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Perceptions and Experiences of Caregivers of Children with Cerebral Palsy on Rehabilitation Therapy in Zimbabwe

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Abstract

Purpose: The Children's Rehabilitation Unit (CRU) in Zimbabwe provides rehabilitation services for children with disabilities, including cerebral palsy (CP), through hospital-based care at Sally Mugabe Central Hospital and community outreach. However, caregiver adherence to therapy appointments remains low. This study explored caregivers' experiences and perceptions of CRU rehabilitation programmes and identified barriers and facilitators to adherence. **Materials and Methods:** An exploratory qualitative design was used. Data were collected through telephone interviews with 10 caregivers of children with CP and online in-depth interviews with three key informants. Selected medical-record data were reviewed to describe participant characteristics and service use. Interviews were audio-recorded, transcribed verbatim and analysed using thematic content analysis. **Results:** Caregivers perceived therapy as beneficial, reporting improved motor function, greater child independence and increased caregiver understanding of CP. Barriers to adherence included transport and financial constraints, stigma and discrimination, limited family support, negative health worker attitudes, time pressures and difficulty accepting the child's condition. Key informants largely confirmed these barriers and highlighted gaps in defaulter tracking, staffing and counselling support. **Conclusions:** In this small urban sample, CRU rehabilitation programmes were valued by caregivers but require service-delivery improvements, stronger caregiver-focused support and more responsive provider practices. Addressing social, financial and health-system barriers may improve adherence to rehabilitation therapy for children with CP in Zimbabwe.

Keywords

Cerebral Palsy, Caregivers, Rehabilitation, Adherence, Qualitative Research,

Zimbabwe

1. Introduction

Globally, the prevalence of cerebral palsy (CP) is 2.11 per 1000 live births [1]. Cerebral palsy is the most common condition that causes paediatric physical disability globally [2]. It is described as an array of abnormalities and developmental disabilities that can arise from damage to a child's brain before, during or soon after birth [3]. According to Boyle *et al.* [4], about 0.2% (2 in every 1,000) of children born in the United States (US) had CP, and in the United Kingdom (UK), about 0.25% (one in every 400) children are affected by CP. The most recent studies in Zimbabwe have estimated that the prevalence of CP is about 1.55 per 1000 in rural areas and 3.3 per 1000 in urban areas [5]. Zimbabwe, like most developing countries, has a high prevalence of childhood disability, much of which is preventable. Most of these children with disabilities in Zimbabwe have limited access to treatment and support [6]. Services, when they are available, tend to be concentrated in large urban areas or are provided in institutions operated by non-governmental organisations. It was noted that CP was the most prevalent physical or motor disability in children in Zimbabwe [6]. However, empirical evidence on the caregiver's experience of providing care for a child with a developmental disability in low- and middle-income setting (LMIC) remains limited. Understanding the perceptions and experiences of caregivers of children with CP is essential for planning and developing rehabilitation therapy programmes to suitably address the needs of children with disabilities [7] and for overall programme uptake and sustainability.

Cerebral palsy represents a range of heterogeneous conditions that have developmental, neurological as well as psychological and educational implications [8]. As CP is a lifelong condition, it can pose a burden on parents or caregivers of children with disability, affecting their health and general well-being and quality of life [9]. This is supported by Dambi and Jelsma [10], who noted that long term caregiving leads to strain, and thus there is need to design activities and interventions to reduce the caregiver burden. In Zimbabwe, childhood disability has several social and economic consequences which impact the entire family. In a study by Dambi and Jelsma [10], most caregivers (83%) indicated that the demands of caregiving overburdened them, and these increased with the chronicity of care. Moreover, the study identified common impacts on caregivers to include inconvenience, physical strain, confining, family adjustments, personal plans and work adjustments. The highest number of reported problems were financial strain (74%) and feeling overwhelmed (84%) [10].

The intersection of poverty and disability made it hard for the caregivers to effect changes in their lives because of the training they had received [11]. Poverty was identified as a key barrier to the rehabilitation of children with cerebral palsy in other low-and middle-income countries (LMICs) [11]. Several caregivers in Ethiopia indicated that they had financial difficulties that hindered access to treat-

ment, and this was because they could not get employed as they had to take care of their children with disabilities [12]. Parents in Malawi reported that the cost of taking care of a child with a disability was high, particularly the cost of transport when accessing services [13]. Where rehabilitation services are present, it has been shown that their use is influenced by economic factors such as family income [14]. This was consistent with a study in Zimbabwe highlighting that mothers of children with disabilities struggled to meet their own needs and those of their children as resources were scarce [15].

Discrimination of the child with a disability causes social isolation and brings grief to the mother, which affects her participation in activities [15]. Caregivers in Ethiopia experienced high levels of stigma, which made them feel ashamed about their child's condition, which resulted in them not seeking or attending rehabilitation services [12]. A study in Ghana revealed that stigma was at times so severe that a child with a disability was not thought of as a human being [11]. The same study found that both the child and the caregiver experienced stigma in the home and the community. Fathers were almost always absent in households with children with disabilities.

