Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe

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Declaration

"I declare that *Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe* is my own work, that it has not been submitted before for any degree or assessment in any other university, and that all the 89 sources I have used or quoted have been indicated and acknowledged by means of complete references".

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Key words

Adherence

Caregivers

Cerebral palsy

Children

Experience

Harare

Perceptions

Rehabilitation

Therapy

Abbreviations

ACPF	The African Child Policy Forum
COVID-19	Coronavirus disease caused by the SARS-CoV-2 virus
CP	Cerebral Palsy
CRU	Children’s Rehabilitation Unit
KOICA	Korea International Cooperation Agency
LMIC	Low- and middle-income country
MOHCC	Ministry of Health and Child Care
MRCZ	Medical Research Council of Zimbabwe
PedsQL	Pediatric Quality of Life Inventory
UNICEF	United Nations Children’s Fund
WHO	World Health Organisation

Contents

Abstract

Background: The Harare Children's Rehabilitation Unit (CRU) was established to serve the needs of children with disabilities, including those with cerebral palsy (CP) in Zimbabwe. The primary objective of the CRU is to support the Ministry of Health and Child Care policies on hospital-based and community-based rehabilitation. The outreach programme at CRU was created to make rehabilitation therapy services accessible. Despite the services being provided for free, caregivers of children with CP do not adhere to appointments for therapy. This research explored some of the facilitators and barriers to attending rehabilitation therapy.

Aim: The study aimed to explore the experiences and perceptions of caregivers of children with CP regarding rehabilitation therapy programmes provided by the CRU.

Methodology: The study utilised an exploratory qualitative research methodology to explore the experiences and perceptions of the caregivers regarding rehabilitation therapy. Data was collected through telephonic interviews with caregivers and online in-depth interviews with key informants. All data collected were audio-recorded and transcribed verbatim. Data was analysed through thematic content analysis.

Results: Reasons for adherence to therapy programme among caregivers of children with cerebral palsy included improved motor function, increased independence for children, education, being treated well, and increased frequency of sessions. Negative experiences that caregivers have had with the therapy programme included negative health care worker attitudes, stigma and discrimination, lack of family support, financial challenges, transport challenges, lack of time, fear of harming children during exercises, lack of acceptance of child's condition, and unrealistically high expectations. Areas that require improvement on the rehabilitation programmes for children with cerebral palsy include service delivery, the behaviour of service providers, activities targeted at caregivers, improved health education, and tracking of defaulters.

Conclusion: Caregivers of children with cerebral palsy appreciated the purpose of rehabilitation therapy. However, there is a need to improve service delivery, improve the behaviour and attitude of service providers, build resilience amongst caregivers, increase health education to reduce stigma and discrimination, and resume tracking of defaulters.

Chapter 1: Introduction

This chapter provides a background to the study, presents the problem statement and the purpose of the study. It concludes by giving a synopsis of the rest of the study report.

1.1 Background

It is estimated that 90 to 100 million children aged 14 years or younger worldwide live with moderate to severe disabilities. Ninety five percent of the 56 million children under five years with developmental disabilities live in low- or middle-income countries (LMIC) (WHO, 2011). As the under-five survival increases worldwide, there has been a growing recognition of the importance of the quality of that survival and a new focus on the epidemiology of and interventions for developmental disabilities in LMIC, where previously child survival had taken precedence (Olusanya et al., 2018). Cerebral palsy is one such condition with complex developmental significance.

Globally, the prevalence of cerebral palsy (CP) is 2.11 per 1000 live births (Oskoui et al., 2013). Cerebral Palsy is the most common condition that causes paediatric physical disability globally (Gagliardi et al., 2008). 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 (Aisen et al., 2011). According to Boyle et al. (2004), 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 (Dambi et al., 2015).

Zimbabwe has a high prevalence of childhood disability, much of which is preventable. Such is the case in most developing countries. The majority of these children with disabilities in Zimbabwe have limited access to treatment and support (Ministry of Health and Child Care, 2013). Services, when they are available, tend to be concentrated in large urban areas or are provided in institutions operated by non-government organisations. The Living Conditions Among Persons with Disability Survey (2013) found that 7% of Zimbabwe's population (13 million people) had disabilities, and more than 600 000 of them were children (MoHCC, 2013). It went on to note that CP was the most prevalent physical or motor disability in children in Zimbabwe. Socioeconomic indicators revealed a higher dependency ratio and lower possession scale in families that included a person with a disability (MOHCC, 2013). Although the survey provided some insight into the living conditions of persons with disabilities in Zimbabwe, it did not explore the lived experience of direct caregivers of children with developmental disabilities in this setting.

The African Report on Children with Disabilities notes in one of their key findings that the dual combination of stigma and discrimination negatively impacts all families of children with disabilities (ACPF, 2014). 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. This paucity of research evidence is even more pronounced regarding the experiences of caregivers for children with developmental disabilities in urban/peri-urban Zimbabwe. This dearth of research, particularly concerning Zimbabwean children with disabilities, presents a dire situation for the most marginalised and mistreated members of Zimbabwean society, further impacted by deep-rooted stigma (van der Mark and Verrest, 2014).

1.2 Problem Statement

While programmes for children with disabilities in various African countries such as Nigeria, Ghana, Ethiopia, Tanzania, South Africa and Kenya focus purely on medical aspects of disability (Donald et al., 2014), the CRU, which builds on 30 years of experience working on disability, has developed a holistic approach which seeks to address the dynamic needs of these children and their caregivers (Jelsma et al., 1995). This approach is premised on the realisation that the impact of having to provide care for a child with a severe disability often has profound and pervasive effects on the social and economic well-being of the entire family (UNICEF, 2011).

The CRU has maintained a database of all children with disabilities receiving services in the unit since 1986. This has provided valuable information on the patterns of disabilities in Zimbabwe and shows that the most prevalent form of disability presented at the CRU is CP (Jelsma et al., 1995). The database also indicates a significant number of caregivers of children with CP who default from the therapy programme. However, the perceptions and experiences of caregivers of children with cerebral palsy have not been investigated in this programme. Understanding the perceptions and experiences of caregivers of children with CP is essential for planning and developing rehabilitation therapy programmes in order to suitably address the needs of children with disabilities (Kamenov et al., 2019) and for overall programme uptake and sustainability.

1.3 Purpose

This study explored the experiences and perceptions of caregivers of children with cerebral palsy and how they influenced adherence to rehabilitation therapy programmes offered by the CRU. The information generated from this research may be used to improve the programme's design so that caregivers’ adherence to the therapy programme can be improved, which may result in better functional outcomes for children with CP.

1.4 Study setting

All study activities occurred at the Children’s Rehabilitation Unit (CRU) at Sally Mugabe Central Hospital (formerly Harare Central Hospital) in Harare, Zimbabwe. The CRU opened in 1986 and has been continuously operating, with the exception of a COVID-19 related closure in March-August 2020. The CRU serves urban and peri-urban Harare with free developmental, diagnostic and therapeutic services at a main urban clinic and 13 community outreach sites.

The CRU has been able to develop and sustain an innovative hospital and community-based programme which has provided a range of services for children with disabilities and their caregivers in Zimbabwe for over 30 years. The CRU attends to children with different disabilities. The unit also provides screening, assessment, referrals to other specialists, aids and appliances, appropriate intervention plans, follow-ups at home and in the community, education to caregivers/parents and counselling. CRU clinicians include a neurodevelopmental paediatrician, physiotherapists and occupational therapists, social workers, rehabilitation technicians, and a mental health counsellor. Diagnostic and therapeutic services are available in all these areas of expertise. The CRU is also an education site for trainees in medicine, paediatrics, physiotherapy, occupational therapy, and the rehabilitation technician program, whose trainees are deployed to district hospitals and bring their skillsets to rural Zimbabwe.

The programme is family-focused and has provided training and support to caregivers which address broader social and economic effects of childhood disability on the family as a whole.

Despite the programme’s holistic approach, there have been problems with non-adherence to therapy by caregivers.

1.5 Outline of this report

This study has six chapters. Chapter one sets the scene for the study. Chapter two presents a review of the literature associated with caregivers’ perceptions and experiences of rehabilitation therapy for children with cerebral palsy. The third chapter details the study methodology. Chapter four outlines the study findings. The fifth chapter presents a discussion of the study findings. Chapter six highlights the conclusion and suggests recommendations for research, training and practice drawn from the study.

Chapter 2: Literature Review

2.1 Introduction

The most common cause of childhood disability is cerebral palsy, with a prevalence of 2 to 2.5 per thousand live births globally (Donald et al., 2015). Cerebral palsy represents a range of heterogeneous conditions that have developmental, neurological as well as psychological and educational implications (Moster et al., 2010). Cerebral palsy is defined as an impairment of both movement and posture resulting from a non-progressive brain disorder due to events during pregnancy, delivery, early childhood, or hereditary factors (Aisen et al., 2011). Most disabilities are attributable to preventable factors reflecting a lack of access to quality antenatal and post-natal care and general health services.

2.2 Prevalence of Cerebral Palsy

Prevalence of cerebral palsy is higher in low to middle-income countries than in developed countries, with prevalence estimates of 1.5 – 3 per 1000 in developed countries compared to a range of 2 – 10 per 1000 in developing countries (Durkin et al., 2016). In 2017, the prevalence of cerebral palsy in Egypt was estimated to be 2.04 per 1000 live births (Abas et al., 2017). Research in Zimbabwe indicates that the prevalence of cerebral palsy is estimated at 1.55 per 1000 in rural areas and 3.3 per 1000 in urban areas (Dambi et al., 2015).

2.3 Effects of Cerebral Palsy on caregivers

As cerebral palsy (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 (Hamzat & Mordi, 2007). This is supported by Dambi and Jelsma (2014), who noted that long term caregiving leads to strain, and thus there is a 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 (2014), 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%) (Dambi & Jelsma, 2014). Some common challenges faced by caregivers of children with cerebral palsy, as reported in the reviewed literature, are presented below.

2.3.1 Financial challenges

Poverty has been reported as a major barrier by caregivers of children with cerebral palsy in seeking and utilising rehabilitation therapy in Ghana (Zuurmond et al., 2019). Poverty affected the ability of the caregivers to implement the training that they had been given and attend sessions, as they lacked the resources to do so. The intersection of poverty and disability made it hard for the caregivers to effect changes in their lives as a result of the training they had received (Zuurmond et al., 2019). Poverty was identified as a key barrier to the rehabilitation of children with cerebral palsy in other low-and middle-income countries (LMICs) (Zuurmond et al., 2019). Several caregivers in Ethiopia indicated that they had financial difficulties that hindered access to treatment, and this was because they could not get employed as they had to take care of their children with disabilities (Tilahun et al., 2016). Parents in Malawi also noted that the cost of taking care of a child with a disability was high, particularly the cost of transport when accessing services (Paget et al., 2016). Where rehabilitation services are present, it has been shown that their use is influenced by economic factors such as family income (Al Imam et al., 2021). A study in Zimbabwe highlighted that mothers of children with disabilities struggled to meet their own needs and those of their children as resources were scarce (van der Mark & Verrest, 2014).

2.3.2 Stigma and discrimination

Research in Zimbabwe showed that parents or caregivers of children with disabilities frequently face stigma (Dambi et al., 2015). Similarly, Choruma (2007) describes people with disabilities in Zimbabwe as experiencing oppression and discrimination daily. Discrimination of the child with a disability and the mother causes social isolation and brings grief to the mother, which affects her participation in activities (van der Mark & Verrest, 2014). Caregivers in Ethiopia experienced high levels of stigma, which made them feel ashamed about their child's condition, which was likely to result in them not seeking or attending rehabilitation services (Tilahun et al.,2016). A study in Ghana revealed that stigma was so severe that a child with a disability was not thought of as a human being (Zuurmond et al., 2019). 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. Mothers in South Africa revealed that their children with disabilities faced scolding and call outs from extended family and neighbours, which gave the mothers discomfort and emotional pain (van der Mark et al., 2019).

2.3.3 Lack of family support

A study by van der Mark et al. (2019) in South Africa found that mothers of children with disabilities took care of their children independently, without support from other family members. Out of thirty mothers, only five said they received assistance from someone in their family. The mothers indicated that fathers and other family members did not want to associate with a child with a disability. A health worker in Malawi echoed the same by suggesting that it was extremely difficult to get fathers involved in caring for children with disabilities (Paget et al., 2016). Caregivers in Ghana also indicated that family members were unwilling to take care of children with disabilities (Zuurmond et al., 2019). This leaves mothers as the typical caregiver in difficult positions as they have to take care of the child on their own, a situation which may lead to poor adherence with rehabilitative care.

2.3.4 Health care worker behaviour

Negative attitudes and practices by health care workers have been cited as concerns of caregivers of children with cerebral palsy. 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. The mothers were evidenced to lead isolated lives and reported experiences of being treated rudely at hospitals by health care workers (van der Mark et al., 2019). The same was echoed by parents in Malawi who expressed that they and their children faced stigma from health workers (Paget et al., 2016). Health care workers in Malawi indicated that they lacked motivation. Negative attitudes of service providers were identified as a barrier to healthcare services utilization in a study in Bangladesh (Nuri et al., 2020). It can be implied from these studies that if health care workers have negative attitudes, it makes the caregivers reluctant to attend therapy sessions.

2.3.5 Lack of time

Carers of children with cerebral palsy may fail to attend therapy sessions due to their demanding life schedules. It is argued 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 (Zuurmond et al., 2019). A study in Zimbabwe revealed that mothers were busy due to the household duties that they were expected to perform and the time that they devoted to helping their children with disabilities in activities of daily living (van der Mark & Verrest, 2014). Because of the restricted time schedules, mothers of children with disabilities sometimes do not seek medical and rehabilitation care and support (van der Mark & Verrest, 2014).

2.3.6 Transport problems

The transportation of children with disabilities is a problem in low-to-middle-income countries. Mothers of children with disabilities in South Africa cited challenges in accessing public transport for purposes of seeking health services (van der Mark et al., 2019). The mothers mentioned that local minibuses tended to refuse to take wheelchairs on board and hence would not transport them with their children who were using wheelchairs (van der Mark et al., 2019). The transportation problem presented difficulties for the mothers to access services with their children in other low resource settings. Caregivers in Bangladesh also highlighted limited access to transportation services (Nuri et al., 2020). Sinha and Sharma (2017) identified the transportation of the child with cerebral palsy to a physiotherapy centre as a barrier to accessing services in Punjab, even if the services were free.

2.3.7 Lack of acceptance of child’s condition

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 (Paget et al., 2016). The health care workers felt that parents who understand their child’s condition would be better able to care for the child. Paget et al. (2016) further revealed that health workers indicated that caregivers’ lack of insight impacted acceptance of their child’s condition. The health care workers in this study showed that this was evident in the mothers’ claim that they did not know what was wrong with their child even after a health worker had done psychoeducation sessions.

2.3.8 Unrealistically high expectations

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 (Paget et al., 2016). To counter these expectations, the health workers were forced to make sure that they gave as much information as possible. Frustrations among these caregivers were exacerbated when caregivers observed no significant improvement in the child's condition. A development which resulted in caregivers not attending rehabilitation sessions or seeking medical services. It is interesting to note that conversely, Sinha and Sharma (2017) identified expectation of normalcy as a variable that was a driver of physiotherapy use in Punjab. They indicated that caregivers would attend therapy sessions diligently if they thought that the child would be healed.

2.3.9 Shortage of staff

The severe shortage of rehabilitation professionals experienced in many low-and middle-income countries (LMICs) has also been reported as a major challenge (Al Imam et al., 2021). This sentiment was echoed by the WHO (2019), that there were severe shortages of rehabilitation personnel and services. The critical shortage of trained rehabilitation professionals and facilities in LMICs acts as an access barrier for children with cerebral palsy (Jesus et al., 2016).

In Malawi, Paget and colleagues reported the challenge of a few occupational therapists, physiotherapists and speech and language therapists who could provide services to children with disabilities (Paget et al., 2016). Nuri et al. (2020) revealed a shortage of providers of services for children with disabilities in Bangladesh. Zimbabwe is in a similar position, and a study on health-related rehabilitation services revealed that there were only two physiotherapists per 10000 population (Gupta et al., 2011).

2.3.10 Poor government systems

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 (van der Mark & Verrest, 2014). According to Paget et al. (2016), barriers to accessing therapy in Malawi included a poor health system. Similarly, a study in South Africa found that governmental institutions play a crucial role in providing a suitable environment for mothers of children with disabilities to receive professional services (van der Mark et al., 2019). In Zimbabwe, the policy framework was reported to be largely dysfunctional due to the economic challenges and the fact that the government neglects people with disabilities (van der Mark & Verrest, 2014).

