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Page: 01-14

CHALLENGES FACING CAREGIVERS IN ACCESSING THE REHABILITATION SERVICES FOR CHILDREN WITH CEREBRAL PALSY IN IRINGA MUNICIPALITY, TANZANIA

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ABSTRACT

This study examined challenges faced by caregivers accessing rehabilitation services for children with cerebral palsy in Iringa Municipality, Tanzania. The used a qualitative approach and explanatory design. Forty participants were purposively selected: 30 caregivers and 10 rehabilitation service providers. Data were collected through three focus group discussions with caregivers and key informant interviews with providers, then analysed thematically. Findings show there are barriers such as there being not enough rehabilitation centres in the Municipality and not having enough trained personnel or proper equipment and therapy programs. These therapy programs are far and hence take longer time to travel and long waiting times and coordination between service providers is weak. Costs of transport, and low incomes for patients plus not enough financial support make it hard to get access and to attend regularly. There is not enough information and guidance which kept caregivers from knowing and getting the services they need.. The study concludes that access to rehabilitation services in Iringa Municipality is limited due to inadequate services and lack of resources, geographical barriers and weak coordination. It suggests that there should be an expansion of rehabilitation and community-based services, bringing in more trained personnel, making equipment more available, strengthening the systems for appointments and follow-ups and reduce waiting times. Health facilities, rehabilitation centres, social welfare offices, schools, and other stakeholders should improve referrals, information sharing, and collaboration to ensure children with cerebral palsy receive accessible and continuous rehabilitation.

KEYWORDS: Caregivers; Cerebral palsy; Rehabilitation services; Service access; Rehabilitation challenges; Children with disabilities; Iringa Municipality.

INTRODUCTION

1.1 Background of the Study

Rehabilitation services are essential for children with cerebral palsy because they improve movement, communication, daily functioning, and participation in family and community activities (Novak et al., 2020). Early and continuous rehabilitation supports children's functional development and quality of life (Rosenbaum et al., 2021). However, access to these services depends on the availability of rehabilitation centres, qualified personnel, appropriate equipment, transportation, and reliable information. Therefore, caregivers may experience difficulties when services are inaccessible, costly, or irregularly provided.

Globally access to rehabilitation services can vary quite a bit and this is across countries and also different groups of people (Kuper et al., 2020). High-income countries usually have better rehabilitation systems that are developed more thoroughly, but still there are inequalities that relate to income, where someone lives, and how available services are, which can keep families from getting the help they need. Limited resources and the unequal distribution of services that are linked to disability could stop children from getting the right support (Olusanya et al., 2022). In low- and middle-income countries, there are often shortages not only of facilities for rehabilitation but also of professionals who are trained and equipment that assists, and this creates more barriers for kids with disabilities (Abubakar et al., 2021). Plus long distances to travel, issues with transportation, and not being aware of what services are out there can make regular attendance really tough (Mung'ala-Odera et al., 2020).

In Tanzania, the rehabilitation services are delivered through systems for health and disability support, but caregivers might run into problems when it comes to how available these services are, how much they cost, and how they can access specialized care (Sanga et al., 2021). Some studies that have been done before have shown troubles connected to the cost and availability of services, along with some shortcomings in specialized support that should be available at health facilities (Moshi et al., 2022). These barriers have a potential to raise the financial and time demands on caregivers and can get in the way of children continuing their rehabilitation.

In Iringa Municipality, services for rehabilitation are important for helping kids with cerebral palsy, however there is limited evidence about the specific experiences that caregivers face when they try to access these services (Gona et al., 2021). There are challenges such as rehabilitation centers that are inadequate, not enough personnel, costs related to transportation, long distances, and not having much information that could affect how they

use the services (Moshi et al., 2022). Consequently, this study examined the challenges facing caregivers in accessing rehabilitation services for children with cerebral palsy in Iringa Municipality to generate local evidence that can inform improvements in service accessibility and continuity of care.

LITERATURE REVIEW

2.1 Theoretical Literature Review

The Behavioural Model of Health Services Use developed by Andersen (1995) guided this study. The Model explains that utilisation of health services is influenced by predisposing factors, enabling factors and need factors. Predisposing factors include caregiver behavior characteristics such as knowledge, education and attitudes towards seeking rehabilitation services, while enabling factors include household financial resources, availability of rehabilitation services and transportation. Need factors relate to the child's condition and level of rehabilitation support required (Andersen, 1995). The model is relevant to this study because it provides a framework for explaining how caregiver characteristics and service-related factors influence access to rehabilitation services for children with cerebral palsy in Iringa Municipality. The model therefore guided the study in examining challenges such as limited rehabilitation centres, shortages of trained personnel, inadequate equipment, transport difficulties, costs and limited information that may affect caregivers' ability to access rehabilitation services.

