

Effects of An Educational Programme on Knowledge of Cerebral Palsy among Informal Caregivers of Children Presenting at Selected Physiotherapy Clinics in Ibadan

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ABSTRACT

Background: Children with Cerebral Palsy (CP) often require assistance from their informal caregivers to perform age-expected functions. These caregivers require sufficient knowledge of CP to effectively perform their roles. Effects of a structured education programme to improve CP knowledge among caregivers have been separately studied using single-module and multi-module educational programmes. Information is however scarce on their differential effects.

Objective: To compare the effects of single and multi-module educational programme interventions on the knowledge of CP among their informal caregivers.

Methods: A quasi-experimental design involving 40 consecutively sampled informal caregivers of children with CP. They were assigned into either the single-module or the multi-module educational intervention groups. Baseline and post-intervention knowledge of CP were assessed using the Knowledge of Cerebral Palsy Questionnaire and compared using Wilcoxon signed-rank test and Mann-Whitney U test at $p=0.05$.

Results: There was a significant within-group increase in the knowledge of CP in each of the two groups ($p=0.001$). Between-groups comparison revealed no statistically significant difference in the effects of either models ($p=0.26$).

Conclusion: The single-module and multiple module educational programme are equally effective in improving knowledge of CP and should be incorporated into the total management of CP.

Keywords: Caregiver, cerebral palsy, disease knowledge, education.

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I. INTRODUCTION

Cerebral Palsy (CP) is a childhood-onset disorder that presents with motor disability and accompanying impairments including compromised ability to independently perform age-expected activities, or attainment of appropriate developmental milestone. It has been described as the most common motor disability in childhood and the most common cause of physical impairment in children [1], [2]. One of the health professions at the core of habilitation for the children with CP is physiotherapy. The goal of physiotherapy intervention is to support the children in achieving their full potentials for physical independence and fitness levels within their community, by minimizing the effect of their physical impairments, and improving the quality of life of the child and their family who play a major role to play in the process [3]-[5]. In spite of the habilitation interventions however, most children with CP require assistance with performance of day-to-day activities, such as

feeding, bathing, and dressing, amongst others [1], [6]. Such assistance is usually provided by their formal or informal caregivers, the latter being typically their immediate family members, who are also often their primary caregivers [6], [7].

In order to play their roles effectively, the informal caregivers would require as much information as possible about their child's condition, including on prognosis and rehabilitation intervention needs [8]. This information is expected to be provided by the health care professionals [9]. However in spite of their central role in the total management of cerebral palsy, the caregivers have reported feeling that health professionals underestimated their desire for information [10], [11]. This information, often called a caregiver education, is typically provided during the first appointment of the child with the health care provider. This approach had been questioned by some researcher who opined that the duration may be insufficient to fully explain the complexity of CP and the requirements of the day-to-day care [12]. Nevertheless, being equipped with the right

knowledge promotes a better understanding of the child's condition, empowering caregivers to provide therapeutically accurate care and improving compliance with treatment schedules [13], [14]. Caregiver education also increases the likelihood of caregivers exhibiting high self-efficacy, positive psychosocial indices, and better health-related quality of life [15], [16]. An important approach to delivering the education to the informal caregivers is through a single or multi-module educational programme.

Studies assessing the impact of educational programmes on parental knowledge of cerebral palsy in Zimbabwe [12] and India [16], [17], have established the benefits of education on cerebral palsy to their informal caregivers. There is however a paucity of information on the difference between the effects of single-module educational programmes and multi-module educational programmes on the informal caregiver's knowledge of CP. This study was aimed at determining the differential effects of single-module educational programmes and multi-module educational programmes on the knowledge of CP among Nigerian informal caregivers of children with CP.

II. METHODS

Participants in this quasi-experimental study were informal caregivers of children with cerebral palsy, recruited from among the informal caregivers bringing children with cerebral palsy for treatment at the physiotherapy clinics of two purposively selected public-funded hospitals in Ibadan, Nigeria. These health facilities namely the University College Hospital (UCH) and the Oni Memorial Children's Hospital (OMCH) are major referral centres for paediatric physiotherapy services in Ibadan, Nigeria. The study eligibility criteria included being directly involved in the daily care of the child with CP for at 6-8 hours per day in at least three months before the study. Informal caregivers who are health care practitioners were ineligible to participate.

