

## Original Research

# Does an educational workshop have an impact on caregivers' levels of knowledge about cerebral palsy? A comparative, descriptive cross-sectional survey of Zimbabwean caregivers

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### Abstract

#### Background

The diagnosis of a child with a life-long disability, such as cerebral palsy (CP), can be catastrophic to parents. It is often accompanied by feelings of despair, anxiety, hopelessness, and the fear of the unknown. Knowledge about CP is thus essential for caregiver adjustment and preparation for the caregiving role. However, there is a paucity of empirical evidence regarding the best method for educating caregivers. The aim of this study was therefore to evaluate the impact of an educational intervention on caregivers' knowledge about cerebral palsy.

#### Methods

This cross-sectional survey included 49 caregivers of children with cerebral palsy. Convenience sampling was used to select participants from two central hospitals in Harare, Zimbabwe. The caregivers were divided into two groups based on whether or not they had attended an educational workshop. The knowledge of cerebral palsy questionnaire (KCPQ) was administered once to assess the caregivers' CP knowledge.

#### Results

The caregivers were comparable in terms of sociodemographic characteristics. The mean KCPQ scores for caregivers who attended workshops was 17.4 (SD 1.5), versus 13.8 (SD 2.5) for those without exposure to workshops. The differences between the two groups was statistically significant ( $U = 77.0$ ,  $Z = -4.45$ , and  $P < 0.001$ ).

#### Conclusions

Our findings suggest that educational workshops may lead to improved CP knowledge among caregivers. This may better equip parents and guardians to meet the extra caregiving demands associated with CP, leading to improved health outcomes for children with CP and their caregivers.

## Introduction

Diagnosis of a child with a lifelong disability, such as cerebral palsy (CP), can be catastrophic to parents or caregivers.<sup>1</sup> It is often accompanied by feelings of despair, anxiety, hopelessness, and the fear of the unknown.<sup>1-5</sup> Predominantly, CP is known for causing disturbances in movement and posture, often accompanied by disturbances in cognition and perception, and resulting in profound activity limitations for affected children, with delayed attainment of developmental milestones.<sup>6</sup> Further, CP is a lifelong condition with a complex and variable presentation and is the most common childhood disability worldwide.<sup>6-10</sup>

Invariably, most children with CP require assistance with the performance of day-to-day activities, such as feeding, bathing, and dressing, among others.<sup>11,12</sup> In low-resource settings, parents and the immediate family are usually the primary caregivers.<sup>11,13</sup> Unfortunately, these caregivers are not always well-equipped or formally trained to assume the caregiving role, as opposed to formal caregivers, such as nurse aides.<sup>14,15</sup> In contrast, a formal caregiver, by definition, is someone who is formally trained and remunerated for provision of care to someone with special healthcare needs.<sup>14</sup>

Unfortunately, provision of care for a child with a lifelong disability has been shown to lead to poor health outcomes among informal caregivers.<sup>16</sup> Empirical evidence from a systematic review suggests that provision of care for a child with CP is often associated with anxiety, pain, depression, financial strain, and poor health outcomes among informal caregivers.<sup>12</sup> Overall, caring for a child with a disability can have a negative impact on the life of a caregiver, especially if the caregiver feels inadequate, or if the caregiver fails to

meet the child's needs.<sup>17</sup> To this end, it is hypothesised that caregivers who are more knowledgeable about CP are more likely to adjust and cope with the demands of caregiving.<sup>18</sup> Studies have shown that knowledgeable caregivers are likely to exhibit high self-efficacy and report positive psychosocial indices and better health-related quality of life (HRQoL).<sup>19</sup> Furthermore, appropriate care can only be given if caregivers have pertinent information and skills to meet a child's needs.<sup>20</sup> Therefore, healthcare professionals play an essential role in diagnosis, treatment, advocacy, and health education.<sup>5,21</sup> To this end, various methods of information provision have been outlined in the literature. The most basic method is a one-on-one session with a healthcare practitioner. In essence, most parents and caregivers learn about CP upon diagnosis of the condition.<sup>10</sup> It is the obligation of the healthcare practitioner to provide information on the condition, as diagnosis of CP is often a mystery to caregivers.<sup>24</sup> The inherent weakness of this method is that there may be minimal time to fully explain the complexity of CP in a single session. This is even more true in low-resource settings, where there is a high patient-to-provider ratio. Consequently, caregivers may not be afforded the opportunity to comprehensively learn about their child's diagnosis. Alternative educational methods, such as the use of multimedia (including videos and the Internet)<sup>18</sup> may also have minimal efficacy as caregiver educational strategies in low-resource settings.

