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Original Article

Knowledge and Beliefs of Informal Caregivers of Children with Cerebral Palsy in Nigeria Concerning Cerebral Palsy

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ABSTRACT

Background: Caregivers of children with Cerebral Palsy (CP) play an important role in the habilitation of their wards. Their knowledge and beliefs about CP may affect their disposition to habilitation and the quality of care and habilitation their wards would receive. Knowledge and beliefs of informal caregivers of children with CP in Southwest, Nigeria were investigated in this study.

Methods: Ninety-three informal caregivers (relatives or friends) of children with CP who routinely provide an average of 3-5hours of care per week without pay were surveyed. A 56-item questionnaire was used to collect information on socio-demographics, knowledge and beliefs of the informal caregivers about CP. Data were summarized using descriptive statistics of mean, percentages and standard deviation.

Results: Participants were aged 36.6 ±8.6 years and their age ranged from 16-66 years. Majority of the respondents (*n* = 85; 91.4%) were female. Most of the participants (*n* = 87; 93.5%) were married and (62.4%) had completed tertiary education. Sixty six(71%) respondents reported good knowledge while 9(9.7%) reported poor knowledge about cerebral palsy. Most of the caregivers responded correctly in expressing their belief, causes and management of cerebral palsy

Conclusions: Informal caregivers of children with cerebral palsy in southwestern Nigeria had good knowledge and positive beliefs about cerebral palsy hence the need to ensure that they seek appropriate intervention to this condition.

INTRODUCTION

Cerebral Palsy (CP) is an umbrella term covering a group of non-progressive but often changing motor impairment syndromes that is secondary to lesions or anomalies in the brain, arising in the early stages of development[1]. CP has been reported to be the most common cause of physical disability among children[2]. In Low and Middle Income Countries (LMIC), the estimated prevalence rate is 1.5–5.6 cases per 1000 live births [3]. It is a common neuro-developmental condition and the most common paediatric neurological case accounting for about 50.3% of all cases seen in the clinics[4,5]. There are estimated 15million people living with CP worldwide, more than half of whom are mentally retarded [6].

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Children with CP often require a caregiver, who will take care of all the activities that the child cannot perform by himself and also take responsibility for his treatment and well-being [7]. Caring for a child with a developmental disability requires significant and prolonged periods of time and energy, giving attention to physically demanding and unpleasant tasks, and frequent disruption of family routines and activities [3]. Caregivers of children with CP have been reported to receive very little information from the treating physicians, nurses and therapists and are also left with many questions unanswered about this disorder. Knowledge and perception of caregivers about daily care of children with CP has substantial impact on the success of the child's rehabilitative management as well as compliance with treatment regimen [8].

The African society generally holds a negative attitude towards disability [9]. It is believed that the wrongdoings of mothers of children with CP is the cause of the children's condition and such caregivers are often advised to terminate the life of their children or seek complimentary treatments from herbalists/spiritualist[10]. Knowledge and beliefs of caregivers determines and/or contributes to their response to societal beliefs, attitude and practice about children with CP. Knowledge and beliefs of caregivers about other neurological conditions such as stroke and poliomyelitis have been reported in Nigeria [11,12]. CP is the most common paediatric neurological disorder in Nigeria[4,13]. Yet, the knowledge and beliefs of caregivers of children with CP about CP has not been investigated. This study was conducted to investigate the knowledge and beliefs of informal caregivers of children with cerebral palsy about cerebral palsy. Also, Association between knowledge and selected variables such age, gender, educational status, employment status will be explored.

METHODS

Informal caregivers of children with CP receiving physiotherapy in seven teaching hospitals in Southwestern, Nigeria were purposively recruited for this study. Informal caregiver were relatives or individuals who provide unpaid care on regular basis and at an average of 3-5 hours per week to children with CP. Eligible participants were eighteen years and above and could comprehend instructions in English and/or Yoruba language. Ethical approval for the study was obtained from the appropriate Health Research Ethics committee (UI/EC/15/0125). Informed consent was obtained from all participants.

A 56-item structured questionnaire comprising three sections was used for data collection. The questionnaire was modified from the one used in similar studies conducted in Nigeria [11,12]. Section A was made up of 15 items eliciting information on socio-demographic data of the participants and their respective wards.

