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The Barriers to Caring for a Child Living with Cerebral Palsy (CP) in Rural Limpopo, South Africa

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Abstract: Maternal primary caregivers in rural low-income contexts who care for children with cerebral palsy (CP) experience significant barriers related to their caregiving responsibilities that have a profound impact on all aspects of their lives. This paper reports on a study that aimed to explore barriers related to caring for a child living with CP in the rural province of Limpopo, South Africa. An exploratory qualitative research design was employed. Purposive, convenience, and snowball sampling was used to recruit 10 primary maternal caregivers of children living with CP between the ages of 3 and 18 years. A semi-structured interview was used to collect data. The data were analyzed using a thematic analysis. This study found six barriers related to caring for a child living with CP in rural areas, which included physical, financial, social, emotional, spiritual, and health barriers. The primary maternal caregivers of children living with CP in rural areas experience a significant burden of care. Consequently, they need support and respite care to ease these challenges.

Keywords: cerebral palsy; disability; primary maternal caregiver; rural; South Africa

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1. Introduction

Cerebral palsy (CP) is the leading pediatric disorder worldwide that causes physical disability [1]. It accounts for a global prevalence of three cases per 1000 live births [2]. However, there is a significant disparity in the CP rates in developed and developing nations [3]. For instance, South Africa (SA)'s estimated CP prevalence is 10 cases per 1000 live births [4], compared to the United States of America (USA) with a prevalence of 2 to 2.5 cases per 1000 live births [4]. Cerebral palsy describes a group of ongoing, activity-restricting disabilities, mostly affecting mobility, the muscle tone, and postural control, caused by an absence of typical progress in the brain of a growing fetus or newborn [2,5]. Movement abnormalities in individuals with CP are commonly in conjunction with sensory, perceptual, cognitive, communication, and behavioural difficulties, along with epilepsy and bone and joint problems [2,5].

Consequently, children with CP frequently necessitate lifelong rehabilitation training and extensive care, which impose a significant psychological, physical, and economic burden on their families [6]. The mothers of children with CP often bear the primary burden of providing multifaceted and ongoing care for their children's CP [7]. Previous research has demonstrated that caregivers' emotional and physical well-being, as well as their ability to carry out their family responsibilities and maintain social connections, are significantly impacted by the load of caring for children with CP [8,9]. Thus, this can result in a lower overall quality of life for caregivers while meeting the needs of their children [10,11]. Previous research conducted in low-income countries has indicated that these barriers are a persistent concern [9,10,12–17].

Over the past ten years, there has been a growing body of research focused on the caregiving burden related to caring for children living with CP [6]. However, most of the research on this caregiving experience has been conducted in high-income countries [10,18–25]. For instance, research in Australia determined that the physical, social, and financial well-being, freedom, and independence of parents were all impacted by them caring for their child living with CP [19,22]. In addition, Whittingham et al. [25] discovered that a CP diagnosis was distressing for some parents, while others perceived it as a source of relief, leaving parents feeling uncertain about their children's future. It was also discovered that parents reported that medical and allied health interventions were extremely challenging. Taylor [21] also reported that in Australia, the caregivers of children with CP reported experiencing health problems, including physical pain and psychological issues, in addition to being exhausted by the demands of caregiving. Cross-sectional research conducted across nine areas of Europe revealed that the parents of children living with CP who have speech challenges, intellectual disabilities, or pain are at an elevated risk of experiencing stress [23]. Moreover, a Canadian study showed that the caregivers of children living with CP were more than twice as likely to report chronic diseases, activity limitations, and higher depressive symptoms, as well as lower overall health, as the caregivers of 'healthy children' [18]. In the Netherlands, caregivers reported insufficient disability support from the government and a lack of buffers for healthcare costs [24]. Caregivers felt the need to be empowered through knowledge, communication, and collaboration [24].

