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Experiences of Parents of Children with Physical Disability on Physical Rehabilitation Services at the University Teaching Hospital of Butare (CHUB): A qualitative Study, 2024

Peter Mooni Nyangezi[1,*], Joseph Nshimiyimana[1], Divine Girizina[1], Jean Marie Vianney Iradukunda[1], Philemon Iradukunda[2], Ruth Umutoni[3], Celestin Bigirimana[4]

[1]*Department of Occupational Therapy, School of Health Sciences, College of Medicine and Health Sciences, University of Rwanda, Kigali-Rwanda*
[2]*Department of Medical Imaging Sciences, School of Health Sciences, College of Medicine and Health Sciences, University of Rwanda, Kigali-Rwanda*
[3]*Department of Occupational Therapy, Rwanda Military Referral and Teaching Hospital, Kigali, Rwanda*
[4]*Department of Occupational Therapy, University Teaching Hospital of Kigali, Kigali, Rwanda*

***Corresponding author:**
Peter Mooni NYANGEZI

Department of Occupational Therapy, School of Health Sciences, College of Medicine and Health Sciences, University of Rwanda, Kigali-Rwanda

Email: moonipeter500@gmail.com

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ABSTRACT

INTRODUCTION: Access to rehabilitation services is essential for improving functional outcomes and quality of life among children with physical disabilities. In Rwanda, however, families often face multiple barriers when seeking these services, and evidence on caregiver experiences remains limited. This study aimed to explore the lived experiences of parents of children with physical disabilities regarding access to and utilization of rehabilitation services at the University Teaching Hospital of Butare (CHUB).
METHODS: A qualitative phenomenological design was employed. Ten mothers of children with physical disabilities who had attended rehabilitation services for at least five months were purposively selected. Data were collected through in-depth, semi-structured interviews conducted in Kinyarwanda and later translated into English. Audio-recorded interviews were transcribed verbatim and analyzed using Braun and Clarke's six-phase thematic analysis approach.
RESULTS: Three main themes emerged: barriers to accessing rehabilitation services, rehabilitation outcomes, and parental adaptability and experienced burden of disability. Key barriers included high transportation and treatment costs, long distances to services, limited awareness, health system constraints, and social stigma. Despite these challenges, parents reported improvements in their children's physical and emotional functioning following rehabilitation. Caregivers also demonstrated resilience, drawing support from peer interactions and gradually adapting to their caregiving roles. However, significant economic strain, caregiving stress, and disruptions to family life were consistently reported.
CONCLUSION: Parents of children with physical disabilities in Rwanda face substantial financial, structural, and social barriers to accessing rehabilitation services. Strengthening decentralized services, improving community awareness, and enhancing financial protection mechanisms are critical to improving equitable access and outcomes.

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INTRODUCTION

Disability is a profound global public health issue that touches nearly every community worldwide. More than one billion people, approximately one in seven of the global population, live with a disability [1]. This challenge is particularly acute in developing countries, where 80% of people with disabilities reside [1,2]. As the global population ages, this prevalence is projected to intensify, with the number of affected individuals expected to reach two billion by 2050 [2].

The prevalence of disability among children presents a significant concern, especially in Africa and other developing regions. Globally, UNICEF estimated that 236.4 million children aged 0–17 years have moderate-to-severe disabilities [3]. In Africa, disability prevalence is estimated at 10% of the population, a figure that doubles to 20% in impoverished regions [4]. Among children, cerebral palsy (CP) is a major cause of physical disability, with an estimated prevalence of 2 to 2.5 per 1,000 live births across Africa [5]. Despite this, national data on childhood disability in Rwanda remains scarce [6]. While national surveys estimated the overall disability rate at 5% of the population [7,8] the government has initiated programs to address this issue [9], but the capacity for care is severely constrained.