A study by van der Mark *et al.* [16] in South Africa found that mothers of children with disabilities took care of their children independently, without support from other family members. Only 17% reported receiving assistance from a family member. The mothers indicated that fathers and other family members did not want to associate with a child with a disability.

In an ethnographic study that explored the daily lives of 30 mothers of children with cerebral palsy in South Africa, negative attitudes, and practices on the part of practitioners was a cause of concern. Negative attitudes of service providers were identified as a barrier to healthcare services utilization in a study in Bangladesh [17]. It can be implied from these studies that if health care workers have negative attitudes, it makes the caregivers reluctant to attend therapy sessions.

Carers of children with cerebral palsy may fail to attend therapy sessions due to their demanding life schedules. It has been reported that providing care to children with disabilities is quite time-consuming. Caregivers in Ghana expressed that they were exhausted and had no time because of the demands of taking care of children with cerebral palsy [11]. Because of the restricted time schedules, mothers of children with disabilities sometimes do not seek medical and rehabilitation care and support [15].

Health care workers in Malawi indicated that not much progress would be achieved with children until the parents clearly understood and accepted their child's condition [13]. The health care workers felt that parents who understand their child's condition would be better able to care for the child. Sometimes caregivers believe that their children with cerebral palsy will be healed when they attend therapy, and they get discouraged when their expectations are not met. Research in Malawi revealed that parents or carers had unrealistic expectations about their children getting healed [13]. However conversely, Sinha and Sharma [18] identified expectation of normalcy

as a variable that was a driver of physiotherapy use in Punjab.

The shortage of trained rehabilitation professionals and facilities in LMICs acts as an access barrier for children with cerebral palsy [19]. In Malawi, a few occupational therapists, physiotherapists and speech and language therapists could provide services to children with disabilities affecting service delivery [13]. Government organisations are vital in providing services, but the quality and availability of the services are dependent on the condition of the state and the available disability policies [15]. According to Paget *et al.* [13], barriers to accessing therapy in Malawi included a poor health system. Access to the service, acceptability of services, compliance with the training programme given, and perceived efficacy of the intervention need to be considered when implementing any method of service delivery. A family-centred service is an approach to service delivery that is regarded as the best practice in early intervention and children's rehabilitation [20].

The effectiveness of a particular treatment may depend on patient compliance [21]. Noncompliance can be defined as not adhering to prescribed rehabilitation therapy appointments, educational sessions, or a home exercise programme [21]. Alexandre *et al.* [21] summarised factors that resulted in non-adherence, and these included emotional, behavioural, cultural, social and family-related, disease-related, treatment-related, and organisational and economic.

Several strategies adopted by health professionals were identified by Medina-Mirapeix *et al.* [22] as significant factors that impacted the adherence to therapy. These include providing information about progress, justifying the use of treatments, providing advice regarding exercises into the daily routine, and asking about home adherence. [22]. Other methods of improving compliance for children with developmental disabilities include providing information during clinic visits, advising how to incorporate exercises into the caregivers' daily tasks and routine, and checking the ability of the caregiver to perform exercises and adherence during follow-up [22].

The provision of care within the community as part of an outreach programme may be a better method of service delivery, especially in an environment with limited resources. In Zimbabwe, this community outreach program model has been associated with an increased improvement in physical functioning, better appreciation of services, better compliance, and improved quality of life on the part of the caregivers [10].

2. Conceptual Framework

The conceptual framework for the study (**Figure 1**) was derived from literature review. The framework represents relationships between factors and adherence to rehabilitation therapy sessions.

3. Methods

3.1. Study Design

An exploratory qualitative design was used to understand caregivers' perceptions

and experiences of rehabilitation therapy for children with cerebral palsy and to explore factors influencing adherence to therapy appointments.

