

Caregiver Perceptions about Factors Impacting their Ability to Carry out Home-Based Therapy Programmes in Central Botswana: A Qualitative Study

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ABSTRACT

Purpose: Home-based programmes, as an aspect of Community-Based Rehabilitation (CBR), are provided as an integral part of remedial programming for children with disabilities in central Botswana. Difficulties with integration of these activities into daily living have been observed. The study therefore aimed to gain an in-depth picture of caregiver and therapist perceptions about the factors that impacted ability to carry out prescribed therapy at home.

Method: Purposive sampling was used to recruit therapists and caregivers of children with disabilities, through active occupational therapy and physiotherapy contacts in central Botswana. Caregivers lived in different villages served by CBR and the children had been referred for therapy at the NGO branch office. Semi-structured qualitative interviews were conducted for data collection. Twelve questions for caregivers and 9 for therapists were presented during in-person meetings. Interviews with 5 caregiver family members and 4 therapists were audio-recorded and transcribed by the first author. Thematic analysis combined manual coding and NVivo software.

Results: Participant response themes described both direct and indirect influences on adherence to the home programme. Direct influence themes were child characteristics, therapy competence and frequency, competing demands, and other issues. Indirect influence themes, which represented major impediments for carrying out a home programme, were insufficient preparedness of healthcare providers, mismatched social welfare services, support system inadequacies, and language barriers.

Conclusion: Although onset of the COVID-19 pandemic interfered with completion of all planned interviews, which was a limitation of the study, the

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findings underscore the need for understanding the lived experiences of parents and other caregivers who are charged with carrying out home-based therapy programmes for children with disabilities. Given this knowledge, workers in the CBR system can implement solutions in the community that are designed to educate policymakers and workers in the social welfare system, while assisting clients to overcome barriers and advocate for their needs.

Key words: *children with disabilities, Botswana, home programmes, qualitative research, community-based rehabilitation, barriers, effectiveness, social welfare services, caregiver support*

INTRODUCTION

Botswana, one among many developing African nations, was described as one of the poorest counties in the world at the time it achieved independence in 1966. It has since progressed to becoming a middle-income country, striving to promote social justice and inclusion for children and adults with disabilities. It is an established welfare state, in that social assistance programmes are in place, which are financed primarily by mineral rents (Botlhale et al, 2019). The social assistance and rehabilitation programmes that were developed have been modelled after the 2008 United Nations Convention on the Rights of Persons with Disabilities (CRPD), the National Policy on Care for People with Disabilities (NPCPD), and the Convention on the Rights of the Child, ratified in 1995 (Botswana Institute for Development Policy Analysis, 2013; United Nations Development Programme, 2019). Botswana ratified the CRPD on August 12, 2021 (Southern Africa Litigation Centre, 2022). Community Based Rehabilitation (Helander, 1999; WHO, 2004, 2010) was field-tested in Botswana from 1981 to 1984 (Ingstad, 1997).

This qualitative study was conducted in the central region of Botswana. The first author, a practising occupational therapist in the region, frequently noted in his encounters with caregivers and other therapists that home-based programmes for a child living with a disability were being carried out inconsistently or not at all. Caregivers – either parents or other family members - were facing difficulties with incorporating therapist-prescribed therapeutic exercises, functional activities, play and positioning into daily living. These families received rehabilitation services through a non-governmental organisation (NGO) that worked closely with government agencies and delivered a variety of programmes, including community outreach intended to support rehabilitation and social inclusion for individuals with disabilities. The first author was hired by the NGO to provide

occupational therapy in an outreach project that was termed Community-Based Rehabilitation (CBR) and was supported by the larger healthcare system.

Findings of research conducted in other Southern African countries echoed the first author's observations about challenges faced by caregivers of children with disabilities. Families faced barriers to community participation, access to health services, and educational resources, all of which would compound hindrances to successful home-based programme adherence and compliance (Lundgren-Lindquis & Nordholm, 1996; Chappell & Johannsmeier, 2009; Grut et al, 2012; Hansen et al, 2014; Bongo et al, 2018).

In the current study, the authors aimed to gain an in-depth understanding of the lived experiences of parents and other caregivers charged with providing home-based therapeutic programmes and to corroborate these experiences with the reports of therapy professionals. They anticipated that an interplay of factors - some consistent with published reports of research and others unique to central Botswana - had been influencing caregivers' capacity to incorporate a child's home programme into the daily routine of the household. Ultimately, the knowledge gained could be used to provide a foundation for educating workers within CBR and welfare systems, as well as policymakers, and lead to implementation of solutions for overcoming barriers and advocating for needs in the community.