Section B: comprised 26 items. These close-ended statements inquired about participants' knowledge of cerebral palsy in terms of causes, clinical features and risk factors. Response options to this section were 'Yes', 'Undecided' and 'No'. A score of 1 was given for each correct response while an incorrect or 'No' response earned a 0. The maximum obtainable score for was therefore 26. Each participant's score was scale-transformed and expressed as a percentage. Percent scores were subsequently classified as poor (0-39%), fair (40-59%) and good (60-100%). Section C contained 15 statements inquiring about the beliefs of respondents in the context of their cultural belief system about cerebral palsy. This section had a 'Yes' and 'No' response options. Responses to each of the statement in this section was reported in frequencies and percentages (Additional file I).

Questionnaire was content and face validated by experts comprising physiotherapists, an epidemiologist and a sociologist before use. In addition, the validated questionnaire was pretested among informal caregivers of children with CP who were not allowed participate in the main study and the knowledge and belief sections had a Cronbach's alpha of 0.75 and 0.86 respectively. The pre-test questionnaire was translated into Yoruba language by an expert linguist for the benefit of those who

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could not comprehend English language. Both the English and the Yoruba versions were used in data collection as appropriate. Questionnaires were hand distributed to participants in their respective physiotherapy clinics and were collected after they were completed. Questionnaires were self-administered by the participants. Data was cleaned and analyzed using SPSS version 20. Descriptive statistics was used to summarized and illustrate data. Chi-square test was used to investigate the association between knowledge and sociodemographic variables of the participants at 0.05 alpha.

RESULTS

A total of 93 informal caregivers of children with CP participated in this study. Their ages ranged from 16 to 66 years, with a mean of 36.6 ±8.6 years. Majority of the respondents were females (91.4%), most (93.5%) were married and about two-thirds (62.4%) had completed tertiary education (Table 1). Majority of the children with CP were males (62.4%) and most (44.4%) were over 24 months old.

Majority of the respondents 66 (71%) had good knowledge about cerebral palsy (Figure 1). There was no significant relationship (p>0.05) between participants' knowledge scores and their sociodemographic variables (Table 2).

More than half of the participants (53.8%) believed that CP was not a spiritual attack or punishment from God and that witches and wizards were not the causes of CP as shown in table 3. More than four-fifths (83.0%) of the participants believed that children with CP cannot be managed by traditional healers. Although majority of the participants (91.0%) believed that CP could be managed with a combination of orthodox medicine and prayers, only a fifth (22.0%) believed that prayer alone could cure CP. Majority of the participants (86.0%) believed that CP could not be inherited. (59.0%) of the participants believed that CP affects only children. (91.0%) of the informal caregivers believed that physiotherapy improves of functional abilities of children with CP.

Variables	N	%
Age (years)		
17-26	6	6.5
27-36	48	51.6
37-46	24	25.8
47-56	15	16.1
57-66	0	0.0
Gender		
Male	8	8.6
Female	85	91.4
Marital Status		
Single	6	6.5
Married	87	93.5
Religion		
Christian	66	71
Islam	27	29
Education		
Primary	6	6.5
Secondary	28	30.1
Teritary	58	62.4
None	1	1.1
Relationship with Children		
Father	8	8.6
Mother	77	82.8
Grandparent	8	8.6
Employment Status		
Paid employment	28	30.1
Self employment	57	61.3
Unemployed	8	8.6
Age of Children		
7-12	27	29.0
13-24	25	26.9
Above 24months	41	44.1

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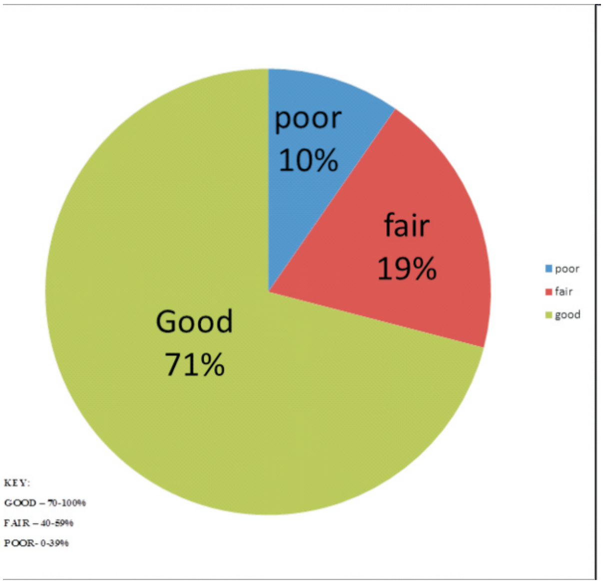

Figure 1: Knowledge of informal caregivers about cerebral palsy.