While the above sections detail several challenges faced by caregivers, it is worth noting that mothers of children with cerebral palsy in South Africa indicated that they no longer considered their children with disabilities to be a burden, but they derived joy, pride, satisfaction and happiness from their children (van der Mark et al., 2019).

2.4 Management of Cerebral Palsy

Rehabilitation treatment is a critical component of the holistic and multi-disciplinary approach needed to alleviate the problems of children with CP and their families (Aisen et al., 2011). Researchers have not been successful in identifying the most effective mode of service delivery in terms of enhancing the child's potential whilst supporting the carer, especially in low-income countries like Zimbabwe (Dambi & Jelsma, 2014). Issues such as 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 (King et al., 2004).

The use of rehabilitation services has been shown to influence the disability status of a child directly, so it is recommended that children with cerebral palsy must have access to and utilise rehabilitation therapy services (Sinha & Sharma, 2017).

2.5 Compliance to rehabilitation therapy

The effectiveness of a particular treatment may depend on patient compliance (Alexandre et al., 2002). Noncompliance can be defined as not adhering to prescribed rehabilitation therapy appointments, educational sessions, or a home exercise programme (Alexandre et al., 2002). Alexandre et al. (2002) 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 factors have been suggested as being associated with compliance, including but not limited to personality, marital status, family relationships, financial status, religion, race, and the caregivers' attitude towards her child's illness or disability and toward the services that are provided (Galil et al., 2001).

2.6 Strategies to improve adherence to the rehabilitation therapy programme

Several strategies adopted by health professionals were identified by Medina-Mirapeix et al. (2017) 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. These variables increased the odds of the parents adhering to the therapy programme (Medina-Mirapeix et al., 2017).

Peplow and Carpenter (2013) found that exercise programs are often characterised as prescriptive and focused on the child's lack of function or impairment. They suggested that these need to be integrated into a comprehensive approach that considers caregiver, family and child preferences, likely to improve compliance. 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 (Medina-Mirapeix et al., 2017).

In families of children with CP, Raina et al. (2005) suggested additional strategies for supporting caregivers such as behavioural management and activities of daily living and techniques to manage stress. These data support clinical pathways that require psychosocial frameworks that are family centred, not merely technical and short-term rehabilitation therapy exercises focusing primarily on the child.

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 (Dambi & Jelsma, 2014).

There is also evidence urging health care workers to respect caregivers and provide education on causes of the disability and strategies on how to manage the condition to improve insight and service uptake (Tilahun et al., 2016).

2.7 Summary

The literature review sought to provide an overview of the broad range of issues related to the perceptions and experiences of caregivers of children with disabilities in general.

The prevalence of cerebral palsy was described, and the effects of having a child with cerebral palsy were explored with reference to low to middle-income countries (LMICs), which are likely to have similar circumstances with Zimbabwe. The experiences of caregivers with children with disabilities were detailed. The management of children with cerebral palsy was described, and the importance of compliance to a rehabilitation therapy programme was highlighted. Finally, a few strategies to improve adherence to rehabilitation therapy were detailed.

Chapter 3: Research Methodology

This chapter describes the methodology that was used to conduct this research study. The chapter presents the aim and the objectives of the study. The chapter also describes the study design, the population and sampling techniques, methods of data collection and analysis. The limitations of the study are also be described. The chapter concludes with the steps taken to ensure rigour and address ethical issues relating to the study.

3.1 Aim

To explore the experiences and perceptions of caregivers of children with cerebral palsy and how these influence adherence to rehabilitation therapy programmes offered by the Children's Rehabilitation Unit (CRU).

3.2 Objectives

1. To explore caregiver's understanding of rehabilitation therapy programme
2. To explore reasons for adherence to therapy programme among caregivers of children with cerebral palsy
3. To explore the reasons for the non-adherence of caregivers of children with cerebral palsy to the therapy programme.
4. To establish from key informants the reasons for adherence and non-adherence of caregivers of children with cerebral palsy to the therapy programme.
5. To explore caregivers' strategies that could help them adhere to therapy.

3.3 Study Design

The study utilised an exploratory qualitative research methodology. This approach was chosen because the study aimed to gain rich, in-depth knowledge and a deeper understanding of caregivers' experiences of caring for children with cerebral palsy. This approach provided complex textual descriptions of how participants experienced a given research issue (Mack et al., 2005). The explorative qualitative study design that was utilised allowed the researcher to understand how participants felt about the events that they had experienced. Participants could share their personal knowledge and experiences on the research topic through this approach (Neergaard et al., 2009).

3.4 Population and sampling

The study population was caregivers of children with cerebral palsy in Harare who were treated at the Children's Rehabilitation Unit (CRU) in 2019 and referred to three outreach sites in high-density residential areas. In this study, the research defined caregivers as people responsible for the daily care of the children who had a diagnosis of CP, according to their doctors' notes.

Purposive sampling is a technique that employs the deliberate choice of a participant due to the qualities the participant possesses (Etikan et al., 2016). Purposive sampling was used to select the study participants with the desired characteristics, that is, caregivers of children with cerebral palsy. In order to select the caregivers for interviews, medical records of children with cerebral palsy were chosen in the order in which they appeared so that there was no selection bias, and ten primary caregivers of children with CP were selected from the records. The researcher started with ten participants and was open to extending if there were new emerging issues. However, after the ten interviews, there were no further issues that emerged. This is supported by Hennink & Kaiser (2020), who found that even small samples (n = 10) can be sufficient to identify 95% of salient themes.

Three key informants who work at the CRU were also included in the study to provide more in-depth insight into factors affecting adherence and corroborate caregivers' accounts. The following three people were purposively selected for key informant interviews:

1. CRU Administrative Assistant - responsible for arranging outreach schedule and contacting caregivers to attend on specific dates.
2. Physiotherapist - provided direct therapy to children with CP and interacted with caregivers and could shed light on their perceptions and experiences.
3. Social worker - provided psychosocial support and counselling to caregivers, therefore, was likely to know the perceptions and experiences of caregivers.

3.4.1 Inclusion and exclusion criteria

Only caregivers of children up to twelve years of age were recruited as the age at which clients are discharged from the CRU programme is twelve years. Children had to have a diagnosis of cerebral palsy confirmed by a doctor in the doctors' notes.

Children with diagnoses such as "delayed milestones", which are indicative of cerebral palsy but not confirmed as cerebral palsy, were excluded so that we had a homogeneous sample of caregivers of children who had cerebral palsy and no other health conditions.

3.5 Data Collection

A pilot study to test the data collection tools was conducted in December 2020. Data collection took place online and via telephone due to the COVID-19 lockdown restrictions. The researcher interviewed two caregivers and one key informant in the pilot to validate the interview guide for caregivers and the interview guide for key informants, respectively. A PhD student was asked to do the initial coding of two structured interviews from caregivers and one in-depth interview from a key informant. This was compared to the initial coding of the same two structured interviews from caregivers and one in-depth interview from a key informant that the researcher did. The researcher excluded the responses from the pilot in the study results.

Interviews for the main study were conducted in Harare in March 2021. Interviews were conducted over the phone with the ten caregivers. Three key informants were purposively selected and interviewed online for purposes of triangulation in order to "increase the understanding of complex phenomena" (Malterud, 2001:487). The caregiver telephone interviews were audio-recorded using the True Caller™ application, and key informant interviews were recorded on Zoom to ensure that the data collected was accurate and complete (Robson, 2011). Key informants were sent participant information sheets that detailed the research (Appendix 2) via email, and caregivers were sent participant information sheets (Appendix 1) via WhatsApp or text message. Key informants were sent consent forms (Appendix 5) via email, and they were asked to read and sign the consent forms and send them back to the principal investigator. Caregivers had the consent forms (Appendix 6) read to them over the phone, and they were asked to provide verbal consent if they agreed to participate in the study. The participant information sheets, consent forms and interview guides for caregivers were translated into the local language (Shona) (Appendices 3, 6 & 8) so that the caregivers could understand and voluntarily participate. The participant information sheets, consent forms and the interviews for the ten caregivers were administered in Shona. Participant information sheets, consent forms and interview guides for the key informants (Appendices 2, 5 & 9) were administered in English.

3.6 Data Analysis

Thematic analysis was used for data analysis. After the interviews, all interview recordings were transcribed verbatim into Microsoft Word transcripts. The researcher familiarised himself with the data by reading and re-reading the interview transcripts and fieldwork notes (Maguire & Delahunt, 2017). The data were coded manually by the researcher by writing down the codes on the margins of the interview transcripts (Braun & Clark, 2006). The coding was descriptive and analytical. The codes were examined and categorised, and themes were identified (Maguire & Delahunt, 2017). The researcher reviewed the themes and refined them so that they were coherent and gave a true reflection of the whole data set (Braun & Clark, 2006). The data was then interpreted to explain caregiver experiences and perceptions, as well as to answer why caregivers adhered to or failed to comply with the therapy programme.

3.7 Rigour of the study

Rigour was ensured through the researcher asking his colleague to independently code selections of the data and come up with themes for analysis to limit his own biases. Mrs Jacqueline Maguranyanga is a PhD student, and she assisted in the coding of the data. She did the initial coding of two structured interviews from caregivers and one in-depth interview from a key informant. This was compared to the initial coding of the same two structured interviews from caregivers and one in-depth interview from a key informant that the researcher did. We compared our codes, discussed them, and modified them before the researcher continued the data analysis (Moira & Delahunt, 2017).

The researcher ensured the trustworthiness of the research through various methods.

Credibility, which was achieved by*:*

Triangulation of data sources and methods: The utilisation of various data sources countered threats to internal validity (Robson, 2011). Data was collected from caregivers using interviews. In addition, key informants were selected for in-depth interviews for purposes of triangulation which aimed "to increase the understanding of complex phenomena" (Malterud, 2001:487).

Transferability was achieved by:

Providing a 'thick description': It is the responsibility of the researcher to provide a 'thick description' of the participants and the research process so that the reader can ascertain whether or not the findings will be applicable or transferable to their setting; this is transferability (Korstjens & Moser, 2018). The researcher gave a detailed description of the research methodology to enable other researchers to replicate the study in a different context with different respondents.

Conducting theoretic and purposive sampling: The researcher only selected respondents who were knowledgeable on issues of cerebral palsy and connected to the Children's Rehabilitation Unit (CRU).

Dependability was achieved by:

Audit trail: The researcher maintained an audit trail; he kept a record of all the activities conducted during the research, including the raw data, coding and data analysis, to reduce the threat of researcher bias (Robson, 2011). Robson (2011) notes that an audit trail enhances reliability by showing that the researcher has been thorough, honest and meticulous in carrying out the research.

Reflexivity: A researcher's background can affect what they decide to investigate, methods used, which findings are appropriate and how the conclusions are communicated (Malterud, 2001). A personal value system may be a threat to validity (Robson, 2011). The researcher's background as an Occupational Therapist meant that the researcher held therapy in very high regard as a form of addressing the needs of children with CP, but this may not have been the case with the caregivers. To ensure reflexivity, the researcher was objective and framed questions openly without bias so that the caregivers could respond freely and describe whatever challenges they may have faced. The researcher declared his beliefs and professional preconceptions before the study (Malterud, 2001).

3.8 Limitations

Participants of this study were drawn from caregivers receiving services for children with cerebral palsy at the Children's Rehabilitation Unit (CRU), which is in the urban area of Harare. It may not be possible to generalise the study's findings to the whole population of Zimbabwe as the focus was on an urban population.

Another limitation of the study is that data collection was conducted during the COVID-19 pandemic. This resulted in the interviews being done over the phone and via Zoom as there were restrictions to travel and face-to-face meetings. This meant that some of the interpersonal interaction that comes with conducting face to face interviews was lost, and the researcher missed the opportunity to read the facial expressions and body language of the participants.

3.9 Ethics Considerations

Ethical approval was sought and received from the University of Western Cape Biomedical Research and Ethics Committee (BMREC) (Appendix 10), the Medical Research Council of

Zimbabwe (MRCZ) (Appendix 12) and from Sally Mugabe Central Hospital (Appendix 11), where the CRU is based, to conduct the study. Participants were given autonomy. The participants were informed that they had the right to refuse to participate in the study or agree to take part in the beginning and change their minds later. Whatever they decided, it would not affect their regular care. The dignity and rights of all those who participated in the study were respected and protected. Each of the participants was given unique identity numbers to grant anonymity, and only the researcher had access to the collected raw data, which will be kept in a safe locker for five years. Thereafter all the data will be destroyed. The principle of beneficence was considered. All efforts will be made to ensure that the research findings are used to improve the services delivered to children with CP and their caregivers to benefit from the study. The researcher also upheld the principle of justice. All participants in the study were treated equally to achieve social justice.

3.10 Conclusion

This chapter outlined the methodology that was utilised to conduct this study. The study population and sampling methods used were also described. The researcher also provided details about the data collection methods and analysis procedures. The chapter further described the study's limitations and the measures that were taken to ensure that rigour was maintained and that ethical considerations were considered. The next chapter presents the findings of the study.

Chapter 4: Results

4.1 Introduction

This chapter describes the main findings of the study. The socio-demographic characteristics of the study participants are described to give insight into their background. This chapter also describes caregivers' understanding of rehabilitation therapy, as well as the reasons for adherence and non-adherence to therapy.

4.2 Socio-demographic characteristics of caregivers and children

Ten caregivers participated in the study. The caregivers were all female and were between the ages of twenty-two and forty years. The average number of children per caregiver was two children, with some caregivers having as many as four children. Eight out of the ten children had a diagnosis of cerebral palsy with no co-morbidity. The other two children had an additional diagnosis of hydrocephalus and epilepsy, respectively. The average age of children at diagnosis was three and a half months, with the youngest diagnosed at one month and the oldest diagnosed at eight months. The children's ages at the point of data collection ranged between one year to three years. The ages of the ten children are shown in Table 1 below. The children were predominantly male, with only one female out of the ten children. The socio-demographic characteristics of caregivers and children are summarised in the table below.

Table 1: Socio-demographic Characteristics of Caregivers and Children

		Caregivers		**Children with Disability**	
		Frequency (N=10)	Percent	Frequency (N=10)	Percent
Age of Caregivers	20-24 years	1	10%		
	25-29 years	1	10%		
	30-34 years	3	30%		
	35-39 years	4	40%		
	40-44 years	1	10%		
Number of children per caregiver	One	3	30%		
	Two	3	30%		
	Three	2	20%		
	Four	2	20%		
Children’s diagnosis	Cerebral palsy			8	80%
	Cerebral palsy and Epilepsy			1	10%
	Cerebral palsy and hydrocephalus			1	10%
Gender	Male	0	0%	9	90%
	Female	10	100%	1	10%
Age of child at diagnosis	One			3	30%
	Two			4	40%
	Three			3	30%

4.3 Socio-demographic characteristics of key informants

Three key informants from the Children’s Rehabilitation Unit (CRU) participated in the study. The three key informants were an administrative assistant, a physiotherapist, and a social worker. They were aged 37, 45 and 31 years old, respectively. Two of the key informants were females, and one was male.

The administrative assistant is responsible for arranging outreach, contacting caregivers to attend rehabilitation therapy on specific dates, referring clients appropriately to the clinic, and data collection of clients who attend therapy. The physiotherapist’s role is to provide rehabilitation therapy services to clients with disabilities at the CRU. Moreover, the physiotherapist's role includes assessment when a patient is diagnosed with CP and delivery of an exercise programme, health education for different conditions so that caregivers can have insight into the condition, and referral to specialists like nutritionists, speech and language therapists, audiologists, and psychologists. The social worker's role is to help assess children's disabilities for additional needs unrelated to rehabilitation. This involves assessing the children and linking them with other services not found at the Rehabilitation Unit. The social worker also provides psychosocial support for the caregivers.

The three key informants had worked at the CRU for varying amounts of time. The physiotherapist had been at the CRU for 14 years, the administrative assistant for ten years and the social worker for six years.

The following sections describe the caregiver's understanding of services offered to children at the Children's Rehabilitation Unit and explore the caregivers' knowledge of the rehabilitation therapy programme. The positive experiences that caregivers have had with the therapy programmes are described, and also the negative experiences that caregivers have had with the content or delivery of therapy programmes. The problems faced by caregivers in attending therapy sessions with their children and the challenges faced by service providers in providing rehabilitation therapy services are detailed. Finally, areas that require improvement on the rehabilitation programmes for children with cerebral palsy are explained.

