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Knowledge, Attitudes, Challenges and Coping Strategies Amongst Caregivers of Children with Cerebral Palsy in Dar Es Salaam, Tanzania

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Abstract

Background

Cerebral palsy (CP) is a disorder in the development of posture and movement causing activity limitation due to a non-progressive injury on the developing fetal or infant brain. Advanced medical care has increased the survival of children with CP, resulting in an increased burden of care for caregivers. The continuum of care for a child with CP depends on the caregivers' understanding of their condition, complications and required treatment. Therefore, an understanding of the knowledge gaps, attitudes, challenges and coping strategies amongst caregivers raising children with CP, will help clinicians to develop more family-oriented treatment protocols incorporating caregivers' needs.

Objectives

We aimed to determine the level of knowledge, attitudes, challenges and coping strategies amongst caregivers raising children with cerebral palsy (CP), at Muhimbili National Hospital (MNH).

Method

A cross-sectional, hospital-based study using structured interviews was conducted amongst 139 consecutively recruited caregivers. A pre-tested questionnaire was used to collect information including: social demographics, caregivers' attitudes towards CP and challenges involved in caring for children with CP. Univariate analysis was done and summarized using frequencies; Fischer's exact test was used to determine association between factors influencing caregiver's knowledge and attitudes.

Results

Of the 139 caregivers, only 20.9% showed satisfactory knowledge on CP. Persistent negative attitudes amongst caregivers were significantly influenced by the severity of CP ($p \leq 0.001$), caregivers' level of knowledge on CP ($p \leq 0.001$), their satisfaction with the diagnosis disclosure process ($p=0.031$), the perceived negative attitudes of their partners ($p=0.006$), extended families ($p=0.001$) and the society ($p=0.010$). Challenges facing caregivers of children with CP included: an increased burden of care, broken family relationships and increased expenditure. Caregivers coped by quitting work and up to 64.7% sought spiritual and/or traditional healing, which showed a limited understanding of CP.

Conclusion and Recommendations

Caregivers' level of knowledge on CP was low, which can be improved by comprehensive disclosure of the CP diagnosis by healthcare personnel through stage-wise counseling. Family support is key in helping caregivers' improve their attitudes and cope with the major challenges facing them. Policy makers should ensure the decentralization of comprehensive CP clinic services to ensure access to rehabilitative health care, including the provision of health education and caregiver support from the health system to the community level.

Keywords: *Cerebral Palsy, Knowledge, Attitudes, Challenges, Coping.*

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Background

Cerebral palsy (CP) is a disorder in the development of posture and movement causing activity limitation due to a non-progressive injury on the developing fetal or infant brain. (1) Advanced medical care has increased the survival of children with CP, resulting in an increased burden of care for caregivers. Globally, the incidence of CP has been on the rise in the last forty years to an estimated 1.4-2.0 per 1000 live births. (2) In Tanzania, no comprehensive study has been done to determine the countrywide incidence of CP. However, up to 500 new cases of CP are seen at MNH annually; with an almost 10% annual increase. (3, 4)

The continuum of care for a child with CP depends on the caregivers' understanding of their condition, complications and required treatment. A confirmatory diagnosis of CP should come from the primary physician seeing the child, which should be coupled with follow-up counseling visits. (5) However, in developing countries with a high patient load, caregivers receive little information from healthcare personnel regarding the diagnosis and the long-term implications of CP in their children. Studies have shown that even after educational sessions; majority of caregivers (81%) did not know the meaning of CP and a further 34% did not understand the implication of early intervention therapy for children with CP. (6) In our setting, there are no clear guidelines or dedicated personnel for counseling of caregivers of at-risk children on the potential for developing CP. Often the diagnosis may be delayed until the child develops outright signs of CP leading to dissatisfaction amongst the caregivers.

Children diagnosed with CP draw mixed sentiments from the immediate family and community. Initially, mothers go through shock, anger and denial; but within 18 months they learn to accept the diagnosis. (7) Their attitudes towards CP are said to be influenced by their level of education, marital status and the presence of a supportive social network. However, existing social constructs of what is normal and abnormal, result in predominantly negative attitudes towards children with CP; contributing towards poor communication and misunderstanding in the home. Therefore, in many African societies, care of children with disability is often left to the mothers. (8, 9)

Caregivers of children with CP also face various challenges including: increased healthcare and upkeep costs, broken family relations and loss of employment. Some caregivers quit their jobs whilst others seek family support to care for their children. (10, 11) Desperation for a cure leads majority of the caregivers to seek alternative traditional therapies and/or spiritual healing. (12)

Inadequate knowledge on CP, negative attitudes towards raising children with CP and an increased burden of care, has been shown to be associated with a low quality of life in that caregiver; (13) which negatively impacts on the behavioural and developmental potential of their children with CP. Understanding the knowledge gaps, attitudes, challenges and coping strategies amongst caregivers raising children with CP, will help clinicians to develop more family-oriented treatment protocols when handling patients with CP and their caregivers.

