

## Factors affecting adherence to physiotherapy appointments for caregivers of children with cerebral palsy in Kano metropolis

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### Abstract

**Background:** Cerebral palsy (CP) is the most commonly occurring physical disability in childhood. Poor adherence to physiotherapy appointments after discharged is one of the most problematic issue that makes the assessment of progress very difficult for children with CP in Kano state. The aim of the study is to find out the factors affecting adherence to physiotherapy appointment for caregivers of children with cerebral palsy in Kano metropolis.

**Method:** The research method was a cross-sectional survey and 75 caregivers were recruited from Murtala Muhd Specialist hospital, Abdullahi Wase specialist hospital and Hasiya Bayero Pediatric hospital using purposive sampling technique, however, 60 participants were eligibly enrolled into this research. Respondents were the principal caregivers of the children. Case notes and questionnaires were the major instruments used to obtain the data, however, verbal communication with the caregivers was done where necessary.

**Results:** Socio-economic level was determined using Kuppusswamy scale. Descriptive statistics of means and standard deviation in form of percentages, tables and graphs was used to summarize the results. Inferential statistics of Chi-squares (at 5% level of significance), was employed to determine the associations between pairs of categorical variables in the study.

**Conclusion:** According to the results of this study: level of education, marital status, knowledge of the condition and socioeconomic class of the caregivers were found to significantly affect the adherence (P-value <0.05), while age of the caregivers was found to have no significant association with their adherence to physiotherapy appointment. (P-value >0.05).

**Key words:** cerebral palsy, adherence, physiotherapy, Kuppusswamy scale.

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### Introduction

Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain [1]. The motor disorders of CP are often accompanied by disturbances of perception, cognition, sensation, communication, behavior, epilepsy and by secondary musculoskeletal problems. Cerebral palsy is the most commonly occurring physical

disability in childhood [1]. Although cerebral palsy rates are thought to be similar in developed and developing countries [2], the aetiology does seem to differ as the contribution of severe birth asphyxia, kernicterus and central nervous system infections (e.g. tuberculosis, meningitis, cerebral malaria etc.) continues to be significant problem in many developing countries [3].

Adherence has been defined as: “the extent to which person’s behavior corresponds with agreed recommendations from a healthcare provider” [5].

Within physiotherapy, the concept of adherence is multidimensional [4] and could relate to attendance at appointments, following advice, undertaking prescribed exercises, frequency of undertaking the prescribed exercises, correct performance of exercise. Many factors related to patients, healthcare providers and health care organizations are thought to influence patient adherence with treatment [6].

Like any other clinical condition, patient adherence to treatment appointment is important for the therapeutic regimen to be effective in the management of cerebral palsy. Without compliance, the therapeutic goals cannot be achieved, resulting in poor patient outcomes [7]. Research on adherence to pediatric treatment regimes has received attention in recent years as such optimal adherence to medical and other therapeutic regimens can have personal, social and clinical implication for the child as an adult [9]. Lack of information regarding reasons for poor adherence to the hospital appointments makes it difficult for health providers to determine the impact of treatment on health status or weigh the cost/benefit ratio for the prescribed treatments [10].

According to [11], the emphasis of health care in many developing countries is directed primarily to curative and preventive aspects of disease, the rehabilitation getting less attention. Scarcity of resources and poor distribution of health care professionals between rural and urban regions add to problems of rehabilitation in developing countries, this has resulted in many patients in rural settings going without treatment or having to travel long journeys to urban areas for treatment [11].

One of the main challenges for parents/caregivers is to adhere to physiotherapy appointment in the management of their child's chronic health problems effectively and juggle this role with the requirements of everyday living [5]. Consequently, the task of caring for a child with

complex disabilities might be somewhat daunting for caregivers [2]. The provision of such care may prove detrimental to both the physical health and the psychological well-being of caregivers of children with chronic disabilities, it is not fully understood why some caregivers cope well and others do not [5]. Mothers of children with cerebral palsy are usually the primary caregivers of their children, and the care of these children occurs both at home and hospital [12]. In some instances the whole family becomes active participants in caring for the child. This role places great demand on time and energy of the family and primary caregivers and also requires more resources.