Resource-constrained environments, such as rural parts of SA, vary significantly from those of developed countries. Despite the potential for a greater incidence of CP in these countries, there is a lack of research on the degree to which different factors may contribute to challenges related to caring for a child living with CP in low-income nations [11]. There is a developing interest in examining the experiences of raising a child living with CP in rural Africa [10,12,14,15,26–30], and it has been found that there has been some improvement in the services offered to caregivers from historically marginalized populations. Nevertheless, more efforts are required to assist caregivers of children with CP, including social support, increased public knowledge of the causes of disability, governmental financial assistance, and access to disability-friendly services. Further, previous research in a low-income context in SA revealed that the caregivers of children with CP encounter challenges associated with insufficient social support and respite care, difficulties with acceptance, attitudes towards disability, financial strain, and environmental conditions [10]. This study parallels the present research by emphasizing the social, financial, and emotional barriers to caring for a child with CP in rural settings. Apart from our study supporting these findings, it also distinguishes itself by emphasizing additional challenges, including spiritual and healthcare barriers, indicating that caregiving is context-dependent and suggesting the need for further research into various factors that contribute to the caregiving burden when raising a child with CP in a low-income nation. This paper is an expansion upon that work and seeks to explore barriers associated with caregiving for a child with CP residing in the rural, under-resourced province of Limpopo, SA. A barrier, in this study, refers to any circumstance or problem which must be resolved for progress to be made [31]. A maternal primary caregiver refers to any female caregiver who takes care of a child with CP full-time [32].

2. Materials and Methods

A qualitative exploratory research design was chosen [33]. A non-probability purposive sampling method [33] was employed to recruit primary maternal caregivers from non-government organizations and social media platforms supporting the caregivers of children living with CP. Participants' children were aged 3 to 18 years, residing in rural districts (Capricorn, Sekhukhune, and Waterberg) in the Limpopo province of SA. Snowball

sampling was also used. Data were collected from the ten participants via 45–60 min semi-structured interviews conducted by the first author. The interview guide included questions such as: What are the challenges you face raising your child with CP? Who, if anyone is helping you raise your child? What is helpful or unhelpful about this? What other kinds of support systems do you have? Please see Appendix A for the full interview schedule. After interviewing ten participants, data saturation [34] was reached. Prior to conducting the interviews, ethical permission was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Medical) under protocol number M231023-B-0001. Ethical standards of informed consent, confidentiality, and the management of information were adhered to. The interviews were digitally recorded, transcribed verbatim, and analyzed using the six-step process of thematic analysis (TA) by the first author [35]. The TA steps are summarized below:

- Familiarization with the data
- Generating initial codes
- Searching for themes
- Reviewing themes
- Defining and naming themes
- Writing a research report

The six-step process of TA was used reflexively to identify and analyze patterns or themes, facilitating a continuous evaluation of how the researcher's role influenced the emerging themes [36]. The first author independently coded and analyzed the data and the second author cross-checked this process to add to the rigour and dependability of the research, among the other steps taken, thus ensuring coding reliability. The Social Ecological Model (SEM) 37] was used to make sense of the findings. The SEM is a conceptual model for understanding human development that places an individual in the centre, surrounded by various systems, including at the micro (individual), meso (interpersonal), exo (institutional), macro (societal norms, values, and beliefs) and chrono (policy) levels [37]. The theory was used to explain the many systems that influence caregiving processes and how their interrelatedness may hinder or enhance caring for a child living with a disability in a resource-constrained setting.

3. Results

The demographics of the caregivers (all biological mothers) who were interviewed in this study are presented in Table 1. The six themes and subthemes of this study are presented in Table 2.

Table 1. Demographic data of the participants.

Participant Pseudonym		Age	Relationship Status	Employment Status	Child's Age	Diagnosis Type
1.	Anna	36	Married	Self-employed	13 years	Unknown to the mother
2.	Eve	45	Married	Employed	5 years	Spastic quadriplegia CP
3.	Diana	36	Single	Unemployed (volunteering)	14 years	Spastic CP
4.	Elisa	41	Married	Self-employed	7 years	Dyskinetic CP
5.	Maria	40	Single	Unemployed (volunteering)	15 years	Choreoathetoid CP
6.	Johana	45	Single	Self-employed	8 years	Unknown to the mother
7.	Esther	39	Single	Unemployed	6 years	Unknown to the mother
8.	Abigail	34	Married	Employed	9 years	Unknown to the mother
9.	Ruth	42	Married, separated	Unemployed	3 years	Unknown to the mother
10.	Magdeline	38	Married	Self-employed	10 years	Spastic diplegia CP

Table 2. Themes and subthemes.