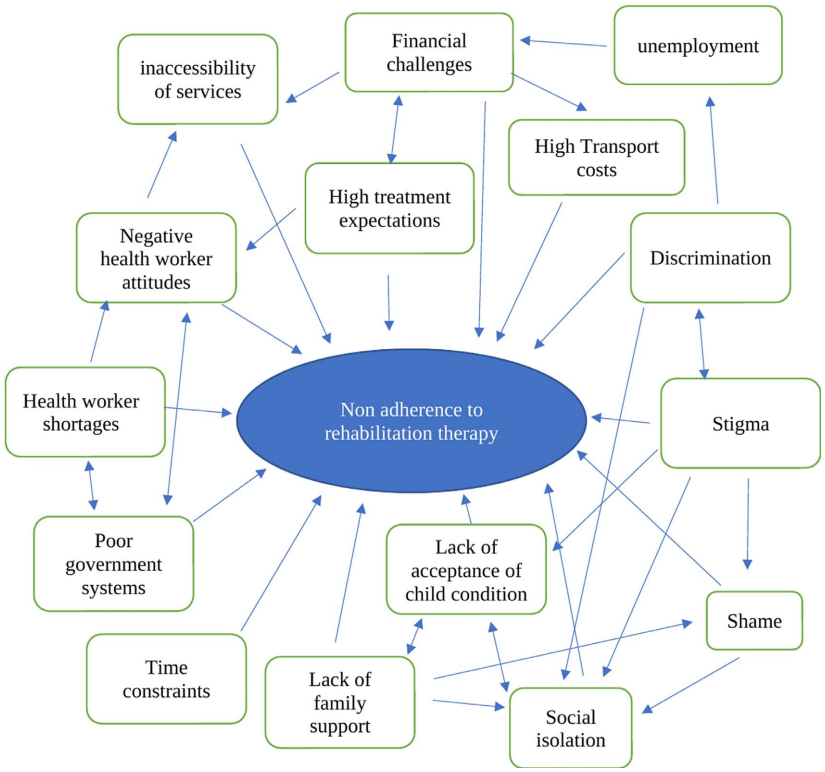

Figure 1. Conceptual framework of the study derived from literature review.

3.2. Study Setting

The study was conducted through the Children's Rehabilitation Unit (CRU) at Sally Mugabe Central Hospital in Harare, Zimbabwe. The CRU has developed and sustained a hospital-based service and a community outreach programme that provide screening, assessment, referrals to specialists, aids and appliances, intervention planning, follow-up at home and in the community, caregiver education and counselling for children with disabilities and their caregivers in Zimbabwe for over 30 years. Caregivers in this study had been assessed and treated through the hospital-based CRU service and were referred to outreach sites in high-density residential areas. Their reported experiences therefore mainly relate to CRU hospital-based care and linked outreach rehabilitation services. CRU clinicians include a neurodevelopmental paediatrician, physiotherapists, occupational therapists, social workers, rehabilitation technicians and a mental health counsellor. The CRU is also an education site for trainees in medicine, paediatrics, physiotherapy, occupational therapy, and the rehabilitation technician program.

3.3. Study Population and Sampling Strategy

The study population comprised caregivers of children with cerebral palsy in Harare who were treated at the CRU in 2019 and referred to three outreach sites in

high-density residential areas.

Purposive sampling was used to select caregivers of children with cerebral palsy from CRU medical records. Recruitment and preliminary analysis proceeded iteratively, with the intention of increasing the caregiver sample if new themes continued to emerge. Three key informants with knowledge of CRU services were identified and all were included in the study.

Recruitment summary: CRU records were screened to identify caregivers who met the inclusion criteria and were reachable by telephone during the study period. Ten eligible caregivers were contacted, all consented and all were enrolled; no contacted caregiver declined participation. Three key informants were invited and all agreed to participate. Data collection stopped after 10 caregiver interviews and three key-informant interviews because the final interviews repeated issues already identified in earlier interviews and no substantively new themes were emerging.

Inclusion criteria: caregivers of children aged 12 years or younger with a documented, confirmed diagnosis of cerebral palsy.

Exclusion criteria: caregivers who did not consent to the study or who could not be reached during the study period.

3.4. Data Collection

A pilot study was conducted to test and refine the caregiver and key-informant interview guides. Participant information sheets explaining the study were sent to caregivers via WhatsApp or text message. The consent form was read to each caregiver and verbal consent was obtained before the interview. Telephone interviews with caregivers were conducted in the local language and audio-recorded using the True Caller™ application. Participant information sheets and consent forms for key informants were sent by email. Key informants were interviewed in English on Zoom and the interviews were recorded. Secondary data were obtained from medical records to complement the interview dataset and describe participant and child characteristics.

3.5. Data Analysis

Interview recordings were transcribed verbatim into Microsoft Word transcripts and analysed using thematic content analysis, informed by Braun and Clarke's approach to thematic analysis [23]. The first author coded the transcripts manually using both descriptive and analytical codes. Codes were grouped into categories and then developed into themes that reflected caregiver experiences, perceptions of rehabilitation therapy and factors influencing adherence. Medical-record data were cleaned and analysed in Microsoft Excel version 16 to describe caregiver and child characteristics, then integrated with the interview findings during interpretation. The medical-record data were used to contextualise and compare the qualitative themes rather than to generate separate statistical findings.

3.6. Trustworthiness

To enhance trustworthiness, transcripts were checked against audio recordings

before coding. The first author undertook initial coding and discussed emerging codes and themes with the second author to support code checking and peer debriefing. Reflexive notes were maintained during data collection and analysis to document assumptions, decisions and the researcher's relationship to the CRU context. Credibility was also strengthened by comparing caregiver accounts with key-informant perspectives and selected medical-record data.

3.7. Ethics

Ethical approval for the study was obtained from the University of the Western Cape Biomedical Research Ethics Committee (Reference BM20/6/11), the Medical Research Council of Zimbabwe (Ref. MRCZ/B/1983) and Sally Mugabe Central Hospital (Ref. HCHEC240820/39). Participants were informed of their right to refuse participation or withdraw from the study at any time. Each participant was assigned a unique identity number to protect anonymity.

4. Results

Ten caregivers participated in the study. All were female and were aged between 22 and 40 years (Table 1). The average number of children per caregiver was two. Nine caregivers had completed secondary education and one had attained tertiary education. Nine caregivers were married or living with a partner, while one was divorced or separated. The sociodemographic characteristics of caregivers are summarised in Table 1.

