

Barriers To Physiotherapy Accessibility For Children With Cerebral Palsy In Ghana: The Caregivers' Perspective

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Abstract

Introduction: Cerebral Palsy (CP) is a neurodevelopmental disorder of movement and posture that begins in infancy and persists throughout one's lifespan. It is one of the most common childhood movement disabilities affecting between 2 to 4 children per 1000 live births globally and 2 to 10 per 1000 live births in Africa. Children with CP require lots of regular and ongoing rehabilitation services such as physiotherapy. However, access to physiotherapy services remain inadequate worldwide, especially in Low and Middle-Income Countries (LMICs) such as Ghana and hence the need for this research.

Aim: The aim of the study was to investigate the factors that hinder access to physiotherapy for children with cerebral palsy in Ghana from the caregivers' perspectives.

Methods: A qualitative in-depth interview with primary caregivers of children with cerebral palsy was conducted at the Ho Teaching hospital. Snowball sampling method was used in this study.

Participation was voluntary and each participant signed a consent form before the interview was conducted. A mobile phone with quality recorder was used for the interview. The interview was transcribed and analysed using thematic approach.

Results: A total of 10 primary caregivers of children with cerebral palsy were interviewed. All were females and between the ages of 20 to 60 out of the 10 participants, 2 were out of jobs. Three main themes emerged from the data analysis; ease of accessibility, affordability of service and effectiveness of therapy.

Conclusion: The study found major obstacles that caregivers of children with cerebral palsy faced when receiving physiotherapy, which, include long travel periods, bad road conditions, and financial constraints. This study also emphasizes the value of further investigation and activism to build a more welcoming and encouraging environment for caregivers and children with cerebral palsy.

Keywords: Cerebral Palsy, physiotherapy, perception, caregivers, accessibility.

Introduction

Cerebral Palsy, popularly known as CP is a neurodevelopmental disorder of movement and posture that begins in infancy and persists throughout one's lifespan.¹ It is one of the most common childhood movement disabilities

affecting between 2 to 4 children per 1000 live births globally and 2 to 10 per 1000 live births in Africa.^{2,3} CP is a diagnosis given to a group of permanent disorders in movement and posture-causing activity limitations that are attributed to non-progressive disturbances which occurred

in the developing foetal or infant brain. The manifestation of CP varies significantly between individuals and often includes impairments in sensation, perception, cognition, communication, behaviour, and secondary musculoskeletal problems.⁴ CP displays heterogeneity or diversity in presentation, aetiology, evolution, severity, comorbidities and outcomes.⁵ Nevertheless, various medical and rehabilitative interventions throughout development have the potential to help children with CP engage in meaningful life activities. Observingly, a steady increment in CP prevalence is apparent, which could be due directly or indirectly to improved documentation of cases by national registries, advances in neonatal care, and proper and accurate diagnosis of new cases, amongst other factors.^{6,7}

Children with CP require lots of regular and ongoing rehabilitation services such as physical, occupational, speech and language therapy as well as medical and psychological services.⁸ Besides frequent and timely therapy, children with CP also require services that are well-coordinated and easily accessible.⁹ Also, according to Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), it is a fundamental human right for all persons with disabilities to have unhindered access to healthcare and health-related rehabilitation services.¹⁰ Regarding rehabilitation services, physiotherapy service is the most frequently used as it focuses on gross motor skills and functional mobility.¹¹ The role of the physiotherapist is to correct the physical impairments suffered by the children and to improve their quality of life.¹²

Access to rehabilitation services such as physiotherapy for children with cerebral palsy is not only essential but also a right and in line with Sustainable Development Goal 3 (SDG3), which requires states to promote healthy lives and well-being for every individual.¹³ However, access to rehabilitation (physiotherapy) services remains inadequate worldwide, especially in Low and Middle-Income Countries (LMICs) due to many barriers such as inadequate and unavailable services

within the community and lack of awareness of rehabilitation services among the general public. In these countries, many children with disabilities, such as those with CP, do not often have access to healthcare services, e.g. physiotherapy services. For example, it is estimated that worldwide, about 85% of children with disabilities live in LMICs and less than 5% of them have access to basic rehabilitation services.^{14,15} Physiotherapy service is a major component in the rehabilitation of a child with CP as it helps to improve the quality of life and as well as the functional independence of a child.¹² It may be that most caregivers do not come for physiotherapy services due to financial problems, long travel time to the facility and stigmatisation by society. Physiotherapy is a long-term approach, aimed at achieving functional independence in the children, which requires patience, time and effort from the caregivers.