III. INSTRUMENTS

The Knowledge of Cerebral Palsy Questionnaire (KCPQ) which is a 20-item reliable and valid questionnaire developed by [12] was used in assessing the level of knowledge of caregivers about CP before and after the educational intervention. Psychometric evaluation demonstrated the KCPQ to be internally consistent, with a Cronbach's alpha (α) value of 0.89, and stable with a reliability coefficient (r) of 0.80, content validity index of 0.85 and displayed a four-factor structure [16]. The KCPQ was interpreted into Yoruba language and the Yoruba version made available to participants during data collection. A data gathering form was used in obtaining information on the socio-demographic data of the participants and the clinical profile of the child with CP.

Training syllabuses derived from the Getting-To-Know-Cerebral-Palsy (GTKCP) manual were used in educating participants in the multi-module group and the single-module group. The GTKCP manual was developed in 2005 by the Cerebral Palsy Association (Eastern Cape), South Africa through the Hambisela Community-Based Project

[18], [19]. The training was aimed at mothers/ fathers/ caregivers/ grandparents of children with CP and is considered suitable for caregivers of children with cerebral palsy of any age [18]. This instrument had been adapted for use in a caregiver training programme in Bangladesh and Ghana [19].

IV. PROCEDURE

University of Ibadan/ University College Hospital (UI/UCH) Health Research Ethics Committee approved the protocol of this study. The rationale and procedure for the study were explained to the respondents and their informed consent obtained. Copies of the KCPQ were self-administered to the participants before the commencement of the educational programme (pretest). Those who could neither read nor write had the questionnaire administered to them by one of the authors. Participants were then assigned to either of two groups namely the Single-Module Syllabus or Multi-Module Syllabus. The developers of the GTKCP training material recommend 8-10 participants per educational group [18] although smaller size groups were also reported to be more effective in the Bangladesh study. In the present study, the caregivers were grouped into small groups of 10 per group for the educational programme. They were all thereafter taken through the educational programme based on the respective group as presented in Table I. The KCPQ was re-administered to participants after the completion of the educational programme (posttest).

TABLE I: DESCRIPTION OF PARTICIPANTS GROUPINGS AND THE EDUCATIONAL PROGRAMME RECEIVED

Group description	Number of participants		Educational programme	Duration of intervention
Multi-module Educational Programme group	1	10	Syllabus I	Three weeks (one module per week)
	2	10		
Single-module Educational programme group	1	10	Syllabus II	One day (Single module)
	2	10		

V. DATA ANALYSES

Obtained data was cleaned and analysed using SPSS (version 26.0) for Windows. Descriptive statistics of mean, standard deviation, frequency, and percentages were used to summarize the socio-demographic variables of participants. Wilcoxon signed-rank test was used to compare the pre and post intervention knowledge of CP among informal caregivers of children with CP who received a single module educational programme as well as the pre and post intervention knowledge of CP their counterparts who received multi-module educational programme. Mann-Whitney U test was used to compare the mean pre-educational and the mean post-educational programme knowledge score between informal caregivers of children with CP who receive single-module educational programme and those who receive multi-module educational, at $\alpha = 0.05$.

VI. RESULTS

A total of 60 informal caregivers of children with CP were approached to take part in this study. Out of those, 55 caregivers indicated interest in participation, and their contact details were collected. At the time of commencement of the educational programme, all informal caregivers who initially indicated interest in participating were contacted. However, 15 of those who gave their consent became unreachable or unavailable during the duration of the study. Forty informal caregivers of children with CP were thus enrolled for participation and completed this study, giving a completion rate of 100%.

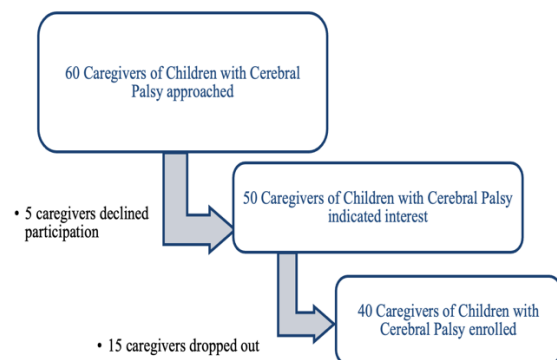


Fig. 1. Flow chart for recruitment of participants in the study.