Physical rehabilitation is crucial for promoting functional development and a successful transition to adulthood [10]. However, access to these services is limited, particularly in resource-poor settings. Key barriers include a shortage of trained professionals, with the availability of occupational and physical therapists falling significantly below recommended standards [11]. This functional gap places an immense strain on the healthcare system and has severe consequences for families [12]. The burden of disability on families is often catastrophic, resulting in financial hardship, job alterations, and psychological stress for caregivers, especially mothers [13]. Families seeking care also face substantial barriers, including a lack of knowledge about available services [14], high costs, and long distances to facilities [15]. Despite increasing recognition of the importance of rehabilitation services for children with physical disabilities in Rwanda, there is limited evidence on the lived experiences of parents and caregivers navigating these services. Understanding these experiences is essential for improving service delivery and addressing barriers to care. In Rwanda, there is a critical lack of evidence on pediatric rehabilitation services and their local impact, leading to limited knowledge on people's perceptions of the rehabilitation services they receive [16]. Thus, this study aims to examine parents' perceived knowledge of rehabilitation services for children with physical disabilities in Rwanda.

METHODS

Study design

This study utilized a qualitative phenomenological design to explore the experiences of parents of children with physical disabilities on physical rehabilitation services being received at CHUB.

Study Setting

This study was conducted at the University Teaching Hospital of Butare (CHUB), situated in the southern province of Rwanda, specifically in the Huye district and Ngoma sector. This teaching hospital provides physical rehabilitation services to the surrounding region and referral population. The number of people living nearby who need rehabilitation services, and those living in its coverage area, are referred to this hospital for rehabilitation and other specialty services, as it is a teaching hospital where experts specialize and teach university students.

Study population

Participants included parents and caregivers (all female, mothers) of children with physical disabilities who attended the physical rehabilitation at CHUB. A child whose parents were included in this study had to be at least not old than 12 years of age and attend rehabilitation services for a minimum of 5 months for the parents to be included in the study.

This was to ensure that participants had sufficient experience with the rehabilitation services and could provide accurate and detailed information about the impact of these services on their child's physical disability.

The study excluded individuals/participants whose children had other types of disabilities, such as multiple disabilities, and parents/caregivers of children who had not attended services for at

least 5 months to rule out potential bias in data collection that could influence the findings.

Sampling strategy and sample size

A non-probability purposive sampling technique [17] was used. Participants were purposively selected, mothers of children with physical disabilities attending rehabilitation services for at least five months. A total of 10 participants were recruited. Recruitment continued until thematic saturation was achieved. There was no existing themes or subthemes or existing insights whose related questions could affect participants in answering the study question.

Data collection methods

In-depth semi-structured interviews were conducted using a designed interview guide. This guide was developed by the study team in alignment with the study's objectives, informed by a thorough review of relevant literature and the researchers' expertise in physical rehabilitation. Its primary purpose was to explore participants' perceptions and lived experiences regarding the physical rehabilitation services provided to their children with physical disabilities.

To ensure trustworthiness, the interview guide was piloted with three individuals who were not part of the main study. This pilot phase demonstrated that the guide was efficient in eliciting the intended information and allowed for minor adjustments to enhance its relevance and flow.

Data collection procedures

Following approval of the study by the University of Rwanda Institutional Review Board and the University Teaching Hospital of Butare (CHUB), the researcher contacted the Head of the Department of Functional Rehabilitation and Workshop. This departmental leader played a key role in facilitating access to eligible study participants.

All interviews were conducted by the principal investigator, a trained healthcare professional with prior experience in qualitative interviewing. Data were collected using semi structured interviews conducted in a private consultation room. Interviews lasted 45–60 minutes, were conducted in Kinyarwanda, and audio recorded with participant consent. Field notes were taken to capture non-verbal cues and contextual observations.

Data Analysis

Audio recordings were transcribed verbatim and translated into English by the principal investigator, who is fluent in both languages. Themes were derived inductively from participant narratives. To ensure accuracy, the transcripts were carefully compared with the original audio files. To ensure accuracy, translated transcripts were cross-checked against original recordings.

Data were managed using ATLAS.ti version 24 (Scientific Software Development GmbH version 24) to facilitate systematic data analysis.

The data were analyzed using the principles of thematic analysis, following Braun and Clarke's six phase approach [18], whereby themes emerged directly from the data rather than being predetermined:

Familiarization: Members of the study team thoroughly read and re-read the transcripts to immerse themselves in the data.

Initial coding: The team generated preliminary codes to capture key features of the data.