To this end, in Zimbabwe, the Children's Rehabilitation Unit (CRU), which is based at Harare Central Hospital, conducts caregivers' training workshops for educating caregivers on various neurodevelopmental disorders. By definition, workshops are educational interventions aimed at giving groups of caregivers the necessary knowledge and skills—

through lectures, role playing, and other demonstrations—about a certain health condition.<sup>22,23</sup> As for the CP workshops, caregivers are taught about the presentation, aetiology, and management aspects of CP. Various healthcare personnel, such as physiotherapists, occupational therapists, rehabilitation technicians, speech therapists, nurses, social workers, and counsellors, facilitate the workshops. There is evidence that educational interventions may increase caregiver knowledge and skill in providing care and subsequently increase parenting self-efficacy and decrease in stress levels.<sup>2,24</sup> However, there is a dearth of empirical evidence of the impact of various educational strategies used to impact knowledge of CP among caregivers in Zimbabwe. This is a significant shortcoming in a setting with a high prevalence of CP.<sup>11</sup> Further, with the advent of the client-centred approach, caregiver education has evolved as a prerequisite for optimal rehabilitation outcomes.<sup>18</sup> Therefore, this study was carried out to evaluate the impact of an educational intervention on caregivers' levels of CP knowledge.

## Methods

### **Study design**

A comparative, descriptive cross-sectional study was conducted between July 2014 and June 2015. In terms of knowledge about CP, caregivers who had undergone CP workshops were compared with caregivers who did not receive any formal CP-related guidance.

### **Setting**

The study was carried out at the Parirenyatwa Group of Hospitals and Harare Central Hospital, which are the two largest referral, tertiary healthcare institutions in Harare, Zimbabwe.

### **Interventions**

The Children's Rehabilitation Unit (CRU) at Harare Central Hospital is the largest paediatric rehabilitation referral centre in Zimbabwe.<sup>11</sup> The CRU holds workshops for caregivers of children with CP on a monthly basis under ideal circumstances. During these workshops, caregivers are taught on the presentation, aetiology, and management of CP. These workshops are facilitated by physiotherapists, occupational therapists, counsellors, and rehabilitation technicians at the CRU. Further, other healthcare professionals, such as nurses and doctors, may be called in to give specific health education talks. For instance, a nurse can be called in to provide a health talk on prenatal, perinatal, and postnatal care. Unfortunately, at present there is no standardised curriculum to guide the facilitation of these workshops. Additionally, as part of the educational workshop, caregivers are given the chance to share their experiences in taking care of a child with CP. Further, the caregivers also receive psychosocial support in the form of individual counselling sessions. At the end of the three-day workshop, the children receive individual assessments and treatment from rehabilitation personnel. As for the Parirenyatwa Group of Hospitals, the children with CP receive rehabilitation services on an outpatient basis, and at present, the hospital does not run support groups for caregivers of children with CP.

### **Participants**

Participants in this study were caregivers of children with CP who had either attended CP workshops or had not attended such workshops. Primary and informal caregivers of children diagnosed of CP were recruited.

### **Sampling and sample size calculation**

Convenience sampling was used. In a similar study carried out in Nigeria, 70 % of the caregivers were knowledgeable about CP.<sup>19</sup> Assuming 50% of respondents in the present study to be knowledgeable, the expected minimum number of cases was 46, at a 95% confidence level and 80% power. The sample size was calculated using Statistica (version 12) statistical software.