Twenty participants each were assigned to the Multi-Module Educational Programme (MMEP) and the Single-Module Educational Programme (SMEP) group.

All 40 of the participants in this study were female and aged from 22 to 50 years (34.05 ± 7.324 years). Majority (30.0%) of them were in the 26 to 30 years age group. In terms of relationship with the child, 37 (92.5%) were the biological mother while 3 (7.5%) were the grandmother. The children were aged between 7 to 120 months, with a mean age 26.78 ± 23.73 months (Table II). Majority (45%) presented with spastic type of CP; 32.5% presented with the choreoathetoid type, while 22.5% had a mixed presentation type of CP and 28 (70%) presented as quadriplegic type of CP (Table III).

The results from Mann-Whitney U test used to compare the pre- training domain scores and total scores between the MMEP and the SMEP groups showed that there was no statistically significant difference ($p=0.76$) in the mean total knowledge score of the two groups (Table IV).

In the pre-test, the most incorrectly answered statement on the KCPQ was 'Cerebral Palsy can be cured', with 90% of participants in both the Multi-Module Educational Programme (MMEP) group and the Single-Module Educational Programme (SMEP) group having responded incorrectly. Comparison of the post training domain score and total scores of both groups using Mann-Whitney U test was showed no significant difference ($p=0.26$) between the post training domain score and total scores of both MMEP and SMEP groups (Table V). Majority of participants in both groups responded correctly to the questions in the management domain of the KCPQ after the educational programme.

The statistical analysis carried out using the Wilcoxon signed- rank test to compare the pre- and post-training scores within each group revealed that there was a significant increase ($p=0.001$) in the knowledge of CP among the caregivers in the single-module educational programme (Table VI). Wilcoxon signed- rank test also revealed a significant increase ($p=0.001$) in the knowledge of CP among informal caregivers of children with CP who participated in the multi-module educational programme (Table VI).

TABLE II: SOCIODEMOGRAPHIC VARIABLES OF THE CAREGIVERS(N=40)

Variable	MMEP n=20	SMEP n=20	Total N=40	%
Age (years)				
21-25	2 (5.0%)	3 (7.5%)	5	12.5
26-30	7 (17.5%)	5 (12.5%)	12	30.0
31-35	5 (12.5%)	6 (15%)	11	27.5
36-40	2 (5.0%)	2 (5.0%)	4	10.0
41-45	1 (2.5%)	3 (7.5%)	4	10.0
46-50	3 (7.5%)	1 (2.5%)	4	10.0
Relationship with child				
Mother	18 (45%)	19 (47.5%)	37	92.5
Father	-	-	-	-
Grandmother	2 (5%)	1 (2.5%)	3	7.5
Level of education				
None	-	-	-	-
Primary education	1 (2.5%)	1 (2.5%)	2	5.0
Secondary Education	8 (20.0%)	11 (27.5%)	19	47.5
Tertiary Education	11 (27.5%)	8 (20.0%)	19	47.5

MMEP: Multiple-session Module Educational Programme, SMEP: Single-session Module Educational Programme

TABLE III: CLINICO-DEMOGRAPHIC VARIABLES OF THE CHILD WITH CEREBRAL PALSY (N=40)

Variable	n	%
Age (months)		
1-20	25	62.5
21-40	8	20.0
41-60	4	10.0
61-80	1	2.5
81-100	1	2.5
101-120	1	2.5
Type of cerebral palsy		
Spastic	18	45.0
choreoathetoid	13	32.5
Ataxic	-	-
Mixed	9	22.5
Topography		
Quadriplegia	28	70
Diplegia	12	30
Hemiplegia	-	-

TABLE IV: STATISTICAL COMPARISON OF KNOWLEDGE SCORES OF THE CAREGIVERS IN THE SINGLE-MODULE VERSUS MULTI-MODULE GROUPS BEFORE THE EDUCATIONAL PROGRAMME USING MANN-WHITNEY U TEST