Therefore, it is important to understand how parents/caregivers of the children with cerebral palsy manage their children's physiotherapy services and the potential barriers they encounter during the utilization of the services. Hence knowledge of those factors that affect adherence to physiotherapy appointment among the children with CP has significant implication for ongoing efforts directed at proper rehabilitation of those children.

Kano state is located in north-western Nigeria and the most populous state of the Nigerian federation, and has a population of 11,058,300 people [13] with a total local government area of 44. The total area of Kano is 20,131km (7,773 sq mi)[14]. One of the problematic aspect in the management of children with cerebral palsy is poor adherence to appointment[6]. Poor adherence to physiotherapy appointment after discharged is one of the most problematic issue that makes the assessment of progress very difficult for children with CP in Kano state. Despite this, there seems to be a paucity of research on the factors affecting adherence to physiotherapy appointments in the state. Hence, this research is aimed at finding out the socio-demographic factors affecting adherence to physiotherapy appointment in Kano state.

**Materials and Method**

Ethical approval was obtained from the ethical committee of Kano state hospital management board (Nigeria). The sample size used was sixty (60) principal caregivers of children with CP in this cross sectional survey. The participants were recruited from Murtala Muhd Specialist Hospital (MMSH), Hasiya Bayero Pediatric Hospital (HBPH) and Abdullahi Wase Specialist Hospital (AWSH) all in Kano metropolitan, using simple random sampling technique. Each participant was required to sign a consent form, agreeing to participate in the study. The aims of the research and the importance of the outcomes were explained to the participants. The respondents were assured of the confidentiality of their responses.

The instruments were the case notes of the children with cerebral palsy and questionnaire. The questions in the instrument were generated through literature reviewing and studying sample of questionnaires from related articles. So the questionnaire was validated by the panel of expertised in the department. It comprises mostly the close-ended questions, however open-ended were included to allow the participants to express their feelings.

Socio-economic status in this study was assessed by adopting the use of Kuppaswamy socio-economic status scale, this is an important tool used in hospital and community based research [15]. It was proposed in 1976 in India [15]. The scale takes account of education, occupation and income to classify study groups into high, middle and low socio-economic status. It gives a maximum score of 29 and lowest of 3. An income scale however has relevance for the period under study and is peculiar to its location, hence the current Income rating peculiar to Nigeria which has been used previously by [16] was adopted. Each of the division of Kuppaswamy scale i.e. Education, Occupation and Income has a number

ascribed to the equivalent status of the individual in each division.

Adherence in this research, was determined by considering the number of attendance of the prescribed appointments divided by the total sessions prescribed appointments (from the first appointment) multiply by one hundred i.e.

$$\text{Adherence} = \frac{\text{Number of attendance}}{\text{Total sessions prescribed appointments}} \times 100$$

Where a score of  $\geq 70\%$  considered to be adherence, while  $< 70\%$  considered to be non-adherence [21].

Descriptive statistics of means, standard deviation, percentages in form of tables and graphs was used to summarize the results. Inferential statistics of Chi-squares (at 5% level of significance), was employed to determine the associations between pairs of categorical variables in the study.