Searching for themes: Codes were organized into potential themes based on patterns and relationships.

Reviewing themes: Themes were refined and validated against the dataset to ensure coherence and relevance.

Defining and naming themes: Clear definitions and labels were assigned to each theme and subtheme.

Reporting: The final themes were used to structure the findings and facilitate meaningful interpretation.

Trustworthiness of the study

To ensure data reliability, trustworthiness was established through credibility, confirmability, transferability, and dependability. Credibility was strengthened by supporting themes with verbatim participant quotations and conducting peer discussions with qualitative research experts. Confirmability was enhanced by maintaining objectivity during data analysis. Transferability was supported through detailed descriptions of the study setting, participant selection, data collection, and analysis procedures. Dependability was ensured through a systematic code-recode procedure to maintain consistency during analysis.

Ethical Considerations

Ethical approval was obtained from the University

of Rwanda College of Medicine and Health Sciences Institutional Review Board (Ref: CMHS/IRB/517/2023). Permission to conduct the study was granted by the University Teaching Hospital of Butare, CHUB management (Ref: CHUB/DG/NC/12/2858/2023), with approval notice (No: REC/UTHB/103/2023). Written informed consent was obtained from all participants; for those unable to read, information was read aloud, and consent was confirmed by signature. Participation was voluntary, and participants could withdraw their consent at any time; confidentiality was maintained throughout the study.

RESULTS

Participant's Demographics and Socio-economic profile

The study included 10 participants, all of whom were mothers and primary caregivers of children with physical disabilities. No male caregivers were included in the final sample. Their ages ranged from 25 to 43. Participants were formally employed but also engaged in small household businesses, farming, or other agricultural activities to earn a living.

Although the inclusion criteria allowed children up to 12 years old, all children in the study were younger than 5 years old. This limited age representation may restrict the transferability of findings, as parents of older children may experience different rehabilitation challenges, including schooling, long-term care planning, and social integration.

The 10 children with physical disabilities ranged in age from 1 year and 3 months to 4 years old. The diagnoses included Cerebral palsy (n=6), Down syndrome (n=3), and Erb's palsy (n=1).

All participants reported having accessed general healthcare services for their children at health centers. Six children had attended rehabilitation centers before being referred to a University Teaching Hospital in Butare, while four began rehabilitation at a referral hospital via an internal transfer. Of all the children, only one was enrolled in preschool or kindergarten.

Themes and Sub-themes

Table 1 organizes the findings from the semi-structured interviews, highlighting the main themes and sub-themes that emerged from participants' experiences with physical rehabilitation services for their children with physical disabilities.

During in-depth semi-structured interviews, participants were asked about their perceptions and experiences of physical rehabilitation services for their children with physical disabilities. Three main themes emerged: barriers to accessing rehabilitation services, rehabilitation outcomes, and parental adaptability and experienced burden. These themes were further divided into related sub-themes. Theme 1: Barriers to Accessing Rehabilitation Services resulted in 4 sub-themes: cost of transportation and treatment, Structural and system-related barriers, limited knowledge of service availability, and social stigma. Theme 2: Rehabilitation outcomes, merged into three subthemes: improved physical and emotional abilities; acceptance, adaptability, and resilience; and Peer connection and support. Lastly, theme 3: Parental adaptability and experienced burden

Table 1: *Identified themes and subthemes from interviews conducted*

Themes	Sub-themes
Barriers to Accessing Rehabilitation Services	High cost of transportation and treatment
	Structural or system related barriers
	Limited knowledge of the availability of the services
	Social stigma
Rehabilitation Outcomes	Improved Physical and Emotional abilities
	Acceptance, Adaptation and Resilience
	Peer connection and Support
Parental adaptability and experienced burden of disability	Parenting stress and scheduling difficulties
	Economic burden and its Impact to Family Life

of disability, resulted in two subthemes, which include Parenting stress and scheduling difficulties, and Economic burden and family dynamics.

Barriers to Accessing Rehabilitation Services: This theme captures structural, financial constraints, transportation challenges, long waiting times, limited awareness, and social stigma as the major barriers.