	Themes	Subthemes
1.	Physical barriers	
2.	Financial barriers	
3.	Social barriers	Varying social support
		Absent social life
		Negative social responses
		Romantic relationship rejection
4.	Emotional barriers	
5.	Spiritual barriers	
6.	Healthcare barriers	Challenges in understanding and managing CP
		Limited/lack of health professional support
		Lack of local services

3.1. Theme 1: Physical Barriers

This barrier pertains to difficulties encountered by the participants in carrying their children as they increase in weight and height, primarily due to the absence of assistive devices and suitable means of transportation. This, in turn, adversely affects the physical and social well-being of the family. Many participants reported experiencing physical fatigue and chest and shoulder pains, as well as being on pain medication because of their children's growth and need for constant physical care because of their CP. Thus, the caregivers expressed an amplified need for physical strength:

> *"Because he always wants to be held or always be in our hands, it's a 24-h thing. . .I get tired, my shoulders are so painful because my child needs a lot of physical strength to carry him, by the time I sleep, I am so tired, eish."*
>
> (Eve)

> *"But now I gave up, I am no longer going [to the hospital] because now he is old, he is heavy, I can't carry him on my back anymore. . .he is growing in height, 15 years."*
>
> (Maria)

> *"Like it has affected the father, like because sometimes when we are going to church, it's a distance from where the taxi drops us, so I remember the other time he complained about chest pains, and I realised it's because he was carrying her, so it has affected him more."*
>
> (Anna)

Participants also mentioned a lack of appropriate assistive devices and transportation, which negatively influenced their physical well-being to the point that they chose to confine their children at home because of their inability to carry them or the requirement for special transport at an additional cost:

> *"Another challenge is that she doesn't walk, we don't have a mode of transport. . . she doesn't have a wheelchair, so sometimes we are always in the house, and it's not good for her, I am happy to be with her in the house because she is now a big girl, I can't carry her, I can't be walking around carrying her, I can't because of weight, she is heavy."*
>
> (Anna)

> *". . .where I stay is in the middle of the village, so it's far from the main road, so I walk for a distance to get a transport, so when she is about 15, I am going to need transportation*

for me to be able to move around with her. . .the taxi is far, I need to pay extra R100 for them to take me straight home."

(Esther)

3.2. Theme 2: Financial Barriers

This theme is related to the challenges experienced by the mothers of children with CP in meeting the financial needs of their children, their own needs, and those of the family due to their full-time caregiving role.

Many participants reported receiving insufficient financial help from the government and that the disability grant they received for their children was not enough. Their caring expenditures included purchasing special food and nappies and taking their children to the doctor or clinic. Many participants reported an inability to afford to buy wheelchairs, and those who could found that their children rapidly outgrew them, so they could not afford to keep meeting such large expenditures:

"We need money to take her to the clinic when she is not fine, and I feel like the money is little because there's no one who is working at home and we need to buy her pampers [nappies] as well and take her to the doctor."

(Johanna)

". . .the kind of wheelchair that my daughter needs is expensive, it's around R16 000 s hand one, so, for now, I am not affording it because I do not have money. . .the other thing I don't understand is why is it that things like the wheelchair for these kids are these expensive. . .they are expensive and most they know that it is obvious that a parent with a child like these, you won't be able to go to work. . ."

(Anna)

Another common financial difficulty reported by the participants was the inability to work or seek employment. The mothers mentioned difficulty in searching for a job because of a lack of confidence in alternative daycare possibilities caused by their children's incapacity to speak. Other mothers felt they could not continue to work or search for jobs while their children were completely dependent on them. Hence, the financial assistance received from the government also helped to care for their personal needs and those of their families, and thus it was insufficient:

"We also rely on that money because we are not working. We depend on them, even if you get a job, you can only take a part-time job and it's not well paying, you end up getting the same R2000, so it is better to just stay at home and look after your child."

(Maria)

"It has affected me a lot, even to look for a job, I have some job offers, but I can't, because I won't trust anyone to leave with my child. . .so basically I can say it has shuttered everything for me."

(Anna)

"Before she was born, I used to be very busy, I would go to the market, look for a job, but when I heard the news, I realized that I can't do that anymore."