In Ghana, although there are no official statistics on the number of children with CP, Cerebral Palsy Africa (CPA) estimates that 1 per 300 births has CP thus, the gap in access to rehabilitation services in LMICs requires the need to explore challenges and barriers hindering the accessibility of physiotherapy rehabilitation services in Ghana, an LMIC.¹⁶

Methods

A qualitative in-depth study was done on 10 primary caregivers of children with Cerebral Palsy at the Ho Teaching Hospital, Trafalgar. The choice of the number was because according to a study, less than 20 participants in a qualitative study helps a researcher build and maintain a close relationship and would hence improve the “open” and “frank” exchange of information.¹⁷

Inclusion and Exclusion Criteria

Inclusion criteria for this study were caregivers of 18 years and above with accurate or near-accurate diagnosed children with CP

Exclusion criteria were caregivers with children having more than one neurodevelopmental disorder or other co-morbidities.

Interview Guide

An interview guide was used in this study to know or determine the perceptions caregivers of children with cerebral palsy have about the physiotherapy rehabilitation service provided and how accessible the service was. (Demographics of participants e.g. sex, age group, and employment status; Ease of Access and Affordability e.g. what mode of transportation do you use; Effectiveness of Therapy e.g. what progress have you seen in your child after starting physiotherapy). Dr Gillian Saloojee, a paediatric physiotherapist, who did a similar study in Gauteng and Limpopo hospitals in South Africa was contacted for an assistance.¹⁸ This guide had three sections which covered demographics, access to therapy and affordability, and effectiveness of therapy. The interview was recorded with a smartphone that had a quality voice recorder.

Ethical Clearance

Approval was sought from the Ethics and Protocol Review Committee of the School of Biomedical and Allied Health Sciences (SBAHS/AA/PT/10660071/2022-2023) and permission was sought from the management of the Ho Teaching Hospital (Trafalgar). The study procedure was explained to the caregivers who agreed to take part in the research. An information sheet explaining the aim of the study was given to the participants for their consent. Those who agreed to participate signed the consent form. All ethical considerations were strictly adhered to throughout this study. The interview guide was piloted on two participants before conducting the actual study and the results indicated that indeed caregivers faced barriers when accessing physiotherapy services. The questions were interpreted and explained to participants who did not understand English so language was not a barrier.

Data Analysis

Data analyses was performed manually. Thematic analysis was used for analysing the data. The interviewees’ responses were captured using a smartphone voice recorder. Each transcript was read and re-read to obtain a general sense about

the whole content. Significant statements relating to the topic under study were extracted and recorded on a separate sheet, noting their pages and line numbers.¹⁹ Meanings were formulated from these significant statements. The formulated meanings were sorted into categories, sub-themes and themes.²⁰

Results

This study was conducted to explore caregivers’ perception towards accessibility of physiotherapy for children with cerebral palsy.

This chapter shows the findings of the data collected, which are based on the themes generated via the analysis of data obtained through participant interviews.

4.1 Background characteristics of the participants and their children

Table 1 shows the characteristics of participants being all females with ages ranging from twenty-seven (27) to fifty-one (51). The table further indicates that two (2) out of ten (10) participants were unemployed. Six (6) of the children with CP were males while the remaining four (4) were females with ages ranging from 1 year to 11 years.

Table 1: Characteristics of caregivers

CHARACTERISTICS	FEMALE	MALE	TOTAL
Age of Participant			
20-30	2	0	2
31-40	3	0	3
41-50	4	0	4
51-60	1	0	1
Sex of participants			
Male/Female	10	0	10
Employment Status			
Employed	8	0	8
Unemployed	2	0	2
Sex of Children	4	6	10

4.2 Themes from interview

Three themes emerged; ease of access, affordability of service and effectiveness of therapy.

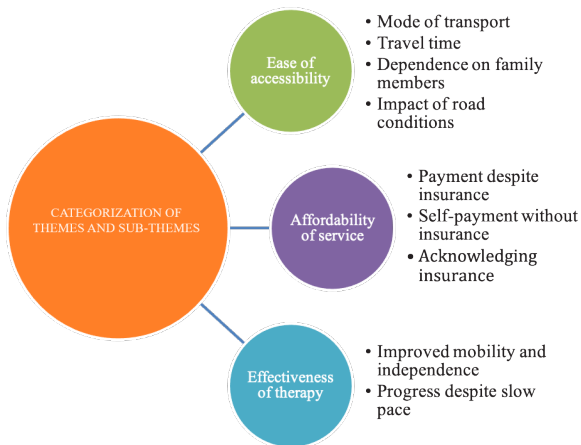


Figure 1 shows the categorization of themes and sub themes.