Table 2: Association between age group, gender, educational status and employment status with Knowledge of caregivers about cerebral palsy

Variables	Knowledge of Informal caregivers					
	Good n(%)	Fair n(%)	Poor n(%)	Total n(%)	χ^2	P
Age group (years)						
17-26	5 (83.3)	1 (16.7)	0 (0.0)	6(6.5)	13.81	0.087
27-36	31 (65.9)	10 (21.3)	6(12.8)	47(50.5)		
37-46	20 (80.0)	3(12.0)	2(8.0)	25(26.9)		
47-56	10(71.4)	4(28.6)	0(0.0)	14(15.1)		
57-66	0(0.0)	0(0.0)	1(1.1)	1(1.1)		
Total	66 (71.0)	18(19.4)	9(9.7)	93(100)		
Gender						
Male	6(75.0)	2(25.0)	0(0.0)	8(8.6)	1.01	0.603
Female	60(70.6)	16(18.8)	9(10.6)	85(91.4)		
Total	66(71.0)	18(19.4)	9(9.7)	93(100)		
Educational Status						
Primary	4(57.1)	1(14.2)	2(28.6)	7(6.5)	10.94	0.205
Junior secondary	2(66.7)	1 (33.3)	0(0.0)	3(3.2)		
Senior secondary	17(68.0)	6(24.0)	2(8.0)	25(26.9)		
Tertiary	43(74.1)	10(17.2)	5(8.6)	58(62.4)		
Total	66(71.0)	18(19.4)	9(9.7)	93(100)		
Employment Status						
Employed	21(75.0)	4(14.3)	3(10.7)	28(30.1)	0.884	0.927
Self-employed	40(70.2)	12 (21.1)	5(8.8)	57(61.3)		
Unemployed	5(62.5)	2(25.0)	1(12.5)	8(8.6)		
Total	66(71.0)	18(19.4)	9(9.7)	93(100.0)		

Table 3: Respondent's Beliefs about children with Cerebral palsy

Item-Statements	**Yes**	**NO**
	N (%)	N (%)
Cerebral palsy is caused by witches and wizards.	32(34.4)	61(65.6)
Cerebral palsy is a spiritual attack.	43(46.2)	50(53.8)
Cerebral palsy is a punishment from God for doing evil.	18(19.4)	75(80.6)
Cerebral palsy is the fault of the mother.	43(46.2)	50(53.8)
Cerebral palsy can spread to others.	5(5.4)	88(94.6)
Cerebral palsy can be cured with prayers alone.	20(21.5)	73(78.5)
Cerebral palsy can be cured with prayers and medical treatment.	91(97.8)	2(2.2)
Cerebral Palsy can be managed with traditional and orthodox treatment.	28(30.1)	65(69.9)
Children with cerebral palsy cannot be cured by medical treatment alone	54(58.1)	39(41.9)
Children with cerebral palsy can improve with Physiotherapy.	91(97.8)	2(2.2)
Cerebral palsy is preventable.	60(64.5)	33(35.5)
Children with cerebral palsy may be cured by traditional healers.	10(10.8)	83(89.2)
Cerebral palsy runs in some families.	7(7.5)	86(92.5)
Cerebral palsy affects only children	59(63.4)	34(36.6)
Cerebral palsy affects only children	39(41.9)	54(58.1)

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DISCUSSION

Mothers constituted majority of the informal caregivers of children with CP in this study. This is in line with the findings of Hamzat et al[14] that mothers constitute the majority of informal caregivers of children with CP. These authors claim that this finding may be related to their traditional role as the primary care provider for children in most parts of the world [14]. Respondents were young adults, from the Yoruba tribe which is the dominant ethnic group in Southwest Nigeria where this study was carried out[15]. Tertiary education was the predominant level of education among the respondents. This is not surprising because, this study was conducted in the southwestern part of Nigeria, a region that is reported to constitute a larger proportion of educated individuals in Nigeria [16]. Caregivers in this study were largely self-employed, an outcome that is in congruence with that of Ogwumike et al[12]. This finding could be attributed to the dominant population of women in this study. The continuous rise in the economic contribution of women in sub-Saharan Africa[17] has been reported in literature. Hence, in addition to their traditional roles as mothers, they also engage in varying entrepreneur/business opportunities to support their families.