4.4 Services offered to children at the Children's Rehabilitation Unit

The caregivers described a range of services provided at the CRU. Most caregivers indicated that their children did exercises 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)
>
> *"He gets exercises. My child's limbs get stiff, so they are trying to normalise his tone."* (27 year old mother)

> *"Exercises so he can do what he couldn't before. Different exercises. Improving his motor functions, helping him hold objects and play and to recognise objects. Teaching him to eat on his own and massages and stretches for flexibility."* (37 year old mother)

> *"He receives therapy and exercises. Because he couldn't stand or really move on his own before the exercises. So the exercises have helped."* (39 year old mother)

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

> *"The child is receiving physiotherapy, and. It's 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 less challenges with his condition."* (31 year old mother)

> *"They do everything like we do physiotherapy and OT. In physiotherapy, we start by doing exercises; they administer exercises on the child. Then they ask us to show them what we do with the child at home, and we do that…Then at OT, they will be teaching us how to play with the child to check if the child can now hold (grasp) things, if the child can eat on his/her own; what things that child can now do that we have observed as changes and improvements since we started therapy"* (31 year old mother)

> *"They stretch his arms and legs and back and toes at physical therapy. Then in occupational therapy, they place a ball in front of him and then encourage and help him reach for it."* (40 year old mother)

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

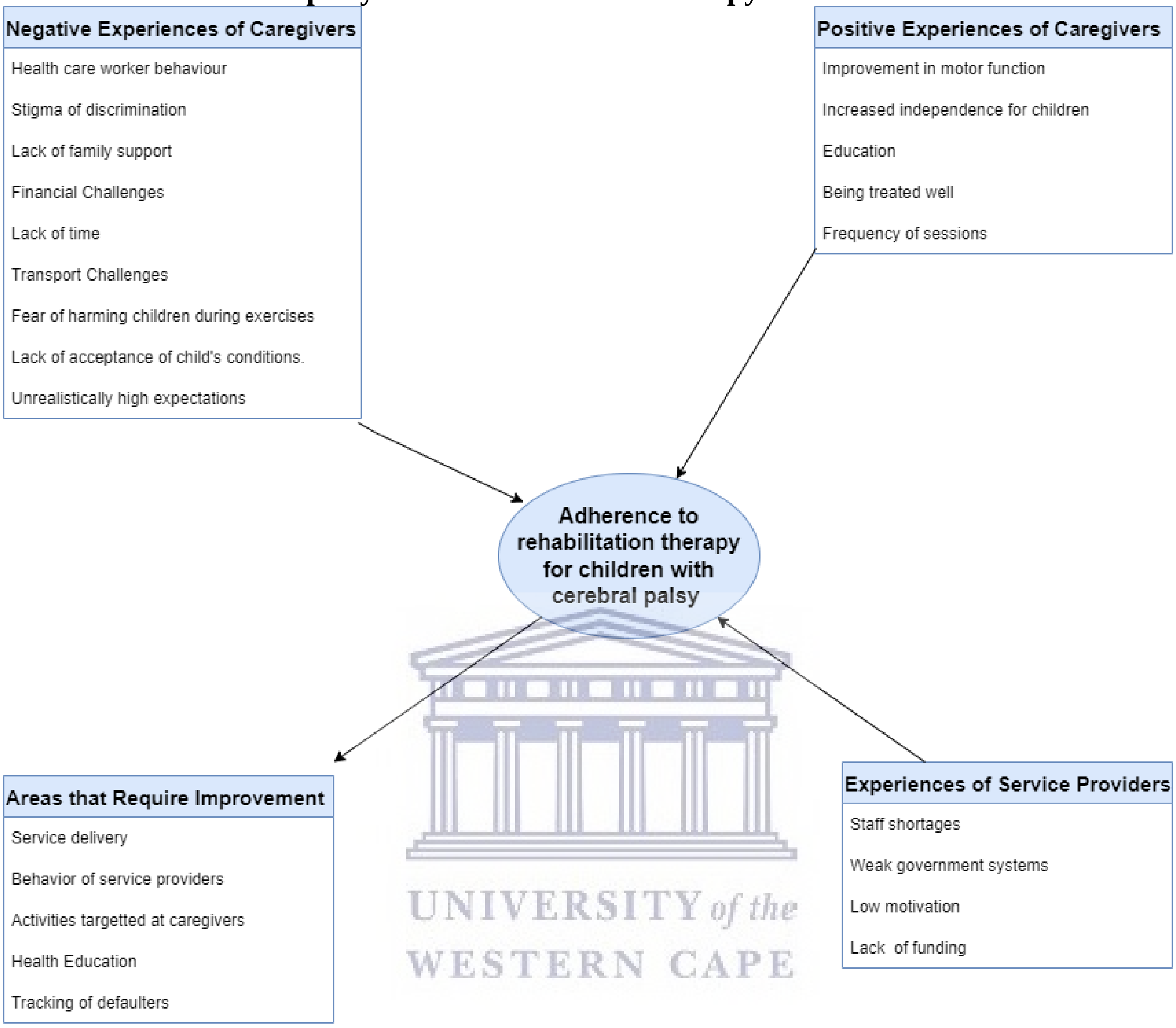
> *"…and I'm also getting educated on how to take care of a child with CP."* (33 year old mother)

The caregivers mentioned various other activities, which include drawing, play and feeding.

> *"They also 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)

> *"When we go to CRU, they tell us how to handle the child and his condition. They taught us to massage him before feeding him. I don't have all the information, but those are some of the services we received there, and it's working. There is also the play we engage in, where I put him down and which helps their limbs stretch out."* (37 year old mother)

Figure 1: Schematic representation of the experiences and perceptions of caregivers of children with cerebral palsy about rehabilitation therapy



4.5 Caregivers’ understanding of rehabilitation therapy programme

A number of the caregivers revealed that they felt the purpose of the therapy was to increase a child’s independence.

> *“In addition, if they do these exercises, they will then gain some independence. They will be able to use their hands to do things for themselves. They can feed themselves; they can 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)
>
> *“They help him be independent and to be able to do what he needs to do for himself.”* (33 year old mother)

> *"So that continual physiotherapy really helped him to be able to do a lot of things he couldn't even do for himself before."* (31 year old mother)

One of the caregivers felt that the rehabilitation therapy assisted the children by improving their use of limbs.

> *"To improve their mobility and function of limbs, I have seen improvements in this regard for my child."* (35 year old mother)

It also emerged that caregivers acknowledged that the therapy programme helped with child development.

> *"Because they are slow in their development and in knowing which stage they should be developmentally impaired, so they need help to progress from one stage to the other."* (22 year old mother)

> *"We were told that when children have cerebral palsy, it is because their brains would have been damaged, so they are slow, and for them to catch on to anything, they need constant repetition."* (31 year old mother)

Caregivers realised that therapy helped their children to be like other children and to be able to play with others.

> *"…To normalise his tone, so that he can do what other children can do, which is normal because what he does is not the same as other children his age."* (27 year old mother)

> *"...And when you go where there are other people, he would want to play with others but will not be able to, but because of exercises and all that we will be doing, now when we go where there are other people, and you sit down, he can now interact with and play with others."* (39 year old mother)

Another caregiver was uncertain of the purpose of therapy but indicated that she was advised that the child needed therapy as something was wrong with the child.

> *"They said that something went wrong with his body, so he needs the therapy."* (37 year old mother)

This is interesting as the key informant emphasised that health information and education was a crucial part of the programme for caregivers whose children had just been diagnosed with cerebral palsy.

> *"...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)
>
> *"At CRU we are helping them to understand more about the condition and how to care for the child with that condition, and basically—when we are doing the health education, it was mainly centred on issues to do with the disabilities."* (Key informant 3, male)
>
> *"Then after that, we kind of turn to counselling in terms of why it is important to do physical therapy and any other kind of rehabilitation therapy."* (Key informant 3, male)

4.6 Positive experiences that caregivers had with the therapy programmes

The caregivers noted several good experiences in participating in the rehabilitation therapy programme at the CRU. These included improved motor function, independence, education, being treated well, and frequency of sessions. The positive experiences are outlined below.

4.6.1 Improvement in motor function

A significant number of the caregivers reported seeing an improvement in motor function in their children due to the therapy programme.

> *"My experiences have been good. My child couldn't sit or wake up. But now he can actually walk. Yes, there's still a problem with the leg, and he still drags it when he walks, but it's much better."* (31 year old mother)
>
> *"When I started going, he could sit up and move, but he couldn't crawl. Now he can crawl; they taught him to use his muscles. He can even say 'mama' and a few other words though not audible. He can pick up objects and use furniture for support to stand."* (22 year old mother)

> *"He can turn and roll now and reach out for things, grab and hold objects for prolonged periods. He has better neck and head control now and can turn his head."* (27 year old mother)

> *"My child could only sit, but now he can get into a crawling position and can move and roll, and now he is almost able to stand. He is making efforts to stand. All those are things he could not do before."* (35 year old mother)

> *"He never used to be able to really chew, but now he can. Also, he can move his arms and bend and move his legs thanks to the stretching. He can turn to all sides so he can sit up."* (37 year old mother)

4.6.2 Increased Independence

Caregivers felt that the rehabilitation programme increased the functional independence of their children.

> *"And through the exercises, he is getting; now he can even do certain things for himself."* (33 year old mother)

> *"Because some things she can now do by herself. Even now, she can grasp objects."* (31 year old mother)

> *"So that is when I started to notice a lot of changes on my child. He can do more things on his own."* (31 year old mother)

4.6.3 Education on child's condition

It was clear from the participants that education and information sharing on the child's condition was one of the areas that they regarded as positive in terms of the rehabilitation programme. Several caregivers described the impact or importance of education to them.

> *"I learnt how to handle him properly. I didn't even know how to handle him with his condition. But I learnt how to hold him properly, and that I can even play with him even and entertain him so that he also feels like a human."* (33 year old mother)

> *"The services are helpful. They are good. I even know what to do with the child at home."* (39 year old mother)

> *"He explained what cerebral palsy is and what the condition entails. So these workshops help. They informed me about the child's condition and what they need because they are different from other children. So that helped us."* (40 year old mother)

> *"They instruct you on the next stage when the child has made progress. Sometimes you don't know exactly what to do, and then they explain it to you, so I'm really grateful and will keep going."* (39 year old mother)

One caregiver contrasted the information and education received at the CRU with the lack of information provided at the paediatric clinic.

> *"I really like their workshops. When he was diagnosed with cerebral palsy, the doctor just informed us of the condition and referred us to services. He didn't really explain what it all meant, so it was at Harare Hospital where the doctor explained it all in workshops."* (40 year old mother)

One of the key informants emphasised that education or information sharing was a vital part of the rehabilitation process, and it was given continuously to the caregivers throughout the process of accessing rehabilitation services.

> *"I would say that at every stage of assessing the rehabilitative services, there is some form of counselling that is done. For example, if someone is coming for the first time, if they are actually initiated on services, they are given what is called informative counselling, where they are being told about what to expect, what not to expect—things like that. Even detail about what type of disability their child has."* (Key informant 2, female)

4.6.4 Being treated well

Only a couple of caregivers noted that they were treated well by service providers and listed this as one of the positive experiences of the rehabilitation therapy programme.

> *"As I am going, I have noticed that my child is improving rapidly, and I am being treated well when I go, so I have no complaints."* (22 year old mother)

One caregiver went further to describe the treatment received at the CRU as showing love.

> *"I wouldn't want to lie, really, if it weren't for these services; I don't think my child would be alive. But because of the love they showed to [name of child] – they [services at CRU] are really good."* (40 year old mother)

4.6.5 Frequency of sessions

It was interesting to note that some caregivers described the frequency of attending rehabilitation therapy sessions as a positive experience.

> *"It is such that each time I wish I could go more frequently because my child is improving. I used to go once a month until they started doing outreaches close to where we were…Then I enrolled in one of their programs and started going twice a week.".* (22 year old mother)
>
> *"There is a program called KOICA. My child was selected for the KOICA program. It is a good program because we used to go to therapy twice a week. So he would do the exercises frequently, rather than once a week outside of KOICA."* (27 year old mother)
>
> *"So this program really helped us because we used to do it twice a week for four months."* (35 year old mother)
>
> *"They instructed us on what we should do daily at home, which has helped the child. Still on that if you go there twice a week, you'll get help and clarification on if you're doing the right thing."* (39 year old mother)

A key informant acknowledged that generally, caregivers appreciate rehabilitation therapy, although they require additional education and support.

> *"…it depends, but I think most of them appreciate the therapy's benefit to their children. But I think it also takes a bit of education, a lot of reassurance, so they really know what it is supposed to do."* (Key informant 2, female)

4.7 Negative experiences that caregivers had with the content or delivery of therapy programmes

The caregivers of children with cerebral palsy highlighted some of the negative experiences or challenges they have experienced in the rehabilitation therapy programme at the CRU. These included health care worker behaviour, stigma and discrimination, lack of acceptance of child's condition, fear, the inexperience of caregivers, and not observing any benefit. The negative experiences are described below.

4.7.1 Health care worker behaviour

Caregivers stated that they had negative experiences with the behaviour of healthcare workers who provided services to children with cerebral palsy. The negative attitude of healthcare workers was the issue raised the most by caregivers when they recounted the negative experiences they had with rehabilitation therapy.

> *"The other challenge is the healthcare workers. Some are very rough and end up sulking. This is because we get trained at the physio sessions to do these things for our children at home, the various exercises. When I get home, I do what they have taught me, but it takes time for the child to improve, and when we go back to the hospital, the nurses shout at us and say we are not doing the exercises with the children at home."* (31 year old mother)
>
> *"So these health workers shouting at and scolding caregivers causes some to stop going and stay at home with their child, rather than to come so that just get scolded and shouted at by the nurses… these nurses are so rough and cheeky."* (31 year old mother)
>
> *"It's just that at times, well you know how human beings are, there may be a day when the healthcare worker can come to work in a bad mood, and that is not very good."* (35 year old mother)
>
> *"So when the therapists are telling you what to do, and you display fearfulness or hesitation, they get very upset you. They get very angry with you."* (35 year old mother)

One of the key informants, a service provider, emphasised the importance of the caregivers complying with the exercise programme they would have been given as the caregivers spend more time with the children. They explained that the nonadherence with home programmes influenced the therapists' attitude towards caregivers.

> *"Our main aim is to teach the caregiver what to go and do at home. It's not about us treating the patient, but it's for them to understand and grasp the concept so that they will do exactly what they have been taught at home because they will have the child for 24 hours, but for us, it's only a few minutes with a client then they're gone."* (Key informant 2, female)

The key informant explained her frustrations with how some caregivers do not seem to find rehabilitation therapy necessary.

> *"The second time they come, and you ask, can you show me what I showed you last time, what I taught you last time. Then there's a total disaster. Someone will say, 'No, I've totally forgotten. I don't even know what you did last time. I'm sorry.' They don't even show enthusiasm for the whole thing, so sometimes you think they don't even value the therapy; they don't think it works."* (Key informant 2, female)

A key informant also alluded that some caregivers do not seem to recognise the importance of rehabilitation therapy.

> *"But to some, I don't know if—I don't know what, because they don't seem to…to give it that importance that it has. They don't give it [therapy] that importance."* (Key informant 2, female)

One of the caregivers felt that her child's behavioural problems led to the frustration displayed by the health workers.

> *"Sometimes we face challenges because the child doesn't want to participate in the therapy sessions. My child actually has behavioural problems, and he throws tantrums…Sometimes we can get there, and he is moody and does not want to cooperate with the therapists. This causes them [the therapists] to get frustrated and annoyed with him, and at times they end up just leaving him."* (22 year old mother)

4.7.2 Stigma and discrimination

Caregivers noted stigma and discrimination as influencing the negative experiences that they had in seeking services for their children with cerebral palsy.

> *"Plus, if you get to where other people are with the child, like before the child could sit, it was difficult to move around with the child, and it was also difficult to leave the child. And if you were to say to people the child can't sit or do anything for herself, the comments you would get from people were not good at all. They would really put you down."* (33 year old mother)

4.7.3 Lack of acceptance of child's condition

It emerged that some caregivers had difficulty accepting their child's condition, and they listed this as a negative experience on accessing rehabilitation therapy.