The results are presented by data source where appropriate. Caregiver findings are reported first, followed by key-informant perspectives and areas where the two perspectives converged or differed.

Seven of the 10 caregivers had two or more children, while three had one child each. All caregivers resided in urban areas.

Most of the children (9) were male and aged between 1 and 3 years (Table 2). Only one child was first seen at CRU after the age of 1 year. Onset of disability was reported to have occurred before 6 months of age in all children. Six children were born at a hospital after referral or transfer. Nine of the 10 children had been admitted to hospital for neonatal seizures, delayed sucking and/or jaundice. Two received phototherapy and one had a blood transfusion. Eight children were diagnosed with CP only, while two had CP with hydrocephalus and epilepsy.

Table 1. Sociodemographic characteristics of caregivers.

Variable	Category	Frequency
Age	20 - 24	1
	25 - 29	1
	31 - 34	3
	35 - 39	4
	41 - 44	1

Continued

Sex	Male	0
	Female	10
Level of education	Primary	0
	Secondary	9
	Tertiary	1
Marital status	Married/living together	9
	Divorced/separated	1
	Never married	0
	Widowed	0
Caregiver status	Both parents	9
	Mother	1
	Father	0
	Other relative	0

Table 2. Sociodemographic characteristics of children.

Variable	Category	Frequency
Sex	Male	9
	Female	1
Age	0 - 12 months	0
	13 - 24 months	3
	25 - 36 months	7
	37 - 48 months	0
Age first seen at CRU	0 - 3 months	2
	4 - 6 months	5
	7 - 9 months	2
	10 - 12 months	0
	13 - 18 months	1
Age at onset of disability	0 - 3 months	7
	4 - 6 months	3
Place of birth	Central hospital	6
	District/Provincial hospital	3
	Urban clinic	1
	Rural clinic/Health center	0
	Home	0
Mode of delivery	Normal vaginal delivery	6
	Breech	2
	Vacuum extraction	0

Continued

	Forceps	0
	Elective caesarian section	2
	Emergency caesarian section	0
Transferred	Yes	6
	No	4

4.1. Caregiver Findings

The caregivers described a range of services provided at the CRU as shown in the following quotes.

"*My child has CP, but he's also developing faster in some regards, so when I go there, he is moved to the next stage, and they make him do exercises*" (22-year-old mother).

Some of the caregivers went further to describe the exercises as physiotherapy or occupational therapy.

"*The child is receiving physiotherapy. It is just that my child's condition is not like that of other children whom I see at the CRU. I can actually say that he is much better and has fewer challenges with his condition.*" (31-year-old mother)

One of the caregivers spoke about the education that they receive at the CRU.

"*…and I'm also getting educated on how to take care of a child with CP.*" (33-year-old mother)

The caregivers mentioned various other activities, which included drawing, play and feeding. These caregiver experiences are summarised in **Figure 2**.

"*They let him draw with crayons, join those plastic fruits, it's a lot of things and other exercises that I'm forgetting …trampoline, where I would jump with him.*" (22-year-old mother)

4.2. Caregivers' Understanding of the Rehabilitation Therapy Programme

"*In addition, if they do these exercises, they will gain some independence and be able to use their hands to do things for themselves. They can feed themselves; or walk alone. It will take time, but it will be helping them.*" (35-year-old mother).

"*So that he can be independent and not be reliant on me at all times.*" (37-year-old mother).

Caregivers reported that the therapy programme improved their children's use of limbs, development and ability to play with other children. One caregiver was uncertain about the purpose of therapy but indicated that she had been advised that her child needed therapy because something was wrong with the child.

4.3. Key-Informant Perspectives

A key informant explained that counselling and education included discussing possible causes of CP with caregivers and linking these discussions to pregnancy, delivery and early childhood history:

"*…we tell them the different causes. We highlight the different causes so that we can also enquire from the client what really happened during the delivery, during the time of pregnancy, what really could have caused the cerebral palsy.*" (Key informant 2, female)

Factors influencing adherence to therapy were grouped into positive experiences that encouraged attendance and barriers that contributed to defaulting.

Among caregivers, adherence to therapy was motivated by perceived improvement in motor function and increased functional independence (**Figure 3**). Eight caregivers reported improvements in their children's physical functioning after therapy sessions. Eight caregivers also reported receiving education on CP at the CRU, including three who received information from medical doctors and five who received information from therapists. Caregivers described this information as useful for caring for the child at home and understanding the condition.

One caregiver appreciated the information and education received at the CRU, particularly when compared with the limited information received at the paediatric clinic. Key informants similarly described education and information sharing as continuous and essential components of rehabilitation.

Two caregivers reported that good service at the CRU encouraged them to adhere to the programme. One caregiver hoped that the frequency of sessions would be increased.