1. High cost of transportation and treatment: Parents reported significant costs, including medical expenses and high transportation fares, which were often prohibitive.

"*It has greatly affected our family financially. We struggle to find money for twice-weekly appointments, and transport and service costs are exhausting our family economy. We have no choice because helping our child is a priority, and even his siblings are affected.*" (P10)

Financial strain was the most significant barrier. Parents reported prohibitive costs for treatment and high transportation fares due to long travel distances

"*The hospital is far, and we must walk long distances, which is very costly. The expenses are overwhelming and leave the family in poverty because the child requires constant assistance."* (P02)

"Transport cost is a major barrier. Sometimes I postpone appointments because I cannot afford the fare, even though my child needs treatment." (P08)

2. Structural or system-related barriers: There are several reasons why some mothers or family's experiences difficulties to sending their children with disabilities (CWD) to rehabilitation centers or hospitals for treatment. Challenges included long waiting times due to limited staff and an inadequate referral system where primary health centers lacked knowledge about CWD conditions.

"At the health center, they did not understand my child's condition and were reluctant to refer us, which delayed access to proper care." (P01)

"We wait for many hours because there are few therapists, which disrupts my daily responsibilities." (P10)

In a remote village in Rwanda, nestled amidst the rolling hills, accessing even basic healthcare services at a distance can be challenging for residents. With no paved roads leading to the village and public transportation at best, a journey to the health facility or hospital can take hours on foot some mothers recount the struggle of carrying their children on their backs, navigating steep and rocky paths to the bus stop to take children to the hospital.

"Reaching the hospital is difficult due to long distances and lack of transport, making access to care very challenging." (P02)

3. Limited knowledge of the availability of the services: This was also reported as a barrier to accessing the rehabilitation services as the essential need for CWD due to lack of information on service availability as narrated by some of the participants.

"We did not know what rehabilitation was or how it could help our child, which delayed seeking care." (P09)

"I can't explain how rehabilitation helped us even our mental health was not good before we had no hope but now, we have testimonies. Many parents in the village do not believe rehabilitation works and do not bring their children for treatment because they lack information." (P07)

4. Social stigma: Societal judgments and negative attitudes towards disability from others were also reported as main challenges affecting access to care as the main contributing factors to the stigma affecting the families where social discrimination and gossiping false narrations about the families of children with disability led the parents to live hopeless life for the children limit their decision to seek service access.

"When you have a child with a disability, people gossip and say discouraging words to you and your family" P09

"When I started bringing my child, they used to tell my husband that we were wasting time and money, and the child wouldn't improve or get better but we didn't care because we believed our child could be healed here" P07

Participants reported experiencing stigma, discrimination, and negative community attitudes toward their children's disabilities. Mothers described being subjected to gossip, blame, and

harmful societal beliefs linking disability to moral wrongdoing or punishment. These experiences affected their emotional well-being and willingness to seek services. One participant explained:
"People spread negative rumors, blaming my child's disability on my behavior and calling it God's punishment, but I was not affected because I knew I was not guilty." (P06)

Rehabilitation outcomes

1. Improved Physical and Emotional abilities: Rehabilitation services have significantly improved the child's condition including physical and emotional well-being, and participants reported tangible, positive changes in their children, serving as a powerful motivator.
"My child has improved emotionally and physically. He can now stand, hold objects, and express happiness." (P09)
"My child is happier now. He interacts more, laughs, and shows improved physical movements." (P01)

2. Acceptance, Adaptation and Resilience: The rehabilitation services have positively impacted the well-being of both children as beneficiaries as well as their families especially their mothers as their everyday caregivers, majority of the parents/mothers of children with disabilities in the interview narrated personal improvement resulting from the service given to their children. The service experience facilitated personal growth, improving parents' commitment to care and acceptance of the child's condition.
"Seeing other children and sharing experiences with parents and therapists helped me accept my situation and realize I was not alone. Rehabilitation requires sacrifice, but I am committed because it helps my child improve" P05
"Sharing experiences with other parents gives me strength, hope, and emotional support. If my heart is down, I call one of the parents we talk and counsel each other and then life goes on" P10