> *"I would say it was not easy to accept the diagnosis. It was difficult to accept. But we received counselling and encouragement until we accepted it. So that is the major challenge."* (31 year old mother)

> *"To quickly accept that this is now my situation is a huge challenge that we face because there is also the family and society to deal with. So, for a person to accept that 'this is my child's condition is very difficult."* (35 year old mother)

Each of the three key informants noted the inability to accept the child's condition as a challenge that caregivers of children with disabilities faced.

> *"Some will be in shock and disbelief. It's an ongoing process of accepting the child's condition, where they have to pass through counselling."* (Key informant 1, female)

> *"Some, they don't really believe that it's cerebral palsy. They don't believe it. But for some, they believe it, but it may take some time, you know. The process of grieving, you know how it is, sometimes they get into denial, bargaining, whatever."* (Key informant 2, female)

> *"So when they are told that the child has cerebral palsy, they are like—it's traumatic for them. Most of them don't understand. Sometimes they break down. I've seen some parents conflicting among themselves when they're told their child has CP."* (Key informant 3, male)

It would appear that the role of assisting the caregivers in accepting the condition, whilst shared by different service providers, was considered the counsellor's primary role, as one of the key informants explained.

> *"...and those that are providing services, they actually realise that the parent is not taking it too well, then they refer to the counsellor, who will also provide psychosocial support and counselling, which is mainly targeted at making sure the caregiver accepts the condition."* (Key informant 1, female)

It emerged that the challenges with accepting the child's condition highlighted above occurred despite rehabilitation counselling to the caregivers, which was described by one of the key informants.

> *"So they will talk about adherence and defaulting issues during rehab counselling. They are informed that if they don't come for exercises, the child can become worse. They also talk about issues of accepting the condition and denial and the importance of therapy."* (Key informant 3, male)

4.7.4 Fear of harming children during exercises

The issue of fear was also raised as one of the challenges caregivers faced. A caregiver described fear of conducting the exercises as instructed as they were afraid of causing harm to their child. The fear they experienced was also linked to the negative behaviours or attitudes healthcare workers displayed when attending to their children.

> *"So for me, to be able to do that physio and all those stretching exercises are not easy. In addition, when it is done, the child will be crying, and as a caregiver, you will be fearful and might be thinking, 'if I overdo it, my child's limb may be broken, or I may hurt my child'."* (35 year old mother)
>
> *"However, they [the therapists] will be expecting that you as the parent should have accepted and be understanding of your child's condition. But for some that have not come to terms with it, doing those exercises is not easy; they will be afraid."* (35 year old mother)

4.7.5 Inexperience

Some caregivers listed inexperience as one of the challenges, alluding that healthcare workers expect the caregivers to be proficient in performing the exercises. Yet, the caregivers were not experts in rehabilitation.

> *"Now, you have to understand that no parent wants their child to continue to be or remain disabled. I didn't go to school and learn these things nor train for this work, so I will not get it perfectly like you, the healthcare provider who went to school and trained to do these things."* (31 year old mother)
>
> *"Others bring children for the exercises, but when they go home, they stop doing them because they don't know how to do them properly."* (33 year old mother)

One key informant explained that they expected the parents to grasp the concepts and carry them out at home.

> *"After the explanations, we also teach the parents. So we really explain –they will be trained like half-therapists, the caregivers. They will be trained so that they can do the therapy at home."* (Key informant 2, female)

The key informant, however indicated that this was easier said than done as the caregivers had difficulty understanding what they would have been taught to do.

> *"For them, it's Greek. They don't even understand what's going on."* (Key informant 2, female)

4.7.6 No benefit observed

Another interesting finding to note was when caregivers were asked about challenges other caregivers faced, not necessarily themselves; they raised the issue that sometimes one does not see a benefit or improvement after undergoing rehabilitation therapy.

> *"She would say that she would feel sorry for her child… I told her if you do that, your child wouldn't improve and will always be on the same level. Her child can't sit on his own, and she's always holding, and I told her that he needed therapy, and she should help him do exercises, but she didn't really see the benefit."* (37 year old mother)

> *"…you notice that when you come back for therapy, other caregivers' children will be way more advanced than yours, and your child will not have made progress, and yet we started sessions at the same time."* (33 year old mother)

4.8 Problems faced by caregivers in attending therapy sessions with their children

The caregivers were asked to share the issues that they felt led to non-adherence to the therapy programme, which means the general problems they faced in attending rehabilitation therapy sessions with their children. Several issues emerged, and these are described in the following paragraphs. The issues raised may be summarised as social discrimination, lack of family support, financial challenges, transport challenges, lack of time and unrealistically high expectations.

4.8.1 Social discrimination

One of the caregivers noted that although her family is supportive because her child's condition is not very severe, other caregivers of children with cerebral palsy faced discrimination from society.

> *"Most caregivers are also not accepted well in society... For example, some mothers even end up not going to church because when they go with their child, some people shun them. You can find someone changing their seat because they are disgusted by your child's drool. These children drool a lot."* (31 year old mother)

Other caregivers noted the discrimination her child experienced in the community as others did not want to be close to the child or appeared to be afraid of the child.

> *"Some [children] don't want to be close to him; some are even afraid of him. I don't know if it is because maybe they think it's contagious – I don't know…This causes him to just end up playing with his siblings only because those from the community do not like him."* (22 year old mother)
>
> *"Then in the community, people also just talk, they will comment about his disability and the fact that he can't walk saying 'this child can't walk, he is disabled', and other such things."* (31 year old mother)
>
> *"And many of their landlords and family members are embarrassed by having someone with cerebral palsy at their home and in their family."* (40 year old mother)
>
> *"You face a lot of rejection and almost no support. People seem to be disgusted by him or something like that."* (33 year old mother)

The key informants also cited social discrimination as one of the challenges faced by caregivers.

> *"And those things that might have a psychological effect on the caregivers—discrimination from the community and such."* (Key informant 1, female)

The discrimination faced by caregivers in the community is terrible to the extent that caregivers can fail to get accommodation because they have a child with cerebral palsy, was highlighted by one of the key informants.

> *"And also accommodation—they are having challenges with accommodation, where they are staying. Sometimes they are kicked out because they have a child with cerebral palsy. You know how it is; people don't understand. There's that stigma."* (Key informant 2, female)

Another key informant indicated that the constant relocation that the caregivers had to go through due to stigma in the communities where they live might lead to the caregivers defaulting to therapy sessions.

> *"And some of them are tenants so that one might lead to defaulting because they will be relocating, from a location to another location, which makes it difficult for them to come for therapy sessions."* (Key informant 1, female)

One of the key informants also noted discrimination against the caregivers due to the child's disability even occurs at the hospital when the caregivers come with their children to receive services.

> *"In a broader way to say in the hospital, yes, there are issues where people with disabilities may feel that the treatment they are receiving is not fair and people are not accommodating them."* (Key informant 3, male)

4.8.2 Lack of family support

The abovementioned discrimination also sometimes manifested itself in a lack of family support, as shown by the examples cited below. Some caregivers noted the lack of support from their spouses, and some indicated that having a child with cerebral palsy had led to abandonment and divorce.

> *"Some mothers are actually rejected and abandoned by their husbands because of the child with CP."* (31 year old mother)
>
> *"We had a workshop once, and some talked about how the partners had left them when the children were born because of the child's condition."* (39 year old mother)
>
> *"[I live] alone, with my children. Yes, in speaking to other mothers who are in a similar situation, many have been abandoned by their partners. Three-quarters of the caregivers say their partners left them when they had their children as they were embarrassed by it."* (40 year old mother)
>
> *"When I gave birth to my second child, he [husband] left because it looked helpless. First engagement broke because of my child's disabilities, and then the second time he said, 'You've given birth to a child with disabilities.'"* (40 year old mother)

> *"Then if it is family, I can't even begin to talk about it because my son was rejected by the family because of that, starting with his own father. He does not want to hear anything about the child; he does not comment, he does not do anything... Right now he has actually married another woman and does not even care or bother to ask what the doctors have said or what the child is now able to do and the progress he is making."* (22 year old mother)

> *"Plus, the one thing I discovered by going to the CRU is I noticed that men do not want to have children with challenges. There are some caregivers that are actually very young, like twenty years, and this will be her first born, but the man would have left her because of that condition that the child has."* (22 year old mother)

Other caregivers cited a lack of support from in-laws or extended family.

> *"My husband's family have never embraced it, and they actually say that child is not theirs. My child will be alright, and he is improving."* (31 year old mother)

> *"About the family and community, you find that no one will even be supporting you. You have to be the one persevering so that your child can get help… Especially in the family, most people do not like the fact that your child has a disability. So they will just 'say you and your child are on your own."* (37 year old mother)

> *"They [my family] don't accept my children."* (40 year old mother)

Traditional beliefs were also cited as tied to the lack of family support and indicated by two of the caregivers.

> *"In the family, some will be saying, 'this is from your ancestral lineage; that is where such children come from…other people in his family and other relatives who are difficult say it's my fault and that this is from my side of the family."* (37 year old mother)

> *"My partner didn't accept the child. He says there is nothing of the sort on his side of the family. Because my first child is blind, and then this one experienced complications. So they said to me, "You only give birth to children with disabilities."* (40 year old mother)

In contrast, other caregivers noted that they received support from their families.

> *"Yes, they have [accepted it]. Especially my husband. People are different. You'll find one or two who will stand with you. Some people are indifferent and just isolate you and the child."* (37 year old mother)

Another caregiver explained why she thought her family was supportive and expressed that while her family was supportive at present, she was uncertain if they would continue to support her as the child grew up.

> *"Even family can shun you. Most caregivers are then rejected by their own families. I have a very supportive family, though. Maybe it's because I struggled to have a child and then eventually had him after ten years. So they accept him and love him as he is."* (27 year old mother)

> *"My child has been embraced in the family. Maybe it will be different when he grows up. I have no complaints so far. Even his father truly loves him because you know some fathers don't accept this and may want nothing to do with their child."* (31 year old mother)

One caregiver mentioned that despite the challenges she had faced from her in-laws, her husband appeared to have a change of heart.

> *"I ended up moving from my mother-in-law's house because it was like they were disgusted by my child. So I thought it was better to leave and rent somewhere. My partner stayed behind and never used to visit, but now he does."* (33 year old mother)

One of the key informants noted that in some cases, because of the slow progress made by the children, families that were initially supportive tend to withdraw their support after some time.

> *"You know when caregivers come for two or so months, they have high support from family members, but when they kind of see the benefits that they are getting, it's kind of not very fast, I think sometimes they just get discouraged."* (Key informant 3, male)

4.8.3 Financial Challenges

Financial challenges in accessing therapies were highlighted by the caregivers of children with cerebral palsy as one of the problems they faced. Some of the caregivers noted the high costs associated with the upkeep of their children as they had special needs.

> *"I do need money for things like walkers so he can push himself around and walk with it — the accessories and toys he might want. I don't have the money to buy those things."* (31 year old mother)

> *"I would say financially. He's still wearing diapers, even though he's at the age when he shouldn't be. They are expensive."* (22 year old mother)

> *"Yes, there are challenges. The child needs a specialised diet, with many fruits and vegetables, but because of how things are, our diets mostly consist of Sadza [cornmeal], of carbohydrates. The diapers are expensive, as he is not potty trained yet."* (39 year old mother)

> *"Then, every Tuesday, we would have feeding sessions, but we wouldn't have enough money to buy the food they wanted the child to learn to chew... I would ask other mothers if they could share their food."* (37 year old mother)

The key informants echoed these sentiments of the caregivers as they also spoke about how financial constraints were a significant challenge for the caregivers. The medical expenses for a child with cerebral palsy were reported to be high.

> *"Maybe they are unable to access drugs. You know, for some of the children who are epileptic, the drugs are very expensive...you know, private hospitals are very expensive, so caregivers are not able to pay for medical investigations such as MRI scans and CT scans."* (Key informant 1, female)

> *"The cost of caring for a child with cerebral palsy is very high. Sometimes let's say the child has got cerebral palsy and has also got epilepsy. They have to get medication. Sometimes the medication is not available at the hospital, and they have to buy from private pharmacies, and the medication is very expensive… Even for some investigations-maybe, they are supposed to take a CT scan or MRI; those investigations are very expensive."* (Key informant 1, female)

One of the key informants reiterated the high costs that caregivers of children with cerebral palsy faced in providing diapers and special food.

> *"Even when caring for their children with cerebral palsy, because some of them will never be toilet independent. They will rely on pampers, and you know how it is. The pampers are very expensive... Even the food, because they need to have special food, some of them because they have difficulty feeding, difficulty chewing. So all those expenses are very, very high."* (Key informant 2, female)

A key informant also indicated that the caregivers of children with cerebral palsy faced additional financial costs as the children had to attend special schools, which were expensive.

> *"They face challenges in school fees—you know special schools are very expensive. When the child has reached the age to go to school, the enrolment process is long and special schools are very expensive here in Zimbabwe."* (Key informant 1, female)

Although most interviewed caregivers were not employed, it was notable that even one of the caregivers who was formally employed expressed that she was having financial challenges in accessing rehabilitation therapy services.

> *"Yah that is where there are the most problems! I personally have the advantage that I work, I work at NRZ. Yes, of course, there are times when I used to walk on foot from Harare Hospital to get to town because I didn't have bus fare."* (31 year old mother)

4.8.4 Transport Challenges

Caregivers noted transport challenges which were linked to the financial difficulties highlighted above as an impediment to them accessing rehabilitation therapy services.

> *"Even transport money for them [other caregivers] to take the child for physiotherapy is a major challenge."* (22 year old mother)

> *"Yes, my child used to live with his grandfather, my father, but he passed away. I used to live with my sister. Right now, I'm living in Marondera, so sometimes at CRU, they ask me when I'm able to come and when I can find transport fare. So that's one challenge."* (33 year old mother)

One caregiver indicated that she could still afford transport as she could carry the child on her back as the child was still young.

> *"I have transport money. We use public transport. Right now, it's still fairly easy because he is still young, and I can carry him on my back."* (31 year old mother)

The above comment was considered pertinent as the key informants noted that as children get older and use wheelchairs, the caregivers struggle with transport to attend rehabilitation therapy sessions. They must pay for bus fare and the wheelchair when they use public transport.

> *"Some of them might default coming to therapy due to transport challenges. They are being charged extra fees for transportation of the wheelchair."* (Key informant 1, female)

> *"Sometimes when the child is older, when they become a bit older, now they will be moving on wheelchairs, so those wheelchairs, they are difficult to move with, like on public transport. And if they are fortunate to be allowed to get in the public transport,*

> *they are supposed to pay an extra fare for that wheelchair, and the person as well."* (Key informant 2, female)

> *"Yeah, I think the problems about bus fares and the problem of having to travel with their wheelchairs. They end up just giving up and say, 'Let's just stay home. There is nothing we can do. We can't afford the bus fares.'"* (Key informant 2, female)

The COVID-19 induced lockdown also presented transport challenges as public transport was not available.

> *"The challenge I've experienced is lockdown. It was difficult to move about; public transport was not easy to find…transport was hard to find, so sometimes I would arrive late because of transport issues."* (37 year old mother)

> *"Transport is a problem. There are no kombis [public taxis]. So you might not make it in time. Transport is where we face our major challenge."* (27 year old mother)

Some caregivers also highlighted the challenges they faced with the availability of public transport even when they had the money for bus fare.

> *"We face challenges in terms of transport; we have to use public transport to get to the therapy sessions, and getting there is difficult."* (40 year old mother)

> *"I'd say using public transport. It's difficult carrying him about; it would be easier with my own car. So I would say that's the major challenge. Carrying him about and using public transport."* (31 year old mother)

4.8.5 Lack of time

One of the key informants indicated that some caregivers might not have the time to come to the CRU to attend rehabilitation therapy sessions as they were also busy trying to raise money to fend for their families.

> *"Then another challenge is that the people who are responsible for bringing the children to CRU are also the people who are also responsible for taking care of the family through different economic activities... So sometimes for them to come to CRU twice a month, it's a challenge."* (Key informant 3, male)

It emerged that there is also a heavy burden of childcare on elderly caregivers who also will not have time to come for rehabilitation therapy sessions as they were overwhelmed with the work that they had to do at home.

> *"Then another one: caregivers of children with disabilities are not biological parents. Mostly they are grandmothers because sometimes the mothers are overwhelmed, sometimes they run away, sometimes they say we are going to South Africa to work. So the grandmothers who remain behind, sometimes they are very elderly, so that commitment of going to CRU, even on a monthly basis, sometimes it's a challenge."* (Key informant 3, male)

4.8.6 Unrealistically high expectations

It emerged from the key informants that the lack of acceptance or lack of understanding led to unrealistically high expectations among the caregivers about the progress that their children should make after commencing rehabilitation therapy.

