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Experiences of the caregivers on the healthcare and psychosocial services available for cerebral palsy children in Mangochi district in Malawi

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Abstract

Background

Children with cerebral palsy require multidisciplinary and holistic care to manage their medical needs and maximise their developmental and educational potential. Exploring experiences of caregivers on healthcare and psychosocial services available for children with cerebral palsy is key in addressing gaps existing in provision of quality health care and psychosocial services both at community and hospital settings.

Methods

We conducted a qualitative exploratory descriptive study. Twelve caregivers of children with cerebral palsy were interviewed face-to-face using interview guides at Mangochi district. Twelve caregivers of children with cerebral palsy were interviewed face-to-face using interview guides at Mangochi district. Purposive and snowball sampling were used to select the study participants.

Results

The findings of the study showed that some of the participants received inadequate information related to the etiology and prognosis of cerebral palsy, alternative treatments, and information related to childcare at home. There was also a lack of follow-up and home visits by health care workers. The majority of participants received informal psychosocial support from their relatives and friends. However, there was lack of formal psychosocial services, such as counselling services, unavailability of support groups, and lack of assistive devices. Challenges encountered by children with cerebral palsy and their caregivers were related to inadequate finances, transport challenges, and lack of basic needs, which resulted in the inability to provide necessities to children with cerebral palsy and inability to take their children to the hospital for regular physiotherapy services. In addition, caregivers face physical strain and burden during care.

Conclusion

The study found that there was inadequate provision of health care and psychosocial services to children with cerebral palsy. The study recommends the provision of comprehensive cerebral palsy information to caregivers, the formation of support groups, conducting outreach clinics and home visits to children with cerebral palsy, and provision of assistive ambulation devices by healthcare professionals and the department of social welfare.

Key words: cerebral palsy, experiences of caregivers

Background

Cerebral palsy is a group of disorders that affect a person's ability to move and maintain balance and posture and is often accompanied by sensory, communication, cognitive and musculoskeletal dysfunction[1]. Children with cerebral palsy require multidisciplinary and holistic care to manage their medical needs and maximise their developmental and educational potential[2]. In addition, many children with cerebral palsy have complex limitations in self-care functions rendering them completely reliant on their caregivers[3]. The provision of such care may therefore be detrimental to both the physical health and psychological well-being of parents of children with cerebral palsy[4]. Exploring caregivers' experiences with healthcare and psychosocial services available for children with cerebral palsy is therefore key to addressing gaps in the provision of quality healthcare and psychosocial services in community and hospital settings.

Globally, the prevalence of cerebral palsy is 1 to nearly 4 per 1,000 children[1]. However, the prevalence of cerebral palsy in African countries is higher than in Western countries1. In Africa, the prevalence of cerebral palsy varies widely from country to country, ranging from approximately 2 to 10 per 1000 children[2]. In the country of Malawi, cerebral palsy is a major disability among children[5]. According to the 2021 the Health Management Information System (HMIS) data , there were 6,149 children below the age of 15 years with cerebral palsy who attended physiotherapy[6]. Furthermore, 23% of children with neurological problems in Malawi have

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cerebral palsy[7]. In Mangochi, there were 462 children aged 0-15 years with cerebral palsy attending physiotherapy from January to December 2022[6].

Family centred care (FCC) is an approach used in healthcare service delivery for children with cerebral palsy. This approach focuses on family strengths and promotes mutual respect and information sharing between families and healthcare providers[8]. Despite the use of FCC, parents of children with cerebral palsy continue to experience dissatisfaction with their children's care[3,8,9]. Parents of children with cerebral palsy were dissatisfied with cerebral palsy management due to limited access to healthcare facilities and specialists, as well as a lack of adaptive equipment, such as wheelchairs and other ambulation aids, which contribute to the treatment gap for children with cerebral palsy[2]. Moreover, there wasinadequate information provided to caregivers about the disability of children with cerebral palsy[3,8,10]. Furthermore, high levels of social stigma have been reported among families of children with neurologic disorders, resulting in failure to seek treatment[2].

Few studies have focused on the experience of caregivers regarding the availability of services for children with cerebral palsy, while most studies are grounded more on biomedical approaches with the aim of fixing impairment and achieving normality[11]. Therefore, this study aimed to explore the experiences of caregivers of children with cerebral palsy regarding healthcare and psychosocial services at the community and hospital levels.