Methods

Study design

A hospital-based cross-sectional study was conducted over a period of six months, from November 2013 to April 2014 at the Muhimbili National Hospital (MNH) in Dar es Salaam region. This is a tertiary level public health facility which offers specialized medical, occupational therapy and physiotherapy services for children with CP.

Study population and sample size

All children (aged 6 months to 18 years) with CP and their caregivers attending the outpatient department, physiotherapy clinic or admitted in the general paediatric wards were eligible. Sample size was estimated using the calculation for a finite population using a known proportion of the variable of interest, in this case the proportion of parents with reported satisfactory knowledge on CP from a Nigerian study which was 70%. [10] One hundred and thirty-nine caregiver-child pairs were consecutively recruited into the study. Caregivers with inadequate information about the accompanied child or those with critically ill children were excluded from this study.

Data collection and measurement

A structured questionnaire, which was prepared in English and translated into Swahili was used. Data was collected by the Principal investigator (PI) and four research assistants who were final year medical students after having being trained on the study protocol. Assessment of the children's type and severity of CP was done using the universal classification system, which looked at the severity, topographical distribution and motor function. (14) Complications of CP were assessed based on the child's history and clinical signs. The level of caregivers' knowledge on CP was assessed based on questions on the risk factors for CP in their children, long-term medical implications and treatment options. A score of one was given for a correct answer and zero for a wrong answer. The level of knowledge was graded on a scale of zero to three; where three meant satisfactory knowledge on CP. Attitudes towards CP were measured using a 5-point Likert scale ranging from strongly positive to strongly negative attitudes. A response of strongly positive showed the best attitude towards the children with CP.

Data analysis

Statistical Package for Social Sciences version 20 was used for data entry and analysis. Univariate analysis was done on the socio-demographic characteristics, caregivers' level of knowledge, attitudes towards CP, challenges faced, and these were summarized as frequencies. Continuous variables were described using measures of central tendencies and measures of dispersion whilst categorical variables were described as proportions. Contingency tables were drawn to calculate Fisher's exact test to determine the associations between the independent and dependent variables. A p-value of <0.05 was statistically significant.

Results

Demographic and baseline characteristics

Of the 139 children in the study, majority 118 (84.9%) were aged below five years with a median age of 28 months; most were male 80 (57.6%) with predominantly spastic CP 72 (51.8%), of the severe form 87 (62.6%). Majority of the caregivers 132 (95.0%) were females, with a median age of 30 years. Most caregivers (71.2%) were married, 69.8% had attained primary level education and 45.3% were unemployed. Most families (79.9%) had a maximum of three children, whilst 95.7% did not have children younger than their child with CP, as shown in Table 1 & 2. A greater proportion of the children, 74.8% were diagnosed with features of CP by the age of six months, though 40.3% had a delayed in diagnosis. Only 7.2% of the caregivers had received pre-counseling on their at-risk child's potential to develop CP.

Table 1: Socio-demographic characteristics of the children with cerebral palsy

Variables	Number	Percent
Age groups (years)	**(n=139)**	
0-4	118	84.9
5-9	18	12.9
≥ 10	3	2.2
Sex		
Male	80	57.6
Female	59	42.4
Types of CP		
Spastic	72	51.8
Hypotonic	47	33.8
Dyskinetic	10	7.2
Mixed	10	7.2
Severity of CP		
Mild	12	8.6
Moderate	40	28.8
Severe	87	62.6
Complications of CP*		
Delayed speech	75	54.0
Learning disability	64	46.0
Seizures	60	43.2
Mental retardation	53	38.1
Visual impairment	37	26.6
Hearing loss	22	15.8

**Most of the children with CP had more than one complication*

Caregivers' level of knowledge on cerebral palsy

Caregivers' self-assessment revealed that 70.5% felt they had no knowledge on CP, whilst 7.2% reported they had adequate knowledge and 22.3% felt they were somewhat conversant with CP. This was also reflected in their knowledge scores whereby most of the caregivers had little 46 (33.1%) or no knowledge 45 (32.4%) on CP; whilst only 29 (20.9%) had satisfactory knowledge on CP.