> *"And the problem is some clients think if they're initiated on therapy, just after two or three sessions, they should find the child walking. You know how it is. So it's all about explaining to them that it's not—it's gradual."* (Key informant 2, female)

> *"There are caregivers who are coming for the first time. They kind of feel like or they kind of hope that the physiotherapy helps the children in a very short period of time, whereby they actually expect their child to walk or talk within a very short period of time."* (Key informant 1, female)

It was interesting to note that these unrealistically high expectations that the caregivers held occurred despite a comprehensive counselling programme that was described by one of the key informants.

> *"There is the medical aspect of counselling. That is done by doctors and the rehab staff. Counselling on the condition, so they get to know what is really happening, what is cerebral palsy, what the child is going to do, what are they supposed to expect, what are the associated problems with cerebral palsy. That is done by therapists. Then on the psychosocial aspect, we have a resident counsellor at CRU, [name]."* (Key informant 2, female)

4.9 Challenges faced by service providers in providing rehabilitation therapy services

The key informants highlighted challenges that they faced in delivering rehabilitation therapy services. These included staff shortages, low motivation, lack of funding and weak government systems.

4.9.1 Staff shortages

One of the key informants indicated that they were short-staffed, making it challenging to provide quality services to the caregivers and their children.

> *"I think the big challenge is the staff. We have a shortage of staff. We are overwhelmed…under normal circumstances; maybe you get 15 patients a day, and we are only four. And you have to give quality service to those clients. So it becomes very, very difficult to provide the quality service."* (Key informant 2, female)

It also emerged that the service providers were not motivated to work as they felt their remuneration was low.

> *"And maybe also a bit of motivation, sometimes (chuckling). There is not enough motivation; that's the truth. The work we are doing and what we are getting, in the end, is not meeting… the remuneration is very low, and you're supposed to be working extra hard and providing the best service that you can, so people are not motivated at all. So it's like a sacrifice; we are like sacrificing, providing a community service."* (Key informant 2, female)

4.9.2 Lack of funding

Donor-funded programmes supported some of the activities that were provided at the CRU. One of the key informants stated that the absence of this funding affected the programmes as some activities were stopped.

> *"I think the main challenge right now is there is no funding at all. A lot of programs that have run in the past have just stopped because of a lack of funding. I think that is a big challenge for the programmes that help the mothers—the workshops have been stopped. Even the outreaches…So funding is a huge problem for us."* (Key informant 2, female)

Caregivers also mentioned this lack of funding. It would appear that some caregivers were accessing rehabilitation therapy at the CRU using bus fares that they were given at the CRU as part of a donor-funded programme. The absence of this programme has led to significant challenges, as shown in the comments below.

> *"KOICA used to send us money via Ecocash [mobile money service], but it was insufficient, so we ended up using it to buy airtime instead."* (37 year old mother)
>
> *"Yes, transport is difficult because we don't always have bus fare. But there's a program there called KOICA where they send us Ecocash funds, but the money was insufficient to take you both ways to and from the facility."* (22 year old mother)

4.9.3 Weak government systems

One of the key informants mentioned that their work was made difficult as the government systems within which they worked were not efficient, and there was no accountability in terms of service delivery which led to frustration among the caregivers.

> *"...sometimes you'll assess a child then come up with a care plan to say this child, you should also take them to social welfare, maybe education. I think generally there are weak mechanisms in terms of, I would say in terms of accountability, to say if I send a case to social welfare, how accountable will they be in terms of making sure the child receives services. Sometimes we refer services and don't get feedback."* (Key informant 3, male)

4.10 Areas that require improvement on the rehabilitation programmes for children with cerebral palsy

The caregivers were asked to suggest strategies that could improve adherence to rehabilitation therapy by asking them to state how they felt that the rehabilitation therapy programme for children with cerebral palsy could be improved. The caregivers' suggestions were grouped into areas of service delivery, the behaviour of service providers, activities targeted at caregivers, and tracking of defaulters.

4.10.1 Service delivery

The caregivers had several suggestions on areas for improvement in service delivery. Some caregivers felt that the frequency of sessions should be increased to get optimal results.

> *"I think they should increase therapy days. We should go at least once weekly. Yes, I think if we keep going, it will be beneficial. When I used to go once a month, you'd have*

> *challenges at home like doing household chores or fetching water."* (22 year old mother)

> *"I would say we need more therapy sessions. One can look for transport money so that you can go there, and your child can receive help, but we should have more sessions. A lot of parents don't really understand the condition…So some people just give up. Yes, because it would be helpful if we went for therapy, say, every week."* (27 year old mother)

> *"It should be easier to access services more regularly, maybe two days a week. Right now they sometimes say we should only come when the child presents problems, and you will only briefly see the doctor."* (37 year old mother)

> *"I would personally want them to see us every month at least. I think they should regularly check-up and the children should have appointments at least every month."* (31 year old mother)

> *"Because even though I might be doing it at home, there may be some things I am getting wrong, which require the one is more experienced with it who can then show you the way to do it. That is what I simply desire."* (39 year old mother)

Another caregiver felt that the mode of delivery should be changed; she suggested that machines and devices should be used during therapy.

> *"I think there is a great need for more machinery like those machines they use to do the physiotherapy with children. We've noticed that some of the machines are too few, so if those can be added, then the children can be helped better."* (31 year old mother)

However, another caregiver spoke as if the addition of more machines had already taken place.

> *"Now they have machines that aid in the child's mobility, and these have really brought about an improvement. When I started taking him to therapy at three months and now— there is a major difference. It has helped."* (39 year old mother)

It was also suggested that there was a need to educate fathers and the general community so that myths and misconceptions could be addressed and hence more family support and less discrimination.

> *"For workshops, I'd say they should write letters to the children's fathers so that the fathers attend these workshops so that they understand the problems because a lot of them think it's witchcraft. That way, they could understand the condition. The service providers should also conduct home visits to explain the condition and educate people*

> *on it because mothers are the only ones who understand because we fend for ourselves. Most people don't understand."* (27 year old mother)

Another suggestion was the decentralisation of the programme to ensure easy access to all who needed the services.

> *"My observation is that maybe they can increase centres… I feel that if they increase the centres and have more therapists, at least if the child has thorough therapy once or twice a week, that helps the child improve."* (31 year old mother)

> *"We used to get some services here, but I asked to be transferred to Harare because Harare is better for these things. You can find the money for transport, but you can't buy your child's life, so I'd rather sacrifice to come to Harare."* (35 year old mother)

4.10.2 The behaviour of Service Providers

The caregivers had several suggestions around the issue of the behaviour of the service providers. They felt that service providers needed to have a better attitude, be more patient, treat the caregivers kindly, and provide care and support.

> *"Their behaviour needs to change. They need to have better attitudes, be patient, and have a kind heart towards us, and understand that our challenge [our child's condition] is also very distressing to us; it really bothers us psychologically, sometimes it really bothers us psychologically too. So if they can just treat us kindly and in love, I think things will be better."* (40 year old mother)

> *"I think we need a lot of care and support because when they are harsh, you start stressing, so if they're always kind and helpful, it would be good for us. It's different from person to person. We need care and support. Some of the health workers are harsh. People are different and have different needs…. They should be more patient."* (27 year old mother)

In contrast, one of the caregivers felt that there was no need for change in the behaviour of the service providers as they were doing a good job.

> *"So far, those that are at the CRU are doing a great job for me. They are really good; they are really good when it comes to physiotherapy because I noticed some children who were actually worse than mine but have improved."* (22 year old mother)

One caregiver felt it would help if the number of therapists could be increased and if a waiting area could be provided for caregivers to play with their children as they awaited to attend sessions.

> *"But also because there are few therapists if they could maybe have waiting rooms where we could sit and play with our children while waiting for therapists. When we used to go, we would have to wait for therapists and take turns. If they could allow us to go and spend the day there and just do exercises with our children."* (31 year old mother)

4.10.3 Activities targeted at Caregivers

The caregivers also suggested some activities that could be targeted directly at them so that they could be better able to take care of the children with cerebral palsy. Caregivers mentioned that they required training in income-generating projects so that they could meet their financial needs.

> *"It would be nice if we could have workshops for caregivers where they can continue to teach us things like how to do projects."* (31 year old mother)
>
> *"I think maybe if they can help those who are not working and have come into this situation. If they could help them at least with projects that are meant for parents of children with that problem, at least it will help them to get a little bit of money. Because the problem is that it is rare to leave a child with cerebral palsy in someone's care while you go to work."* (35 year old mother)
>
> *"Because in most cases children with cerebral palsy have certain pills that they have to take…So if they can find at least some NGOs who will help them to do some projects where they can work, I think it will be better."* (37 year old mother)
>
> *"I would say that when we meet up as caregivers, and we talk, there are those who don't have enough money for food...I would say the best way isn't to constantly supply someone. It would be better for the person to be employed in some way so that they can fend for themselves."* (39 year old mother)

Caregivers again highlighted the need for intensive education campaigns in the communities, which would enable them to integrate well in their communities.

> *"Plus, they should move around in the communities doing extensive education among the community members and teaching them to know that this problem is a problem that is common…So I notice that most people don't have knowledge."* (37 year old mother)

> *"So at least if they can have programs where they educate relatives in families maybe people can then help each other out if there is a child that condition and figure out how to support in terms of food and pills if there are any needed."* (31 year old mother)

One caregiver recounted how the education of colleagues at work had made it possible to attend rehabilitation therapy sessions.

> *"At work, I used to face challenges at the beginning such that sometimes I would end up crying or getting angry. As time went on and I explained to them, some were understanding, others at times feel like I am being favoured at work."* (37 year old mother)

The importance of education was highlighted by one of the key informants who mentioned that in the past, the CRU used to have a comprehensive health information programme.

> *"Because if we educate those caregivers, we would have educated the whole nation. To have the awareness campaign in the school—we used to do all that, but now we can't."* (Key informant 2, female)

Another caregiver highlighted a need for more counselling *"because a lot of people don't understand the condition".*

It was highlighted that counselling was essential due to the high levels of stress encountered by caregivers.

> *"Worse still, maybe she has returned and is now staying at the parent's house, and the parents will be stressing you, and there are also stressors coming from the husband's side."* (31 year old mother)

It was evident that caregivers felt that more counselling would lead to more caregivers accepting their child's condition.

> *"I would say if we are able to accept our situations, then all will go well for us. If we fail to accept it, there is no one from outside who can come and understand our children and us. The one who has a problem is the one who truly understands it."* (40 year old mother)

> *"You find that for some [caregivers] even buying nice clothes for a child like that to wear one feels like they are wasting/throwing away resources."* (31 year old mother)

4.10.4 Defaulter tracking

It emerged that the CRU employed different methods in the past to address non-adherence to rehabilitation therapy. Unfortunately, not much was still being done to address the issues related to defaulting, as one of the key informants highlighted.

> *"Nothing is being done. Of course, I want to be honest; nothing is being done. Sometimes what we can only do is maybe to call."* (Key informant 2, female)

The key informants mentioned three approaches that they had utilised in the past to follow up on clients who default. They had used a defaulter register to record the details of caregivers who had missed rehabilitation therapy appointments. Unfortunately, from the key informant responses, it was evident that the register was used only sometimes or not at all.

> *"But sometimes, you know that in terms of—of course we have registers, but we have not developed strong mechanisms in terms of following up."* (Key informant 3, male)

> *"I'm not sure of late, but we used to have a defaulters' register. Where we would record all the defaulters, all the phone numbers. And all things being equal—but now we've just stopped."* (Key informant 2, female)

The CRU had also used phone calls to follow up on caregivers who would have defaulted on therapy sessions as described by the key informants. Unfortunately, it also appeared as if the phone call follow-ups were done infrequently.

> *"Sometimes we have phone calls to find out how the child is doing, where they are living—just simple questions to inform you how the child is doing. Some will then tell you that the child died, which is why they are no longer coming."* (Key informant 1, female)

> *"So what usually happens is we will have phone numbers for every client that we serve. Sometimes we will call those clients who will not have come for a long time to actually understand those issues which would have caused them to relapse."* (Key informant 3, male)

The final method used by the CRU, which seemed to be very effective in the past, was home visits. From the responses given by the key informants, it emerged that the home visits were no longer taking place.

> *"Before we used to do home visits to examine what led to defaulting. That's when you would find some saying their relationships ended or they are now staying in the rural areas, so they can't come back because a lot of rentals here [Harare] are being charged in foreign currency."* (Key informant 1, female)

> *"We used to even go for, what do you call it—home visits. We used to do follow-ups for defaulters. Like really going to their residence to find out what's really going on. Why are they not attending? Why are they not coming?"* (Key informant 2, female)

4.11 Conclusion

This chapter describes the findings of the research study. The socio-demographic characteristics of the participants were described. The caregivers' understanding of rehabilitation therapy was detailed. The reasons for adherence and non-adherence to therapy were also described.

Chapter 5: Discussion

5.1 Introduction

This study sought to explore the experiences and perceptions of caregivers of children with cerebral palsy (CP) about rehabilitation therapy programmes provided by the Children's Rehabilitation Unit (CRU).

The purpose of this chapter is to discuss the significance of the findings of the study. The researcher first discusses the caregiver's understanding of the rehabilitation therapy programme. The researcher then goes on to explore the positive and negative experiences which influenced adherence or non-adherence to the therapy programme among caregivers of children with CP. The challenges faced by service providers are also discussed and their impact on adherence and non-adherence. The chapter also discussed identified suggested improvements for rehabilitation therapy from the perspective of the caregivers.

5.2 Caregivers' understanding of rehabilitation therapy programme

Caregivers of children with cerebral palsy showed that they appreciated the purpose of rehabilitation therapy. They gave various reasons as to why they felt rehabilitation therapy was important for their children. Reasons cited included increased independence in children, improved use of limbs, improved child development, and that their children with cerebral palsy could function like their able-bodied counterparts and play with them. An appreciation of the purpose of rehabilitation therapy is essential as other studies have shown that parents who did not understand rehabilitation and their child's condition, also did not participate fully in rehabilitation. However, this changed with the acceptance of their child's condition and the appreciation of rehabilitation (Paget et al., 2016).

The above, however, contradicts the sentiments of one of the key informants who said that some caregivers did not seem to recognise the importance of rehabilitation therapy as they did not seem to comprehend the importance of rehabilitation.

5.3 Reasons for adherence to therapy programme among caregivers of children with cerebral palsy

Caregivers of children with cerebral palsy described several positive experiences with the rehabilitation therapy programme at the CRU. It was essential to capture these positive experiences, as they can be used to craft the programmes that appeal to the caregivers and will likely increase acceptance and sustainability.

5.3.1 Improvement in motor function

A significant number of caregivers noted an improvement in motor functions. An improvement in motor functions enables adherence to a rehabilitation programme for caregivers of children with cerebral palsy. A study in Nigeria showed that improvements in a child with cerebral palsy saved as facilitators for caregivers to actively participate in rehabilitation therapy (Addullahi & Isah, 2020). A study in Brazil also found that mothers of children with cerebral palsy considered physical therapy vital because it increased their children’s motor development (Domenech et al., 2016).

5.3.2 Increased independence for children

Caregivers alluded to increased independence in their children with cerebral palsy. For a mother with a child with cerebral palsy, any improvement in independence was very important as the mothers had to do much more in terms of caregiving than mothers with non-disabled children. Similarly, a study in Brazil found that mothers considered physical therapy for their children with cerebral palsy important as it increased their independence (Domenech et al., 2016).

5.3.3 Education on the child's condition

Caregivers in this current study indicated that the educational support they received at the CRU was vital. A recent study by Dambi et al. (2016) confirms this data as transformative in the lives of caregivers. In that study, Dambi and colleagues 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 has been found to compromise the outcomes of rehabilitation for the affected child (Natividade et al., 2016). 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. (Alruwaished et al., 2020). Vadivelan et al. (2020) 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.

5.3.4 Being treated well

Few caregivers appreciated being treated well by service providers as a positive experience at Children's Rehabilitation Unit. When caregivers felt that they had been treated well, they were more likely to adhere to rehabilitation therapy for their child. It is possible they felt encouraged to have therapists and other health care workers who empathised with them. A study in Nigeria showed that empathy and being treated with kindness were facilitators for caregivers to actively participate in cerebral palsy rehabilitation therapy (Addullahi & Isah, 2020).