Theme 1: Ease of accessibility

Caregivers are always with the children and they bring them for therapy sessions, hence describing ease of accessibility to the physiotherapy unit is relevant. Four sub-themes were generated as follows:

- Mode of transport
- Travel Time
- Dependence on guardian
- Impact of road conditions

Mode of transport

Out of the 10 participants interviewed, three (3) take tricycles popularly called 'Pragya', five (5) participants go to physiotherapy in a taxi and two (2) have their own car that they drive to the physiotherapy unit. Most caregivers describe their mode of transport as quite challenging.

'We usually go to the physiotherapy unit in a tricycle, commonly referred to as 'pragya', which is cheap but occasionally we opt for a taxi to get there'. [Participant 1]

'Since I have a car, I personally drive to the physiotherapy unit every time we have an appointment, which gives me the autonomy to manage my healthcare needs'. [Participant 7]

'Before going to physiotherapy, I have to back him and walk to the roadside before getting a taxi to the hospital'. [Participant 6]

Travel time

Each participant has a varied time at which they spent on the road before getting to the physiotherapy unit. Some take shorter travel times, others moderate and some take a longer travel time.

'When coming for physiotherapy service with my child, we rely on taxi transportation since our house is such a distance from the hospital and the journey typically takes 25-40 minutes on the road. Sometimes, it is tiring because getting a taxi is challenging.' [Participant 6]

'I take on the responsibility of driving both myself and my child for physiotherapy sessions and we spend approximately more than an hour on the road. It is quite a struggle for me because I have to go back to work after our physiotherapy session'. [Participant 7]

Dependence on family members

Some participants depend on family members (husband) for transportation. Others rely on taxis when alternative transport is unavailable.

'My husband usually takes us to physiotherapy, but in instances when he is not available or out of town, we opt for a taxi, which most times makes our journey to the physiotherapy unit inconvenient because of the long distances'. [Participant 10]

Impact of road condition

Some participants mentioned that bad road conditions or construction processes of roads affect travel time to the physiotherapy unit.

'The road from my house to the physiotherapy unit is in a very deplorable state, causing us to spend more time coming to the physiotherapy unit'. [Participant 2]

Theme 2: Affordability of service

Each participant explained how they are able to afford or pay for physiotherapy services. Three (3) sub-themes were generated as follows;

- Payment despite insurance
- Self-payment without insurance
- Acknowledging insurance

Payment despite insurance

Participants 1, 5 and 9 emphasised that they pay for services despite having insurance coverage and they also stated that insurance covers a portion of the bill.

'I take care of the expenses or the hospital bills even though I am enrolled in an insurance scheme that covers half of the bill'. [Participant 1]

Self-payment without insurance

Out of the 10 participants, two (2) stated that they are not under any insurance scheme, therefore, they pay for services entirely by themselves.

'I do not have any insurance coverage for my child, so I personally cover all the costs associated with the services my child receives'. [Participant 6]

Acknowledging insurance

Out of the 10 participants interviewed, 5 mentioned that they are under insurance coverage but they do not elaborate on whether they pay for services partially or entirely.

'I am under insurance coverage but I still pay for the services I received when I come to the hospital'. [Participant 2]

Theme 3: Effectiveness of therapy

Two (2) sub-themes were developed under the effectiveness of therapy

- Improved mobility and independence
- Progress despite slow pace

Improved mobility and independence

Out of 10 participants interviewed, 7 stated that there has been much improvement in the children's movement and independence.

'My encounter with physiotherapy has been good because now, my son can sit and stand without the siblings or anyone assisting him to do that. Before physiotherapy, he couldn't do any of these. [Participant 1]

'I have seen much improvement in my child's condition because, at first, she couldn't do anything but now, she is able to raise her head and hold it for 3-5 minutes and also can turn and roll from side to side'. [Participant 4]

Progress despite slow pace

The caregivers stated that they were seeing progress in their children's condition but it is slow.

