

# Extra-Institutional Factors Limiting Access to Rehabilitation Services for Children with Cerebral Palsy: Perspectives of Caregivers in Marsabit County, Kenya

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## ABSTRACT

**Purpose:** *This paper explored the factors limiting access to and use of hospital-based rehabilitation services for children with cerebral palsy in Marsabit County, Kenya. The factors were unrelated to healthcare institutions providing the services and the focus was on the perspectives of caregivers of children with cerebral palsy.*

**Method:** *A qualitative study was conducted with a total of 18 participants who were selected by purposive sampling. Semi-structured interviews were used to collect data from the participants. Data was analysed using Erlingsson and Brysiewicz's approach to content analysis.*

**Results:** *The major barriers for the caregivers were belief systems, lack of awareness of rehabilitation services, no support at home, transport problems, and cost of transport.*

**Conclusion and Implications:** *Access to rehabilitation services for caregivers of children with cerebral palsy appear to be limited. Health policymakers, service providers and other stakeholders should ramp up their efforts to improve access to these services and make them services not expensive, but caregivers experience transport problems in terms of its unavailability and cost as well. Efforts at improving access could be supported by information and awareness-creation among caregivers about the importance of rehabilitation services for children with cerebral palsy.*

**Key words:** *disability, traditional healers, service users, caregivers, cerebral palsy, service providers, utilisation*

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## INTRODUCTION

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 (UN, 2006). Thus, access to rehabilitation services for children with cerebral palsy is not only essential but is also a right and in line with the Sustainable Development Goal 3 (SDG3), which requires States to promote healthy lives and well-being for every individual (UN, 2017).

The Government of Kenya's (GoK) efforts to improve access to healthcare for children with disabilities predates the UNCRPD and the SDG3. For example, Kenya's Children Act 2001 has provisions to promote the right to health for all children. The Act states that good health is a basic right of every child and thus, children with disabilities shall be treated with dignity and without discrimination in terms of access to healthcare services. The Act mandates that persons with disabilities should be provided with free healthcare services or at a reduced cost whenever possible (Kenya Children's Act, 2001).

Furthermore, the 'Kenya Health Policy 2014–2030' recognises the need for accessible healthcare, including health-related rehabilitation, to all persons with disabilities (GoK, 2014). To ensure access to health facilities, the policy advocates for physical access to health facilities and services by 2030, defined as "living at least 5 km from a health service provider where feasible and having the ability to access the health service" (GoK, 2014).

However, access to rehabilitation services remains inadequate worldwide, especially in low- and middle-income countries (LMICs) due to many barriers (WHO, 2017). These barriers include lack of awareness of rehabilitation services among the general public (Barnes, Dolan, Gardner, Stevens & Zack, 2012), as well as inadequate and unavailable services at community level (WHO, 2017; UN, 2018). Many children with disabilities, such as those with cerebral palsy, do not often have access to healthcare services, let alone rehabilitation 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 (Maloni et al, 2010; WHO, 2017; Bright, Wallace & Kuper, 2018). Poor public transport has been reported to have negatively influenced access to rehabilitation services in rural areas of LMICs, such as Kenya (Ensor & Cooper, 2004; Moisi et al, 2011). Long-distance travel to and from the health facilities is one major

reason for discontinuation of rehabilitation services by caregivers of children with disabilities (Mishra & Siddharth, 2018).

The limited access to rehabilitation services in LMICs is affected by other barriers such as cultural beliefs and financial constraints. A study in Bangladesh revealed that lack of understanding of the causes of cerebral palsy limited children's access to rehabilitation services. The study reported that most caregivers believe the condition was caused by bad spirits and, as a result, many caregivers visited traditional healers for treatment (Zuurmond, Mahmud, Polack & Evans, 2015). Due to cultural reasons, some people opt for traditional healing methods instead of formal rehabilitation services (Wegner & Rhoda, 2015). In some cases children are hidden from public view by their parents, due to stigma and shame attached to the conditions, resulting in late detection and appropriate intervention for the children (UNICEF, 2007). Additionally, the socioeconomic status of families, like occupation and level of income, has been reported to be the major barrier to access rehabilitation services, even in higher-income countries such as the USA (O'Neil, Costigan, Gracely & Wells, 2009).