Overview of Social Welfare Services in Botswana

Among the state-run social welfare services, the ones most relevant to families of children living with a disability are child support grants, destitute persons allowances, vulnerable groups supplemental feeding food baskets, transport allowance for medical check-ups, community home-based care, and other assistance such as emotional or psychological support. These services have been instituted to provide assistance to the most vulnerable, particularly those who are poor and excluded, in adherence to the concept of *kutlwelo bothoko* or compassion, and guided by the National Poverty Reduction Strategy (NPRS). Social welfare service workers are tasked with assessing the socioeconomic status of families and determining their level of qualification for specific benefits (Maudeni & Mupedziswa, 2017; Bothale et al, 2017).

Deficiencies in welfare system programmes in Botswana, however, have been described in terms of insufficient clarity and comprehensiveness of policies or operational guidelines, "lack of coordination, poor implementation, and

ineffective utilisation of resources and lack of accountability” (Maundeni & Mupedziswa, 2017). Analysts and researchers have pointed to the need for reforms to optimise social spending (Botlhale et al, 2019), as well as multiple barriers to the exercise of rights, including stigma and discrimination, deficiency of supporting infrastructure and transportation, and poor availability of information and communication technologies that would enhance access to essential knowledge about disability rights and available services (Mukhopadhyay & Moswela, 2019). Philpott (2014) commented on the potential of the CRPD as a lens to identify and transform gaps and limitations in policies for children with disabilities. Clearly, the ongoing work that is essential for identifying and supporting caregivers of children with disabilities is just beginning, and that is why the CBR approach to supporting families that have members with disability is widely advocated.

Community-Based Rehabilitation in Central Botswana

The context for this study was the existing CBR outreach project. According to CBR Guidelines, providing a remedial programme for a child with a disability in the natural home or classroom environment will enhance development of his or her innate abilities and optimise the benefits of therapeutic services (Khasnabis & Motsch, 2010). Bongo and colleagues (2018) studied the effectiveness of the Chipinge World Vision CBR programme for children with a variety of disabilities in a region of Zimbabwe and concluded, “CBR has been successful in reaching some of the poorest families and their children with disabilities by making daily life better with valuable, practical skills, devices, creating integration and lessening discrimination and social integration”. The capacity of the primary caregiver to administer a programme is of key importance, nonetheless. As an illustration, mothers in Zambia reported lack of social acceptance, misunderstanding of disability, travel inaccessibility, financial burdens, experiences of self-doubt and fear, and feeling alone and isolated despite support from the CBR programme and their own resourcefulness (Hansen et al, 2014). These broader patterns, though often undisclosed, are important considerations. What an occupational therapist or physiotherapist in central Botswana might judge as noncompliance and neglect on the part of caregivers might be the result of constraints created by the interaction of individual misfortune and existing medical, social, cultural, and historical influences.

The first author was part of a team of CBR therapists who travelled to a number of remote villages in central Botswana on a daily basis from Monday through

Thursday. Each village was served by a primary care clinic or smaller health post facility within an average radius of one to two kilometres, staffed mainly by nurses and sometimes by doctors. Travelling therapists provided rehabilitation services in these primary care clinics, as well as in homes and schools. It should be noted that service availability varied considerably among villages and not all locations are served by the CBR outreach. When it comes to the attention of a nurse, therapist or volunteer that a child with a disability has medical or rehabilitative needs beyond what CBR can offer, they can be referred for specialised health-related medical or rehabilitative care to a government primary care hospital or the NGO branch office rehabilitation centre, which are both located in a town 30 to 120 kilometres from villages in central Botswana that are served by the outreach project. After being seen, the child may be referred for monthly or bimonthly outpatient visits at either the hospital or NGO branch office. CBR therapists coordinate with the clients, social workers, volunteers and clinics regarding various referrals. The CBR therapy team members are available for outpatient visits at the NGO branch office on Fridays.

Though the outreach programme in which the first author initially provided occupational therapy was called CBR by the NGO, his observations indicated that this service was more consistent with the medical model and health-related specialist rehabilitation. In keeping with a CBR Joint Position Paper (WHO, ILO, UNESCO, 2004), CBR should be “implemented through the combined efforts of people with disabilities themselves, their families, organisations and communities, and the relevant governmental and non-governmental health, education, vocational, social and other services”. In other words, the programme should be ongoing within the village and run by the community, with professionals coming in as consultants. “Because CBR belongs to the community, representatives of the community must be involved in the planning, implementation and evaluation of CBR programmes” (p. 13).

Therefore, the first author set up exploratory wellness programmes via partnership with community members in some of the villages in central Botswana. These addressed chronic health issues in adults as well as the health, function and activity restrictions of children with conditions such as autism and cerebral palsy. CBR volunteers who were residents of the villages were recruited to work with clinic staff, village development committees, village leadership, and the outreach team, on issues of community members with disabilities. He worked with community volunteers who helped check on people with disabilities in their

homes and various environments, and also with social workers, nurses and other community leaders who assisted with highlighting the issues of people with disabilities to the healthcare community in general. The aim was to exemplify the evolving social model of CBR by enhancing community involvement, promoting continuation of care, and increasing awareness of environmental barriers to inclusion and participation. Therapists provided technical support by teaching techniques that could be applied independently in the wellness centres and in the home. Members of the villages expressed a sense of ownership. The first author also helped to organise community groups to deal with some of the challenges related to caring for a child with a disability, offer support and solutions amongst themselves about caregiving, and initiate advocacy channels that included support groups. Nevertheless, this CBR community outreach was apparently not addressing all component factors that would ensure the success of a home-based programme in central Botswana. As failure to carry out home-based programmes for children persisted, the authors determined that this problem should be a key research focus.