(Esther)

3.3. Theme 3: Social Barriers

The third theme presented is the social barriers. The various challenges faced by the participants in caring for a child with CP affected their ability to maintain a typical social

life. These challenges included the responses they received from their social circles, which had an impact on their mental well-being.

3.3.1. Subtheme 1: Varying Social Support

Mothers reported a lack of social support, mostly due to the belief that no one can care for their child as well as they can. Others reported an absence of additional help at home. Some mothers felt that others were incapable of assisting them or lacked the ability to provide support:

> *"...like at church, people they know I am having this kind of a child, and you go to church and those who have their own cars they won't assist you, can we go with you what what, no, so it's challenging, even for me, it's like, it's so hard."*
>
> (Anna)

> *"When I go to work, there is no one to help me with her, so it is painful, even if I look for a person to look after her, I must look for someone who understands her, because even so, I still get worried about how she is treating her, if my child is happy, those things are hard, they stress me."*
>
> (Abigail)

Despite the considerable barriers posed by the lack of support for almost all the participants, they also indicated receiving various forms of support from their families, friends, community, the government, and healthcare professionals that made the caring experience more manageable:

> *"My children help me, my siblings help, my mom help, even though she doesn't have the patience, my children know him, so they help feed him, bath him, and they play with him and keep him active, he is never alone...even the Malamulele NGO helped, we are a group of 20, 20 parents of children with CP, so having those mothers in a group is helpful."*
>
> (Maria)

> *"The people who support me are the mothers at the hospital, they help me with wheelchairs, my child did not have a wheelchair before, they helped get one. They also help me get the standing frame so that when the child is tired of sitting on the wheelchair, she can use it. They are ones who support me because they know lot of things."*
>
> (Abigail)

3.3.2. Subtheme 2: Absent Social Life

Participants also mentioned the effect that raising their children with CP had on their social lives and community involvement. Mothers reported difficulties in maintaining social connections, including going out, attending local events such as church services and funerals, or pursuing aspirations like going to school or getting a job:

> *"I don't have a social life, like you know, like, like going out, I can't go to the shopping mall...I can't go out maybe with other people, maybe shopping, like now if I want something at the shops, I have to write my husband a list...he is the one who is going to buy, or sometimes when I need something, he will come in the house, then me I go...even if I want to go to a salon, I have to talk to my husband like you know what, I want to do my hair, he will have to be at home so that I can go...we are suffering and imagine how can you carry a child with 18 years at your back, meaning your life is stuck."*
>
> (Anna)

> *"My life was affected because sometimes I want to attend community events such as funerals, I can't attend anything...things I am used to do I can't do anymore...I can't*

attend some events, like the life I used to have is no more, for example, I used to go to church on Sundays, it's no longer the same, I used to work too, I can't anymore. . ."

(Ruth)

3.3.3. Subtheme 3: Negative Social Responses

Mothers also reported negative responses as a regular social barrier. Participants mentioned several instances in which they received a negative response about their children's CP from family members, neighbours, or health practitioners. The negative responses included statements such as "their children will not live long", "their children will be cabbages", and even advice not to have more children to prevent having similar babies. Mothers described being questioned about their child's disabilities, being frequently asked about their child's growth and development, and being referred to different places for their child's potential healing, which they found stressful, exhausting, and upsetting. Furthermore, participants reported the stigmatization of having a disabled child, alluding to a fear of mistreatment by others. Some expressed concern about the reaction of others since disability in their village is associated with witchcraft:

"It was painful, I was mostly concerned about how people were going to react because disability where I come from is still associated with witchcraft or misfortune, people treat you differently when you have a disabled child, and they make fun of you. You begin to wonder who I did wrong, who wants to punish me."

(Magdeline)

"When she was in ICU, I remember the nurses saying, 'this one she must just allow us to kill the child, this child is going to be a cabbage'. . .one of my cousins. . .and you know what she says, she says 'ah, you know what if you have a child like this one again'. . .and she said, 'if I were you, I will just leave it, I will just be with this one, how about if you have a child like this one?' At that moment she instilled fear in me to an extent that I was even afraid of being pregnant, I was so afraid to be pregnant and some would be like ah, this one, her husband will run away."