2.2 Empirical Literature Review

Studies have shown that caregivers who look after children with cerebral palsy experience challenges with getting rehabilitation services due to long distances, and costs of transport, also limited rehabilitation centres along with shortages of trained professionals all affect access. Harawo and Mprah (2022) found that issues with transport and long distances influenced how often caregivers in Kenya used rehabilitation services. Al Imam et al. (2021) reported that there are differences in how rehabilitation services are used in low- and middle-income countries, and Abuga et al. (2022) identified that a lack of rehabilitation resources and trained professionals presents barriers in getting access to these services in sub-Saharan Africa. Fonzi et al. (2021) also found that when it comes to caregivers in Ghana, costs related to treatment and transport impacted on their continued use of the rehabilitation services.

The way services are organized plus access to information can influence how easy it is to obtain these rehabilitation services. Saloojee et al. found that long waiting times, certain administrative processes, and not enough proper communication made it hard for caregivers

to attend cerebral palsy clinics which are located in South Africa. Harawo and Mprah (2022) also pointed out a limited understanding of what rehabilitation services are available, and Duma et al. (2023) mentioned while looking at low- and middle-income countries that the rehabilitation resources were very inadequate. But, there's a lack of evidence that shows the specific problems caregivers face when trying to access rehabilitation services for children with cerebral palsy in Iringa Municipality.

RESEARCH METHODOLOGY

The study employed a qualitative research approach and an explanatory research design to examine challenges facing caregivers who take care of the children with cerebral palsy in accessing rehabilitation services for children with cerebral palsy in Iringa Municipality, Tanzania. The study was conducted in selected centres, including Nyumba Ali, Neema Craft, Lebao, Unique Child Academy, and Call Africa. The study involved 40 purposively selected participants, including 30 caregivers and 10 rehabilitation and related service providers. The caregivers participated in three focus group discussions of 10 participants each, while the 10 service providers participated in individual key informant interviews. Data were collected using focus group discussion and semi-structured interview guides. The discussions focused on availability of rehabilitation centres, trained personnel, equipment, distance, transport costs, waiting time, and service information, while interviews focused on service availability, staffing, referral procedures, equipment, and other factors affecting access to rehabilitation services.

Data from the focus group discussions and key informant interviews were analysed using thematic analysis by transcribing, coding, grouping similar codes, and developing themes (Braun & Clarke, 2021). The main themes included service availability, rehabilitation personnel, equipment, geographical access, transport costs, waiting time, information, and referral processes. Trustworthiness was ensured through credibility, dependability, transferability, and confirmability, including comparison of information from caregivers and service providers, member checking, and proper documentation of research procedures. Ethical considerations were observed through obtaining permission from the University of Iringa, relevant authorities, and selected service centres. Informed consent, voluntary participation, confidentiality, anonymity, and secure storage of information were maintained throughout the study.

DATA PRESENTATION AND DISCUSSION

4.1 Challenges Facing Caregivers in Accessing the Rehabilitation Services for Children with Cerebral Palsy

This section gives findings about the challenges that caregivers must face when they try to access rehabilitation services for children who have cerebral palsy in Iringa Municipality. Data were gotten by using focus group discussions with caregivers and key informant interviews with those who provide services. The responses were analysed semantically by coding issues and then grouping them. The main issues were availability of rehabilitation centres and trained personnel, how often the therapy programmes happen, distance and transport worries, how long people have to wait, whether there was enough rehabilitation equipment, coordination among different service providers, and how available services actually are. These findings show how these obstacles influence caregivers' ability to get rehabilitation services.