Objective

The primary objective for this project was to inform practices in both health-related specialist rehabilitation and in the CBR-affiliated aspects of programme delivery in order to fully understand barriers to effective care for children with disabilities. This required obtaining a comprehensive picture of caregiver and therapist perceptions regarding factors that influenced the lives of these children directly or indirectly. In particular, the authors wished to learn details about caregivers' reports of factors that impacted their ability to carry out home programmes. The perspectives of occupational therapists and physiotherapists, as well as caregivers, were sought to determine the degree to which points of view were consistent. The objective in the long term was to equip CBR therapists and workers with tools they could use to empower parents and caregivers to overcome barriers, and to communicate with various official bodies regarding recurrent issues and needs, particularly governmental and non-governmental departments that provide services to children with disabilities and their families. The research questions were:

- 1) Why are parents and other caregivers of a child with a disability in rural central Botswana not carrying out home-based therapeutic programmes?
- 2) Could barriers be addressed in the context of the CBR outreach project?

METHOD

Study Design

A phenomenological qualitative research design was used to gather information about the lived experiences and perceptions of study participants (Vagle, 2018). Qualitative research was selected as a foundational approach for identifying unique issues relevant to this local population and as a basis for improving the effectiveness of care for children with disabilities.

The first author carried out the study, and the second author served as research design and academic writing consultant. Throughout the time of the study, the first author was employed by the NGO in Botswana that oversees a variety of rehabilitation and social inclusion programmes for people with disabilities.

Study Participants

A purposive sampling method was used, based on familiarity with the population of interest.

Five caregivers from among clients who lived in different villages served by CBR were recruited for semi-structured qualitative interviews by the first author. Children sometimes received alternate therapy sessions in the government hospital and a few caregivers could afford the services of a private physiotherapy clinic in town. Because of the need for special attention, they had been referred for outpatient rehabilitation at the NGO branch office and had attended one or more sessions. Caregivers who participated in the interviews represented a range of backgrounds and experiences, including position on a socioeconomic spectrum that ranged from middle class to destitute, married couples and single parents, employed and unemployed. The caregivers looked after children who were clinically complex - either a child with a physical disability or a condition such as autism or sensory motor deficits - who were ambulatory but presented a high burden of care.

Prospective participants were identified from among caregivers encountered when they brought a child to receive therapy and during home visits or phone calls to book appointments. To qualify for inclusion, the prospective participant needed to be fluent in English or Setswana—which is the local language—and caring for one or more children currently receiving occupational therapy or physiotherapy services or who received one of these therapies in the past one

year but were not being seen currently. During initial contact, the purpose and nature of the research was explained by the author and after obtaining verbal informed consent, an appointment was scheduled for a one-on-one qualitative interview at the clients' preferred location. At the first interview meeting, the clients were provided with a printed copy of the consent information in either English or Setswana that they could keep.

Four therapists were recruited for qualitative interviews through occupational therapy and physiotherapy contacts in the region. Again, the purposive sampling method was used to select participants from a variety of representative backgrounds. The only criterion for inclusion was fluency in English. Of those who participated in the interviews, three therapists worked as part of the CBR outreach and made visits to the villages, in addition to seeing families in the NGO branch office. One was also employed at a government hospital, and one was in private practice. Three were foreign therapists practising in Botswana and one was a native Motswana. The purpose and nature of the research was explained to participants and confidentiality was assured. An interview meeting was scheduled to take place in person. Before commencement of the interview, the participants were asked to read and sign a printed consent form.

Data Collection

The semi-structured in-depth interview sessions with caregivers and with therapists were completed from April through September 2020. Three enrolled caregivers were interviewed at their homes as a couple i.e. with their spouses, while two chose a secluded area at the rehabilitation centre for their sessions. Therapists were interviewed at their places of work in a private office. As the first author understands spoken Setswana, participants were invited to use their native language when they struggled to express themselves in English. During and after each interview, the author made notes on his observations of non-verbal expressions to ensure that emotional nuances were captured. Each participant's name and any personal details were removed from the audio recordings, and a letter-and-number code was used to label all data and findings. The document that linked a participant to his or her code and personal information was stored in the password-protected research computer. Only the first author had access to a participant's identity. Brief background information and the code designation for each participant are provided in Table 1.