### **Instrument**

In our literature review, we did not come across a standardised and psychometrically sound tool for measuring caregiver knowledge levels about CP. Accordingly, we developed the Knowledge of Cerebral Palsy Questionnaire (KCPQ) through a five-stage process. We initially performed a review of the relevant literature to identify related tools, after which we extracted an initial list of candidate items. We then interviewed five healthcare professionals to elicit some of the context-specific questions for inclusion. We also interviewed 10 caregivers of children with CP to gain insight into what they would expect to learn and what they want to know about CP. Thereafter, we drafted the initial version, which was evaluated for face validity by a panel of five experts. Thereafter, the preliminary version was then administered to a group of 10 caregivers for cognitive debriefing. The second draft was then administered to a larger sample of caregivers ( $N = 49$ ) for further psychometric evaluation. Preliminary psychometric evaluation has demonstrated the KCPQ to be internally consistent, with a Cronbach's alpha ( $\alpha$ ) value of 0.891, and to be stable, with a reliability coefficient ( $r$ ) of 0.80. The panel of experts endorsed the face validity of the tool. Further, the tool yielded a content validity index (CVI) of 0.850 and displayed a four-factor structure, thus demonstrating its validity. Therefore, the KCPQ has been demonstrated to be a reliable and valid tool in measuring the level of knowledge of CP amongst Zimbabwean caregivers.

### **Ethical considerations**

Ethical approval was granted by the Medical Research Council of Zimbabwe (MRCZ/B/760). Institutional approvals were granted by Harare Central Hospital and the Parirenyatwa Group of Hospitals. Informed written consent was obtained from the caregivers. Caregivers were assigned identity numbers to preserve confidentiality, and only the principal researcher had access to the collected raw data, which was kept in a safe locker.

### **Data analysis**

Descriptive statistics were used to present the sociodemographics. The Mann–Whitney U test, the independent t-test, and Fisher's exact test were used to compare the two groups. The analysis of data was done using Statistica (version 12) statistical software. P-values  $\leq 0.05$  were considered statistically significant.

## Results

### **Sociodemographic characteristics**

As shown in Table 1, most of the caregivers were mothers ( $n = 24$ ; 80%), married ( $n = 28$ ; 96.7%), unemployed ( $n = 18$ ; 60%), and all caregivers were literate.

### **Knowledge about cerebral palsy**

Outlined in Table 2 are frequencies of the study sample's responses to the KCPQ.

Caregivers responded correctly to most of the KCPQ questions, as the percentage of correct responses were in the

**Table 1: Sociodemographic characteristics of caregivers and children**

Variable	Attended CP	Never attended CP	Total	Statistic	P-value
	workshop before	workshop			
<b>Age of children with CP (months)</b>					
Median (range)	36 (12-144)	20 (3-132)	30 (3-144)	U = 141.5 Z = 3.16	0.001
<b>Caregiver's age (years)</b>					
Mean ± standard deviation	31 ± 5.8	30 ± 7.9	30 ± 6.8	t = 5.41 df = 47	0.59
<b>Caregiver's marital status — n (%)</b>					
Married	24 (96.0)	20 (83.3)	44 (89.8)	Fisher's exact	0.19
Single	1 (4.0)	4 (16.7)	5 (10.2)		
<b>Caregiver's highest educational level — n (%)</b>					
Primary	3 (12.0)	4 (16.7)	7 (14.3)	Fisher's exact	
Secondary	19 (76.0)	16 (66.7)	35 (71.4)		0.74
Tertiary	3 (12.0)	4 (16.7)	7 (14.3)		
<b>Caregiver's relationship to child — n (%)</b>					
Mother	24 (96.0)	21 (87.5)	45 (91.8)	Fisher's exact	0.35
Other	1 (4)	3 (12.5)	4 (8.2)		
<b>Caregiver's employment status — n (%)</b>					
Unemployed	14 (56.0)	18 (75.0)	32 (65.3)	Fisher's exact	
Informally employed	9 (36.0)	2 (8.3)	11 (22.4)		0.064
Formally employed	2 (8.0)	4 (16.7)	6 (12.2)		

CP = cerebral palsy

range of 80% to 100%. Question 15 ("Cerebral palsy can be cured: yes/no") was the most incorrectly answered question, with 70% (n = 21) of the caregivers giving incorrect answers.