4.1.1 Availability of rehabilitation centres and service utilisation

Rehabilitation services available in Iringa Municipality, but there aren't enough centres for the increasing number of children with cerebral palsy who need support. Caregivers in the focus group discussions said that having services located in just a few locations made it hard to access them. They said they spent a lot of time and money travelling to those centres, and transport costs made it too difficult to visit these facilities regularly. So, some caregivers had a hard time keeping up with the scheduled rehabilitation sessions. The findings show that the real problem wasn't that services were completely missing, but rather that they were not well distributed all across the Municipality. Missing these rehabilitation sessions could break up children's rehabilitation programmes and affect the continuity of care as time went on. An interview with a physiotherapist (Key Informant 01) revealed that:

The institution provides physiotherapy, developmental assessment, caregiver counselling, training on the use of assistive devices and referral services for children with cerebral palsy. However, these services are provided in only a few centres, while the number of children requiring rehabilitation continues to increase. This situation results in many caregivers depending on the same facilities, leading to overcrowding and increased demand for services. In some cases, caregivers fail to receive services on the scheduled day because the available centres are unable to serve all clients. Expanding rehabilitation services to additional health facilities would improve caregivers' access and increase utilisation of rehabilitation services. (Key Informant 01, Physiotherapist, 18 June 2026).

The findings showed that rehabilitation services in Iringa Municipality are kind of concentrated in a few facilities which causes long distances, high transport costs, overcrowding, and difficulties with regular attendance. Caregivers talked about the challenges they face when reaching rehabilitation centres and physiotherapists pointed out that there just aren't enough facilities to handle the growing number of children who need services. These findings kind of show how easily people can access services is based not just on whether there are rehabilitation centres but also on where they are located and how much capacity those places have. Tanzania's National Rehabilitation Strategic Plan 2024–2029 talks about the need to strengthen rehabilitation services and improving access at the proper healthcare levels (Ministry of Health, 2024). Likewise, the National Disability Mainstreaming Strategy 2021–2026 encourages better access for persons with disabilities and their families (United Republic of Tanzania, 2021). Past studies have also pointed out the lack of adequate rehabilitation facilities as barriers to people using services regularly (Gona et al., 2021; Melak et al., 2020). This goes along with Andersen's Behavioural Model which suggests that if there are more accessible rehabilitation centres then service usage would improve.

4.1 2 Availability of trained rehabilitation personnel and access to services

There were shortages in trained rehabilitation personnel which limited how caregivers could access rehabilitation services for children that have cerebral palsy in Iringa Municipality. Caregivers have mentioned that the number of specialists available wasn't enough for the demand for therapy and follow-up, leading to long waits, missed appointments, and interruptions during treatment. When therapists were not available on the days they were supposed to be, caregivers had to come back later which added to travel time and transportation costs. These interruptions ended up delaying physiotherapy and made keeping up with regular rehabilitation schedules difficult. Caregivers even worried that having long gaps in treatment could hurt the progress kids were making, which shows how having enough trained personnel is important for continuity of care. An interview with a rehabilitation service provider (Key Informant 02) explained that:

The availability of trained rehabilitation personnel affects the ability of caregivers to obtain regular services for children with cerebral palsy. The number of rehabilitation professionals is not sufficient to meet the needs of children requiring continuous therapy and follow-up. Caregivers may therefore experience delays in receiving professional assessment and treatment when service demand is high. Limited availability of specialised professionals also affects opportunities for caregivers to receive adequate guidance on supporting children at

home. Increasing the number of trained rehabilitation personnel would improve the regularity and accessibility of rehabilitation services for children with cerebral palsy. (Key Informant 02, Rehabilitation Service Provider, 2026).

The shortage also reduced the time available for service providers to guide caregivers on rehabilitation activities that could be continued at home. This shows that limited rehabilitation personnel affected not only the treatment received at the service centre but also the support caregivers received for continuing care at home. Increasing the number of trained rehabilitation personnel would help reduce waiting time and provide caregivers with more support during rehabilitation. An interview with a social welfare officer (Key Informant 04) also indicated that:

Many caregivers approach the social welfare office seeking assistance after experiencing delays in obtaining rehabilitation services. In most cases, these delays are associated with the limited number of qualified rehabilitation personnel available in health facilities. The shortage affects not only treatment but also counselling and follow-up services that caregivers require to support children at home. Families often become frustrated when they repeatedly visit service centres without receiving the expected assistance. Addressing the shortage of rehabilitation professionals would improve both service accessibility and caregiver satisfaction. (Key Informant 04, Social Welfare Officer, 20 June 2026).