Table 1: Participant Description

Participant Codes and Case Overviews	
S3.	A couple who cared for a female child with microcephaly and quadriplegia. No response to visual stimulation, mostly smiley. Often had what was described as stomach complications and feeding difficulties, since she could not chew. Excessive crying reported. Father was a primary school teacher and mother was the full-time caregiver. They described that they struggle to maintain the family with the father's salary.
NV7.	A single parent who had a child with cerebral palsy hemiparesis with difficulty in crawling and lower limbs dissociation, born preterm at 6 months. Stayed with her parents, as she was unemployed and dependent on them for support.
MK2.	A mother with an autistic child who was also hyperactive. She was interviewed alone, but both parents were very dedicated to caring for their child. Mother was a primary school teacher and father had a stable good job; reported that they would go all the way in meeting the child's needs.
CC6.	A couple caring for a child with cerebral palsy. Father was an accountant; mother, who was expecting at the time of the interview, was a full-time caregiver. The child had quadriplegia with emotional sensitivity, poor neck control and a major concern of excessive crying.
K1.	A couple caring for a child with cerebral palsy and quadriplegia, who spent time in a wheelchair and had minimal environmental responses. Father worked at a mining company and mother was a full-time caregiver. At the time of the interview, the couple, who were not legally married but living together, were in the process of separation due to what the mother reported as problems with their relationship exacerbated by their child with disability. The author organised a counselling session with a psychologist for both; only the mother attended.
M4.	A foreign physiotherapist working with a non-governmental organisation that was providing Community-Based Rehabilitation. Two years of living and practising in Botswana.
JB9.	A foreign occupational therapist working with a non-governmental organisation with 7 years of practice in Botswana. Was working in both Community-Based Rehabilitation and residential rehabilitation for children.
DM5.	A foreign physiotherapist with over 10 years of practice experience in Botswana, working at the government hospital at the time of the interview. Treated outpatient, inpatient and Community-Based Rehabilitation clients.
TM8.	A physiotherapist who ran her private clinic where she attended to both adults and children. She was a Motswana, or citizen of Botswana, with many years of experience practicing within the country, working in government hospitals before going into private practice, and was also a participant in the Community-Based Rehabilitation outreach.

An instructor at the Psychology Centre in Botswana, with an MA in research psychology, who was also an expert in qualitative analysis and a Botswana native, assisted with translating consent forms and interview questions to ensure

consistency with the intended meaning. The records officer at the rehabilitation centre, whose duties included serving as a Setswana-English translator and who was legally permitted access to client personal information, was called upon on rare occasions to provide assistance with interviews. The role of the records officer included explaining the purpose of the study and gaining consent where needed. Each session was electronically audio-recorded.

A sequence of semi-structured interview questions was read to each participant. The questions were designed to elicit comments on direct and indirect factors that interfered with carrying out a home programme. Direct factors were considered to be embedded in characteristics of the child, the family situation and medical and rehabilitative service provision that would have an immediate impact on the ability of the caregiver to conduct home-programme activities, while indirect factors were anticipated to be secondary issues in the healthcare and social welfare systems that impeded a caregiver's ability to carry out these activities. Verbal prompts were employed to further elicit each participant's expression of views, feelings, and experiences relevant to the interview questions. Sufficient time to answer each question was given, and it was possible to complete each interview within one hour. Interview questions are depicted in Tables 2 and 3.

Table 2: Caregiver Semi-structured Interview Questions

Question
1. Tell me about your child with a disability. <i>Probe:</i> Journey since diagnosis, the child's current presentation
2. How supportive is the healthcare system towards your child with a disability? <i>Probe:</i> Accessing healthcare services, understanding of the child by physicians, nurses, and other government service departments
3. Is your child receiving therapy? If so, please describe the therapy and its effectiveness
4. Do you work? <i>Probe:</i> What makes it difficult?
5. Are there therapy activities that you are supposed to do at home with your child?
6. Do you and the therapist discuss and agree on these activities?
7. As there are a number of foreign therapists and other healthcare specialists in Botswana, what role does language barrier play in understanding home programmes and other healthcare instructions?
8. Do you currently engage in home programmes and other healthcare activities with your child?

9. What makes it difficult or easy to carry out these activities? <i>Probe:</i> How the programme fits into their daily lives, support system
10. How can these activities be made better?
11. What would be your advice to the therapists?
12. What would be your advice to the healthcare system and government in general about the needs of children like yours?

Table 3: Therapist Semi-structured Interview Questions

Question
1. Does your practice include giving home programme instructions?
2. Do you believe home programmes are important in rehabilitation of a child with disabilities?
3. What have your experiences been with providing home programme instructions to caregivers living with children with disabilities?
4. Do you or any therapists you know place enough emphasis on home programmes?
5. From your experience, what factors determine the success or failure of a home programme?
6. What would be your advice to caregivers about home programmes?
7. What advice would you give to other therapists about giving home programmes?
8. Do you feel that children with disabilities and their families are supported enough by the healthcare system and the government in general? If not, explain your views.
9. Do you base your home programme activities and how to engage the caregiver on available evidence?