5.3.5 Frequency of sessions

Caregivers described 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 (Domenech et al., 2016). 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 supports this as it found that when caregivers of children with cerebral palsy had more sessions, it gave them more opportunity to discuss their problems and receive attention for their concerns from health workers (Brehaut et al., 2016).

5.4 Negative experiences that caregivers had with the therapy programme

5.4.1 Health care worker behaviour

The negative attitude of healthcare workers was an issue raised the most by caregivers when they recounted the negative experiences with rehabilitation therapy. Caregivers described being shouted at or scolded by the health care workers, and caregivers said that the health care workers were often in a bad mood. If health care workers have negative attitudes, it makes the caregivers reluctant to attend therapy sessions (Nuri et al., 2020). Many studies have cited the negative attitudes of nurses as a deterrent to accessing and utilizing care. Caregivers in a research study in Nigeria felt that they did not receive adequate encouragement from the therapists (Addullahi & Isah, 2020). Health care worker behaviour has been identified as a "service-related barrier" to accessing rehabilitation (Bright et al., 2018:26). On the other hand, health care workers expressed concern that the caregivers did not comply with the exercise programme that they would have been given, and this led to the health care workers getting frustrated. Despite the state of participation of caregivers, health care workers are expected to provide an environment conducive for caregivers so that they feel free to attend rehabilitation therapy sessions with their children.

5.4.2 Stigma and discrimination

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, as research has shown that caregivers in Zimbabwe frequently face stigma (Dambi et al., 2015). 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 they mentioned that their children were not able to mix with other non-disabled peers (Bunning et al., 2020). A study in India also showed that mothers of children with cerebral palsy felt "left out and isolated from society" (Vadivelan et al., 2020:7). 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 (Chiluba & Moyo, 2017). There is, therefore, need for health education in communities and health facilities to reduce stigma and discrimination.

5.4.3 Lack of family support

Lack of support from spouses and other family members was a common concern expressed by caregivers of children with cerebral palsy who participated in the study. Some women were abandoned by their partners and highlighted that men did not participate in activities at the

CRU. Such findings were similar to a study in Malawi (Paget et al., 2016). In this study, in-laws and extended family were reported as not supportive, which was found in other studies (Zuurmond et al., 2019). 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 (Addullahi & Isah, 2020). 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 (Bunning et al., 2020). Domenech et al. (2016) found in a study in Brazil that other family members must 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 improves 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 (Vadivelan et al., 2020). The lack of family support is likely to result in missed sessions and non-compliance with an exercise programme.

5.4.4 Financial challenges

The majority of the caregivers noted the high cost associated with raising a child with cerebral palsy. Chiluba and Moyo (2017) also identified the financial strain as a burden faced by caregivers of children with cerebral palsy in Zambia. The caregivers in this current 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 (Brehaut et al., 2004). It is worth noting that the majority of the caregivers in this present study were not employed, which is consistent with findings in other studies (Tilahun et al., 2016). 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 (Addullahi & Isah, 2020). 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 (Vadivelan et al., 2020). 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 (Zuurmond et al., 2019). 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 (Brehaut et al., 2004).

5.4.5 Transport challenges

Transport challenges were a recurring theme mentioned by caregivers. Where rehabilitation services exist, utilisation is influenced by environmental factors such as transportation systems (Al Imam et al., 2021). Caregivers either did not have the money to pay for transport 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. A study in India also found that mothers could not participate fully in rehabilitation as they had difficulties accessing inclusive public transport (Vadivelan et al., 2020). The COVID-19 induced lockdown created further problems in this current study as public transport was difficult to find or not available. There is a need for education and lobbying of transport officials so that transportation is both available and appropriate to meet the needs of children with disabilities and their caregivers.

5.4.6 Lack of time

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 trying to get money to raise their families. They had a heavy burden of childcare at home, which left them feeling overwhelmed (van der Mark & Verrest, 2014). Mothers of children with cerebral palsy have more roles in caregiving than mothers of non-disabled children, and a study in Zambia revealed the same (Chiluba & Moyo, 2017). Caregivers in Kenya also reported time pressures as one of the socio-economic challenges they faced in caring for children with disabilities (Bunning et al., 2020). A study in India also found that mothers of children with cerebral palsy were overburdened with childcare and had no time for other activities because of gender norms (Vadivelan et al., 2020). A study in Nigeria showed that lack of time was a barrier for caregivers to participate in rehabilitation actively, and therapists should work with caregivers to assist the caregivers in balancing their workloads (Addullahi & Isah, 2020). This finding links with the finding that caregivers do not have support from family members at home and illustrate that much still needs to be done to address social discrimination.

5.4.7 Fear of harming children during exercises

Fear of inadvertently causing harm to their children whilst performing exercises was one of the fears that caregivers highlighted. Fear has been identified as a barrier to accessing rehabilitation (Bright et al., 2018). From the other findings in this study, it can be suggested 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 (Chiluba & Moyo, 2017). A study in Nigeria also found that therapists needed to find innovative ways to help caregivers of children with cerebral palsy have the confidence to participate in rehabilitation therapy (Addullahi & Isah, 2020).

Caregivers also listed inexperience as one of their challenges, which may be tied to fear. They said that the health workers expected them to be proficient in performing the exercises, yet they were not health workers. A study in Brazil found that mothers needed several counselling sessions to overcome their fear of carrying out physical therapy exercises (Domenech et al., 2016). One of the service providers explained how it was essential for the exercises to be done at home as prescribed but that caregivers struggled to grasp the concepts. It would appear that more time needs to be spent teaching the caregivers the home exercises to ensure that they are correctly done and do no harm to the children.

5.4.8 Lack of acceptance of child's condition

Some of the caregivers expressed that it was difficult for them to accept the diagnosis and condition that their child had. Key informants concurred with these findings as they observed this among the caregivers regularly. Acceptance of a child's condition is vital as health care workers have indicated that not much progress would be achieved with children until the parents understand and accept their child's condition (Paget et al., 2016). A study in Brazil found that parents of children with cerebral palsy who were well informed and accepted the child's diagnosis tended to participate more in the rehabilitation process and had better intervention outcomes (Domenech et al., 2016). Health care workers should use "differentiated approaches" that allow the mothers the opportunity to share their; feelings, needs, doubts and concerns about the child as this will promote better understanding and acceptance (Domenech et al., 2016: 763). Lack of acceptance of the child's condition by caregivers suggests the need to introduce counselling to parents and caregivers very early after diagnoses and follow-up sessions. Follow-up sessions could provide psychological assistance to caregivers so that they can cope better.

5.4.9 Unrealistically high expectations

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 (Paget et al., 2016). A study in Riyadh on the knowledge and attitudes of caregivers of children with CP also showed that guardians of children with CP had poor knowledge about the prognosis of CP, and many of them believed that their children would be cured (Alruwaished et al., 2020). Health workers in Zimbabwe could benefit from giving as much information as required to caregivers so that they clearly understand the condition and the prognosis to prevent unrealistic expectations. Despite the comprehensive counselling programme that the CRU offers, which describes cerebral palsy and details what parents should expect, it may be prudent to review the content of the counselling sessions to ensure that they deliver the message to the caregivers in a way that is clearly understood.

5.5 Challenges faced by service providers in providing rehabilitation therapy services

5.5.1 Staff shortages

In this study, the staff shortage was identified as a factor affecting the quality of the services provided. It follows that if there is inadequate staff, then the quality of the services or sessions given to caregivers and their children with cerebral palsy would be compromised. This situation prevails in many low to medium-income countries (LMICs), as shown by various studies (Al

Imam et al., 2021; WHO, 2019; Bright et al., 2018). It is important to lobby for rehabilitation staff training and recruitment as a shortage of rehabilitation workforce has been identified as a critical access barrier for children with cerebral palsy (Jesus et al., 2016). Staff at the CRU listed low motivation as a result of poor remuneration as another challenge that they faced, consequently compromising service delivery.

5.5.2 Weak government systems

The inefficiency of the government systems, which led to poor quality services offered to children, was another health system challenge reported in this study. According to the respondents, in Zimbabwe government delegated the function of provision of services to children with disabilities and their caregivers to Non-Governmental Organisations (NGOs). Such actions might compromise the quality of services provided. Similarly, in Bangladesh, 45% of services are provided by NGO centres, and only 31% are provided by the government (Al Imam et al., 2021). Previous studies in Malawi and Zimbabwe showed similar results, with a weak government and health systems being a barrier to accessing therapy (Paget et al., 2016; van der Mark & Verrest, 2014). A study in India noted that public health systems must provide support systems for and ensure the well-being of caregivers of children with CP (Vadivelan et al., 2020). It is important to lobby the government not to abdicate their role as government organisations are vital in providing services (van der Mark & Verrest, 2014). A study in Nigeria found that government should explore ways to make rehabilitation services more accessible and should subsidise costs that caregivers may incur in accessing services (Addullahi & Isah, 2020), and this is something that could be adopted in Zimbabwe.

5.6 Areas that require improvement on the rehabilitation programmes for children with Cerebral Palsy

5.6.1 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, which would, in turn, improve family support and reduce stigma and discrimination. Targeting fathers and community members to address myths around disability was also supported by Peplow & Carpenter (2013) and Dambi & Jelsma (2014). It is clear that more needs to be done to ensure that the therapy sessions are achieving their goals. Monitoring care received is essential for informing programming and designing improvements to service delivery (Bright et al., 2018). Service delivery also needs to be decentralised so that services are closer to the people who need them. A study in Nigeria showed that this could be done by having therapists situated at primary healthcare facilities (Addullahi & Isah, 2020).

5.6.2 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. (2017) 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 (Addullahi & Isah, 2020). This illustrates the importance of the attitude of the health worker in improving the rehabilitation service for caregivers of children with disabilities. A study in Brazil showed that if health workers provide support and guidance and constantly monitor the caregivers, they will improve the quality of care they provide and make it more humane (Domenech et al., 2016). Health care workers need to create a bond of trust with the mothers, leading to better treatment outcomes for children with cerebral palsy.

5.6.3 Activities targeted at caregivers

More often, caregivers for children with CP visit health sites to access health for their children. In this study, caregivers suggested that there should be activities targeted at them to take care of their children better. An example of such activities included income-generating projects to enable them to be financially independent and able to meet the various costs that they incur. A study in Nigeria showed that the low income of caregivers was a burden that militates active participation in cerebral palsy rehabilitation (Addullahi & Isah, 2020). Financial incentives and health education are “demand-side interventions” that can be targeted at caregivers in low to middle-income countries (Bright et al., 2018:27). A study in Kenya showed that groups of caregivers of children with disabilities that engaged in income-generating activities had better adherence to therapy as the income-generating project acted as an incentive for the mothers to keep attending rehabilitation. The groups formed a support system for the mothers where they motivated one another (Bunning et al., 2020). Benefits of income-generating projects include financial support and combining efforts to gain resources to address the various financial challenges of caring for a child with a disability (Bunning et al., 2020).

5.6.4 Health Education

Caregivers highlighted the need for intensive education campaigns in the communities that would enable them to integrate into their communities as stigma and discrimination would be reduced. Caregivers also said there was a need to educate their families so that harmful myths and misconceptions about cerebral palsy would be addressed, and their families would support them. 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 (Addullahi & Isah, 2020). A study in Brazil also found that health education was essential, as parents of children with cerebral palsy who are not well informed on the importance of exercises will have difficulties doing the exercises at home and will not follow recommendations given by health workers (Domenech et al., 2016). Vadivelan et al. (2020) found that in low- and middle-income settings if caregivers are provided with adequate information on how to support the child with cerebral palsy, they will be able to effectively care for the child.

Other caregivers in this study indicated a need to strengthen health education and counselling of the parents of children with cerebral palsy to enable them to accept their child’s condition. It was highlighted that counselling is essential to address the high-stress levels of having a child with cerebral palsy.

5.6.5 Tracking of defaulters

It emerged that in the past, the CRU used to follow up clients that had defaulted on therapy, and there was a programme that aimed to ensure that defaulters resumed treatment. Unfortunately, this was no longer happening. 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 (Al Imam et al., 2021). A study in Brazil found that physical therapists should work more with mothers of children with cerebral palsy who failed to comply with home treatment and identify the reasons for non-compliance, proffer solutions and clarify doubts that the caregivers would be having (Domenech et al., 2016). It is crucial to find out why caregivers default so that programmes can be designed that improve the rehabilitation service and address the causes of caregivers defaulting therapy. It is also important to acknowledge that adherence to treatment for a lifelong condition is not easy and requires caregivers to be more committed.

Chapter 6: Conclusions and Recommendations

This chapter presents a conclusion of the study and a description of some of the recommendations on strategies that can help caregivers adhere to rehabilitation therapy. This research set out to answer the following research question: 1) What are the experiences and perceptions of caregivers of children with Cerebral Palsy, and 2) How do these experiences and perceptions influence adherence to rehabilitation therapy programmes offered by the Children's Rehabilitation Unit.

6.1 Conclusion

Caregivers of children with cerebral palsy appreciated the purpose of rehabilitation therapy. Various reasons about the importance of rehabilitation therapy included increased independence of the children, improved use of limbs, improved child development, and assisting children with cerebral palsy to be like other children and play with others. Caregivers understood the importance of adhering to therapy. They identified improved motor function, increased independence for their children, receiving education about their child's condition, being treated well by service providers, and frequency of sessions as positive experiences that they encountered. On the other hand, factors that deterred caregivers from adhering to a therapy programme included bad health care worker behaviour, stigma and discrimination, lack of family support, financial challenges, transport challenges, lack of time, fear of harming children during exercises, lack of acceptance of child's condition, not observing any benefit, and unrealistically high expectations. Key informants identified staff shortages, low motivation and weak government systems as challenges service providers faced in providing rehabilitation therapy services.

6.2 Recommendations

Based on the aforementioned conclusions and the associated literature review, the following recommendations are suggested. The proposed recommendations are not exhaustive but seek to proffer strategies that could help caregivers adhere to therapy for their children with cerebral palsy.

6.2.1 Improve service delivery

Service providers need to increase the frequency of therapy sessions so that caregivers have better insight into their children's condition and are more confident about what to do at home. Service providers should also educate fathers and family members so that they know about cerebral palsy and its causes, and by doing so, discard the negative myths and misconceptions around cerebral palsy. This will result in more family support for the caregivers.

The duration of therapy sessions should be increased to allow adequate time for caregivers to learn the appropriate skills from rehabilitation staff, and regular feedback must be sought from the caregivers to improve the therapy sessions.

6.2.2 Improve behaviour and attitude of service providers

Health care workers or service providers must be trained to show empathy so that they can display better attitudes, be more patient and treat caregivers kindly. Health workers must provide information about children's progress and justify the use of treatments. There is a need to train service providers on how to provide appropriate care and support, how to show empathy and how to build rapport with clients, as these are factors that improve adherence to rehabilitation therapy.

6.2.3 Build resilience amongst caregivers

It is crucial to empower caregivers financially so that they can overcome the financial barriers to attending therapy. There is a need to link caregivers to income-generating projects. The CRU can connect with other NGOs that have economic strengthening projects from which the caregivers could benefit.

6.2.4 Increase health education to reduce stigma and discrimination

There is a need for intensive education campaigns in the communities to reduce stigma and discrimination. It was evident that there are harmful myths and misconceptions about cerebral palsy. It is essential to take advantage of the various gatherings in communities to share accurate information about the causes and clinical manifestations of cerebral palsy.

It is imperative to strengthen the health education and counselling of the caregivers of children with cerebral palsy and their families to enable more caregivers and family members to accept their child's condition.

6.2.5 Resume tracking of defaulters

The CRU must set up a robust system to constantly follow up caregivers that default on therapy. Several factors may lead to treatment default. Through follow-up, caregivers can be supported to resume attending rehabilitation therapy and adhering to the home exercise programme that they would have been given.

6.3 Recommendations for further research

This study was conducted in an urban area in Harare, Zimbabwe. However, it would be ideal to conduct a similar study in rural areas of Zimbabwe, where the majority of the population resides and where access to health and rehabilitation therapy services may be more limited.

Further studies could also use validated tools to check the impact of caring for a child with cerebral palsy on the quality of life of the caregivers. Tools such as the PedsQL Family Impact Module could be used on caregivers. This tool has five parent subscales (physical, emotional, social, cognitive functioning, communication, and worry) and two-family subscales (daily activities and family relationships). It has been shown to have strong internal consistency and good discriminant validity. It has been utilized successfully in a similar urban setting with caregivers of children with disabilities in Uganda.