The situation is not different in Kenya. A study by Bunning et al (2014) in Kenya reported transportation problems and inadequate social support for caregivers as challenges to access rehabilitation services. According to the study, poor staffing in rural areas had compelled many parents to travel long distances to seek services in urban areas, coping with the added difficulty of poor transportation from rural to urban areas. Similarly, a study on the rehabilitation of children with cerebral palsy in Nairobi, Kenya, cited not only a high incidence of cases of cerebral palsy but also revealed barriers in utilising rehabilitation services, such as high costs of services (Ngota, 2018). This situation is likely to be worse in remote areas such as Marsabit County because most rehabilitation professionals prefer to render services in urban areas (UN, 2018).

The current study explored extra-institutional barriers limiting caregivers' access to and use of rehabilitation services. The focus is on external factors that did not emanate from the rehabilitation centres.

## **Objective**

Accessible rehabilitation services are essential for children with cerebral palsy in order to improve their functioning, increase independence and quality of life. This study explored the extra-institutional barriers limiting service utilisation that are experienced by caregivers of these children.

## METHOD

### Study Setting

The study was undertaken at the Marsabit County Referral Hospital (MCRH) and Moyale Sub-County Referral Hospital (MSCRH), both in Marsabit County, Kenya. Marsabit County shares borders with Turkana County on the West, Wajir County to the East, Isiolo and Samburu County to the South and Ethiopia to the North. Marsabit County is approximately 70,961.2 square kilometres in terms of land area (Ministry of Health-Kenya, 2018) and Marsabit and Moyale are its two major towns.

The two referral hospitals are the only health facilities where rehabilitation services for children with cerebral palsy are offered in the region. These hospitals receive referral cases from across the County, as far as Illeret, located 550 kilometres away from Marsabit town (Ministry of Health- Kenya, 2018). MSCRH also treats children with cerebral palsy from the Ethiopian side of the County.

### Study Sample

The targeted population was caregivers whose children were diagnosed with cerebral palsy and who were seeking rehabilitation services at MCRH and MSCRH. Purposive sampling was used to select 18 participants for the study - 11 from MSCRH and the rest from MCRH. Emmel (2013) asserted that purposive sampling allows researchers to select cases of rich information that will provide insights into the subject matter. The selection of caregivers was done with the help of service providers, who reviewed the departments' registers of clients to identify those who met the inclusion criteria.

Caregivers who had used services from the selected hospitals for at least one year were considered to have enough experience to be able to contribute to the study. Only caregivers who were able to communicate either in English or Kiswahili were chosen.

The researchers explained the purpose of the study to all the participants individually and those who agreed to participate signed a consent form.

### Data Collection

A qualitative data collection method was used. The focus was on gathering data that would provide in-depth insights into factors that are not created

by institutions providing services but affect access to and the utilisation of rehabilitation services. The perspectives of the caregivers were of interest.

Semi-structured interviews were conducted in private rooms in each hospital, to ensure participants' confidentiality. The interviews helped the study participants to express their views on what influenced their access to rehabilitation services and allowed the interviewers to probe for in-depth information on the topic. Cohen and Crabtree (2006) observed that interviews allow interviewees the freedom to express their views freely on the subject and can provide reliable and comparable qualitative data.

All the interviews were recorded on audiotapes with consent from the participants, and observations made during the interviews were written down in a field diary.

### **Data Analysis**

The data obtained from the interviews was analysed using Erlingsson and Brysiewicz's (2017) approach to content analysis: condensation, coding, categorisation and forming themes.

The process of analysis started with a transcription of the audio-recordings in Word format. Transcription was done by an independent person, fluent in both Swahili and English. The researchers then read the transcripts and compared them with the audiotapes to ensure accuracy. They subsequently re-read all the transcripts carefully, noting significant points (meaning units) made by the participants on the left margins of the transcripts. These were then condensed and assigned codes. Related codes were grouped to form categories. Based on the underlying meanings, similar categories were merged to form themes. The themes were listed and clustered according to the objective of the study. Some verbatim expressions from study participants were quoted to support the themes. To ensure anonymity of participants and maintain confidentiality of the information obtained, the cryptograms MBT P1-P7 (for caregivers from MCRH) and MYL P1-P11 (for caregivers from MSCRH) were used while citing the verbatim extracts from transcripts.

### **Ethical Considerations**

Approval for the study was obtained from each Hospital as well as from the Department of Health Promotion and Disability Studies of Kwame Nkrumah University of Science and Technology (KNUST) in Ghana. Ethical approval was

received from the KNUST Committee of Human Research Publications and Ethics, where the study protocol was reviewed and cleared before study implementation. All those who agreed to participate in the study signed a consent form.