Data Analysis

The audio-recorded interviews were transcribed by the first author in preparation for analysis. The records officer assisted as necessary during transcription where clarification of a spoken phrase in Setswana was needed. The instructor at the Psychology Centre in Botswana was consulted to cross-check themes, but she did not have access to audio recordings. The first author analysed transcribed text to identify recurrent themes using published coding manual guidelines (Saldaña, 2016) and the NVivo computer software. Once text was exported to NVivo, the application helped him to classify, sort and arrange information, and to examine relationships. Zamawe (2015) described the value of NVivo for analysing a qualitative study for theme variations and noted that this software facilitated an accurate and transparent process in which the user always remained in control.

Ethical Considerations

Prior to initiating qualitative research, Institutional Review Board (IRB) approval was obtained from Boston University in Massachusetts, United States of America, where the investigators were affiliated at the time of data collection. The first author was also granted approval for human research from the Republic of Botswana Ministry of Health.

Each study participant was assured that participation was voluntary and without any consequences should they choose not to participate. They were also assured that any information they provided would be kept strictly confidential.

RESULTS

By the completion of the final interviews no new themes had emerged, indicating that data saturation was reached. The authors confirmed that participant response themes could be grouped according to whether they represented direct versus indirect influences on adherence to the home-based programme. Details for themes relating to **direct influences** with sample quotes are provided in Table 4. Themes relating to **indirect influences** with sample quotes are provided in Table 5.

Table 4: Themes relating to Direct Influences

Theme	Description	Sample Quote
Child Characteristics	<ul style="list-style-type: none"> ● One child characteristic reported by caregivers was uncontrollable crying. Some related that they stayed up all night so that he or she would cease crying, unable to comfort the child, while not knowing what was happening. Some spent most of the time during the day trying to stop the crying. ● Children with sensory or behavioural challenges were described as often refusing to initiate or maintain engagement in home programme activities. ● Caregivers whose child cried while activities were being carried out were concerned about causing pain, and they were reluctant to push the child to continue. 	<p><i>"This child can cry and this child would cry. I am telling you, she would cry uncontrollably from morning up to... during that time there would be no time to do some therapy."</i> S3 (Parents)</p> <p><i>"Sometimes when we didn't sleep the whole night, in the morning it would be difficult to say we have to continue doing therapy."</i> CC6 (Mother)</p>

Therapy Competency and Frequency	<ul style="list-style-type: none"> ● All caregivers felt that therapy provided in the clinic once per week, or more typically every two to three months, was not sufficient for their child to make gains. ● They expressed the desire to spend more time with the therapist during each visit so they could better learn how to care for the child as they struggled to carry out the home programme. ● Some reported that they feared they would do the wrong things and cause injury to the child. 	<p><i>“If I may give you an example, this month is just about physical stretching of the child; then you will take 2 months without going there; when you get there after 2 months, you know there is no continuity with what she was doing obviously.”</i> CC6 (Mother)</p>
Competing Demands	<ul style="list-style-type: none"> ● Household chores, basic caregiving, and work-related activities made it difficult for the caregivers to incorporate home programmes into their daily activities. ● This was also noted by therapists who reported their interactions with the caregivers; they related that home programmes were only partially carried out, and then only when the caregiver had the time. 	<p><i>“In my personal view, because at home we have not applied them much based on the situation, I don’t see any problems with these activities, they are fine. The problem is lack of implementation here at home.”</i> S3 (Parents)</p>
Other Issues Connected with Beliefs and Understanding	<ul style="list-style-type: none"> ● A recurring therapist theme was partial involvement by caregivers during therapy sessions, which was negatively impacting how the home programme was carried out. This seemed to stem from the belief that a parent’s duty was simply to bring the child to his or her appointment. While the child was being seen, the caregiver would be engaged on the phone, as opposed to actively participating in the session. ● Cultural themes were prominent. One theme was inadequate home programme follow-up because of a cultural misunderstanding about what therapy entailed. <i>Tshidilo</i>, a Setswana word that means therapy to most in this population, was generally interpreted as involving massage and physical stretching, according to therapists. Therefore, providing training on carrying out a home programme of occupation-based activities did not make sense to some caregivers. 	<p><i>“This is an African set-up; you get some clients or people who believe that, ‘I am bringing my child to you so that you give them the therapy that they need. I pay for that, therefore I am not obliged to do any other thing outside of that.”</i> TM 8 (Physiotherapist)</p>

	<ul style="list-style-type: none"> • Therapists also reported difficulty with implementing a home programme when the child was brought to therapy by the grandmother, which was often the case. Teaching the grandmother was found to be a challenge, presumably because her level of education was insufficient for understanding the child's condition, therapy needs, and home programme. Belief in traditional healers was found to be highly valued by some caregivers, who incorporated these practices into home programme instructions provided by the therapist and used treatments that could be detrimental to the child. 	
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Table 5: Themes relating to Indirect Influences