#### **Subanalysis of the subscores**

The maximum possible subscores on the KCPQ were as follows: 3 for *definition*, 6 for *aetiology*, 5 for *presentation*, 6 for *management*, making the maximum possible total score 20.

As can be seen in Table 3, caregivers who attended workshops had significantly higher KCPQ scores (both in terms of total scores and subscores) than caregivers who had not attended CP workshops before.

#### **Discussion**

The two groups of caregivers were comparable in terms of sociodemographics, except for the age of the children, and therefore the differences in knowledge may largely be attributable to exposure to educational workshops. However, it should be noted that the median age of children whose caregivers attended a CP workshop was significantly (by 16 months) greater than the median age of children whose caregivers did not attend a workshop. This extra experience in taking care of children with CP may have contributed to the higher scores among workshop attendees. The age differences can partly be explained by the way workshops are scheduled. When a child is diagnosed with CP, his or her

name is booked for participation in a future CP workshop. In some instances, the workshop can happen several weeks to months later, owing to financial constraints, as the CRU provides food, accommodation, and travel expenses for all workshop attendees. Additionally, convenience sampling was used to select participants, and the possibility of selection bias cannot be ruled out.

#### **Caregivers' knowledge about the definition of cerebral palsy**

Caregivers who attended a workshop were more knowledgeable about the definition of CP. Under normal circumstances, it is expected that caregivers should receive an explanation of the term *cerebral palsy* at the time of diagnosis. However, given the complexity of the definition, caregivers can take time to consolidate this information,<sup>4</sup> thus the difference in knowledge can be attributed to other sources of information. Additionally, in low-resource settings, time constraints may lead overburdened healthcare personnel to provide parents and guardians with incomplete information about such a complex diagnosis. Caregivers' dissatisfaction with the extent of communication provided by rehabilitation professionals has been previously demonstrated in this setting.<sup>11</sup> A study carried out Nigeria found that caregivers of children with cerebral palsy who received rehabilitation