(Anna)

"I feel somehow when you go with her [child with CP] somewhere, people stare at her, they ask questions, why is she not walking? I am always explaining. Some of the questions I do not have answers to, how will I know what happened to her? They will be asking, have you been training her, do you take her to physio, have you consulted? Okay I have, then they will be like why yours is not walking?...I am tired, I don't even want to hear more of this. . ."

(Abigail)

3.3.4. Subtheme 4: Romantic Relationship Rejection

Another social barrier experienced by mothers was rejection by partners, which eventually led to the end of the relationship. Mothers indicated that they were frequently blamed by their male partners for their child's CP, resulting in their partner being absent and not providing support:

". . .in the whole 14 years, my boyfriend also left me, he was not involved, what makes matters worse was when he said he doesn't give birth to disabled children, it's been tough."

(Diana)

Ruth recounted appealing to social workers to force her partner to financially support their child:

> *"... when you have such a child, and the marriage is shaking...they were rejecting the child...He says the child is not his, he wouldn't have such a child, it's my fault, I was taking pills or contraceptives that's why the baby is like this. You see, that's how I got stressed. Because now he is no longer checking on us...he didn't care for us, he didn't even show he had children, he was no longer sending money, money for check-ups, he didn't care...I ended up taking him to social workers..."*
>
> (Ruth)

3.4. Theme 4: Emotional Barriers

This fourth theme pertains to the emotional encounters that mothers experienced while taking care of their children. One of the shared emotional barriers that produced distress among the mothers was a lack of acceptance of their child's CP. Some mothers shared their initial resistance to the idea of their child being disabled but eventually accepted it after being reassured by their family or doctors, while others found it hard to believe they could give birth to a child with a disability:

> *"I am also confused, it's hard, I am trying, I work with sick people, but this condition is difficult for me...I am still trying to accept, but I am struggling, because some days I am fine, some days I am triggered...it's not easy."*
>
> (Eve)

> *"It took me a lot of time to accept the situation, because from 2014 I kept wishing I could turn back the time, fix, because as the child grows, the body structure also changes, he becomes more stiff...I was struggling to accept that my child is different...I have accepted now, I am glad they told me what was wrong with my child because I would have wasted my money going up and down, trying to figure out why I gave birth to a child with such a condition."*
>
> (Diana)

Further, mothers experienced distress when their child presented with additional medical conditions:

> *"It's scary when she starts getting sick, you get scared when they sick, my child takes the treatment for epilepsy, if you not used to it you can run away."*
>
> (Johana)

> *"I have accepted, the only thing that stresses me is when he is sick, he is crying, throwing up, it's stressful because he can't tell you where he is feeling the pain. At 5 months he was getting sick, he had fever, he wasn't sleeping well, he was fitting, I didn't know the term fitting or what was happening, but I knew something was wrong, he was crying a lot, a painful cry, he wouldn't stop, he was shivering, like he has cold."*
>
> (Ruth)

3.5. Theme 5: Spiritual Barriers

A spiritual barrier pertains to obstacles experienced by the mothers upon receiving a diagnosis of CP for their child. Several mothers claimed that they originated from cultures that hold the belief that disability is connected to supernatural forces. Consequently, many of the participants had sought spiritual remedies for their child's CP in an attempt to avoid being associated with the social shame surrounding having a disabled child:

> *"The first thing I thought of was witchcraft, it was the first thought, to be honest, like what did they do to my child, why is he in this condition, this is because the placenta was attached, and it didn't come out."*

(Eve)

"...white people explanation, you know they don't take witchcraft seriously, because according to me his birth was painful and long and also, he changed color, so it could have been people who did that to him...I started with going to church, doing everything I am told to do, also I went to a traditional healer."

(Maria)

Abigail highlighted the numerous spiritual sites she visited both in and outside of South Africa. However, Abigail had stopped seeking spiritual solutions and only took her child to a physiotherapist; this occurred after she lost a lot of money and saw no improvement:

"I have been to many places...a Nigerian church...I went to some Pentecostal churches in Lenting, I went to Phalaborwa, a place called Ntshotshonong, I even went to traditional churches such as Podungwana, Moria ZCC. I attended many places. The last place I went to was Mozambique, I went to some Tsongas, they advised me to go there, still she can't walk. They told me to use some medications, wake up at 3 am and do this, look for Donkey and Elephant poop, I got them from some lady who works in the zoo, but still, I have been looking for solutions, that is why I am saying, I have been to places, I walked, I spent so much money, by the time she turned 7 years, I knew that I have tried all I could, so I stopped, I only take my child to the physio now. I have met other children in the hospitals, I know their mothers also tried to seek solutions elsewhere."