Theme	Description	Sample Quote
Insufficient Preparedness of Healthcare Providers	<ul style="list-style-type: none"> • Caregivers expressed, with great concern, the theme of unpreparedness of the healthcare system, including lack of knowledge on the child's condition, plus structural and procedural inconsistencies, such that the child's functional deficits could have been mitigated, or even prevented, with better medical care. • Experiences with physicians who attributed symptoms to the child's disability, with minimal to no further exploration conducted, was a recurring theme. • Caregiver experiences led to reluctance to take the child to the hospital, even when they knew he or she was not feeling well and they were certain that something was medically wrong. This in turn affected most other areas of caregiving, including carrying out home programmes and adherence to therapy. 	<p><i>"Almost every day we were at the hospital for the first year, but unfortunately when we get to the hospital...the doctors would say, this is the condition, there is nothing we can do...She is crying because of the condition, she is feeling pain because of the condition, there is nothing that we can do." S3 (Parents)</i></p>

<p>Mismatched Social Welfare Services</p>	<ul style="list-style-type: none"> ● Therapist and caregiver reports included lack of socioeconomic well-being, made worse by delays and denial of social welfare assistance, which interfered with the ability to manage the needs of the child and family. Gaps and inefficiencies in the social welfare system contributed negatively to access to services, and therefore made it difficult or impossible to focus on implementing a therapeutic home programme. ● Caregivers who reported moderate economic status struggled to keep the family afloat; one single parent was destitute and unable to provide basic necessities on her own. They were dependent on relatives and any allowed social welfare services. ● If one or both partners were working, the mother was the primary caregiver who strained to balance frequent travel for therapy visits or medical check-ups with the demands of family upkeep. ● If a child with a disability could not eat regular meals and needed a costly special diet, funds might be diverted from other family subsistence. Despite the sacrifice, the special diet was often unavailable. ● Recurring themes were the difficulties connected with obtaining access to any services because of the long wait for assessment and the poor likelihood of qualifying. Caregivers reported that people in the social service offices did not understand their needs adequately. Lack of sensitivity was reported, with caregivers led to believe that benefits were not an authentic entitlement. ● Stigma was largely reported by caregivers, while negligence was observed by both caregivers and therapists. ● Caregivers experienced misunderstanding of disability and lack of awareness of specific benefits among social welfare service workers, who might perceive the child as not needing sufficient care to qualify the family for disability grants or nutritional assistance based on their status. Food baskets lacked items the child could consume, leading to malnourishment. 	<p><i>“You cannot emphasise on doing home programmes when they do not have food to eat.”</i> DM5 (Physiotherapist)</p> <p><i>“My advice is that they don’t have to give all kids the same thing like when they give to children with disability. They have to look at what K needs. Isn’t it that some other kids can chew, they are with disability but they can eat rice, macaroni and all those kinds of things; as for K she can’t eat those kinds of things so they don’t really go into detail that what does this child really need.”</i> K1 (Parents)</p> <p><i>“We do not know if we are entitled to those services.”</i> CC6 (Mother)</p> <p><i>“Even on that food ration, we use a token; there are some shops where that token is used and most of the times they don’t have the food that she can eat.”</i> S3 (Parents)</p> <p><i>“There are a lot of things that are put in paper but are not really practical, it’s not what is happening on the ground. We can brag about the social welfare office giving disability grants and food baskets and ensuring that there is something but how effective is it? To me I don’t think they are effective.”</i> JB9 (Occupational Therapist)</p>
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<p>Support System Inadequacies</p>	<ul style="list-style-type: none"> ● Caregivers complained that they were not informed about systems for providing emotional or psychological support, given that they went through long periods of stress because of adjustments needed to adequately address the child's condition while meeting challenges inherent to carrying out their daily activities. ● Caregivers reported few to no opportunities for respite, where they were able to engage in activities other than caregiving, as well as few sources of emotional support other than the child's treating therapist and the spouse. This was a recurring theme. ● Almost all of the caregivers that were interviewed were not comfortable leaving their child with someone other than a spouse or immediate family member. This reluctance was often attributed to the child's delicately balanced care requirements, which in one case meant an extended feeding time using specialised techniques. The busy lives of family members and friends made them reluctant to be involved with the care of a child with disability. ● The crucial need for employer support and understanding was another recurring theme. Some caregivers felt well-supported by the employer, while others related that their employer had no idea of the challenges inherent in taking care of a child with a disability. ● When an employed caregiver was called upon to assist a family member with the child who was unwell, or to transport the child to a clinic or hospital, permission was typically needed to arrive at the workplace late or to leave before the end of the workday. ● If periods of respite or access to persons who could provide psychosocial support were not available which is often the case, caregivers reported sporadic burn-out episodes that affected the way the child's home programme and other daily activities were carried out. 	<p><i>"And sometimes maybe he is not affected; for me, I am really affected to the extent that maybe sometimes the care I am supposed to give the child I cannot do due to stress and worry."</i> K1 (Parents)</p> <p><i>"We feel uncomfortable with leaving him with someone else. It's only the siblings to my husband, who also have their own responsibilities."</i> MK2 (Mother)</p> <p><i>"It's like I am stuck with him for life and I am not progressing in any way and again it's difficult to leave him with someone else."</i> CC6 (Mother)</p> <p><i>"I can say I am very lucky because I am working at a rehabilitation centre which knows about people with disabilities and I am very thankful to my employer because he gives me time whenever the baby needs assistance."</i> CC6 (Father)</p> <p><i>"Even where we work, they know the situation of my child, but I remember a situation a couple of years back when I wanted them to give me a house closer to facilities where my child was being helped, but they never understood my language because they are never taught about the sensitivity of these issues."</i> K1 (Father)</p>
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<p>Language Barriers</p>	<ul style="list-style-type: none"> ● Of the four therapists who were interviewed, one was a Motswana, or citizen of Botswana, and three were natives of another country. A theme common to therapists of foreign extraction was their great concern about the impact the language barrier had on their ability to effectively communicate with clients. ● Though each of the three had practiced long enough in Botswana to pick up conversational Setswana, at times they needed translation service to discuss specifics with the caregiver about the child's medical or physical condition and the plan for carrying out a home programme. Not only were translators inconsistently available, they lacked training in medical concepts and terminology and therefore changed the meaning of the therapist's message. ● Therapist resorted to demonstration where there was no way to effectively communicate verbally. ● The caregivers who were interviewed could speak in English, but still reported that it was not easy for them to express themselves at times when they needed to explain complex experiences or feelings. 	<p><i>"I think for us here because we are still youthful and we have been through to maybe these tertiary schools, I think it's not of a big deal, but if I put myself into the shoes of an ordinary Motswana, I think it's a bit of a burden to them. The language barrier I think is something that is a problem. They might see what is being done but understanding of it through verbal communication I think it's a problem."</i> K1 (Parents)</p> <p><i>"Sometimes these doctors can provide someone to translate English to Setswana because sometimes you might understand, but since we are Botswana you find that it is very difficult for us to express in English."</i> K1 K1 (Parents)</p> <p><i>"Language barrier is just a huge one; a client would tell you, 'I don't', even if they understand; as long as you are not speaking their language they would say I don't understand what you said."</i> JB9 (Occupational Therapist)</p>
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DISCUSSION