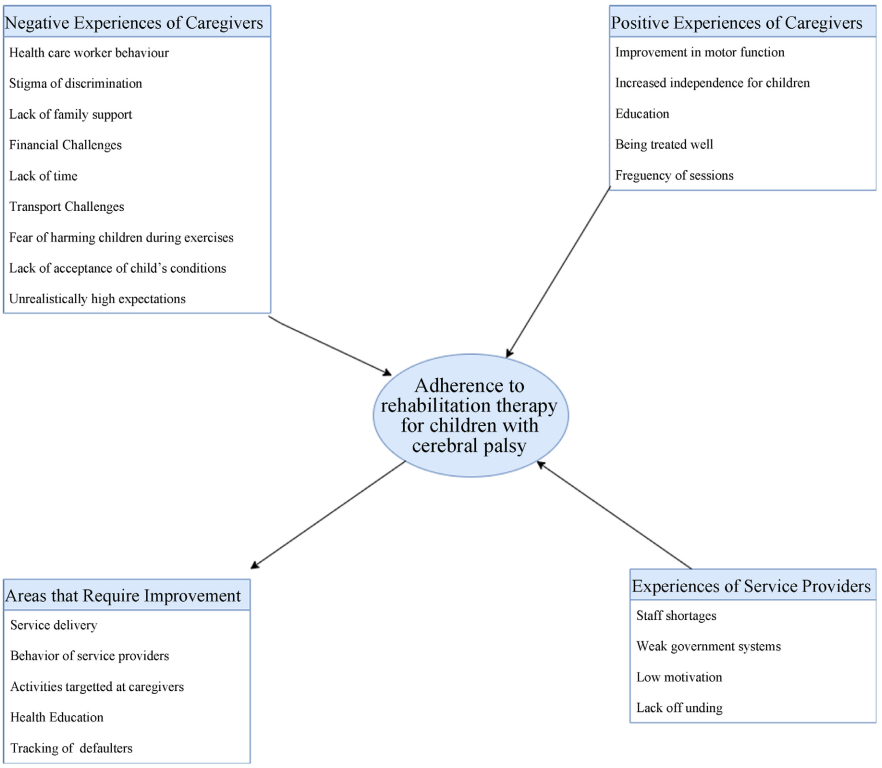

Figure 2. Schematic representation of the experiences and perceptions of caregivers of children with cerebral palsy about rehabilitation therapy.

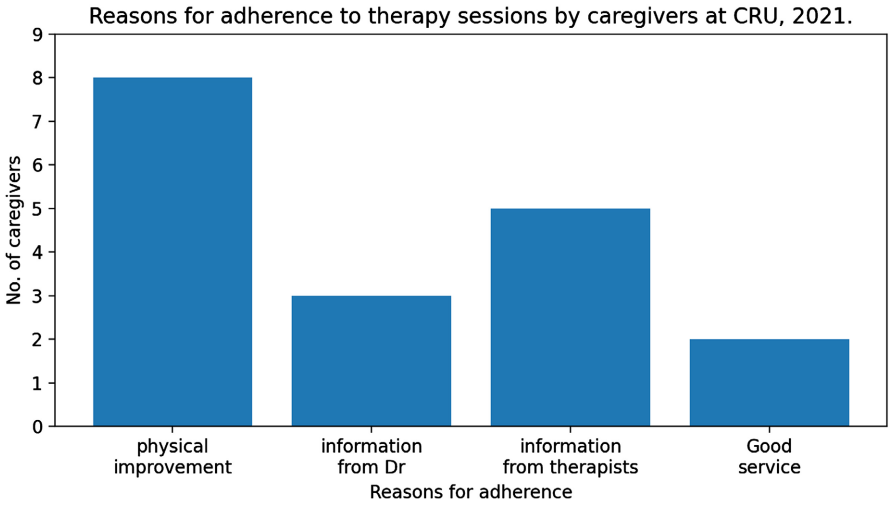

Figure 3. Reported reasons for adhering to rehabilitation therapy sessions at CRU.

The main caregiver-reported reason for defaulting was lack of transport money or transport availability. Three caregivers reported that they sometimes failed to raise enough money for transport to attend CRU sessions. COVID-19 lockdown restrictions created additional transport difficulties because public transport was not available even when caregivers had transport fares.

Negative healthcare worker attitudes were cited by two caregivers as a barrier to attending rehabilitation therapy. Caregivers described feeling scolded when health workers expected more progress with home programmes. One key informant suggested that poor adherence to home programmes could contribute to therapist frustration, while one caregiver explained that nonadherence at home was partly due to fear of harming the child when doing exercises without a therapist present.

Difficulty accepting the child's diagnosis was reported by one caregiver as a reason for nonattendance at CRU. All three key informants also noted that difficulty accepting the child's condition, despite information sharing and counselling, affected adherence to the programme. They linked this difficulty to unrealistic expectations about the progress a child should make after commencing rehabilitation therapy. Key informants reported that counselling was treated as a shared responsibility across staff, although it was primarily led by the counsellor.

Caregivers also described challenges outside the CRU service that affected adherence, including social discrimination, financial difficulties, limited time and unrealistic expectations of therapy outcomes.