The findings showed that not having enough trained rehabilitation staff in Iringa Municipality led to long waiting times, people having to visit multiple times, missing appointments, and stopping treatment sometimes. The limited number of staff also meant there were not many chances for assessment, counselling, follow-ups, and guidance for caregivers who are taking care of children with cerebral palsy at home which is rather important. The Health Sector Strategic Plan V (2021/22–2025/26) stresses how skilled health workers are important to ensure equal access to quality services (Ministry of Health, 2021). In a similar manner, the National Rehabilitation Strategic Plan 2024–2029 puts an emphasis on strengthening the workforce in rehabilitation (Ministry of Health, 2024). Previous research pointed out that not having enough rehabilitation personnel is a barrier to getting continuous treatment and accessibility to services (Gona et al., 2021; Melak et al., 2020). Aligning with Andersen's Behavioural Model of Health Services Use, trained personnel serve as a necessary enabling resource that is needed for using services. Thus, having an effective way to plan for the workforce, recruiting, deploying, and keeping staff is crucial to improve how timely people can access care, ensure treatment continues, and support caregivers better.

4.1.3 The availability of therapy programmes and how often services are used

The availability and regularity of therapy programmes affected caregivers' abilities to access rehabilitation services for children with cerebral palsy in Iringa Municipal Council. Caregivers said that getting regular physiotherapy really helped improve children's movement, posture, and physical functioning, which is good but at the same time, when sessions were postponed or missed, it messed up the recommended schedules for rehabilitation and hindered the children's progress. A few caregivers noticed increased muscle stiffness and difficulties moving after long breaks in therapies. Unpredictable appointments created inconvenience and made it hard for them to show up consistently. The findings indicate that effective rehabilitation is dependent not just on having available therapy programmes but also on trustworthy scheduling, regular provision of services, and making sure treatment continues properly. An interview with a rehabilitation service provider (Key Informant 05) revealed that:

Therapy programmes are arranged according to the rehabilitation needs and appointments of individual children. The frequency of attendance depends on the therapy schedule provided by the service provider and the ability of caregivers to return for subsequent sessions. Some caregivers do not maintain the recommended attendance because of transport difficulties and other responsibilities at home. Missed sessions interrupt the planned rehabilitation programme and can make it difficult for therapists to monitor the child's progress continuously. Strengthening appointment follow-up and providing more flexible therapy schedules would support regular attendance and continuity of rehabilitation services. (Key Informant 05, Rehabilitation Service Provider, June 2026).

Regular therapy was also affected by interruptions in scheduled services and difficulties faced by caregivers in returning for follow-up sessions. The rehabilitation service provider explained that missed sessions were linked not only to changes in therapy schedules but also to transport difficulties and household responsibilities. Irregular attendance resulted from both service-related and household factors. Closer follow-up, better appointment planning and flexible scheduling had supported continuity of rehabilitation. The findings suggested that improving the organisation of therapy sessions while considering the circumstances of caregivers would have strengthened regular attendance and continuity of rehabilitation services. An interview with a special education teacher (Key Informant 03) revealed that:

Children who regularly attend rehabilitation programmes generally participate better in classroom activities because they develop improved posture, movement and coordination. Those who miss therapy sessions frequently experience difficulties in sitting, writing and

participating in learning activities. Teachers often observe that interrupted rehabilitation affects children's confidence and learning progress. Close collaboration between rehabilitation centres, schools and caregivers would help children maintain continuous rehabilitation while supporting their educational development. Regular therapy programmes therefore contribute to both rehabilitation outcomes and school participation. (Key Informant 03, Special Education Teacher, 19 June 2026).

The findings showed that regular rehabilitation therapy helped kids with cerebral palsy to get better at posture, movement, coordination, and also taking part in classroom activities. But therapy interruptions and delayed appointments had an impact on how well children progressed functionally and how much they participated in education. The study pointed out that working together among rehabilitation centres, schools, and caregivers is really important to make sure support does not stop. Tanzania's Health Sector Strategic Plan V, it is focused on giving access to rehabilitation for people with disabilities (Ministry of Health [MoH], 2021), while the National Rehabilitation Strategic Plan 2024–2029 makes continuous rehabilitation services a priority (MoH, 2024). The National Policy on Disability also supports rehabilitation and participation for people with disabilities (United Republic of Tanzania, 2021). Similarly, Novak et al. (2020), Cieza et al. (2021), and Morgan et al. (2021) all make a point regarding how important regular rehabilitation is for functional development and participation. So, scheduling therapy reliably, making follow-up work well, and coordinating among different service providers are very necessary for improving how continuously rehabilitation goes and how much school children participate.