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Appendices

Appendix 1: Participant Information Sheet – Caregivers of children with cerebral palsy

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Tel: 021- 959 2809, Fax: 021- 959 2872

E-mail : soph-comm@uwc.ac.za

Project Title: Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe.

What is this study about?

This is a research study being conducted by Hillary Tafadzwa Tanyanyiwa. The research is being conducted for a mini-thesis for a Master's in Public Health at the University of the Western Cape. You are invited to take part in this research study because I value your knowledge and experiences. Your participation will help me understand some of the reasons why caregivers of children with Cerebral Palsy do not attend therapy sessions with your children. Please read this information carefully before you decide whether or not to take part in the project. Feel free to ask any questions about the project or information in the document.

The purpose of this research project is to explore the experiences of caregivers when they attend rehabilitation therapy sessions for their children with cerebral palsy. It is hoped that this research will provide recommendations on how to improve therapy programmes for children with Cerebral Palsy.

What will I be asked to do if I agree to participate?

You will be given a participant information sheet which explains what the research study is about. If you agree to participate, you will be asked to give consent. By giving consent, you indicate that you understand what you have read or what has been read to you, and you agree to take part in the research study.

You will be asked to participate in a telephone interview with the researcher. The interview will be thirty minutes long. You will be asked questions about how you have been attending therapy and any challenges you have experienced in attending therapy with your child. The interview will be recorded using True Caller software; this will ensure that I capture all the information you provide.

Would my participation in this study be kept confidential?

Your identity will be protected as will the nature of your contribution. A code will be used on the interview notes to ensure your anonymity. Your data will only be linked to your identity through an identification key, and only the researcher will have access to the identification key.

Only the researcher will have access to the voice recording, and you will not be identified. All the notes from the voice recordings and hand-written notes will be kept in a locked cabinet and will be destroyed at the end of the research. I will keep a copy of your signed consent form in a locked cabinet and will destroy it at the end of the research. All typed notes will be kept on a password-protected computer.

If a report or article is written about this research study, your identity will be protected.
In accordance with legal requirements, I will disclose to the relevant authorities any information or event that comes to my attention concerning any child abuse, exploitation or neglect or potential harm to you or others. If this occurs, I will inform you that I have to break confidentiality to fulfil my legal responsibility to report to the responsible authorities.

What are the risks of this research?
There may be some risks from participating in this research study. You may feel upset or sad talking about your child with cerebral palsy. It is possible that you may feel embarrassed by some of the questions. I will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study.

What are the benefits of this research?
This research is not designed to help you personally, but the results may help me learn more about some of the challenges that prevent caregivers like you from taking adhering to a therapy programme. It is hoped that this research will help to gain an understanding of how the experiences and perceptions of caregivers of children with cerebral palsy influence their adherence to therapy programmes offered by the Children's Rehabilitation Unit and use this information to develop strategies to improve adherence.

Do I have to be in this research and may I stop participating at any time?
Your participation in this research study voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you decide to stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify.

What if I have questions?
This research study is being conducted by Hillary Tafadzwa Tanyanyiwa, School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Hillary Tafadzwa Tanyanyiwa at:

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Bellville 7535
Tel: +263 772 433 350
Email: 3814549@myuwc.ac.za

If you should have any questions about this study and your rights as a participant in the study or if you wish to report any problems you have experienced related to the research study, please contact:

Prof Lincoln Hlatywayo
Programme Leader: Department of Disability Studies and Special Needs Education,
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This research study has been approved by the University of the Western Cape's Biomedical Research Ethics Committee

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Appendix 2: Participant Information Sheet -Key Informants

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E-mail: soph-comm@uwc.ac.za

Project Title: Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe.

What is this study about?

This is a research study being conducted by Hillary Tafadzwa Tanyanyiwa. The research is part of a mini-thesis for a Master's in Public Health at the University of the Western Cape. You are kindly invited to take part in this research study because I value your knowledge and experiences. Your participation will help me understand some of the reasons why caregivers of children with cerebral palsy do not attend therapy sessions with your children. Please read this information carefully before you decide whether or not to take part in the project. Feel free to ask any questions about the project or information in the document.

The purpose of this research project is to explore the experiences of caregivers when they attend rehabilitation therapy sessions for their children with cerebral palsy. It is hoped that this research will provide recommendations on how to improve therapy programmes for children with cerebral palsy.

What will I be asked to do if I agree to participate?

You will be given a participant information sheet which clearly explains what the research study is about. Should you agree to participate, you will be asked to sign a consent form. By signing the consent form, you indicate that you understand what you have read and you agree to take part in the research study. You will be given copies of both the consent for and participant information for your records.

You will be asked to participate in an online interview via Zoom with the researcher. The interview will be one hour long.

You will be asked questions about the reasons for non-adherence of caregivers of children with cerebral palsy to a therapy programme. The interview will be recorded using the Zoom facility that allows recording to ensure that I capture all the information you provide.

Would my participation in this study be kept confidential?

Your identity will be protected as will the nature of your contribution. A code will be used on the interview notes to ensure your anonymity. Your data will only be linked to your identity through an identification key, and only the researcher will have access to the identification key.

Only the researcher will have access to the voice recording, and you will not be identified. All the notes from the voice recordings and hand-written notes will be kept in a locked cabinet and will be destroyed at the end of the research. I will keep a copy of your signed consent form in a locked cabinet and will destroy it at the end of the research. All typed notes will be kept on a password-protected computer.

If a report or article is written about this research study, your identity will be protected.
In accordance with legal requirements, I will disclose to the relevant authorities any information or event that comes to my attention concerning any child abuse, exploitation or neglect or potential harm to you or others. If this occurs, I will inform you that I have to break confidentiality to fulfil my legal responsibility to report to the responsible authorities.

What are the risks of this research?
All human interactions and sharing information about oneself or others carry some risks. I will reduce such risks and will quickly help you if you experience any discomfort, psychological or otherwise during the process of your participation in this research study. In the event that one is required, a referral will be made to a relevant professional for further assistance or intervention.

What are the benefits of this research?
This research is not designed to help you personally, but the results may help me to establish the reasons for non-adherence of caregivers of children with cerebral palsy to therapy programme among those who defaulted and use this information to develop strategies to improve adherence and reduce the number of defaulters. It is hoped that this information will be used to develop strategies to improve adherence.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research study is entirely voluntary. You may decide not to participate at all. If you decide to take part in this research study, you may stop participating at any time. Should you decide not to take part in this research study or if you stop participating at any time, you will not be penalised or lose any benefits to which you otherwise qualify.

What if I have questions?
This research is being conducted by Hillary Tafadzwa Tanyanyiwa, School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact Hillary Tafadzwa Tanyanyiwa at:

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Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee

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Appendix 3: Participant Information Sheet - Caregivers of children with cerebral palsy (Shona Version)

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Mvekerwa yekutanga

Zvevachabatsira vanochengeta vana vane hurema hwekuoma mitezo

Musoro wetsvakurudzo : Maonero nezvinosanganikwa nazvo nevanochengeta vana vane hurema hwekuoma muviri pazvirongwa zveurapi hwekutwasasudza zvakakanganisika mumiviri yevana vavo, muZimbabwe.

Tsvakurudzo ino iri pamusoro pei ?

Ino itsvakurudzo iri kuitwa naHillary Tafadzwa Tanyanyiwa. Tsvakurudzo iyi iri kuitwa sechikamu chetsvakurudzo chinodiwa pakuzadzisa dhigirii rePublic Health padanho repamusoro paUnivhesiti yeWestern Cape muSouth Africa. Muri kukokwa kuti muve chikamu chetsvakurudzo iyi nokuti ndinokoshesa ruzivo rwenyu uye shwiro dzamava nadzo pane zvevana vane urema hwekuoma mitezo. Kutora kwenyu chidanho mutsvakurudzo ino kuchandibatsira kunzwisisa zvimwe zvezvikonzero zvionita kuti vanochengeta vana ava vasapinda muhurongwa hwekubetsera paurapi kunorerutsa uye kutasanudza zvakakanganisika mumiviri yevana ava. Ndinokumbira kuti munyatsoverenge umboo huri pachinyorwa chino musati mazvipira kuti muve chikamu chetsvakurudzo ino. Ivai makasungunuka kubvunza zvakanangana netsvakurudzo ino kana humwe humboo huri muchinyorwa chino.

Chinangwa chetsvakurudzo ino kutsvaga zvinosanganikwa nazvo nevanochengeta vana vane urema hwekuoma mitezo pavanopinda muzvirongwa zvine chekuita neurapi hunobatsira kurerutsa kana kutwasanudza zvakakanganisika mumitezo yevana ava. Itarisiro yangu kuti tsvakurudzo ino ichapa kurudziro dzichabatsira panhau iyi.

Ndezvipi zvandichakumbirwa kuti ndiite kana ndabvuma kuva chikamu chetsvakurudzo ino?

Muchange muchipiwa chinyorwa chinotsanangura kuti tsvakurudzo ino yakanangana nei. Kana mabvuma kuva chikamu chetsvakurudzo ino muchakumbirwa kuti musaine pagwaro rekubvuma kuva chikamu chetsvakurudzo ino. Kusaina kwamuchaita chiratidzo chokuti munenge maverenga mukanzwisisa kana kuti maverengerwa mukanzwisisa gwaro iri uye mukabvuma kuva chikamu chetsvakurudzo ino. Muchapihwa gwaro rekubvuma kwanyu uye chinyorwa chinotsanangura nezvetsvakurudzo ino kuti muzvichengetere.

Muchakumbirwa kuti muve chikamu mibvunzo yeparunhare nemutsvakurudzi uno. Mubvunzo ichatora nguva inokwana maminitsi makumi matatu chete uye ichaitirwa parunhare. Muchabvunzwa mibvunzo yakanangana nekuva chikamu chezvirongwa zveurapi hwekutwasanudza zvisina kumira zvakanaka mumitezo yevana ava uye kana pane zvimhingamupinyi/zvigozhero zvamunosangana nazvo pakuva chikamu cheurongwa uhu. Mumibvunzo yaparunhare umu muchange muchitapiwa kuti ndisazorasikirwe nezvimwe zvinenge zvabuda munhaurirano yedu.

Kuva kwangu chikamu chetsvakurudzo ino kuchachengetedzwa sei?

Ndichachengetedza kuti ndimi ani uye zvamunenge mabatsira nazvo mutsvakurudzo ino. Kuchengetedza kwandichaita izvi mucherechedzo uchaiswa pachinyorwa chemubvunzo. Mucherechedzo uyu uchabatsira kuti ndizoziva kuti mhinduro dzipi dzakabva kuna ani. Ini ndini chete ndichakwanisa kuva neumboo uhu. Kuchengetedza zvakare izvi ini ndini chete ndichava nemukana wekuteerera zvatinenge tatapa panguva yatinenge taita mubvunzo yeaprunhare. Zvichatapwa zvose uye zvinyorwa zvose zvichachengetedzwa zvakakiyirwa uye zvozoparadzwa mushure mekunge tsvakurudzo yapera. Gwaro rekubvuma kuita tsvakurudzo ramunenge masayina ndicharichengetedza rakakiyirwa rozoparadzwa mushure metsvakurudzo. Zvinyorwa zvose zvichaitwa pamushini zvichachengetedzwa pakombiyuta.

Kana pakaitwa chinyorwa pamusoro petsvakurudzo ino zita renyu richavanzwa zvakachengetedzeka. Zvichienderana nezvemitemo uye zvekukosha kwebasa rangu ndichabudisa umboo, kune vanokodzera kuziva, uhwo hune chekuita nekushungurudzwa kana kusabatwa zvakanaka kwevana kwauri nevamwe kana ndasangana nazvo mukutsvaga zvakanangana netsvakurudzo ino. Ndichakuzivisai kuti ndave kubvanyangura tendero yekuvanza zita rako neumboo hwamunenge wabudisa kuti ndizadzise zvinotarisirwa pabasa rangu rezvekuchengetedza mitemo kuti ndizivise vanokodzera kuziva izvi.

Ndedzipi njodzi dzetsvakurudzo ino?

Pangangova nenjodzi/zvigozhero pakuva kwanyu chikamu chetsvakurudzo ino. Mungangonzwa kusasungunuka, kusuwa kana kurwadziwa nekutaura nezvemwana wenyu ane urema hwekuoma mitezo. Zvinogonawo kuti mungangonzwa kunyara kupindura mimwe mibvunzo. Ndichaedza kuderedza zvakadai uye ndichaiedza kubatsira pamwe kuti zvakadai zvisakukanganisai kana manzwa zvinokurwadzai kana kukunetsai mupfungwa nekuda kwemibvunzo yangu.

Tsvakurudzo iyi inobatsirei

Tsvakurudzo iyi haipo kukubatsira sedungamunhu asi zvichabuda mairi zvingangondibatsira kuwana zivo yakanangana nezvimhingamupinyi zvinotadzisa vanochengeta vana vane urema hwekuoma mitezo kuva vanotevedzera zvirongwa zveurapi hwekutwasanudza kana kugadzirisa zvisina kumira zvakanaka mumitezo. Ndine tarisiro yekuti tsvakurudzo iyi ichabatsira kuti ndiwane nzwisiso yekuti zvinosanganikwa nazvo nevanochengeta vana vakadai uye mafungiro avo ane nzvenzvero dzipi pakuva kwavo chikamu uye kutevedzera zvirongwa izvi zvinoitwa neveChildren's Rehabilitation Unit. Izvi zvinotarisirwa kubatsira kuzovapo kwenzira kana matanho ekudzivirira zvimhingamupinyi zvingavapo.

Ndinofanira here kuva chikamu chetsvakurudzo iyi uye ndinogona here kuzorega pakati petsvakurudzo?

Kuva kwanyu chikamu chetsvakurudzo iyi kuzvidira uye hakumanikidzwe. Munogona kusarudza kusava chikamu chetsvakurudzo ino. Kana masarudza kuva chikamu chetsvakurudzo ino munogona kuzoregera pakati chero pamunenge wanzwa musisadi, hamumanikidzwi uye hapana mhosva yamunopihwa. Hapanazve zvamunorasikirwa nazvo.

Ko kana ndiine mibvunzo

Tsvakurudzo ino iri kuitwa naHillary Tafadzwa Tanyanyiwa wepaSchool of Public Health paUnivhesiti yeWestern Cape. Kana muine mibvunzo yakanangana netsvakurudzo ino makasungunuka kubata Hillary Tafadzwa Tanyanyiwa pa:

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Pamwe mungave nemibvunzo yakanangana netsvakurudzo ino uye kodzero dzenyu semumwe ari chikamu chetsvakurudzo iyi uye kana muchida kumhangara chero matambudziko amungasangane nawo pakuitwa kwetsvakurudzo ino makasununguka kubata vanotevera:

Prof Lincoln Hlatywayo
Programme Leader: Department of Disability Studies and Special Needs Education,
Zimbabwe Open University, Faculty of Applied Social Science
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Tsvakurudzo ino yakatenderwa kuti iitwe nevebazi reBiomedical Research Ethics Committee reUnivhesiti yeWestern Cape.

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Appendix 4: Participant Consent Form – Caregivers of children with cerebral palsy

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E-mail : soph-comm@uwc.ac.za

Title of Research Project: Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe.

The research project has been described to me in a language that I understand. My questions about the research project have been answered. I clearly understand what my participation will involve, and I agree to participate of my own choice and free will. I understand that my identity will be kept confidential. I understand that I may withdraw from the research study at any time without giving a reason and without fear of any negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

Participant's name……………………………………
Participant's signature……………………………….
Date………………………

Appendix 5: Participant Consent Form – Key Informants

UNIVERSITY OF THE WESTERN CAPE
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Title of Research Project: Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe.

The research project has been described to me in a language that I understand. My questions about the research project have been answered. I clearly understand what my participation will involve, and I agree to participate of my own choice and free will. I understand that my identity will be kept confidential. I understand that I may withdraw from the research study at any time without giving a reason and without fear of any negative consequences or loss of benefits.

___ I agree to be audiotaped during my participation in this study.

___ I do not agree to be audiotaped during my participation in this study.

Participant's name…………………………………..
Participant's signature……………………………….
Date…………………………………………………………

Appendix 6: Participant Consent Form – Caregivers of children with Cerebral Palsy (Shona Version)

UNIVERSITY OF THE WESTERN CAPE
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E-mail: soph-comm@uwc.ac.za

Musoro wetsvakurudzo : Zvinosanganikwa nazvo uye maonero ane nzvenzvero pakubatirira pazvirongwa zveurapi hwekutwasudza zvakakanganisika mumiviri kune vanochengeta vana vane hurema hwekuoma mitezo muguta reHarare, muZimbabwe.