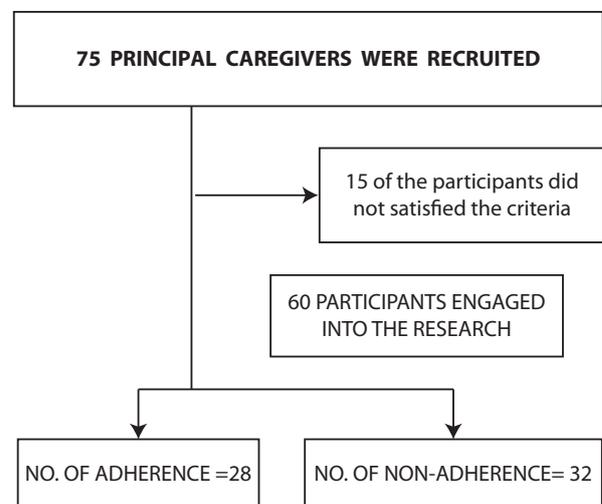


Figure 1: Flow chart shows the distribution of the participants

**Results**

Table 1 depicts the association between age of the caregivers, marital status, level of education, caregivers’ knowledge of CP, socio-economics status and adherence to physiotherapy appointment.

It was found that the highest number of the caregivers, 15(46.9%) that adhered to the appointment were within the age range of 20-40 years, however, the results showed that there is no significant relationship between the age of the caregivers and adherence to physiotherapy appointment (i.e.  $p > 0.05$ ).

It showed that marital status of the caregivers and adherence to physiotherapy appointment. The highest number of adherence 10(55.6%) was recorded among the married caregivers while the highest number of non-adherence 25(62.5%) was seen among the divorced caregivers. The results showed that there is significant association between the marital status of the caregivers and adherence to physiotherapy appointment (i.e.  $p < 0.05$ ).

From this table, out of the 10 caregivers with BSc/HND, 8(30.8%) adhered with their

appointment only 2(5.9%) did not. While out of the 17 caregivers that did not receive formal education, 14(41.2%) did not adhere to their appointment. It was shown that there is significant relation between the caregivers level of education and adherence (i.e.  $P < 0.05$ ).

It was found that, out of 28 number of caregivers that adhered to the appointment, 23(82.1%) had knowledge about the condition, while out of 32 caregivers that did not adhere to the appointment, 23(71.9%) had no knowledge about the CP. The Chi-square test showed that there is significant association between the knowledge of CP and the adherence (i.e.  $P < 0.05$ ).

According to the results in the table 1, the majority 12(42.9%) of the caregivers that adhered to the appointment were in the upper socio-economic level while the highest number 15 (46.9%) of non-

Table 1: Association between the variables and Adherence

Variables	ADHERENCE		df	X <sup>2</sup>	P-value
	YES N=32 n (%)	NO N=28 n (%)			
<b>Age of the caregivers</b>					
< 20	10 (31.3)	5 (17.9)	3	6.57	0.227
20-40	15 (46.9)	10 (35.7)			
40-60	5 (15.6)	10 (35.7)			
60-80	2 (6.3)	3 (10.7)			
<b>Marital status</b>					
Single	1 (3.6)	3 (9.4)	3	9.32	0.008
Married	20 (71.4)	8 (25.0)			
Divorced	5 (17.9)	19 (59.4)			
Widow	2 (7.1)	2 (6.3)			
<b>Level of Education</b>					
BSc/HND	10 (35.7)	2 (6.3)	4	14.43	0.004
NCE/ND	2 (7.1)	3 (9.4)			
Secondary	10 (35.7)	9 (28.1)			
Primary	2 (7.1)	5 (15.6)			
Non formal ed.	4 (12.5)	13 (40.6)			
<b>Caregivers' knowledge of CP</b>					
Known	23 (82.1)	9 (28.1)	1	4.56	0.012
Not known	5 (17.9)	23 (71.9)			
<b>Socio-economic status</b>					
Upper	12 (42.9)	6 (18.8)	2	6.39	0.014
Middle	9 (32.1)	11 (34.4)			
Lower	7 (25.0)	15 (46.9)			

*N=60, ,significant level=0.05.*

adherence was recorded among the caregivers in lower socio-economic level. The results showed significant association between socio-economic status and adherence( i.e.  $P < 0.05$ ).

Figure 2 below shows the percentage distribution of the participants based on adherence and non-adherence, it was found that 28(46.7%) of the participants complied with their appointments, while 32(53.3%) did not.