'The progress is very slow but we are getting there'. [Participant 7]

Discussion

This chapter describes the findings of the study on perceptions of caregivers of children with cerebral palsy from attending physiotherapy rehabilitation services.

Background characteristics of respondents

The study involved ten participants, all of whom were women caregivers of children with CP. This outcome aligns with a previous study, where 100% of the caregivers were also females, indicating that majority of caregivers are women.²¹ In another study, it was noted that most children with Cerebral Palsy are primarily cared for by their mothers, who serve as their primary caregivers.²² This study had majority of participants who were older than 30 years of age. This mirrors the findings of an earlier study, where 80% of the participants (caregivers of children with CP) were above the age of 30.²¹ Similarly, another study produced similar results, with 75% of the participants (caregivers) being older than 30 years.²³

The results of this current study indicated that 2 out of the 10 participants (caregivers) were unemployed. This finding is in line with a study conducted by Nketsia et al., which reported that 25% of their participants were unemployed.²⁴ Based on the data, it was determined that six out of the participants' children were boys. This supports the conclusion that the occurrence of CP per thousand male births is 30% higher than that among females. In essence, this study confirms that CP is more prevalent in males than in females.²⁵

Theme 1: Ease of accessibility

Ease of accessibility was found to be a factor in accessing rehabilitation services. This is further complicated by the lack of transport and the long distances people must travel to and from the health facilities.²⁶ In another study, it was identified that transportation was a major factor that influences access to rehabilitation services. According to the study, the underutilisation of services by poor families, especially those in rural areas of LMICs such as Kenya, Burkina Faso, Congo and Tanzania were affected due to poor public transportation.²⁷

Sub Theme 1: Mode of transport

Physiotherapy services can be accessed through range of transport providers, including both public and private options. According to this study's findings, it was evident that caregivers (about 80%) with children with CP predominantly opted for public transports when seeking physiotherapy rehabilitation services. This is similar to a study done in the UK and Ireland which showed that 81% accessed physiotherapy rehabilitation centres through public transport and 37% accessed through private transport.²⁸ Caregivers also described the cost of transport, as costly as most of them are living lots of kilometres away from Ho. A similar study conducted in Australia found out that adults with CP expressed apprehension regarding the expenses associated with accessing physiotherapy services.²⁹ A study in India also found that mothers could not participate fully in rehabilitation programs as they had difficulties accessing inclusive public transport.²²

Sub Theme 2: Travel time

Caregivers (mothers) of children diagnosed with CP often face significant travel time when accessing or seeking physiotherapy rehabilitation services. This prolonged travel, they say, disrupts their daily routines and affects their access to and consistency of therapy sessions for their children. According to some caregivers, the travel time to the physiotherapy unit has a multifaceted impact on the overall quality of healthcare and assistance they provide for their children. In a similar study, 'Patients with special health care needs living in remote locations are even more seriously challenged in accessing required health care services'.^{30,31}

Sub Theme 3: Dependence on family members

Many caregivers rely on other family members for transportation to physiotherapy appointments. This is due to several factors. The location of the physiotherapy facility may necessitate travel over longer distances or to facilities with specific accessibility features. Additionally, the child's specific needs and functional limitations might require assistance during transportation.

Sub Theme 4: Impact of road condition

The roads leading to the physiotherapy facility are in deplorable conditions, which pose a significant obstacle for both caregivers of CP and children. These conditions often lead to increased stress and hinder their access to physiotherapy and other healthcare services.

Theme 2: Affordability of service

The affordability of physiotherapy varies depending on factors such as insurance coverage and specific services required. In some countries, these services may be expensive, making them less accessible to individuals without adequate insurance or financial means.

Sub Theme 1: Payment despite health insurance

Despite having health insurance, some caregivers (mothers) of children with CP are often faced with unexpected out-of-pocket payments for medical

care, which can create financial challenges and impact for themselves and their children. In a recent study done in Zimbabwe; caregivers expressed a demand for items such as mobility aids, incontinence products and specialised dietary provisions for their children. The caregivers also indicated that the high costs or expenses associated with medications, particularly for managing conditions like epilepsy in their children, posed a significant obstacle for these caregivers.²¹

Sub Theme 2: Self payment without health insurance (Expired health insurance)