Methods

Study design and setting

The study utilized a qualitative research approach which is an exploratory descriptive design in nature. This approach was used to gain a broader understanding of caregivers' perspectives on psychosocial and healthcare services for children with cerebral palsy. The study was conducted at Mangochi District Hospital in the physiotherapy where children attend monthly physiotherapy services. Due to low patient turnover at the physiotherapy clinic some of the participants were followed in their homes in Mtalimanja and Mgundaphiri villages in Mangochi district.

Sample size and sampling technique

We recruited 12 primary caregivers of children with cerebral palsy who attended monthly physiotherapy services with their children at Mangochi district hospital. This sample size was guided by the data saturation which occurred for the 12th participant. Ten (10) participants were interviewed at the hospital, whilst two participants were interviewed in their homes in Mgundaphiri and Mtalimanja villages. Purposive sampling and snowballing techniques were used to select the study participants.

Due to low turnover of caregivers at the physiotherapy department, the researchers were referred to interview two caregivers of children with CP who did not attend the clinic but were available in their homes. Additionally, two participants refused to participate in the study at physiotherapy clinic due to time factors, as they were travelling back to their homes which were far away.

Ethical approval

The study was approved by the College of Medicine Research and Ethics Committee (COMREC) with approval number P. 02/22/3586 dated 13 April 2022. Permission to collect data was granted by the Mangochi District Health Office. Written informed consent was sought from all study participants.

Data collection

Three researchers conducted data collection in July 2022 with the aid of the semi-structured interview guide, which was formulated by the researchers, reviewed by paediatric experts, and pretested before data collection. The interview guide had three sections related to caregivers' experiences with hospital services, community health services and psychosocial services for children with cerebral palsy. In-depth interviews were conducted using a face-to-face approach and the information was tape-recorded. The interviews took approximately 30 to 40 minutes.

Data analysis

Data analysis was performed simultaneously with data collection. The interviews were audio-taped, played back repeatedly, and transcribed verbatim after each interview. All interviews were conducted in the local language (Chichewa) and translated into English. The data obtained from the participants were analysed using a thematic analysis. The analysis followed the steps outlined in Creswell[12]. First, the data were organised by transcribing the interviews; thus, the researchers listened to the tapes to become immersed in the data. Tape-recorded interviews were then transcribed word for word, entered, and stored in a word document. Second, the data were organised and divided into meaningful analytical units. Organised data were then coded and grouped into codes. Data coding was performed by 2 researchers. Coding helped the researchers generate themes and subthemes which were presented as findings in the study.

Results

The sample size for this study was 12, and it included caregivers of children with cerebral palsy. All participants were females, and the majority (n=10) were biological mothers of children with cerebral palsy. Two caregivers were not biological parents (aunt and grandmother); their children's mothers passed away when they were young. The majority of caregivers (n=11) were mothers aged between 20 and 30 years. Regarding educational level, the majority of participants (n=7) were primary school leavers. The majority of participants were not working and depended on their spouses and relatives for support. Mothers' demographic data are shown in Table 1.

Themes

Four themes emerged from the participants' narratives: lack of comprehensive healthcare services for children with cerebral palsy, inadequate psychosocial support, lack of community services for children with cerebral palsy, and challenges encountered by children with cerebral palsy and their caregivers.

Lack of comprehensive health care services for children with cerebral palsy

All participants reported that their children attended physiotherapy services at the hospital once every month. In addition, children received other services, such as immunization, growth monitoring, nutrition support, and treatment of medical conditions. However, some caregivers reported being given inadequate information about cerebral palsy etiology, prognosis, and home carefor children with cerebral palsy. Furthermore, some participants requested

Table 1: Demographic data for caregivers of children with CP children

Category	Characteristics	Frequency (n=12)
Gender	Female	12
	Male	0
Age	20 – 25	8
	26 – 30	3
	31 – 35	0
	36 – 40	1
Level of education	Tertiary	0
	Secondary	4
	Primary	7
	No education	1
Employment	Temporary	1
	Self employed	2
	Unemployed	9
Marital status	Single	1
	Married	10
	Divorced	1
Relationship to child	Mother	10
	Aunt	1
	Grandmother	1

specialist reviews for their children which could not be routinely performed at the facility. Some participants stated:

"My child attends physiotherapy and also receives nutrition supplements (chiponde) at the Nutrition Rehabilitation Unit. He is also reviewed by doctors in the under-five clinic when he falls sick (22- year- old self employed aunt).