**Table 2: Correct and incorrect responses on the Knowledge of Cerebral Palsy Questionnaire (KCPQ)**

Knowledge statement	Attended cerebral palsy workshop N = 25		Never attended cerebral palsy workshop N = 24		All participants N = 49	
	Correct response n (%)	Incorrect response n (%)	Correct response n (%)	Incorrect response n (%)	Correct response n (%)	Incorrect response n (%)
1. Cerebral palsy is caused by injury to the developing brain.	24 (96.0)	1 (4.0)	19 (79.2)	5 (20.8)	43 (87.8)	6 (12.2)
2. Children with cerebral palsy are at a high risk of suffering from seizures/epilepsy.	21 (84.0)	4 (16.0)	16 (66.7)	8 (33.3)	37 (75.5)	12 (24.5)
3. Children with cerebral palsy may attain developmental milestones, such as rolling, sitting, at a late stage when compared to children of similar age.	25 (100.0)	0	22 (91.7)	2 (8.3)	47 (95.9)	2 (4.1)
4. Difficulties during child birth process, such as prolonged labour, may predispose the child to acquiring cerebral palsy.	24 (96.0)	1 (4.0)	19 (79.2)	5 (20.8)	43 (87.8)	6 (12.2)
5. A child may develop cerebral palsy if they do not cry soon after birth.	22 (88.0)	3 (12.0)	15 (62.5)	9 (37.5)	37 (75.5)	12 (24.5)
6. Cerebral palsy may be as a result of witchcraft.	22 (88.0)	3 (12.0)	12 (50.0)	12 (50.0)	34 (69.4)	15 (30.6)
7. If a pregnant woman is promiscuous during pregnancy, it may lead in the child acquiring cerebral palsy.	17 (68.0)	8 (32.0)	8 (33.3)	16 (66.7)	25 (51.0)	24 (49.0)
8. Cerebral palsy may be as a result of punishment by ancestral spirits.	20 (80.0)	5 (20.0)	18 (75.0)	6 (25.0)	38 (77.6)	11 (22.4)
9. If a child suffers from jaundice after birth, they may have high chances of acquiring cerebral palsy.	20 (80.0)	5 (20.0)	11 (45.8)	13 (54.2)	31 (63.3)	18 (36.7)
10. Most children with cerebral palsy present with stiff limbs or muscles.	21 (84.0)	4 (16.0)	11 (45.8)	13 (54.2)	32 (65.3)	17 (34.7)
11. Children with cerebral palsy may have floppy limbs.	24 (96.0)	1 (4.0)	17 (70.8)	7 (29.2)	41 (83.7)	8 (16.3)
12. Children with cerebral palsy may have difficulties in learning.	17 (68.0)	8 (32.0)	14 (58.3)	10 (41.7)	31 (63.3)	18 (36.7)
13. Some children with severe cerebral palsy may have difficulties with chewing and feeding.	25 (100.0)	0	18 (75.0)	6 (25.0)	43 (87.8)	6 (12.2)
14. Saliva drooling can persist in children with cerebral palsy.	21 (84.0)	4 (16.0)	20 (83.3)	4 (16.7)	41 (83.7)	8 (16.3)
15. Cerebral palsy can be cured.	12 (48.0)	13 (52.0)	2 (8.3)	22 (91.7)	14 (28.6)	35 (71.4)
16. Exercises are important in the management of a child with cerebral palsy.	23 (92.0)	2 (8.0)	22 (91.7)	2 (8.3)	45 (91.8)	4 (8.2)
17. Assistive devices such as corner sit may be recommended in the management of a child with cerebral palsy.	24 (96.0)	1 (4.0)	21 (87.5)	3 (12.5)	45 (91.8)	4 (8.2)
18. Rehabilitation professionals may assist in training children with cerebral palsy in daily activities, such as feeding, grooming among others.	25 (100.0)	0	24 (100.0)	0	49 (100.0)	0
19. Participation in self-help groups to share ideas and experiences with caregivers of children with cerebral palsy is essential.	24 (96.0)	1 (4.0)	22 (91.7)	2 (8.3)	46 (93.9)	3 (6.1)
20. If a child with cerebral palsy gets early treatment, they are likely to improve more.	24 (96.0)	1 (4.0)	21 (87.5)	3 (12.5)	45 (91.8)	4 (8.2)

**Table 3: Knowledge of Cerebral Palsy Questionnaire (KCPQ) scores**

CP knowledge domain	KCPQ subscore		Statistic	P-value
	Attended CP workshop (N = 25)	Never attended CP workshop (N = 24)		
<b>CP definition</b>				
Mean ± standard deviation	2.80 ± 0.50	2.38 ± 0.77	U = 208.0	0.024
Median (range)	3.0 (1-3)	3.0 (1-3)	Z = -1.83	
<b>Aetiology</b>				
Mean ± standard deviation	5.00 ± 1.00	3.46 ± 1.19	U = 102.0	< 0.001
Median (range)	5.0 (3-6)	3.5 (2-6)	Z = -3.95	
<b>Clinical presentation</b>				
Mean ± standard deviation	4.32 ± 0.75	3.33 ± 1.34	U = 168.5	0.006
Median (range)	4.0 (3-5)	3.5 (1-5)	Z = -2.62	
<b>Management</b>				
Mean ± standard deviation	5.28 ± 0.68	4.67 ± 0.64	U = 165.5	0.003
Median (range)	5.0 (4-6)	5.0 (3-6)	Z = -2.68	
<b>Total KCPQ score</b>				
Mean ± standard deviation	17.40 ± 1.53	13.83 ± 2.51	U = 77.0	< 0.001
Median (range)	17.0 (15-20)	13.0 (9-18)	Z = -4.45	

CP = cerebral palsy

services could only refer to their children's condition using the abbreviation "CP"; they did not know what the acronym stands for and were unable to define it.<sup>25</sup> Shame, ignorance, and fear of being scolded were cited as reasons why caregivers did not ask healthcare professionals for clarification.<sup>25</sup> However, respondents in the Nigerian study were able to give correct responses after an educational intervention, and this could be the same for caregivers who attended workshops in the present study. In a workshop setting, caregivers are provided an open and conducive environment, where they have ample time to ask any pertinent questions.