Caregivers (mothers) of children with cerebral palsy often find themselves in the challenging position of having to self-finance these essential treatments due to inability to renew their health insurances and some necessary medications and assistance devices, which are not part of the National Health Insurance Scheme. This situation places a considerable financial burden on the caregivers, potentially impacting their household budgets, savings, and overall financial stability, as they have to bear the full cost of specialised care and therapy, which can be substantial. This financial strain not only affects their immediate ability to provide the necessary support and interventions for their children, but also raises concerns about the long-term financial sustainability of managing their child's cerebral palsy condition. A similar study recognized that caregivers of children with cerebral palsy in Zambia grapple with the financial stress associated with their caregiving responsibilities.³² A study conducted in Canada, revealed that caring for a child with a disability tends to result in significant financial expenses, even within well-developed nations.³³

Sub Theme 3: Acknowledging health insurance (Non- expired health insurance)

Recognizing and leveraging insurance coverage is of paramount importance when caregivers (mothers) seek physiotherapy and other services for their children with cerebral palsy. This acknowledgement not only offers substantial financial relief by offsetting the considerable costs associated with specialised care and therapy but also contributes to

a more equitable healthcare system, ensuring that these essential services are within reach for families regardless of their financial means. It provides mothers with the peace of mind that their children can receive the necessary interventions without imposing an undue financial strain, ultimately fostering better overall well-being for both the child and the caregiving mother. In India, in contrast to the above study, a research investigation revealed that despite government efforts to offer financial assistance through disability-related welfare programs for children, the allocated funds were inadequate. Consequently, caregivers continued to grapple with financial hardships.²²

Theme 3: Effectiveness of therapy

Physiotherapy services have been found to be highly effective in improving physical function, reducing pain and enhancing the overall well-being of the child. Most services provided are individualised and include exercises, manual therapy and other techniques. Caregivers (mothers) of children with CP have shared a range of positive encounters regarding the physiotherapy rehabilitation services they received.

Sub Theme 1: Improved mobility and independence

Physiotherapy rehabilitation services play a vital role in enhancing the mobility and independence of children with CP. These improved motor skills help empower the children to perform better in their daily activities. The interviewed mothers (caregivers) have observed improvements in motor functions as well as independence in their children, which encouraged their active participation in rehabilitation programs. A study done in Nigeria supported this, emphasising that such improvements facilitated caregiver involvement.³⁴ Similarly, a Brazilian study highlighted that, mothers viewed physical therapy as crucial for enhancing their children's motor development and independence, recognizing the extra caregiving responsibilities they faced compared to mothers of non-disabled children.³⁵

Sub Theme 2: Progress despite slow pace

Despite the intrinsic challenges of managing children with cerebral palsy, it's vital to recognize that progress, though often gradual, remains a continuous journey. Within the realm of caregiving, where patience and persistence are paramount, incremental steps and achievements, however small, contribute significantly to the overall development and well-being of these children. Acknowledging and cherishing these milestones, despite the slower pace, serves as a source of motivation and inspiration for both the children themselves and their devoted caregivers, reinforcing the belief that with consistent care and support, remarkable improvements can indeed be achieved over time. A previous study revealed enhancements in muscle strength and improvements in the daily activities of children with cerebral palsy, unfortunately, they did not observe a positive impact on their movement disorders as per their data.³⁶

Conclusion

This study found major obstacles that caregivers of children with cerebral palsy (CP) faced when receiving physiotherapy rehabilitation. These barriers, include long travel periods, bad road conditions, and financial constraints. The connection between service accessibility and caregiver experiences highlights the need to tackle these issues. Improved services and coordinated efforts are required to guarantee that children with cerebral palsy receive the care and assistance they require. The study emphasizes the value of further investigation and activism to build a more welcoming and encouraging environment for caregivers and children with cerebral palsy. Recommended interventions would help improve accessibility by addressing geographical and

logistical challenges that caregivers face when trying to access physiotherapy services and also consider setting up more accessible locations, providing transportation options, or offering telehealth services. Financial support; recognizing the financial burden on caregivers. Implementation of financial assistance programs, subsidies, or insurance coverage to alleviate the costs associated with physiotherapy services for children with CP. For example; expanding the National Health Insurance Scheme to include healthcare services for children living with CP has the potential to lower expenses and enhance the healthcare-seeking behaviour and overall well-being of children living with CP in Ghana, launching awareness campaigns to inform caregivers about available services and resources. This can help caregivers navigate the system more effectively and advocate for policies that prioritise the needs of children with CP and their caregivers. Engage with policy-makers to promote inclusive healthcare policies and funding.

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Conflict of interest

The authors declare no conflict of interest.

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