"The healthcare workers should give us more information on what causes cerebral palsy and on how to take care of children with cerebral palsy at home". (24-year-old single mother)

"I wish that my child could be reviewed by other specialists and orthopaedic doctors so that he can be assisted comprehensively." (27-year-old unemployed mother)

Inadequate psychosocial support for children with cerebral palsy and their caregivers

The majority of participants reported that they were supported by their family members in taking care of children with cerebral palsy, such as helping them with basic childcare and providing them with financial support. However, all participants reported that there were no psychosocial services at the hospital level, such as the provision of counselling services to caregivers and the provision of supportive devices such as walking aids and prosthetics for children with cerebral palsy.

Some participants narrated:

"My mother and grandmother assist me with the basic care of the child. My relatives assist me in terms of providing transport money for the hospital visits, they also give me money to buy food and soap for the child" (27-year-old divorced mother)

"We do not receive any psychosocial support at the hospital, I have never interacted with a counsellor or a social worker, my child only receive physiotherapy services." (21-year-old unemployed mother)

Inadequate community services for children with cerebral palsy

The majority of participants reported that there were no formal community structures or organizations within their community that offered their children any type of support. However, one participant reported receiving financial support from an unknown organisation. Less than half of the participants reported that they were visited by the Health Surveillance Assistants (HSAs) in their community for health promotion services, such as the provision of health education on nutrition and environmental hygiene.

None of the participants had ever been visited by health care workers from the physiotherapy clinic or social workers at home. Additionally, there were no support groups for caregivers of children with cerebral palsy in the district. Furthermore, there were no schools for special needs children in their communities, thus denying children with cerebral palsy access to education.

Some participants said that:

"I was one of the beneficiaries to an organization in my home village that gives money (K15,000) to mothers of children who are less than 2 years to buy food stuff for their children." (24-year-old single mother)

"I have never been visited by any healthcare worker or social worker at home" (40-year-old grandmother)

Challenges encountered by children with cerebral palsy and their caregivers

The study found that children with cerebral palsy encountered several challenges, such as lack of food and other basic needs, lack of walking aids (prosthesis), physical problems, and transportation challenges. The study also found that financial challenges hindered caregivers from effectively providing basic support, purchasing ambulatory supportive devices, and from taking their children to the hospital for monthly physiotherapy services and clinical reviews.

Some participants narrated:

"I do not have enough money to buy special food for my child. The child has feeding problems, and she is very selective, she eats soft food easily compared to hard food and I cannot afford to buy soft food which is expensive so when I give her the available food, she just eat a little" (27- year old unemployed mother)

"I find it hard to take the child for monthly physiotherapy services and clinical reviews because I do not have money for transport" (30-year-old unemployed mother)

The study also revealed that participants encountered difficulties in accessing supportive devices, such as bicycles, which could assist children with mobility. Some participants stated:

"I was told to find a small plastic bike with tyres so that the child can stand and walk with the aid of that bike but the bike is expensive and I cannot afford it" (21-year-old self employed mother)

The participants' narratives revealed the physical challenges faced by children with cerebral palsy during home care. Some participants explained the following:

"The child has difficulties in feeding; he does not swallow normally, and sometimes he spills water. The child also cries frequently, this stresses me

a lot" (30-year-old unemployed mother)

"Sometimes the child develops shortness of breath especially during bathing and feeding" (20-year-old unemployed mother).

The participants' narratives also revealed the challenges faced by caregivers of children with cerebral palsy during childcare. It was also revealed that the children's dependence on constant support created physical and psychological stress for caregivers.