## RESULTS

### Demographic Features of Caregivers

Of the 18 caregivers interviewed, 77.8% were females. The majority of the caregivers (83.3%) were Muslims, and more than three-quarters (77.8%) were below the age of 28 years. Also, more than three-quarters (83.3%) of the children were below three years of age, except for three of them who were between four and six years old (see Table 1).

**Table 1: Demographic Features of Caregivers**

Variables	Category	Frequency (n=18)	Percentage (%)
Gender	Male	4	22.2
	Female	14	77.8
	<b>Total</b>	<b>18</b>	<b>100</b>
Age of Caregivers (yrs)	18-28	14	77.8
	29-38	1	5.6
	39-48	2	11.0
	49-58	1	5.6
	<b>Total</b>	<b>18</b>	<b>100</b>
Age of Child (yrs)	<1Yr	8	44.4
	1-2	7	39
	3-4	1	5.6
	5-6	2	11.0
	<b>Total</b>	<b>18</b>	<b>100</b>
Education Level	Primary	5	27.8
	Secondary	6	33.3
	Tertiary	3	16.7
	None	4	22.2
	<b>Total</b>	<b>18</b>	<b>100</b>
Occupation	Employed	2	11.1
	Self-employed	6	33.3
	None	9	50
	Unknown	1	5.6
	<b>Total</b>	<b>18</b>	<b>100</b>

Marital Status	Married	16	89.0
	Unknown	2	11.0
	<b>Total</b>	<b>18</b>	<b>100</b>
Religion	Christian	3	16.7
	Muslim	15	83.3
	<b>Total</b>	<b>18</b>	<b>100</b>
Relationship with the Child	Mother	12	66.7
	Father	4	22.2
	Relative	2	11.1
	<b>Total</b>	<b>18</b>	<b>100</b>
Affiliated Hospital	MYL Hospital	11	61.1
	MBT Hospital	7	38.9
	<b>Total</b>	<b>18</b>	<b>100</b>

### Factors Influencing Access to Rehabilitation Services

The factors influencing access to rehabilitation services for children with cerebral palsy are presented under the following sub-headings: physical distance; cost of transportation; support from family members; parenting role expectations; lack of knowledge of cerebral palsy and rehabilitation services; and belief in religious and traditional healers.

#### Physical Distance

Living far away from the facilities was a challenge for the caregivers. Many participants wished they had services closer to them, because distance made it difficult to access services for their children.

*“If I get a place that is near, I will be very happy because I just take the child to the nearest place” (MYL P11).*

This assertion was supported by another caregiver.

*“If therapy doctors can come home, it is going to be good for us because there are parents who cannot even come here (hospital) because of the distance...” (MYL P1).*

The number of visits to the hospitals was reduced for some caregivers because of distance.

*“...they told me, since I am coming from far, they can see me once in a week... because transport is also a problem...” (MBT P7).*

## Cost of Transportation

An important factor also related to distance is cost of transportation. Many caregivers said that since they could not afford the transport cost to the health facilities, they sometimes had to walk there, and it was very tedious.

*“When I have money, I come on a motorbike because it is faster. Many times, I come on foot because I didn’t have money” (MYL P1).*

*“I stay far from here. I always come on foot. I do not have cash for transport because it’s expensive” (MBT P5).*

Some of the caregivers complained that they experienced health problems such as back pains because of carrying their children and wished they had enough money to travel by vehicles.

*“If I have money, I could have come by car, because now there are times you have back pain because of carrying him....” (MBT P5).*

Consequently, some caregivers stopped going to services when their children grew older because it was difficult to carry them to the facilities.

*“...she (child) is too heavy for me to bring her all the time here (hospital)” (MYL P2).*

## Support from Family Members

Social support from family members played an important role in service utilisation among the participants. Caregivers who had support at home seemed more likely to use rehabilitation services while facing fewer challenges than those without support.

*“At home I have support. The child’s grandmother, my husband’s mother, stays with us... she helps me a lot with the child... I don’t have any problem at home hindering me from coming here (hospital)” (MYL P1).*

Caregivers who received a lot of support from their respective husbands said something similar.

*“The child’s father is also very supportive of the treatment...he always comes with me when he has time” (MBT P7).*

*“His (child’s) father cooperates well, and he does not want the child to miss treatment here (hospital)” (MYL P8).*



However, those without support lamented that they were unable to visit the hospital regularly.