Knowledge on CP was significantly influenced by severity of CP (p=0.002) whereby caregivers whose children had mild CP had higher levels of knowledge compared to those with severe CP; whose caregivers found it hard to comprehend all the complexities. Knowledge on CP was neither influenced by caregivers' age, level of education, pre-counseling of the caregivers on their at-risk infants' potential to develop CP, nor their satisfaction with the diagnosis disclosure process, (**Table 3**).

Table 2: Socio-demographic characteristics of caregivers whose children have CP

Variable	Number	Percent
Age group (years)	**(n=139)**	
≤ 20	4	2.9
21-30	69	49.6
31-40	53	38.1
≥ 41	13	9.4
Sex		
Male	7	5.0
Female	132	95.0
Level of Education		
No education	7	5.0
Primary	97	69.8
Secondary	27	19.4
Tertiary	8	5.8
Occupation		
Unemployed	63	45.3
Casual laborer	5	3.6
Self-employment	46	33.1
Formal employment	18	12.9
Stopped working	7	5.0
Marital status		
Single	24	17.3
Married	99	71.2
Divorced/separated	7	5.0
Cohabiting	9	6.5
Family size (No. of		
1 to 3	111	79.9
4 to 6	26	18.7
≥7	2	1.4
Child younger to one with		
No	133	95.7
Yes	6	4.3

Table 3: Factors influencing caregivers' level of knowledge on cerebral palsy

Variable	No knowledge (%)	Little knowledge (%)	Adequate knowledge (%)	Satisfactory knowledge (%)	Fischer's exact test	p-value
Age group	**n=139**					
≤ 20	2(50.0)	0(0.0)	2(50.0)	0(0.0)		
21 to 30	22(31.9)	25(36.2)	7(10.1)	15(21.7)		
31 to 40	18(34.0)	18(34.0)	6(11.3)	11(20.8)		
≥ 41	3(23.1)	3(23.1)	4(30.8)	3(23.1)	9.297	0.353
Education level						
No Education	2(28.6)	3(42.9)	2(28.6)	0(0.0)		
Primary	36(37.1)	32(33.0)	10(10.3)	19(19.6)		
Secondary	7(25.9)	8(29.6)	4(14.8)	8(29.6)	12.053	0.150
Tertiary	0(0.0)	3(37.5)	3(37.5)	2(25.0)		
Pre-counseling						
No	42(32.6)	42(32.6)	18(14.0)	27(20.9)	0.384	1.000
Yes	3(30.0)	4(40.0)	1(10.0)	2(20.0)		
Disclosure satisfaction						
No	11(40.7)	10(37.0)	4(14.8)	2(7.4)		
Yes	34(30.4)	36(32.1)	15(13.4)	27(24.1)	4.102	0.239
Severity of CP						
Mild	2(16.7)	3(25.0)	1(8.3)	6(50.0)	18.805	0.002
Moderate	12(30.0)	7(17.5)	11(27.5)	10(25.0)		
Severe	31(35.6)	36(41.4)	7(8.0)	13(14.9)		

Caregiver's attitudes towards their children with cerebral palsy

A total of 112 (80.6%) caregivers had initial negative attitudes towards the diagnosis of CP in their children, similar to their partners who were reported to have predominantly perceived negative attitudes 92 (66.7%). On the other hand, siblings (53.1%), the extended families (55.8%) and the society (74.6%) were perceived to have more neutral attitudes towards the children with CP. However, at the time of the study, half of the caregivers 69 (49.6%) had learnt to cope and had developed more neutral attitudes towards CP in their children compared to the time of initial diagnosis.

Factors that influenced caregivers' initial and persistent negative attitudes towards the diagnosis of CP in their children include: the severity of CP ($p \leq 0.001$), a smaller family size ($p=0.044$), their partners' perceived negative attitudes ($p=0.006$), the extended family members' perceived negative attitudes ($p=0.001$), the society's perceived negative attitudes (p=0.010), their satisfaction with the disclosure process (p=0.031) and their knowledge on CP (p≤0.001) respectively. On the contrary, caregivers' attitudes were not influenced by their age, level of education or marital status, as shown in **Table 4**.