Variable	Mean \pm SD		Z	p-value
KCPQ domain	SMEP group	MMEP group		
CP definition	5.30 \pm 1.22	4.85 \pm 1.39	-1.19	0.23
Aetiology	7.45 \pm 2.21	7.75 \pm 2.20	-0.69	0.50
Clinical presentation	8.55 \pm 1.70	7.90 \pm 2.25	-0.86	0.39
Management	10.75 \pm 0.64	10.85 \pm 0.67	-0.55	0.58
Total score	32.05 \pm 3.07	31.35 \pm 4.54	-0.31	0.76

KCPQ: Knowledge of Cerebral Palsy Questionnaire, CP: Cerebral Palsy, MMEP: Multiple session educational programme, SMEP: Single session educational programme, SD: Standard deviation, Z: Mann-Whitney U score

TABLE V: STATISTICAL COMPARISON OF KNOWLEDGE SCORES OF THE CAREGIVERS IN THE SINGLE-MODULE VERSUS MULTI-MODULE GROUPS AFTER THE EDUCATIONAL PROGRAMME USING MANN-WHITNEY U TEST

Variable	Mean \pm SD		Z	p-value
KCPQ domain	SMEP group (N=20)	MMEP group (N=20)		
CP definition	5.85 \pm 0.49	5.85 \pm 0.49	0.00	1.00
Aetiology	9.55 \pm 1.91	9.10 \pm 2.45	-0.49	0.62
Clinical presentation	9.65 \pm 0.67	9.00 \pm 1.22	-1.86	0.06
Management	10.95 \pm 0.40	11.00 \pm 0.46	-0.37	0.71
Total score	36.0 \pm 2.20	34.95 \pm 2.97	-1.13	0.26

KCPQ: Knowledge of Cerebral Palsy Questionnaire, CP: Cerebral Palsy, MMEP: Multi-Module Educational Programme, SMEP: Single-Module Educational Programme, SD: Standard deviation, Z: Mann-Whitney U score

TABLE VI: STATISTICAL COMPARISON OF KNOWLEDGE SCORES OF THE CAREGIVERS IN THE SINGLE-MODULE AND MULTI-MODULE GROUP BEFORE VERSUS AFTER THE EDUCATIONAL PROGRAMME USING WILCOXON SIGNED RANK TEST

Variable	Mean rank (Positive ranks)	Sum of ranks	Z	p-value
SMEP (Post-training score versus pre-training score)	9.00	153.00	-3.64	0.00*
MMEP (Post-training score versus pre-training score)	9.73	146.00	-3.30	0.00*

KCPQ: Knowledge of Cerebral Palsy Questionnaire, CP: Cerebral Palsy, MMEP: Multi-Module Educational Programme, SMEP: Single-Module Educational Programme, *: significant at $p < 0.005$

VII. DISCUSSION

The purpose of this study was to investigate the effects of an educational programme on the knowledge of the informal caregivers of children with CP about the disorder and compare the effects between those placed on single-module educational programmes and those on multi-module educational programmes on their knowledge of CP. There was a 100% completion rate for the educational programme by those who commenced the training. This high compliance rate may be attributed to the informal caregivers' quest for knowledge on their child/ ward's condition. This has been alluded to by previous researchers who noted that caregivers of children with CP wanted as much information as possible about their child's condition, including their prognosis and rehabilitation intervention needs [8], [17], [20], [21].

All the 40 caregivers in this study were female, and were either the mother or grandmother of the child with CP. This is consistent with findings that majority of the informal caregivers of children with CP were either the mother or grandmother of the child [6], [13], [22], [23]. Whereas all the caregivers were recruited from among those who were bringing their children/wards for physiotherapy at the selected hospitals, it has been noted that the trend of biological mothers constituting the majority of the caregivers for children with cerebral palsy might be a reflection of the traditional roles assigned women in the care of children in this African community [22]. The mean

childbearing age of Nigerian women has been reported to be 29.81 years. [24]. This may account for the trend of the prevalent age group (26-30 years) of the participants in this study.