4.1.4 Distance to rehabilitation centres and ability to obtain rehabilitation services

The distance to rehabilitation centres had a big effect on how caregivers access rehabilitation services for children with cerebral palsy in Iringa Municipality. Caregivers said that travelling took a lot of time, cost a lot for transport, and was physically challenging, especially when the children needed help for transporting them. Long trips made people tired and made them spend more money for going back and forth. Some caregivers decided to cancel or even missed appointments because they did not have enough transport money or found it physically hard to travel. These challenges affected how they could get started and sustain attendance in rehabilitation sessions. The findings show that geographical problems and transportation difficulties limit the regular use of services and break the continuity of rehabilitation for children. An interview with a rehabilitation service provider (Key Informant 07) revealed that:

Distance to rehabilitation centres affects caregivers' ability to attend rehabilitation sessions regularly. Some caregivers travel for a long time before reaching facilities that provide the required services for children with cerebral palsy. The journey can become more difficult when caregivers depend on public transport and travel with children who require physical support. Transport expenses also make repeated visits difficult, particularly when therapy requires regular follow-up. Bringing rehabilitation services closer to communities would reduce the travel burden and improve caregivers' ability to obtain rehabilitation services consistently. (Key Informant 07, Rehabilitation Service Provider, June 2026).

Distance and transport costs also affected regular attendance at rehabilitation services. The rehabilitation service provider explained that long journeys and transport expenses made repeated visits difficult for caregivers, particularly when children required physical support during travel. The problem was not limited to reaching the first appointment because rehabilitation required regular follow-up visits. Frequent travel increased the burden on families and contributed to irregular attendance. Bringing rehabilitation services closer to communities would have reduced the distance and transport burden and strengthened continuity of rehabilitation services. An interview with a social welfare officer (Key Informant 04) revealed that:

Distance remains one of the common concerns raised by caregivers seeking support for children with cerebral palsy. Families living far from rehabilitation centres often delay seeking services because travelling requires considerable time and financial resources. Some caregivers attend the initial assessment but fail to continue with scheduled rehabilitation because repeated travel becomes difficult. This situation affects children's access to rehabilitation as well as other social support services linked to health facilities. Expanding community-based rehabilitation services would reduce these barriers and improve access for many families. (Key Informant 04, Social Welfare Officer, 20 June 2026).

Distance to rehabilitation centres really affected how access was and what continued use of services was for children with cerebral palsy in Iringa Municipality. Long trips and transport costs along with travelling with kids needing physical support caused caregivers to miss appointments or just stop coming regularly. Also, these barriers limited access to social support services too. Tanzania's Health Sector Strategic Plan V talks about promoting equitable access to local services (Ministry of Health [MoH], 2021). The National Rehabilitation Strategic Plan 2024–2029 and the National Policy on Disability also really emphasize improving access for persons with disabilities (MoH, 2024; United Republic of Tanzania [URT], 2021). Iringa Regional Referral Hospital's operational plan points out

specialised services and referrals as priorities. Similarly some studies demonstrated how distance, transport costs, along with unequal service distribution disrupted access to rehabilitation and messed up attendance (Abubakar et al., 2021; Kuper et al., 2022; Olusanya et al., 2022). If community-based services were expanded and centres were spread out more, it might help reduce the burden of travel, and also do better improving continuity of care.

CONCLUSION AND RECOMMENDATIONS

Conclusion

The study concludes that caregivers of children with cerebral palsy in Iringa Municipality face several challenges in accessing rehabilitation services. The major challenges include limited rehabilitation centres, inadequate numbers of trained rehabilitation personnel, irregular therapy programmes, long distances to rehabilitation centres, prolonged waiting times, inadequate rehabilitation equipment and weak coordination among service providers. These challenges increase the time and financial burden on caregivers and make it difficult to maintain regular rehabilitation for children. Therefore, improving the availability, accessibility, capacity and coordination of rehabilitation services is important for enabling caregivers to obtain continuous and appropriate rehabilitation services for children with cerebral palsy.

Recommendations

Iringa Municipality and relevant health authorities should expand rehabilitation services to more accessible health facilities and strengthen community-based rehabilitation to reduce the distance and transport burden faced by caregivers. The authorities should also increase the number of trained rehabilitation personnel, improve therapy scheduling and follow-up systems and strengthen clinic capacity to reduce waiting time and interruptions in rehabilitation. Adequate and appropriate rehabilitation equipment should be provided and maintained to support the different needs of children with cerebral palsy. In addition, rehabilitation centres, health facilities, social welfare offices and other relevant service providers should strengthen referral and information-sharing mechanisms to improve coordination and continuity of rehabilitation services. These measures would reduce the barriers faced by caregivers and improve access to regular rehabilitation services for children with cerebral palsy in Iringa Municipality.

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