Table 4: Factors influencing caregivers' current attitudes towards cerebral palsy

Variable	**Caregiver's current attitudes towards**			**Fischer's exact test**	**p-value**
	Positive, %	**Neutral, %**	**Negative, %**		
Severity of CP					
Mild	7(58.3)	5(41.7)	0(0.0)		
Moderate	20(50.0)	13(32.5)	7(17.5)		
Severe	14(16.1)	52(59.8)	21(24.1)	21.474	≤0.001
Family size (n=139)					
1 to 3	5(4.5)	14(12.6)	92(82.9)	9.252	0.044
4 to 6	2(7.7)	4(15.4)	20(76.9)		
≥ 7	1(50.0)	1(50.0)	0(0.0)		
Partners' attitude					
Positive	7(63.6)	2(18.2)	2(18.2)		
Neutral	15(44.1)	15(44.1)	4(11.8)		
Negative	19(20.4)	52(55.9)	22(23.7)	13.570	0.006
E/family attitudes					
Positive	15(31.9)	27(57.4)	5(10.6)		
Neutral	16(20.8)	42(54.5)	19(24.7)		
Negative	9(64.3)	1(7.1)	4(28.6)	18.149	0.001
Society's attitude					
Positive	11(52.4)	7(33.3)	3(14.3)		
Neutral	22(21.4)	58(56.3)	23(22.3)		
Negative	8(57.1)	4(28.6)	2(14.3)	12.617	0.010
Caregiver's on CP (n= 139)					
No knowledge	5(11.1)	25(55.6)	15(33.3)	48.572	≤0.001
Little knowledge	5(10.9)	34(73.9)	7(15.2)		
Adequate	10(52.6)	5(26.3)	4(21.1)		
Satisfactory	21(72.4)	6(20.7)	2(6.9)		
Satisfaction with disclosure (n=139)					
No	4(14.8)	13(48.1)	10(37.0)	6.801	0.031
Yes	37(33.0)	57(50.9)	18(16.1)		
Marital status					
Single	5(20.8)	15(62.5)	14(16.7)	9.112	0.134
Married	31(31.3)	51(51.5)	17(17.2)		
Divorced	3(42.9)	1(14.3)	3(42.9)		
Cohabiting	2(22.2)	3(33.3)	4(44.4)		

Education level					
No Education	0(0.0)	4(57.1)	3(42.9)	7.454	0.247
Primary	27(27.8)	49(50.5)	21(21.6)		
Secondary	10(37.0)	13(48.1)	4(14.8)		
Tertiary	4(50.0)	4(50.0)	0(0.0)		
Caregiver by age					
≤ 20	1(25.0)	1(25.0)	2(50.0)	4.795	0.557
21-30	18(26.1)	37(53.6)	14(20.3)		
31-40	16(30.2)	26(49.1)	11(20.8)		
≥ 41	6(46.2)	6(40.2)	1(7.7)		

Challenges facing caregivers of children with cerebral palsy

A significantly increased financial burden in raising a child with CP was reported by almost two thirds of the caregivers (62.6%), attributable to repeated hospital admissions (80.6%) and the use of chronic medication (70.5%). However, 28.6% reported they could not maintain regular doses particularly when medications were not available at MNH, as shown in **Table 5**. Caregivers also faced other challenges including: failure to attend regular CP clinics (14.4%) due to expenses involved (30.0%), lack of proper instructions from healthcare personnel (30.0%) and the distance from the hospital (20.0%).

Table 5: Challenges facing caregivers of children with cerebral palsy:

Variable	Number	Percent
Increased financial burden	**(n=139)**	
Large negative impact	87	62.6
Moderate negative impact	37	26.6
Mild negative impact	6	4.3
No impact	9	6.5
Recurrent hosp. admissions		
No admissions	27	19.4
1 to 3	87	62.6
4 to 6	17	12.2
≥ 7	8	5.8
Regular clinic visits		
No	20	14.4
Yes	119	85.6
Chronic medication		
No	41	29.5
Yes	98	70.5
Afford medications (n=98)		
No	30	28.6
Yes	74	71.4

Caregivers' coping strategies in raising children with cerebral palsy

Although 80.6% of caregivers reported that they were satisfied with the diagnosis disclosure process, 91.4% preferred to have had pre-counseling on the risk of CP. About half (50.4%) of the families reported shared responsibility between both parents but a significant proportion (35.3%) of the mothers were left to care for their children with CP single-handedly. Ninety (64.7%) caregivers sought alternative therapies for their children including: spiritual healing (51.8%), herbal treatment (37.4%) and traditional healing (9.4%).