Social discrimination was reported by nine caregivers. One caregiver described isolation because family and community members did not want to associate with her and her child. Caregivers and key informants reported that discrimination could be severe enough to affect housing, with some caregivers relocating because landlords or neighbours objected to the child's disability. Constant relocation and stigma contributed to missed therapy sessions. Key informants also noted that discrimination could occur within hospital settings when caregivers sought other

services for their children.

Discrimination sometimes manifested as limited family support. Some caregivers reported lack of support from spouses, in-laws or extended family members, and some linked their child's condition to abandonment or divorce. Two caregivers connected family rejection to traditional beliefs about disability. In contrast, other caregivers described supportive families, although one caregiver was uncertain whether this support would continue as the child grew older. One key informant observed that some families that were initially supportive withdrew support when the child's progress was slow.

Financial challenges were a recurring barrier to accessing therapy. Caregivers described high costs associated with specialised diets, medication for associated conditions and other needs such as diapers and assistive devices. Although most caregivers were not employed, one formally employed caregiver also reported difficulty meeting the costs associated with rehabilitation therapy.

Transport challenges were closely linked to financial difficulties. One caregiver indicated that transport was still manageable because the child was young enough to be carried on her back. Key informants noted that transport becomes more difficult as children grow older and require wheelchairs, because caregivers may need to pay transport costs for both the child and the wheelchair.

Limited time was raised mainly by key informants. They explained that some caregivers struggled to attend rehabilitation sessions because they were trying to earn a living or were overwhelmed by household chores and childcare responsibilities, particularly elderly caregivers.

Overall, caregiver and key-informant perspectives converged on transport costs, financial strain, stigma, limited family support and difficulty accepting the child's condition as important barriers to adherence. The perspectives differed mainly in emphasis: caregivers foregrounded the direct costs, stigma and treatment experiences, while key informants placed more emphasis on caregiver acceptance, home-programme adherence, staffing gaps and defaulter tracking.

Caregivers were asked to suggest strategies that could improve adherence to rehabilitation therapy. Their suggestions were grouped into service delivery, service-provider behaviour, caregiver-focused activities and tracking of defaulters.

Service delivery: Three caregivers felt that the frequency of sessions should be increased to optimise results. One caregiver suggested changing the mode of delivery by using more machines and devices during therapy, while another spoke as if the addition of machines had already occurred. Other suggestions included decentralising the programme to improve access and increasing the number of therapists.

Service-provider behaviour: Caregivers felt that service providers should demonstrate better attitudes, be more patient, treat caregivers kindly and provide care and support. In contrast, one caregiver felt that no change was needed because service providers were already doing a good job.

Activities targeted at Caregivers: Caregivers requested training in income-gen-

erating projects so that they could better meet their financial needs. They also highlighted the need for intensive community education to improve acceptance and reduce stigma. They suggested that fathers and the wider community should be included in education programmes to address myths and misconceptions, increase family support and reduce discrimination. One caregiver recounted how educating colleagues at work made it possible to attend rehabilitation sessions. Another highlighted the need for more counselling because "*a lot of people don't understand the condition*" and caregivers experience high levels of stress.

Defaulter tracking: Key informants described several approaches that CRU had previously used to address nonadherence, including defaulter registers, follow-up phone calls and home visits. However, they reported that these approaches were used inconsistently or had stopped. Home visits were described as particularly effective in the past, but key informants indicated that they were no longer taking place.

5. Discussion

Caregivers of children with CP generally appreciated the purpose of rehabilitation therapy. They cited increased child independence, improved use of limbs, improved child development and the possibility of their children playing with other children as reasons why therapy was important. This appreciation is important because studies have shown that parents who do not understand rehabilitation and their child's condition may participate less fully in rehabilitation, whereas acceptance of the child's condition can support participation [13]. The caregiver findings partly contrasted with one key-informant view that some caregivers adhered to therapy even when they did not seem to recognise its importance.

The comparison between caregiver and key-informant accounts strengthens the interpretation of the findings. Both groups identified transport, financial barriers, stigma and limited family support as barriers to adherence. However, caregivers emphasised lived experiences of cost, discrimination and provider interactions, while key informants emphasised service-system issues such as staffing, counselling, home-programme adherence and defaulter follow-up. This distinction suggests that improving adherence requires both caregiver-centred support and health-system improvements.

Caregivers described several positive experiences with the CRU rehabilitation programme. These experiences can inform service improvements that are more acceptable and sustainable for caregivers. Most caregivers reported improvements in their children's motor function. Similar findings have been reported in Nigeria, where improvements in a child with cerebral palsy facilitated active caregiver participation in rehabilitation therapy [24]. In this study, improved child independence was particularly important because mothers carried a high caregiving burden compared with caregivers of nondisabled children.

Caregivers in this study indicated that the educational support they received at the CRU was vital. A study by Dambi *et al.* [25] found high levels of knowledge

about the causes and prognosis of cerebral palsy among caregivers in Zimbabwe. Educating caregivers of children with cerebral palsy is vital as low levels of knowledge among caregivers compromises the outcomes of rehabilitation for the affected child [26]. A study in Riyadh also showed that lack of education on the child's condition makes it difficult for parents to assist in treating the children. [27]. Vadivelan *et al.* [28] agree to these values of educational support to improve knowledge; they found out that limited knowledge among mothers with regards to caring for their children with cerebral palsy was a barrier to rehabilitation in India. It is therefore crucial for caregivers to have adequate education about cerebral palsy and its prognosis to effectively participate in the therapies their child would be receiving.