This qualitative investigation was undertaken to gain insight into the reasons behind not carrying out home-based therapeutic programmes by parents and other caregivers of children with disability who were part of the CBR outreach project in rural central Botswana. As participants expressed concerns that were foremost on their minds, problem areas came to light that were consistent with prior descriptions by analysts and researchers concerning barriers embedded

in: the Botswana social welfare system (Maundeni & Mupedziswa, 2017; Mukhopadhyay & Moswela, 2019); health-related rehabilitation services in the Southern African region (Veltman et al, 2001; Iezzoni et al, 2003; McColl et al, 2008; Grut et al, 2012; Hansen et al, 2014); and language incompatibility in healthcare (Ali & Watson, 2018). A notable aspect of findings was the consistency in the lived experiences described by both caregiver and therapist participants, despite the uniqueness of each family group. They painted a picture in which children with disabilities and the families who cared for them were underserved, unsupported and at the mercy of social welfare service workers.

It would appear that participants in this study were encountering medical care and social welfare inequality with detrimental effects on their quality of life and that of their families despite governmental efforts, such that they remained vulnerable and providing a therapeutic home-based programme was an uphill battle. Their lived experiences pointed to the existence of insufficiencies in the larger system. Key practical barriers revealed during the study, that could be mitigated in the context of the CBR outreach project “through the combined efforts of people with disabilities...their families, organisations and communities, and the relevant governmental and non-governmental ...social and other services” (WHO, ILO, UNESCO, 2004) are described in Table 6.

Table 6: Key Practical Barriers revealed during the Authors’ Research that could be mitigated in the context of the CBR Outreach Project

Barrier	Goal	Action Plan
Inadequate nutrition because of food baskets that do not meet a child’s nutritional needs or tolerances.	Food basket options suited to the individual child’s nutritional needs, food tolerances, and level of chewing capability are available.	Promote policy change via interaction between the therapist, doctor, dietician and social services as members of the CBR support team. Educate CBR community groups and volunteers in the villages about advocating for appropriate food baskets.
Physician misperceptions and lack of expertise on disability in children.	Physicians take steps to discover and mitigate underlying deficits for caregiver-reported child behaviours, such as crying or refusal of food. They have a grasp of the complexities of caring for a child with a disability.	Inform the Ministry of Health on the need for policy promoting education of doctors on child disabilities, the complexities of care and underlying deficits that require medical intervention. Conduct in-service training of physicians as members of the CBR support team, consistent with developed policy.