"I do not work properly at home, the child wants to be at my back each and every time because she cries when she is left on the floor, I am always tired with childcare and this stresses me alot" (30-year-old unemployed mother)

"*The child does not sit on her own so I help her sit, she does not feed on her and own sometimes she refuses food so I feed her, she constantly need my support for daily basic care."* (21-year-old unemployed mother)

Discussion

This study explored the experiences of caregivers of children with cerebral palsy in Mangochi district. The study revealed great concerns and anxieties among caregivers about their children's well-being and recovery, considering the chronicity of the condition. Similar findings were reported in India by Nimbalkar et al[13], who discovered that caregivers had concerns regarding the future of children with cerebral palsy and expressed concern about the limited possibilities for recovery, resulting in an increasing demand for greater support services that may improve the conditions of the children. The concerns raised by caregivers in the current study were also coupled with a lack of information on cerebral palsy prognosis, and alternative investigations and treatments available for children with cerebral palsy. This finding suggests the need for healthcare workers to provide information on cerebral palsy to families. Similar studies found that caregivers expressed the need for information related to child's condition, behaviour, prognosis, available healthcare facilities and community resources and supports[14,15]. Caregivers often lack knowledge about cerebral palsy hence need to empower them with knowledge about cerebral palsy to enhance confidence and skills in care provision, which will in turn improve a quality of life for children with cerebral palsy[16].

The current study also established that most caregivers faced financial constraints that prevented them from providing basic needs, procuring assistive walking devices, and accessing health care services for their children. These findings are consistent with reports from several studies that stated that financial challenges among caregivers of children with cerebral palsy impedes them from meeting necessities like food, clothes, diapers and hospital and transportation costs[17,18,19,20]. Due to financial constraints, children with cerebral palsy staying from long distances to the health facilities would be hindered from accessing health care services because caregivers will be unable to pay for transportation costs to visit the hospital, hence missing medical appointments and worsening their children's conditions[19,20]. Furthermore, financial limitations can prevent caregivers from fulfilling children's basic needs, such as nutritious food and other basic requirements hence increasing the likelihood of infections and malnutrition[20,21]. Children with cerebral palsy should therefore be supported with nutrition assessments, management and education to ensure intake of balanced diet and prevention of malnutrition.

Furthermore, the study revealed that participants faced challenges in obtaining supportive resources, such as bicycles, toys and walkers which are critical for improving the mobility and general well-being of children. This challenge demonstrates the complex link between financial constraints and the capacity to offer complete care to children with cerebral palsy. The prohibitive costs associated with these essential tools act as a significant barrier for caregivers in obtaining them, impeding the provision of holistic care and mobility support for children with cerebral palsy[22]. Bicycle riding not only improves muscle strength, coordination, and balance, but also serves as a recreational and therapeutic outlet for children with cerebral palsy, encouraging social engagement and independence[23]. This extends beyond physical benefits and includes psychological, social, and emotional components, resulting in a more complete and holistic approach to the children's total well-being.

The current study also revealed that caregivers experienced physical strain and burden while providing care to children with cerebral palsy. Given children's dependency on parental or caregiver support for basic tasks such as feeding, bathing, mobility, and positioning, caregivers found themselves constantly engaged in these roles. This demand for support leaves caregivers with limited capacity to concentrate on other aspects of their lives, underscoring the persistent physical and emotional strain imposed by their caregiving responsibilities, which can eventually affect the quality of care provided[24,25,26]. The burdens associated with caring for children with cerebral palsy give rise to additional challenges for caregivers, such as physical discomforts like back and shoulder pain as they are required to carry the children on their back[27]. These physical challenges, compounded over time, can contribute to burnout, ultimately leading to depression among caregivers[24,26].

Conclusion

The findings of this study have established the experiences and challenges encountered by caregivers when caring for children with cerebral palsy. There are gaps related to cerebral palsy information; hence, there is a need to provide adequate and focused information related to general cerebral palsy prognosis and management to caregivers. Caregivers can also benefit from counselling services and support groups to manage and minimise the emotional burdens associated with the long-term care of children with cerebral palsy. Support groups can help caregivers support and learn from each other about how to take care of children with cerebral palsy. Finally, there is a need for multidisciplinary team approach in the management of children with cerebral palsy to provide comprehensive services to meet special education, health, and psychosocial needs.

Limitations to the study

The study focused on one district due to project requirements; hence, it might have captured participants with similar experiences or perspectives. Further multinational research is required to explore the experiences and challenges faced by caregivers of children with cerebral palsy.

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Conflict of interest

The authors declare that they have no conflicts of interest.

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