*“I was alone, and no one was helping me to bring the child...I couldn’t bring him to the hospital regularly” (MYL P9).*

*“The days I go and fetch water, I do not come (hospital). It’s very tiresome and I cannot make it to come here (hospital) again... you cannot get water immediately and I do not have someone to help me bring him to the hospital. It’s only me” (MBT P5).*

### **Parenting Role Expectations**

The roles expected of each gender influenced the use of rehabilitation services among the participants. According to some of them, although their spouses were supportive, the mothers were responsible for going with their children to the hospital and this was regarded as a big challenge.

*“But you know men about children... they are not so conversant and not responsible for that. So, I have to commit to bringing my child for treatment. He (the father) is so cooperative with treatment..., but now he can’t carry that small child here (hospital). That one is my responsibility” (MYL P10).*

*“Besides that, there was no other person who can take the child to hospital apart from me. Her father is very busy. I also do not expect him to assist me with that... that is my duty” (MBT P3).*

### **Lack of Knowledge of Cerebral Palsy and Rehabilitation Services**

The findings indicated that some caregivers did not have sufficient information about the existence of rehabilitation services. In consequence, they did not utilise the services until they were informed about them.

*“The child was not feeling well. I came to the hospital to see the children’s doctor. I told him everything and the child’s neck is not strong; then he sends me here (physiotherapy). I did not know of places to do children’s exercises before he sends me here (physiotherapy)” (MYL P8).*

*“There is a lady who told us that if a child cannot sit, walk or has a problem like my child, there is a place to treat in the hospital. She said her sister used to take her child to Moyale hospital and after receiving exercises, her child can sit alone.*

*She told us to take the child to a hospital and see how she can be assisted instead of only taking to traditional healers” (MYL P2).*

*“One day the child was sick, with fever, coughing...and we came here (hospital) to see the doctor. After checking the child, he gave us drugs and told us to take him to physiotherapy” (MYL P5).*

It also emerged that many caregivers did not know about the usefulness of rehabilitation services for children with cerebral palsy, and this possibly delayed the use of the services.

*“At first, for me, rehabilitation is a place for taking people with mental problems. I did not know it’s a place where you can even take children with CP too” (MBT P3).*

Lack of knowledge of cerebral palsy had influenced the utilisation of rehabilitation services. Some caregivers said they did not even know anything about cerebral palsy and wished that they did.

*“I did not know a child can develop problems at birth. If I knew the problem, we could have started treatment for a long time. But the problem was that I did not know” (MBT P2).*

### **Belief in Religious and Traditional Healers**

The existing beliefs in the healing power of religious and traditional healers also affected the use of rehabilitation services. The interviews showed that misconceptions about the causes of cerebral palsy and the necessary interventions have led many caregivers to seek assistance from religious and traditional healers.

*“The reason why I did not come early to the hospital is because of many things they are telling me at home...some even told me that I am cursed and thus I need to see the witchdoctor” (MBT P2).*

*“When people see your child like this, they tell you to read the Quran, and his father, following the pressure from people, went to bring a Sheikh home” (MYL P8).*

*“We have taken him to the Sheik to read him Quran for three months and there was no improvement, but now after bringing my child here (hospital) I see there are changes; he can even sit alone” (MYL P5).*

There seemed to be so much trust in religious and traditional healers among some caregivers that they started rehabilitation on the advice of these healers.

*“One of them (healers) told me that this child’s problem is on the legs, just go and see the physiotherapist...that is when I came here (hospital)” (MYL P7) .*

*“...even the traditional healer told us not to stop the hospital exercises” (MYL P5).*

## DISCUSSION

This study explored the barriers that caregivers of children with cerebral palsy face in accessing rehabilitation services. The focus was on barriers that did not emanate from the rehabilitation centres, but rather on the external obstacles limiting caregivers from accessing available rehabilitation services provided by health institutions.

The study’s findings indicated that misconceptions about the causes of disability were one of the major factors that influenced the use of rehabilitation by the caregivers. The perception in the study area is that disability, including cerebral palsy, is a curse or evil. This has caused caregivers to believe that exorcism and interventions by traditional healers could cast out the evil spirit. This belief system has contributed to underutilisation of services among caregivers of children with cerebral palsy. The finding is in line with the findings of other studies done in Bangladesh and South Africa, for instance, in which cultural beliefs about disability have been identified as an obstacle for accessing rehabilitation services (Zuurmond et al, 2015; Wegner & Rhoda, 2015). In these studies, traditional beliefs about the causes of disability were a major barrier as people thought that their condition was spiritual and could not be remedied by biomedical interventions such as rehabilitation.