#### ***Caregivers' knowledge about the aetiology of cerebral palsy***

As expected, caregivers who had undergone an educational workshop were more knowledgeable with regards to the aetiology of CP. During the workshop, caregivers are given lectures on the aetiology of the condition. Caregivers are also given the chance to discuss the possible aetiology of their child's condition. This is especially important in an environment where some myths about what causes CP are still prevalent. For instance, there are beliefs in some African societies that CP can result from witchcraft, maternal promiscuity, and bad omens, among others.<sup>13,26,27</sup> In this regard, the positive impact of the workshops is evidenced by the proportion of attendees who were aware that witchcraft (n = 22.0; 88.0%), promiscuity (n = 17.0; 68.0%), and punishment by ancestral spirits (n = 20.0; 80.0%) do not influence the development of CP. In a similar study, interviews were carried out before and after exposure to an educational film to determine its impact on knowledge

among parents of children with CP (n = 53). The parents displayed a statistically significant increase (P < 0.001) in their knowledge about the causes of CP after watching the film, with 90.6% recording correct responses, versus an initial correct response proportion of 26.4%.<sup>25</sup>

#### ***Caregivers' knowledge about the clinical presentation of cerebral palsy***

Given the multiple teaching strategies and methods applied during the workshops, it was unsurprising that caregivers who had attended at least one workshop had more knowledge about the clinical presentation of CP. The utilisation of practical demonstrations, pictures, and short video clips could have reinforced the caregivers' understanding of the presentation of CP. Further, at the end of each workshop, therapists perform individual assessments and treatments, and give feedback to caregivers. This further reinforces caregivers' understanding of the presentation of CP. It is known that children with CP present in different ways, depending on the area of the brain that is affected.<sup>22,28</sup> During the workshops caregivers are given the opportunity to learn about other subtypes of CP by observing other children attending the workshop.

#### ***Caregivers' knowledge about the management of cerebral palsy***

Although CP has no cure, rehabilitation provision has been demonstrated to be of tremendous benefit.<sup>10,31</sup> As part of the CP workshop programme, children receive one-on-one treatment, as well as group therapy sessions. Caregivers are required to demonstrate to other caregivers the prescribed

home exercise programmes to reinforce their learning, so as to improve the efficacy of the execution of the exercises. It is against this background that differences in knowledge could be attributed to workshop attendance. Further, caregivers are also educated on the benefits of rehabilitation techniques, such as therapeutic exercises, by the health professionals during the workshops.

Caregivers who attended workshops agreed that participation in self-help groups helped reduce caregiver burden. During the workshops, caregivers are given a chance to share experiences and coping mechanisms. There is empirical evidence that social support is essential in mitigating caregiver burden.<sup>20,32</sup> Further, workshops are an excellent platform for networking, and caregivers are also encouraged to form self-help groups. Elsewhere, some caregivers have reported that they find it challenging to discuss the management of CP with health professionals, out of fear of being labelled ignorant about topics that a caregiver of a child with CP should know well already.<sup>33</sup>

## Conclusions

The findings of this cross-sectional study should be interpreted with caution, as confounding variables were not adjusted for. For instance, the potential effect of the Internet as an information source<sup>34</sup> was not accounted for. Moreover, given the high literacy rate of the caregivers, differences in knowledge about CP may not be entirely attributable to exposure to workshops. Further, there is a lack of a standardised curriculum to guide the facilitation of the educational workshops, which makes it difficult to attribute the changes of knowledge to specific aspects of workshop attendance. However, evidence from the current study still suggests the efficacy of workshops in increasing caregivers' knowledge levels about CP. Therefore, we recommend that healthcare professionals make deliberate efforts, using structured interventions (formal workshop curricula, for example), to educate caregivers about CP. There is also need to carry out further studies to evaluate the impact of these workshops over a long period, through use of longitudinal designs.

## Competing interests

The authors declare that they have no competing interests.

## Acknowledgements

We would like to acknowledge the invaluable participation of the caregivers of children with cerebral palsy at the study sites.

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