. This may be attributed to the level of awareness about the management of the condition given to caregivers in the physiotherapy clinics where they present their children. This study showed that no significant association exists between the marital status of the caregivers and their level of compliance with home programme. Nearly four-fifths of the caregivers were married, a trend that may explain why almost half of those who complied regularly with home programme were from the married group in the studied sample. It could also be due to the fact that married people are in a better social position where they get help and support from their spouse, although two of the caregivers that were divorced also reported to have complied regularly.

The findings from this study showed no significant association existed between the family setting, which is type of marriage of the caregivers and the level of compliance of their caregivers. Majority were in a monogamous family setting and a high percentage carried out the home programmes regularly. About one-third of the children involved in this study were an only child. A trend was observed between the number of siblings of the children with cerebral palsy and compliance of caregivers with home programme in this study. We observed that the caregivers who complied regularly with the home programme were those whose children with cerebral palsy had fewer siblings.

CONCLUSION

About half of the informal caregivers of children with cerebral palsy were regularly compliant with home programme. Clinical and demographic variables such as age of the children, type of CP, gender of caregivers, age of caregivers, level of education of caregivers, marital status of caregivers, family setting of caregivers, number of siblings of the children with CP were not significant association with the level of compliance of Nigerian informal caregivers of children with cerebral palsy with home programme.

Based on the outcome of this study, it is suggested that physiotherapists should educate the caregivers of children with cerebral palsy on the effectiveness of home programme as well as continually encourage them to carry it out regularly. Furthermore physiotherapists should identify barriers that could hinder the caregivers from carrying out the home programme regularly and suggest methods to reduce the impact of those barriers to facilitate maximum compliance.

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