(Abigail)

3.6. Theme 6: Healthcare Barriers

The final theme presented is the barriers to accessing healthcare. This theme pertains to the difficulties faced by participants while seeking medical advice and treatment for their children.

3.6.1. Subtheme 1: Challenges in Understanding and Managing CP

Many mothers reported that their lack of understanding of CP management and uncooperating health providers were a barrier. Participants conveyed that they were not entirely cognizant of the definition of and implications of CP:

"No, they [health practitioners] never really had time to explain, but most of the time because I work as a home base, I work a lot with doctors and nurses, they are the ones who explained to me...most of the time I would say epilepsy, I never included cerebral palsy, I would say epilepsy. So many times, I never included this cerebral I don't want to lie, because I never understood it...when I go for a check-up, they would write the return date, I go, they check the baby, and write another return date, so on and so on and that is frustrating and draining, it's discouraging because they only write the return date but nothing, even nurses would tell me that I know my child's disease, the nature of it and that it's not treatable."

(Eve)

"Until 2014, when I met other people in 2014 in the hospital who explained to me that CP is cerebral palsy, and cerebral palsy is brain injury, that's when I started knowing, all along I only knew I am taking my child to the hospital because he has CP, the entire time I just knew CP but no meaning whatsoever...as parents we complain because we can't even read our children's files...then most parents will hear from us the volunteers about what CP is as we workshop them, then the parents would now understand, our doctors

are to be blamed sometimes, they like using this English terms to tell us our children's conditions without telling us what they mean."

(Diana)

The participants also frequently mentioned a misdiagnosis and delayed diagnosis as additional barriers. Mothers indicated that receiving a CP diagnosis could take anywhere from months to years. Some described how they were initially given the incorrect diagnosis. Participants described how, at first, they felt angry and confused since they could tell that their child had a problem, but nurses, doctors, and reportedly even brain scans suggested otherwise:

"I took him to the hospital now and again even sleeping there explaining what I was seeing, but they couldn't see anything, they would do the test but they didn't see anything wrong. . .then when I took him to clinics they didn't see anything wrong, you know. . .But I would see that this child couldn't sit well, he was not right when I played with him, I could tell that this child was not right like other children. . .when we started going to the doctor in a hospital, he was about 8 to 9 months old and that's where they said he has epilepsy and cerebral palsy. . .it's only recently when they took him to a provincial hospital in Polokwane town when they did some scans on his head, not the whole body, then they told me that his brain is small."

(Eve)

"Officially she was diagnosed at the age of two, at the age of three we took her for a second opinion in Pretoria, and the doctor recommended that we take her for an MRI and the scan showed that the white matter in her brain didn't develop as it should have, but at the age two, that's when we got the diagnosis, but we had to wait for age three to get the second MRI."

(Elisa)

3.6.2. Subtheme 2: Limited/Lack of Health Professional Support

Another barrier commonly reported by mothers was limited or a lack of medical professional support. Mothers expressed uncertainties regarding the medical professional support available to them. Many were only aware of the services provided by physiotherapists, whereas others were aware of the services of social workers available at the hospital, but not locally. Many mothers reported that they had not received any mental health services except for the one session they had had with either the social worker or a counsellor/psychologist when their child was first diagnosed with CP:

". . .for me there has not been anything. . .maybe I am not receiving that because I am no longer going to the hospital or clinic but even when I was still going there, I never received any professional assistance for me."

(Anna)

"I only see the physiotherapist, we only get access to the social worker at the hospital not locally, but when I go to the hospital, I only see the physiotherapist."