Discussion

This study demonstrated low levels of caregivers' knowledge on CP, which contributed to predominantly negative attitudes towards their children with CP. It also showed the challenges and caregivers' coping strategies for raising children with chronic disability.

Majority of the children enrolled were less than five years old, which meant that fewer older children were attending rehabilitation clinics, either due to improvement or default. This was in line with findings from Malawi where older children with CP were less likely to attend rehabilitation clinics because caregivers faced difficulties in carrying them to the clinics due to their increasing weight. (15) More than half of the children had severe CP compared to 36% in 1986 (16) and 50.2% in 2010, (17) showing a rising trend in the severity of CP amongst MNH paediatric patients. This could be due to the fact that those children with severe CP were more likely to attend the CP clinic and physiotherapy sessions more often than their counterparts with mild CP. Spastic CP was the leading form of presentation, occurring in 51.8% of children and this was comparable to 56.1% reported by Sissya in the same population, in 2010. (17)

Majority of the caregivers (95.0%) who accompanied their children were mothers; similar to a study done in Kenya whereby 89.5% of the caregivers accompanying children with intellectual disability to the clinics were females. (18) This was also reflected in the fact that 45.3% of the mothers were unemployed and another 5.0% had stopped working to care for their children with CP. This was contrary to the reported shared burden of care amongst 50.4% of the caregivers; meaning that the burden of care falls largely on the mothers, as shown in other studies. (8)

In this study, 95.7% of the children with CP did not have younger siblings and the average fertility rate in this population was reduced to less than 3 in 79.9% of the families. This is much lower than the general population fertility rate of 5.1 reported in the 2013 Tanzania demographic profile. (19) It may be a reflection of the increased burden of caring for children with CP causing parents to postpone childbearing, or may result from fear of having more children with CP.

Majority of the children with CP were diagnosed early, below six months of age, which was favourable for early intervention. Although complete neuronal myelination in a child is not expected below two years of age, and the National Institute of Neurological Disorders and Stroke in the USA advocates that a definitive diagnosis of CP to be made when a child is two years, (20) this does not prevent early intervention in at-risk infants who should have a comprehensive follow up until CP can be excluded. However, up to 40.3% of caregivers reported they had several consultations before a diagnosis of CP was made, which denotes a low index of detecting CP amongst healthcare personnel at primary healthcare level.

Caregivers' level of knowledge on CP was found to be low with only 20.9% showing satisfactory knowledge. This corresponds to findings from an Indian study whereby 81% of parents did not understand the meaning of CP, even after an educational intervention. (6) This contradicted findings from Nigeria with up to 70% of the parents reported to have satisfactory knowledge on CP in their children. This difference was attributed to the fact that majority of the caregivers in Nigeria, whose children had CP, actively sought information from the internet, healthcare professionals or books written on the matter; thereby making them more knowledgeable. (10)

Caregivers of children with mild CP had significantly more satisfactory levels of knowledge on CP than their counterparts. This may be due to caregivers' inability to fully comprehend all the information presented to them at diagnosis; particularly for a child with severe CP whose management is relatively more complicated. On the other hand, it might be because caregivers are overwhelmed by the diagnosis of severe disability in their children and may cope by denying having received enough information. This is a protective mechanism, which allows them to understand the bulk of information in small quantities and at their own pace. (21)

The level of knowledge on CP amongst caregivers was neither influenced by caregivers' age nor their level of education; similar to an Australian study which showed low levels of knowledge on CP even amongst medical students. (22) Therefore, physicians must play a proactive role as the primary source of education to caregivers on CP.

Distress and grief are common following a chronic disease diagnosis and facing the diagnosis is the best way to cope. In this study, majority of caregivers had initial negative reactions to the diagnosis of CP in their children and later changed to more neutral standpoints, as they came to terms with the diagnosis. This reflected the phases of reaction anticipated on receiving bad news on a health matter as documented in other studies. (7) Caregivers' initial negative attitudes towards the diagnosis of CP in their children were significantly influenced by their level of knowledge on CP, a smaller family size, the perceived negative attitudes in their partners and extended families. Lack of knowledge on CP led to discontented caregivers, whereas the lack of a supportive family network deterred caregivers from coping with disability in their children, as shown in a review article by Logar. (23) Caregivers whose first born child had CP were more likely to have negative feelings upon initial disclosure of the diagnosis due to shattered expectations for their children. (12)