The pre-training mean total knowledge score of participants in both the multi-session educational programme group and the single-module educational programme were above the cut-off value of 50% of the maximum obtainable score on the Knowledge of Cerebral Palsy Questionnaire. This indicates that the participants had good knowledge of CP even without having received the education intervention. This is consistent with findings from previous studies who had reported that majority of the caregivers of children with CP had good knowledge about the condition [6], [23]. This significant level of baseline knowledge of CP among participants may be accounted for by the informal caregivers' familiarity with the condition through exposure to information on CP in the course of taking their children to the hospital. This is considering the fact that the mean age of the children with cerebral palsy was 26.78 months, and none was a newly diagnosed case of cerebral palsy. Furthermore, the study eligibility criteria included being directly involved in the daily care of the child with CP for at 6-8 hours per day in at least three months before the study.

Comparison of the baseline level of knowledge between participants in the multimodule educational programme and the single-module educational programme groups showed that there was no significant difference between the two groups. This similarity of the participants in both groups may be explained by the fact that participants were drawn from the same population pool and may have had similar level of exposure to sources of knowledge of CP such as their health care providers and peers.

Statements that were mostly incorrectly responded to by majority of the caregivers included those regarding the aetiology of CP and the possibility of CP being a curable disease. Findings from this study are similar to responses to the statements on the aetiology of CP in the reports of authors who studied caregivers of children with CP [12]. Responses to these statements 'Cerebral palsy may be as a result of witchcraft', 'If a pregnant woman is promiscuous during pregnancy, it may lead in the child acquiring cerebral palsy', 'Cerebral palsy may be as a result of punishment by ancestral spirits' may be an indicator of some myths about causes of CP. This pattern may be associated with the beliefs in some African societies that CP can result from witchcraft, maternal promiscuity, and bad omens [6], [22], [25]-[27]. This observed trend, however, is at variance with the report of the authors on the beliefs of informal caregivers of children about the condition [23]. Majority of the respondents in their study believed that CP was not a spiritual attack or punishment from God and that witches and wizards were not the causes of CP. The response to the statement 'Cerebral palsy can be cured' is congruent with findings from previous studies which reported a lack of knowledge on the progression/course and curability of CP amongst others [12], [16], [19]. This result may be an indication that some information was provided the caregivers by the health practitioners.

Following the educational programme, participants in the multi-module educational programme group demonstrated a significant increase in their knowledge of CP. This is in keeping with findings from studies where the parents or caregivers of children with CP were engaged in multiple modules of an educational intervention [27]. Participants in the single-module educational programme group also demonstrated a significant increase in their knowledge of CP. This correlates with findings from earlier studies in which caregivers of children with CP received a single module of education on basic information of CP [16], [17]. Despite having an increase in the total knowledge score, majority of participants in both the MMEP group and the SMEP group responded incorrectly to the statements on the aetiology of CP and the possibility of CP being cured: 'Cerebral palsy may be as a result of witchcraft', 'If a pregnant woman is promiscuous during pregnancy, it may lead in the child acquiring cerebral palsy', 'Cerebral palsy may be as a result of punishment by ancestral spirits' and 'Cerebral palsy can be cured'. This finding may be as a result of the strength of the participants' belief regarding the cause of cerebral palsy, such that the scientifically supported information provided them in educational programme could not sway their comprehension of the cause of CP. The caregivers' response that CP is curable may be a reflection of the hope for a positive outcome and belief system of the caregivers. Comparison of the post-training knowledge of participants in the MMEP group and their counterparts in the SMEP group revealed that there was no significant difference in the post-training knowledge score. This finding suggests that intervention aimed at enhancing knowledge of CP among the caregivers could be administered either as a one-off or staggered intervention.

VIII. CONCLUSION

Structured educational programmes are useful in improving knowledge of CP among informal caregivers of children with cerebral palsy. Single-module educational programmes and multi-module educational programmes have similar effects on the knowledge of cerebral palsy among informal caregivers of children with CP, and therefore either approach may be utilised in achieving the goal among CP caregivers. It is recommended that structured educational programmes should be routinely organised for caregivers of children newly diagnosed with CP.

CONFLICT OF INTEREST

Authors declare that they do not have any conflict of interest.

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