A small number of caregivers identified being treated well by service providers as a positive experience that facilitated adherence. When caregivers felt respected and encouraged, they were more willing to continue attending therapy. This is consistent with a Nigerian study that identified empathy and kindness from therapists as facilitators of active caregiver participation in rehabilitation therapy [24].

Caregivers noted the frequency of sessions as a positive experience as they felt that the more sessions they attended, the more their child would improve. A study in Brazil found that parents who participated in regular kinesiotherapy exercises and received guidance on performing exercises at home contributed more to the recovery of the affected children [29]. The parents perceived therapy sessions intensity as directly associated with better outcomes; hence they would also be more involved in regiments where the therapy was frequent. A study in Canada supported this as it found that more sessions, gave caregivers more opportunity to discuss their problems and receive attention for their concerns from health workers [30].

Negative Experiences with the Therapy Programme

Caregivers reported negative healthcare worker attitudes, including being shouted at or scolded and perceiving health workers to be in a bad mood. Such interactions can make caregivers reluctant to attend therapy sessions [17]. Health worker behaviour has been identified as a service-related barrier to rehabilitation access [31]. Key informants explained that caregivers' limited adherence to home programmes could frustrate therapists, but service providers are still responsible for creating a supportive environment where caregivers feel safe to ask questions and continue therapy.

Caregivers experienced stigma and discrimination in the community because their children had cerebral palsy. Caregivers ended up not attending social gatherings and not travelling so they would miss therapy sessions. Some caregivers experienced problems with accommodation and were constantly relocating, which resulted in them missing therapy sessions. These findings were consistent with findings of other studies in Zimbabwe, that caregivers in Zimbabwe frequently face stigma [5]. Caregivers of children with disabilities in Kenya also experienced

stigma and discrimination as they reported feeling blamed and disregarded by others in the community, and that their children were not able to mix with other non-disabled peers [32]. A study in India also showed that mothers of children with cerebral palsy felt "left out and isolated from society" which was consistent with reports from this study [28]. However, stigma was not limited to communities, as indicated by key informants who highlighted that some caregivers even experienced stigma at the hospital when they accessed other services. A study in Zambia showed that caregivers of children with cerebral palsy also experienced stigma from health workers [33]. There is, therefore, need for health education in communities and health facilities to reduce stigma and discrimination.

Some women were abandoned by their partners and highlighted that men did not participate in activities at the CRU. Such findings were like a study in Malawi [13]. In this study, in-laws and extended family were reported as not supportive, which was found in other studies [11]. A study in Nigeria showed that lack of family support was a barrier for caregivers to participate in the rehabilitation programme of children with cerebral palsy [24]. Caregivers in Kenya also reported a lack of family support as one of the socio-economic challenges they faced in caring for children with disabilities [32]. Domenech *et al.* [29] found in a study in Brazil that other family members needed to help with caregiving responsibilities for a child with cerebral palsy to reduce the burden on the mother or primary caregiver. The same study also found that active participation of all family members improved participation in treatment and that family members must be instructed on how to care for the child with cerebral palsy so that they can support the mother to attend therapy and other health services. Lack of spousal support has been found to be a stressor to mothers of children with cerebral palsy, affecting their rehabilitation participation [28]. The lack of family support is likely to result in missed sessions and non-compliance with an exercise programme.

Chiluba and Moyo [33] identified financial strain as a burden faced by caregivers of children with cerebral palsy in Zambia. The caregivers in this study in Zimbabwe indicated the need for walkers, diapers, and specialised diets, which they could not afford. The high cost of medications that their children required to manage conditions like epilepsy was also noted as a challenge. The financial burden of taking care of a child with a disability is usually high even in developed countries, as was found in a study in Canada [30]. It is worth noting that most of the caregivers in this study were not employed, which is consistent with findings in other studies [12]. A study in Nigeria showed that the lack of financial resources for a caregiver of a child with cerebral palsy was a barrier for caregivers to actively participate in rehabilitation therapy [24]. In India, another study found that even where the government provided financial support in the form of welfare for children with disabilities, the amount was insufficient, so caregivers still experienced financial challenges [28]. The intersection of poverty and disability means that more attention needs to be paid to the economic viability of caregivers of children with disabilities. These caregivers are often unable to engage in employment due

to childcare responsibilities, and poverty has been identified as a critical barrier to rehabilitation [11]. A study in Canada also found that the financial burden experienced by caregivers of children with cerebral palsy was due to their reduced ability to work full time due to caregiving responsibilities [30].