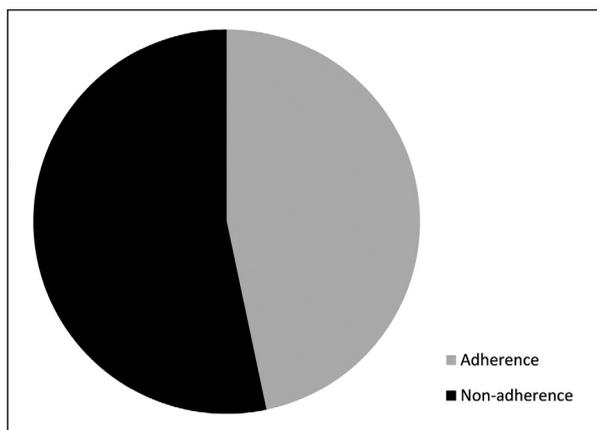


Figure 2: Distribution of the participants with respect to adherence and non-adherence

## Discussion

The result of this study shows that the total number of adherence was 28(46.7%) and non-adherence was found to be 32(53.3%).

The result shows that there was no significant relationship between age of the caregivers and adherence. This is in contrast with the results of study by [16] which also found that non attendees were more likely to be people aged between twenty three and twenty-seven years old. [17] found that rates tend to fall with a minimum non-attendance rate in the seventy to seventy four year age groups. There are contradictory findings in the literature with regards to the age and gender of those patients who do not attend their scheduled appointments.

The result from table 1, shows significant relationship between the marital status and adherence to physiotherapy appointment. The

result shows that most of the principal caregivers are biological mothers of the children, it also shows that there was high rate of adherence among the married caregivers and high rate of non-adherence was recorded among the divorced caregivers.

This study shows that level of education of the caregivers has significant relationship with adherence to physiotherapy appointment. The caregivers with the highest level of academic qualification tend to be more adherent than those with low level or non formal education. This finding is similar to that of [18] on diabetic patients at Kalafong Hospital who found that 55% of patients that did not attend their appointment had primary school education or less with only 3.9% of the patients that did not attend having a degree.

According to this research, caregivers' knowledge of the CP found to have significant relationship with the adherence. This is in agreement with the results of the study on HIV related knowledge and adherence to antiretroviral therapy in New York, USA, [19] found that all the patients that participated in their study had good knowledge about HIV and complied well with the treatment regimen.

Findings from this study show a significant relationship between the socioeconomic status and adherence. The socio-economic status (SES) was assessed using Kuppaswamy's SES scale which evaluated SES of a family by the categorization of the family in respect of defined variables such as, education, occupation and per capital incomes. Socio-economic factors have been shown to be a major hindrance to access to health care services in most resource-poor settings.[20] assert that despite the availability of effective treatment interventions and the high cure rate, the outcome of treatment in many parts of Africa remains sub-optimal due to poor socio-economic conditions and poor health seeking behaviours.

## Conclusion

There were many factors affecting adherence for physiotherapy appointment by caregivers of children with cerebral palsy. According to the results of this study: level of education, marital status, knowledge of the condition and socioeconomic class were found to be the major factors affecting the adherence in Kano state. From the findings of this study, the following recommendations are made:

- I. Caregivers should be fully enlightened about what cerebral palsy is, and what actually causes it, so as to minimize the number of cases that occur especially due to cerebral malaria and birth asphyxia.
- II. Awareness programs should be arranged for the caregivers of these children to know what rehabilitation of a cerebral palsy patients is all about. They should know that CP is a permanent disorder and not something that completely heals with rehabilitation however, with good adherence to clinical appointments the quality of lives of these children can be improved significantly.
- III. Further study with larger sample size should be conducted on barriers to regular treatment adherence, encountered by parents/caregivers, at different parts of Nigeria and the entire world at large.

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