Tsvakurudzo yatsanangurwa kwandiri nemutauro wandinonzwisisa. Mibvunzo yangu nezvetsvakurudzo yapindurwa. Ndinonzwisisa kuti kuve kwangu mutsvakurudzo ino kunoda zvii, uye ndinobvuma kuve mutsvakurudzo ndega nekuzvidira. Ndinonzwisisa kuti zita rangu harizopiwe vamwe vanhu nevatsvakurudzi. Ndinonzwisisa kuti ndinogona kubuda mutsvakurudzo chero nguva pasina kupa/kutsanangura zvikonzero uye pasina kutya uye zvakaipa zvingauye. Ndinonzwisisa kuti tsindidzo ine chekuita nekuchengetedza tsindidzo kwevese vachapinda muhurukuro yeboka.

___ Ndinobvuma kutapiwa ndichitaura mutsvakurudzo ino.
___ Hadibvumi kutapiwa ndichitaura mutsvakurudzo ino.

Zita ………………………..……………

Saina: ………………………………. ……..

Zuva ………………………………………

Appendix 7: Guide to conducting Interviews with caregivers of children with cerebral palsy

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1. Can you tell me your age?
2. How many children do you have?
3. What diagnosis does your child have?
4. At what age was you child given the diagnosis?
5. How old is your child?
6. Is your child male or female?
7. What services are offered to children at the Children's Rehabilitation Unit?
8. Why do you think these services are provided to children with CP?
9. Can you share good experiences you have had with the therapy programmes?
10. Can you share challenges you have encountered with the content or delivery of therapy programmes?
11. What other problems do you face in attending therapy sessions with your children e.g., money, transport, family support?
12. What do you think can be improved on the therapy programmes for children with CP?

- By service providers
- For caregivers

Appendix 8: Guide to conducting Interviews with caregivers of children with cerebral palsy (Shona Version)

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School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa
Tel: 021- 959 2809, Fax: 021- 959 2872

E-mail : soph-comm@uwc.ac.za

1. Munemakore mangani ekuberekwa?
2. Mune vana vangani?
3. Mwana wenyu anechirwere chei?
4. Chirwere chemwana chakabatwa anemakore mangani?
5. Mwana wenyu anemakore mangani ekuberekwa?
6. Mwana wenyu mukomana kana kuti musikana?
7. Nedurupi rubatsiro rwuri kupihwa kuvana kuno kuChildren’s Rehabilitation Unit?
8. Nhemaka yei rubatsiro urwu rwuchipiwa kuvana vane mitezo yakaoma?
9. Kuona kwenyu ndezvipi zvakanaka zvamakaona kana kudzidza maererano nezvichirongwa chekurapa vana vane mitezo yakaoma?
10. Ndeapi matambudziko amakasangana nawo muchirongwa chekurapa nekutwasanudza vana vakaoma mitezo?
11. . Ndeapi mamwe matambudziko amunosangana nawo pakuuya nevana kuti vazobatsirwa zvinhu zvakaita semari, kufamba nevana, rubatsiro kubva kuhama?

12. Ndezvepi zvamunofunga kuti zvingada kugadziriswa kuti chirongwa chevana ichi chifambiswe zvakanaka?

-Kune vanobatsira vana pachipatara

-Kune vanochengeta vana

Appendix 9: Guide to conducting key informant interviews

UNIVERSITY OF THE WESTERN CAPE
School of Public Health

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Tel: 021- 959 2809, Fax: 021- 959 2872

E-mail : soph-comm@uwc.ac.za

1. How old are you?
2. What is your gender?
3. How long have you worked at the Children’s Rehabilitation Unit (CRU)?
4. Describe your role at the Children’s Rehabilitation Unit (CRU).

Prompt

- What is your involvement in the therapy programme for children with cerebral palsy?

5. . How are caregivers informed about their child’s diagnosis of cerebral palsy?

Prompts

- What information do you share about causes of cerebral palsy?
- What information do you share about treatment of cerebral palsy?

6. . What process do you follow before initiating the children on therapy? What is the information given to the caregivers regarding therapy?

Prompt

- Who provides this information?

7.. How do the caregivers react when they are told about cerebral palsy?

8. How do the caregivers feel about therapy in general?

9. Tell me about the counselling and support that is provided by CRU

Prompt

- Who provides this counselling?

10 What are some of the challenges you have faced in providing therapy services?

Prompts

- Health provider personal challenges

- Health facility-related challenges
- Caregiver related challenges

11. How do you/ CRU address these challenges?

12. Are you aware of any challenges experienced by the caregivers that might have led to non-adherence?

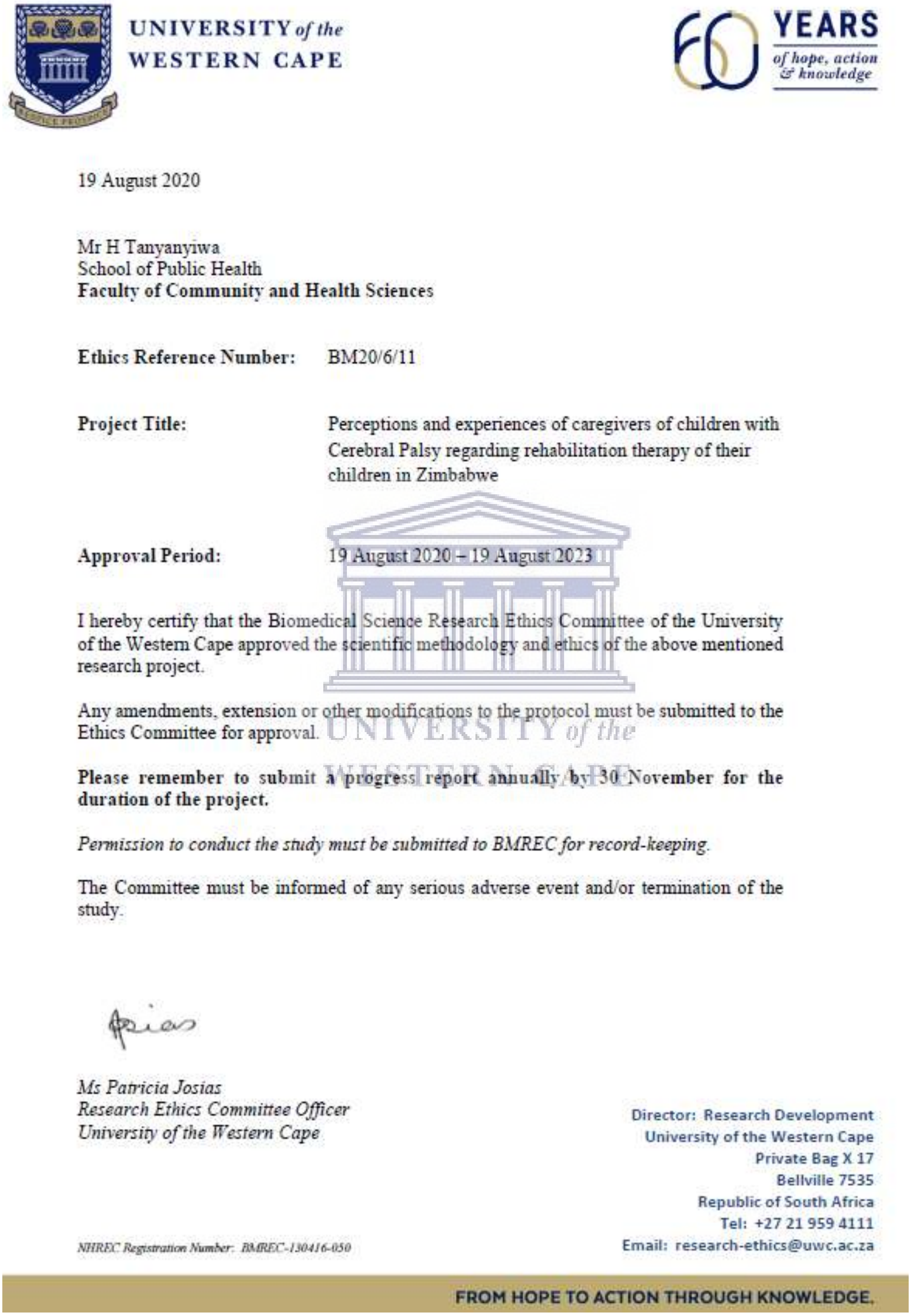
10. How does the CRU help caregivers address these challenges?

11. What is the CRU’s view on non-adherence?

Prompts

- Do you collect data – e.g., how many caregivers default, reasons for non-adherence
- Is the CRU concerned about non-adherence?

Appendix 10: BMREC Ethics Approval Letter



UNIVERSITY *of the*
WESTERN CAPE

60 YEARS
of hope, action & knowledge

19 August 2020

Mr H Tanyanyiwa
School of Public Health
Faculty of Community and Health Sciences

Ethics Reference Number:	BM20/6/11
Project Title:	Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe
Approval Period:	19 August 2020 – 19 August 2023

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report annually by 30 November for the duration of the project.

Permission to conduct the study must be submitted to BMREC for record-keeping.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

Director: Research Development
University of the Western Cape
Private Bag X 17
Bellville 7535
Republic of South Africa
Tel: +27 21 959 4111
Email: research-ethics@uwc.ac.za

NHREC Registration Number: BMREC-130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

Appendix 11: Hospital Ethics Approval Letter

Telephone: 621100-19
Fax: 621157

ZIMBABWE

Reference: HCHEC 240820/39

HARARE CENTRAL HOSPITAL
P. O. Box ST 14
SOUTHERTON
Harare

27 August 2020

Mr. Hillary T Tanyanyiwa
42 Bates Street,
Milton Park
HARARE

Dear Mr. Tanyanyiwa

REF: PERCEPTIONS AND EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY REGARDING REHABILITATION THERAPY OF THEIR CHILDREN IN ZIMBABWE

I am glad to advise you that your application to conduct a study entitled: **Perceptions and Experiences of Caregivers of Children with Cerebral Palsy Regarding Rehabilitation Therapy of Their Children in Zimbabwe** (Ref: **HCHEC240820/39**), has been approved by the Harare Hospital Ethics Committee.

This approval is premised on the submitted protocol. Should you decide to vary your protocol in any material way please submit these for further approval.

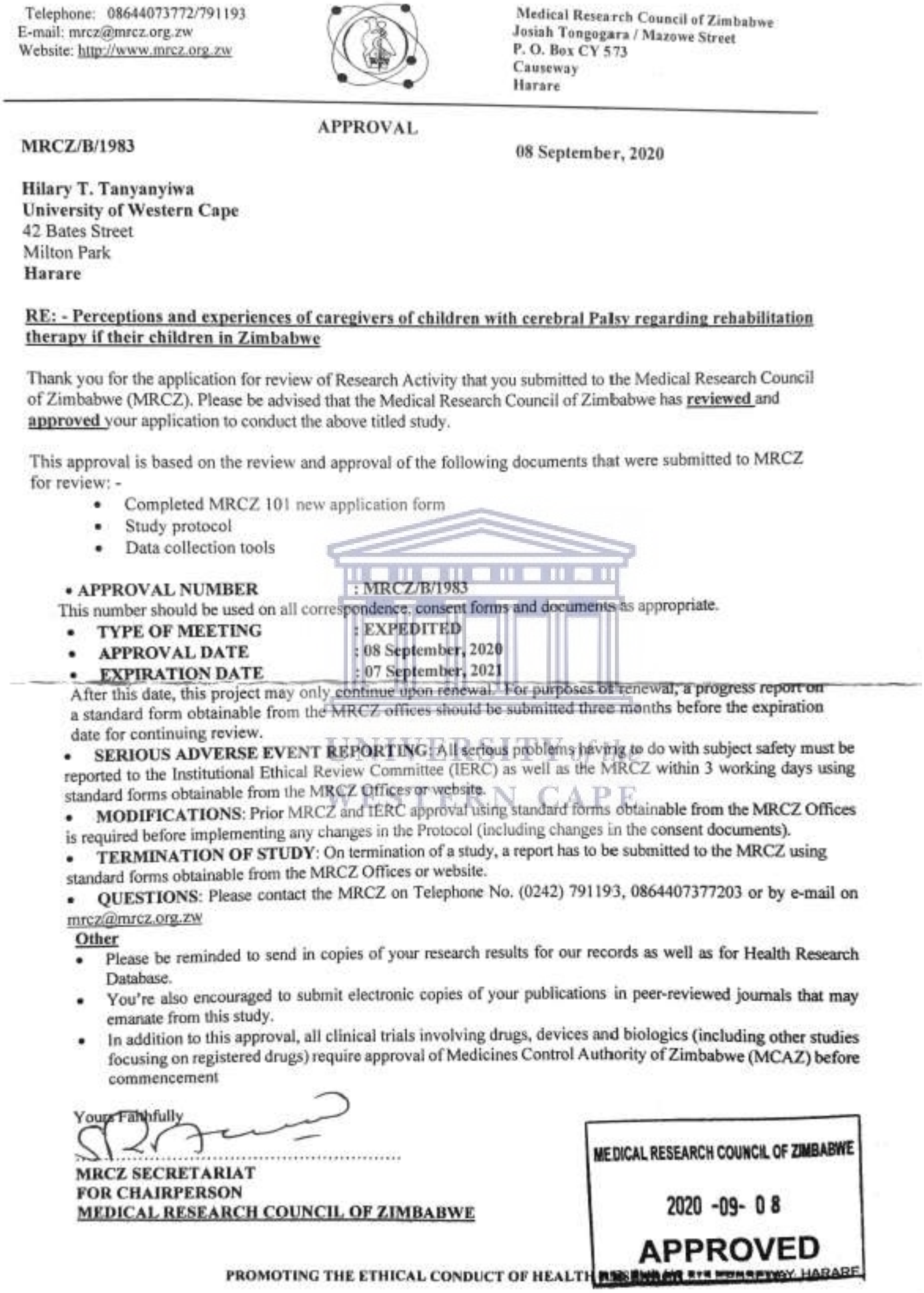
You are advised to avail the results of your study whether positive or negative to the hospital through the committee for our information.

Yours sincerely,

SALLY MUGABE CENTRAL HOSPITAL
CLINICAL DIRECTOR
27 AUG 2020
P.O. BOX ST 14, SOUTHERTON
HARARE, ZIMBABWE

DR. C. Pasi
Chairman Harare Central Hospital Ethics Committee

Appendix 12: MRCZ Ethics Approval Letter



Telephone: 08644073772/791193
E-mail: mrcz@mrcz.org.zw
Website: http://www.mrcz.org.zw

Medical Research Council of Zimbabwe
Josiah Tongogara / Mazowe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL

MRCZ/B/1983

08 September, 2020

Hilary T. Tanyanyiwa
University of Western Cape
42 Bates Street
Milton Park
Harare

RE: - Perceptions and experiences of caregivers of children with cerebral Palsy regarding rehabilitation therapy if their children in Zimbabwe

Thank you for the application for review of Research Activity that you submitted to the Medical Research Council of Zimbabwe (MRCZ). Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study.

This approval is based on the review and approval of the following documents that were submitted to MRCZ for review: -

- Completed MRCZ 101 new application form
- Study protocol
- Data collection tools

- **APPROVAL NUMBER** : **MRCZ/B/1983**

This number should be used on all correspondence, consent forms and documents as appropriate.

- **TYPE OF MEETING** : **EXPEDITED**
- **APPROVAL DATE** : **08 September, 2020**
- **EXPIRATION DATE** : **07 September, 2021**

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ offices should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING**: All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ Offices or website.
- **MODIFICATIONS**: Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ Offices or website.
- **QUESTIONS**: Please contact the MRCZ on Telephone No. (0242) 791193, 0864407377203 or by e-mail on mrcz@mrcz.org.zw

Other

- Please be reminded to send in copies of your research results for our records as well as for Health Research Database.
- You're also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.
- In addition to this approval, all clinical trials involving drugs, devices and biologics (including other studies focusing on registered drugs) require approval of Medicines Control Authority of Zimbabwe (MCAZ) before commencement

Yours Faithfully

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE

MEDICAL RESEARCH COUNCIL OF ZIMBABWE
2020 -09- 08
APPROVED

PROMOTING THE ETHICAL CONDUCT OF HEALTH [illegible] HARARE