3. Peer connection and Support: Despite a child's disability being a catastrophic and challenging factor to parents and families in general, parents of children with disabilities' connection and sharing stories and testimonies at the hospital waiting for the services has built a bridge of hope and resilience in their lives.
"Hearing testimonies and sharing experiences with other parents gave me strength, healed me emotionally, and helped us build confidence and hope. When I feel down, I talk to other parents and we support each other." (P10)
"Meeting other parents and sharing experiences helped me feel supported and build resilience." (P07)

Parental adaptability and Experienced Burden of disability

Parenting stress and scheduling difficulties: The study revealed that these parents experience elevated levels of stress because of the intricacies involved in caring for a child with special needs. Complex appointment schedules frequently forced parents to neglect other essential obligations, elevating stress levels

"Appointments disrupt my daily responsibilities, but I must prioritize my child's care. I carry her everywhere because she needs constant support." (P10)
"My other child is also affected because I must leave her with neighbors during appointments, and I worry about her care and schooling." (P07), "Attending appointments affects my ability to work and support my family, but I sacrifice everything for my child." (P06)

Economic burden and its Impact on Family Life: The financial strain exhausted family resources, impacting the entire family system, including siblings. Family dynamics inevitably undergo significant shifts as parents navigate new challenges, redefine roles, and build stronger bonds with their children.
"Coming for rehabilitation is costing and has affected my family's economy because when I come for an appointment means I don't go to work... and other responsibilities are kept on pending..." (P08)
"The cost of services has greatly affected our family's economy because we receive no financial support. Transport alone was very expensive, placing a heavy burden on us." (P07)

DISCUSSION

Access to rehabilitation services is a critical determinant of health and quality of life for children with disabilities and their families. This

study explored the lived experiences of parents of children with physical disabilities receiving rehabilitation services at CHUB, highlighting key barriers, outcomes, and coping mechanisms. The findings underscore persistent financial, structural, and social challenges that limit access to care, while also revealing parental resilience and adaptive strategies.

Financial constraints emerged as the most significant barrier to accessing rehabilitation services. Participants consistently reported that the cost of transportation and treatment posed a substantial burden, particularly due to long travel distances and frequent appointments. These findings align with previous studies indicating that financial hardship is a primary determinant of limited access to rehabilitation services in low- and middle-income settings [19], [20]. Similar evidence from Sierra Leone and other contexts highlights transportation costs and poverty as major impediments to service utilization [21]. In Rwanda, where services are often centralized in referral hospitals, these costs are amplified by geographic and infrastructural challenges, further limiting equitable access.

Structural and health system barriers also played a significant role. Participants described long waiting times, shortages of rehabilitation professionals, and inefficiencies in referral pathways, particularly at primary healthcare levels. These findings are consistent with global evidence showing that limited human resources and weak health system integration constrain rehabilitation service delivery [19], [22]. The lack of knowledge among frontline healthcare providers regarding childhood disabilities and referral processes further delays access to care, emphasizing the need for capacity building and system strengthening. Additionally, the absence of rehabilitation services at decentralized levels forces families to travel long distances, increasing both financial and time burdens. This supports prior findings that inadequate distribution of services is a major barrier to accessibility [23].

Limited awareness of rehabilitation services among parents and communities was another critical barrier identified in this study. Many participants reported delayed care-seeking due to lack of knowledge about available services or misunderstanding of their benefits. This finding is consistent with previous research demonstrating that low health literacy significantly influences healthcare utilization among caregivers of children with disabilities [20]. Cultural beliefs and misconceptions surrounding disability further exacerbate this issue, shaping parental decisions and contributing to delayed or foregone care. These results highlight the need for targeted community awareness programs to improve knowledge and promote early intervention.

Social stigma and negative societal attitudes toward disability were also prominent themes. Participants described experiences of discrimination, blame, and harmful beliefs linking disability to moral or supernatural causes. Such stigma not only affects caregivers' psychological well-being but also discourages them from seeking care. These findings are consistent with existing literature showing that stigma contributes to social isolation and reduced access to healthcare for families of children with disabilities [24], [25]. Addressing stigma requires broader societal interventions, including community education, advocacy, and inclusive policies that promote acceptance and support.