The findings from this study showed that majority of the informal caregivers had good knowledge about cerebral palsy. Studies by Bamgbade et al[18] and Olawale et al [19], have also reported similar findings. However, Karande et al[20] Huang et al[14] and Ribeiro et al[21] reported poor knowledge among caregivers. This variation in findings may be related to the level of education of participants in the studies. The studies of Karande et al [20], Huang et al[14] and Ribeiro et al[21] were carried out in India and Taiwan respectively. Though these authors did not indicate the level of education of the participants in their studies, our study was conducted in urban settings of a region (Southwest region) which has been adjudged to have the highest number of highly educated people in Nigeria. In addition, patient education is an integral part of physiotherapy management for caregivers of children with CP in most clinics in Southwest, Nigeria. This could also have contributed to the high level of knowledge recorded in this study.

Findings from this study showed that there is no significant association between knowledge and age of the informal caregivers of children with CP. This is contrary findings from the study by Ogwumike et al[12] which found an inverse relationship between knowledge and age of the caregivers of children with CP. Majority of the population investigated by Ogwumike et al[12], were primary school leavers, and teenager/young adult parents of children with poliomyelitis-a neurological condition that has also received more attention in recent times, both nationally and internationally. In contrast, caregivers in this study were mostly middle aged adults who had undergone tertiary education. As Studies have shown that increased level of education improves health knowledge [23], most of the caregivers in this study might have utilized health information resources (Online, radio, television) hence influencing their level of knowledge irrespective of their age.

Similarly, there was no significant association between the knowledge of the informal caregivers and their sex. This is in line with reports from earlier studies that there is no gender difference in knowledge of caregivers about CP [24,25]. This suggests that both male and female informal caregivers obtained needed information about their ward's ailment and were therefore comparable in knowledge about CP.

Knowledge was not significantly associated with educational status in this study. This is in agreement with reports by Ogwumike et al[12] and Shilpa et al[25], but at variance with findings of Ashkanani et al[26] which reported a positive relationship between educational status and knowledge of caregivers. This suggest that information about CP are provided in a manner and/or language that is understandable to the caregivers of children with CP in Southwest, Nigeria. Employment status was not associated with knowledge. Limited studies have investigated the

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association between employment and knowledge about CP. One possible explanation for this could be the level of education of the participants. Employment is related to educational status. Given that majority of the participants had post secondary education, they were likely to be better employed and could afford access to information on CP.

There was a significant shift from the traditional African belief that CP was caused by witchcraft and sorcery, punishment from "gods" for wrong doing of the family member, most especially the mother [10]. Majority of the respondents believed and rightly so that CP was not a spiritual attack or punishment for the wrong doing of the mother of a child with CP. However, some of the participants believed that a child with disability had been ordained to be disabled. It is a common belief pattern among Africans that God or Allah was influential in determining disability and also that a child with disability should be accepted as a gift or blessing [28]. This erroneous belief often led to delay in the diagnosis and less enthusiasm about seeking rehabilitation services[25]. More than half of the respondents were believed that seeking medical care alongside prayer could improve the clinical outcome for children with CP. Majority of the participants alluded to the importance and positive effect of physiotherapy in improving physical function in children with CP.

CONCLUSIONS

Majority of informal caregivers of children with cerebral palsy in Southwest, Nigeria have good knowledge and the correct belief about cerebral palsy. However, Support groups can be established further to reinforce caregivers knowledge and belief about CP as this may help them in seeking appropriate and early interventions for their wards.

Limitations of the study

The inherent limitation of questionnaire is that it is subjective and as such, participant's responses may not be fully captured.

Declarations

Ethics approval and consent to participate

The protocol was for this study was approved by the Health Research Ethics committee (UI/EC/15/0125), College of Medicine, University of Ibadan, Oyo state, Nigeria. All the Participants consented to participate in the study. The authors have no ethical conflict to disclose.

Competing interests

The authors declare no conflict of interest to declare.

Authors' contributions

O.D contributed to the Conceptualisation, study design, data collection, analysis and drafting of the manuscript. T.K participated in the conceptualization, the design of the study's methodology, data interpretation and review of the manuscript. O.O participated in the revision of manuscript and the interpretation of data. All the authors read and approved the final manuscript.

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