In this study, nearly 20% of caregivers remained with persistent negative attitudes towards their children with CP. This was significantly influenced by the severity of CP in their children, which was in keeping with findings from other studies, which showed that the severe form of CP resulted in an unresolved emotional status amongst the parents. (24) Perceived negative attitudes amongst caregivers' partners, extended family members and the society around them significantly fostered their persistent negative attitudes, an observation that has also been reported from other studies. (25, 26) Caregivers' dissatisfaction with the diagnosis disclosure process and low level of knowledge on CP also significantly propagated their persistent negative attitudes towards their children with CP. Therefore, physicians should continuously educate the caregivers on their children's condition using simple language to promote their understanding and facilitate their adaptation, as shown in other studies. Contrary to other studies, caregivers' attitudes were neither influenced by their age, level of education nor marital status. This shows that the limited information received from healthcare facilities rather than the background of caregivers had a negative impact on their attitudes.

Siblings of children with CP had reportedly less positive attitudes towards them when compared to findings in South Africa where they were more supportive. (27) On the other hand, the extended families and the society around had more positive perceived attitudes when compared to a study done in Nigeria where close to 40% of the parents were accused by their families of causing CP in their children. (10) These differences across the studies may be a true reflection of how different communities within the African setting view CP.

Raising children with CP resulted in a significantly higher financial burden due to recurrent hospitalization, the use of chronic medication; regular medical and physiotherapy follow up. Caregivers also reported loss of income from lost employment, inability to work due to pre-occupation with their children and in some cases loss of customer base for small businesses due to social isolation. An increase in financial strain and loss of income due to the inability of one parent to work, have also been reported in previous studies. ([9)

At the time of the study, MNH and Comprehensive, Community Based Rehabilitation in Tanzania (CCBRT) were the only public hospitals with specialized CP clinics and child physiotherapy facilities in Dar es Salaam, making these less accessible to 15% of the caregivers. This was due to caregivers' difficulties in carrying their older children from distant residential areas, which resulted in defaulters as shown in other studies. (15) Other reasons cited for poor clinic attendance include inadequate instructions from healthcare workers. This reiterates the deficiencies in the diagnosis disclosure process but could also be a sign of denial; whereby as a way of coping some individuals pretend they never received enough information on the diagnosis.

Although majority of caregivers reported their satisfaction with the diagnosis disclosure process; a significant proportion felt they should have been pre-counseled regarding the potential risk of CP in their children for better acceptance. This was also recommended from a Swedish study which showed that pre-counseling of parents of at-risk babies showed better adaptation with the outcome of CP. (28)

Similar to other African settings, about two thirds of the caregivers coped by seeking alternative therapies. (9, 10, 12) Among these, more than half took their children for spiritual healing sessions, more than one third used herbal treatments and 9.4% visited traditional healers. Turning to religion may be a natural response to find solace, (9, 12) but it might also indicate misinformation or inadequacy of knowledge on the treatment modalities available for children with CP.

Conclusion and Recommendations

Caregivers' level of knowledge on CP was low, which can be improved by comprehensive disclosure of the CP diagnosis by healthcare personnel in form of stage-wise counselling with continued access to health information to help improve caregivers' attitudes and adaptation to their children's condition.

Family support is key in helping caregivers improve their attitudes and cope with the major challenges facing them. Policy makers should ensure the decentralization of comprehensive CP clinic services to ensure access to rehabilitative health care, including the provision of health education and caregiver support from the health system to the community level.

Study limitations

The study was hospital-based amongst the caregivers attending the CP clinics, hence only the perceived family and societal attitudes were analyzed.

List of Abbreviations

CCBRT	Comprehensive Community Based Rehabilitation in Tanzania
CP	Cerebral Palsy
ENT	Ear Nose and Throat
MNH	Muhimbili National Hospital
MoHSW	Ministry of Health and Social Welfare
MUHAS	Muhimbili University of Health and Allied Science
PI	Principal Investigator
RCH	Reproductive and Child Health
SPSS	Statistical Package for Social Sciences.

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Author's contribution

AEN conceived and designed the study. AEN and NHE jointly analyzed the data, developed the paper and contributed to the writing of the manuscript.

Ethical approval and consent to participate

Ethical clearance was obtained from the Research and Ethics Committee of Muhimbili University of Health and Allied Sciences and permission was sort from the Muhimbili National Hospital authorities. All caregivers signed informed consent forms prior to recruitment.

Consent for publication

All authors have read and agreed to publishing the manuscript.

Competing interests

The authors declare that they have no competing interests.

Data availability

The dataset is available

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