In addition to barriers, the study identified positive rehabilitation outcomes. Parents reported noticeable improvements in their children's physical and emotional functioning, which served as strong motivation to continue therapy despite challenges. These findings are consistent with evidence demonstrating the effectiveness of rehabilitation interventions in improving functional outcomes and quality of life among children with disabilities [26]. Beyond child outcomes, rehabilitation services also contributed to parental adaptation, acceptance, and resilience. Exposure to rehabilitation environments and interaction with healthcare providers helped parents better understand their children's conditions and develop coping strategies.

Peer support emerged as a critical facilitator of resilience. Parents described gaining emotional strength and hope through interactions with other caregivers facing similar challenges. These informal support networks provided psychological relief and practical advice, reinforcing findings from previous studies that highlight the importance of social support in enhancing caregiver well-being [27]. Such peer interactions may serve as an important, low-cost intervention to improve caregiver experiences and should be considered in program design.

Despite these positive aspects, the burden of

caregiving remained substantial. Parents reported high levels of stress, difficulty balancing caregiving responsibilities with work and household duties, and disruptions to family life. These findings are consistent with studies showing that caring for a child with a disability significantly affects parental mental health, employment, and family dynamics [24], [28]. Economic strain further compounded these challenges, as rehabilitation costs reduced household income and affected the well-being of other family members, including siblings. Similar findings have been reported in other settings, where long-term healthcare expenses lead to financial instability and reduced quality of life [29].

Geographical barriers, particularly in rural areas, further intensified these challenges. Participants described difficulties accessing healthcare facilities due to poor infrastructure and lack of transportation, often requiring long journeys on foot. These findings align with previous research highlighting the role of environmental and infrastructural barriers in limiting access to rehabilitation services [30]. Decentralization of services to community and primary healthcare levels has been widely recommended as a strategy to improve accessibility and reduce costs.

Interestingly, despite the significant challenges identified, parents demonstrated remarkable resilience and adaptability. Many developed coping mechanisms, restructured their daily routines, and maintained strong commitment to their children's care. This contrasts with some literature suggesting that childhood disability may lead to family conflict and dysfunction [23]. Instead, this study highlights the potential for positive adaptation and strengthened family bonds in the face of adversity, consistent with findings from studies exploring parental experiences in similar contexts [27].

The findings of this study have important implications for policy and practice. Addressing financial barriers through social protection mechanisms, such as subsidized transportation or insurance coverage for rehabilitation services, is essential. Strengthening health systems by increasing the rehabilitation workforce, improving referral pathways, and integrating services at primary healthcare levels can enhance accessibility and efficiency. Additionally, community-based awareness programs are needed to improve knowledge, reduce stigma, and promote early care-seeking. Finally, incorporating peer support mechanisms into rehabilitation programs may enhance caregiver well-being and improve overall outcomes.

Strengths and Limitations

This study provides valuable qualitative insights into the experiences of parents of children with physical disabilities in Rwanda, contributing to a limited body of local evidence. However, several limitations should be considered. The study was conducted at a single hospital, which may limit transferability to other settings. The sample included only mothers, excluding perspectives from fathers and other caregivers. Additionally, the small sample size and qualitative design limit generalizability. Future studies with larger and more diverse populations are recommended to further explore these issues.

CONCLUSION

This study demonstrates that parents of children with physical disabilities face substantial barriers in accessing rehabilitation services in Rwanda. Financial limitations, structural constraints in the health system, and social stigma significantly affect access and utilization. Strengthening rehabilitation infrastructure, decentralizing services, increasing workforce capacity, and improving financial protection mechanisms are critical to improving access and outcomes. These findings provide important evidence to inform policymakers, healthcare providers, and stakeholders working to strengthen disability and rehabilitation services in Rwanda and similar settings.

Declarations

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Author's contribution: NPM contributed to the proposal writing, data collection, data analysis and

interpretation and drafting of the manuscript. NJ contributed in manuscript writing, restructuring, rearrangement of results and the visualization and cleaning of the data. JI, IP, GD, RU and CB contributed in manuscript editing and restructuring. All the authors have critically appraised and approved the final version of the manuscript.

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