However, findings from the current study suggest that traditional and religious leaders could play an important role in the rehabilitation process of children with cerebral palsy. Caregivers in this area trust these healers so much that some of them started using rehabilitation services based on their advice. Thus, some of the traditional and religious leaders served as ‘referral’ points for the rehabilitation centres. Traditional healers (and religious leaders) do not always prevent people from accessing biomedical interventions such as rehabilitation services. This is a lesson to service providers and therefore they need to be aware of and sensitive to cultural beliefs of the local population. Rehabilitation service providers need

to be knowledgeable about the influence of traditional and religious leaders and invest in collaboration with these people, informing and training them about the importance of rehabilitation services so that they can incorporate the positives of the tradition into their practices.

The study's findings that children with cerebral palsy make less use of rehabilitation services as they get older, is consistent with some studies done elsewhere. For example, in a study that examined the experiences of parents of children with cerebral palsy on accessing therapy services in the US, O'Neil et al (2009) reported that as children aged, their chances of using rehabilitation services decreased. The findings of the current study indicate that children above 3 years of age rarely attend rehabilitation services because they become heavier as they grow older, and caregivers find it difficult to carry them to rehabilitation centres, which is further complicated by lack of transport and long distances people must travel to and from the health facilities (Bunning et al, 2014). Moisi et al (2011) identified transportation as a major factor that influences access to the rehabilitation services. According to the authors, the underutilisation of services by poor families, especially those in rural areas of LMICs such as Kenya, Burkina Faso, Congo and Tanzania was due to poor public transportation. Similarly, Ensor and Cooper (2004) were of the view that attempts to address accessibility issues often lay too much emphasis on skills of staff, treatment protocols, availability of supplies, and health facilities, at the expense of transport and cost, which is viewed as pivotal to service accessibility and utilisation. In the current study, inadequate and unaffordable transport services limited access to services for the caregivers of children with cerebral palsy. This is made worse by poverty and lack of support from family members. This indicates that the Government of Kenya's policy which addresses the importance of making healthcare accessible to all by improving physical access to health facilities, is still a challenge as far as rehabilitative services are concerned (GoK, 2014).

The findings also point to a lack of understanding of the importance of rehabilitation services among some participants. This is not surprising, as previous studies have reported similar findings. According to Wegner and Rhoda (2015) and Barnes et al (2012), the importance of rehabilitation service is often overlooked and undervalued among parents due to lack of awareness about the value of such services. Wegner and Rhoda (2015) discovered that ignorance about disability and the usefulness of rehabilitation services were reasons for caregivers to opt for traditional healers. This may result, in some cases, in children

with disabilities being hidden in homes and could result in too late detection, interventions and underreporting on the condition (UNICEF, 2007). This could contribute to invisibility of this group of children for national policymaking on disability and rehabilitation issues, and hence stop them from benefitting from the necessary rehabilitation interventions.

### **Implications**

The findings of this study have implications for service providers, health policymakers and other stakeholders involved in the provision of rehabilitative services in the County. The findings highlight the need to bring services closer to the communities through outreach and community-based rehabilitation programmes to ensure that those who need them, get them. Although there are some challenges associated with the above approaches, such as inadequate (trained) staff and lack of resources, it is evident that district hospitals and rehabilitation centres by no means offer the solution to the rehabilitation needs of people living in remote and rural areas. If well-planned with community leaders, it will be very helpful in the early detection and referral of cases to the appropriate specialists in the hospitals. For example, outreach programmes could be carried out on specific days, for specific communities. Minor cases which do not require regular medical attention could also be handled during the outreach visits, thus reducing the frequency of travel to health facilities by caregivers.

Measures, such as awareness-creation and education about disability issues and the importance of rehabilitation for children with cerebral palsy, can increase the timely use of rehabilitation services among caregivers. Health promotion and education can also address traditional and cultural beliefs about the causes of disabilities, to reduce misconceptions and increase access to rehabilitation services. For example, promotion of partnership with traditional healers and religious leaders by the rehabilitation service providers will allow the inclusion of positive aspects of traditional practices into the rehabilitation process and consequently improve access to services for the caregivers of children with cerebral palsy.

### **CONCLUSION**

This study explored extra-institutional factors that limit the use of rehabilitation services among caregivers of children with cerebral palsy in Marsabit County. The findings are alerting stakeholders, such as policymakers and rehabilitation

service providers, to the barriers limiting utilisation of rehabilitative services in the region and pointing to the need to adequately respond to those challenges. The study findings are a call to service providers and other stakeholders working with persons with disabilities, to be aware of and understand the local context in order to adapt their services to the specific needs of their clients.

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