Insufficient means to mitigate presence of language incompatibility.	Caregivers understand explanations and instructions for a home-based programme that is provided by therapists and physicians.	Prepare illustrated paper handouts in the caregivers' language. Show prepared instructional videos in the caregivers' language. Recruit informally trained translators from the community to serve on medical or rehabilitation teams. Involve CBR therapists and local community workers as guides.
Need for self-advocacy skills.	Caregivers understand how to communicate with health care, social welfare workers, and the school system regarding qualifications for assistance and needed care for the child.	Empower direct consumers who are the parents and caregivers about navigating the system and how they can self-advocate to access services. Provide teaching in the local villages to individuals and groups.
Denials and delays of social welfare assistance with lack of sensitivity by social welfare workers.	Social welfare workers more fully understand the challenges and complexities connected with caring for a child with a disability, types of handicaps, and special needs of an ambulatory child who may have other impairments affecting cognition or use of the upper extremities. Improved clarity in operational guidelines.	Promote policy change to more fairly connect the child with disability with needed welfare assistance by working with members of the CBR support team. Empower direct consumers who are the parents and caregivers by providing education about navigating the system and how they can self-advocate for appropriate welfare assistance.
Need for respite, insufficient resources for emotional and psychological support and competing demands of duties connected with work and household chores.	Caregivers have opportunities for respite from long periods of stress and the burden of care, where they are able to engage in activities other than caregiving for a child that may be delicate, unwell, and constantly crying. They have sources of emotional and psychological support in the community and a means to leave the child with someone other than an immediate family member.	Village leadership and the CBR outreach team work with volunteers and community groups in the villages to set up a system of mutual emotional and psychological support that includes respite. Parents or other caregivers who understand how to care for a child with a disability are encouraged to come together and share respite by caring for children in the other family.

<p>Need for one-to-one support with carrying out the home programme.</p>	<p>Parents and other caregivers have sufficient understanding of how the child’s home-based programme is carried out correctly. They also understand the benefits of focused therapeutic intervention and the consequences for not engaging the child in therapeutic activities.</p>	<p>Travelling therapists in the CBR outreach periodically conduct home visits based on a scheduling system. During visits, therapists ask parents or other caregivers to demonstrate the home-based therapeutic programme and they provide feedback. Correct techniques are reinforced, and therapists offer flexibility by teaching alternative approaches. Visits can also take place in the local clinic or wellness centre.</p>
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As seen in Table 6, advocacy for the rights of children with disabilities and their caregivers can and should extend from the direct consumers, who are the parents and caregivers, to the CBR support team, volunteers and community groups in the villages, and to the larger organisational structures. Hansen (2014) notes that “CBR staff might consider teaching advocacy skills to all stakeholders of children with disabilities including families and communities...in an effort to develop policies that are holistic, child-centred and address the challenges experienced by children with disabilities and their families”. Further development of approaches to coordination and collaboration is needed that links the CBR teams and village communities with medical and rehabilitation healthcare providers, social service workers, dieticians, and government officials. This essential next step within the CBR outreach project will ultimately lead to practical solutions for community education approaches to medical exploration and treatment, disability grant qualification criteria, and other social policies that impact children with physical, sensory and intellectual disabilities.

Strengths of the Study

Care was taken to achieve the greatest possible rigour in qualitative data collection and analysis. Purposive selection of participants, based on familiarity with the populations, was used to approximate a representative sample of caregivers and therapy providers as much as possible. The sample was composed of direct consumers from villages in the CBR outreach initiative and 3 therapists on the CBR team. Painstaking attention in the study design was directed to ensuring that wording of the questions posed to participants communicated the desired meanings. Cross-checking of themes that were derived from analysis was carried out using a qualified consultant and both manual and computer-assisted qualitative analyses were employed.

Limitations

Though the originally planned number of research participants was 6 therapists and 10 caregivers, onset of the COVID-19 pandemic necessitated discontinuation of personal interviews. Despite this unanticipated emergency, the authors were satisfied that the range of characteristics was consistent with the aims of purposive sampling, particularly as data reached saturation. A larger study may nevertheless have given a broader and more complete picture.

CONCLUSION

The authors' use of qualitative methodology demonstrated an approach of particular value when a situation of service provision is untenable and specific guidelines for change can be learned from the research findings. This study took place within well-intentioned national social welfare and CBR outreach systems whose purpose is to ensure that vulnerable groups with special needs because of poverty and disability would not be excluded from the benefits of rehabilitation programmes. However, there were indicators that the systems might not be working as well as they should.

As a means of enhancing the quality of inclusive care, the authors undertook an investigation to explore the experiences of families in central Botswana who were struggling with the challenges of caring for a child with complex needs because of a disability. The first author experienced the practical advantages inherent in the CBR outreach project, in that therapists, volunteers, and village leadership could try out new approaches on a small scale in the local communities; for example, he spearheaded a new chapter of the International Rotary Club. Their work in the villages to help continue the community programmes and support the needs of parents of children with disabilities has been ongoing. It is hoped that continuing efforts to promote community awareness and improve service delivery will help resolve barriers to home-programme adherence and compliance in this region.

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