Transport challenges were a recurring theme mentioned by caregivers, directly linked to financial challenges. Where rehabilitation services existed, utilisation was influenced by environmental factors such as transportation systems [14]. Caregivers either could not afford transportation fees as they had to pay for themselves and the child's assistive device such as a wheelchair, or transport providers were unwilling to carry wheelchairs in their vehicles. Van der Mark *et al.* (2019) found that caregivers of children with disabilities in South Africa had challenges getting transport to health facilities. Caregivers were thus not able to attend some sessions.

As reported in other studies, caregivers revealed that they were sometimes unable to attend sessions because they were busy with household duties; they were busy fending for their families and the heavy burden of childcare at home, left them feeling overwhelmed [15]. Mothers of children with cerebral palsy have more roles in caregiving than mothers of non-disabled children, a study in Zambia revealed the same [33].

Fear of inadvertently causing harm to their children whilst performing exercises was identified as a barrier to accessing rehabilitation [31]. Findings from this study suggest that caregivers do not get a sound understanding of how to perform the exercises as the health workers display negative attitudes, which may make it difficult to ask questions if a caregiver does not understand. The caregivers lack the confidence to do the exercises at home. This finding is the same as was in a study in Zambia where mothers showed a lack of confidence to carry out the home programme as directed by therapists [33].

Some caregivers expressed difficulty accepting the diagnosis and condition that their child had. Key informants concurred with these findings yet acknowledging that acceptance of a child's condition is vital as not much progress would be achieved until the parents understand and accept their child's condition [13].

The key informants highlighted how caregivers had unrealistic expectations regarding their children's prognosis. This was also noted in a study in Malawi where parents or carers of children often had high hopes that a child would be healed [13]. Health workers in Zimbabwe could benefit from giving as much information and counselling as required to caregivers so that they clearly understand the condition and the prognosis to prevent unrealistic expectations.

In this study, staff shortage was identified as a factor affecting the quality of services provided. It was felt that inadequate staff compromise the quality of the services or sessions given to caregivers and their children. This situation prevails in many low to medium-income countries (LMICs), as shown by various studies [14] [31] [34].

Areas that require improvement on the rehabilitation programmes for children with Cerebral Palsy included service delivery, behaviour of service providers, ac-

tivities targeted at caregivers, and tracking of defaulters.

Service delivery—Several caregivers felt that the frequency of sessions should be increased. Caregivers also suggested that there was a need for more education of fathers and community members so that the myths and misconceptions around cerebral palsy could be addressed. Targeting fathers and community members to address myths around disability was also supported by Peplow and Carpenter [35] and Dambi and Jelsma [10].

The behaviour of service providers—Caregivers felt that service providers should display better attitudes, be more patient and treat caregivers kindly. The caregivers emphasised that they needed care and support, especially bearing in mind their children's condition. Medina-Mirapeix *et al.* [22] identified building rapport with clients, health workers providing information about progress and justifying the use of treatments as factors that improved adherence to therapy. A study in Nigeria showed that encouragement from the therapist who will be treating the child with cerebral palsy facilitated caregivers to actively participate in rehabilitation therapy [24].

Activities targeted at caregivers—In this study, caregivers suggested training on income generating activities for them to be financially independent to meet their needs. A study in Nigeria showed that the low income of caregivers was a burden that militates active participation in cerebral palsy rehabilitation [24]. Financial incentives and health education are "demand-side interventions" that can be targeted at caregivers in low to middle-income countries [31].

Health Education—Caregivers highlighted the need for intensive education targeting the family and communities to reduce stigma and discrimination. A study in Nigeria indicated that caregivers and other family members of children with cerebral palsy needed special training on how to care for the children and that therapists should be available to provide additional help [24].

Tracking of defaulters- It is essential that the use of the defaulter register is resumed, and that clients are followed up through both phone calls and home visits. It is crucial to understand why caregivers stop bringing their children with cerebral palsy for therapy. Active surveillance programs are essential for countries to improve access to rehabilitation [14].

6. Limitations

This study has several limitations. The sample was small, urban and entirely female, and the findings may not represent the experiences of fathers, rural caregivers or caregivers who never reached CRU services. Interviews were conducted remotely by telephone or Zoom, which may have limited observation of non-verbal cues and rapport. The recruitment summary also reflects caregivers who were reachable and willing to participate, so the views of caregivers who had completely disengaged from rehabilitation may be underrepresented. The findings should therefore be interpreted as context-specific qualitative insights rather than generalisable evidence for all caregivers of children with CP in Zimbabwe.

7. Conclusion

This study suggests that caregivers value CRU rehabilitation therapy because they associate it with improved child function, increased independence and greater understanding of cerebral palsy. However, adherence was constrained by transport and financial barriers, stigma and discrimination, limited family support, negative provider interactions, difficulty accepting the child's condition and gaps in defaulter tracking. Within the limits of this small urban qualitative study, the findings point to the need for caregiver-centred counselling, improved provider communication, community education, decentralised or outreach services, and renewed defaulter follow-up. Further research with larger and more diverse samples, including fathers, rural caregivers and caregivers who have disengaged from services, is recommended.

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Data Availability Statement

The data that support the findings of this study are available from the authors on reasonable request.

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The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

Conflicts of Interest

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

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