(Abigail)

3.6.3. Subtheme 3: Lack of Local Services

Another obstacle that participants reported that affected the care of their child with CP was a lack of resources in rural locations. Caregivers reported that the rural location lacked access to wheelchairs, specialist doctors, specialized schools, and the technologies required to improve their children's movement, posture, and development. All participants

mentioned that when they required resources, they had to travel to a provincial hospital in the town, which cost them money:

> *"If I was in towns, I would have received those nice wheelchairs, they have specialists who can help further, they have machines, but here there is nothing, you have to go to Polokwane, I am not saying they will make my child walk, but I'm sure there was going to be some visible changes."*
>
> (Abigail)

> *"...when we took her to school, it was a mainstream school, we used to take her there but we ended up taking her out because she would cry every time she came back from school, she would refuse to go to school the following day because she was bullied, she couldn't make friends and I went there to complain so they advised us to take her to a special school. So eventually she stopped going to school, she has been home since. It pains me because I want her to learn and be like other children, but I just can't find a school appropriate for her."*
>
> (Magdaline)

4. Discussion

This paper has explored the barriers to caring for children living with CP in the rural areas of the Limpopo province of SA. The results of this study identified six barriers: physical, financial, social, emotional, spiritual, and healthcare barriers. Previous research conducted in low-income countries has indicated that these barriers are a persistent concern [9,10,12,14–17,26,38]. South Africa's transition from apartheid to a constitutional democracy over three decades ago led to significant social advancements; however, a significant proportion of the population still experiences poverty, unemployment, low wages, socioeconomic disparities, and a lack of human capital due to persistent inequalities [10,16]. Since nearly all the caregivers in this study originated from disadvantaged backgrounds, these socioeconomic circumstances likely added to the existing barriers that they reported. The participants resided in rural areas with scarce resources, with few employment opportunities, and relied on government aid for their livelihood [39].

Caregivers in this study reported experiencing bodily discomfort such as pain in the back, chest, and neck as well as restricted mobility due to the increasing weight and height of their child. This finding is consistent with a study conducted by Yilmaz et al. [40] which found that the caregivers of children living with CP frequently reported experiencing backaches, body pains, and poor sleep quality. These challenges arose from a lack of assistive devices such as wheelchairs and standing frames, including access to transportation, which necessitated the constant lifting and carrying of their child [41]. Additionally, the need for help with activities for daily living because of the activity restrictions experienced by children with CP might explain the physical strain experienced by caregivers [26]. This finding implies that primary maternal caregivers require support aids that could alleviate the physical strain of caregiving for children with CP.

Additionally, finances were identified as a barrier to providing care for a child living with CP. The caregivers in this research reported that they were unable to seek employment due to their full-time obligation of caring for their child, resulting in an inability to fund their child's basic needs. Despite receiving government assistance, mothers expressed that these aids were insufficient since they were often divided between the needs of both the child and the household. Mothers also indicated that the lack of financial means posed challenges in accessing essential resources such as reliable transportation, specialized schools, and healthcare facilities/doctors. These findings are consistent with previous research that has demonstrated the challenging nature of caring for a child living with CP, which often

hinders caregivers from engaging in employment outside of their home. Consequently, some caregivers leave their jobs to be full-time caregivers for their children, resulting in a significant economic burden for their families, including the inability to provide their children with basic necessities [10,42–44]. This finding signifies the importance of considering the provision of a caregiver grant specifically for those caring for children with disabilities to alleviate the financial strain.

This study also revealed that caregivers face social barriers such as a lack of a social life, including limited social participation; negative responses and inappropriate questions or comments from their social circles, including places where they receive medical care; and rejection by their romantic partner. Research indicates that caregivers frequently transport their children to rehabilitation centres in urban areas for therapy sessions, including occupational or speech and language therapy [45]. Therefore, caregivers invest a significant amount of time in commuting from rural areas to cities and waiting for their children to receive these specialized treatments. Consequently, the presence of these factors results in a reduced amount of time available for engaging in other activities [19,44]. Furthermore, mothers remain vigilant throughout the day and night, even when their children are asleep [46,47]. Caring for a child living with CP has the potential to significantly impact the entire family and affect all aspects of family functioning [47]. According to Cantero-Garlito et al. [43], marital relations in families of children with disabilities suffer, which contributes to maternal feelings of blame, guilt, and anxiety. This was evident in the current study, where mothers reported the end of their relationship or marriage with their child's father due to a lack of intimacy or being blamed for the CP; this is a finding consistent with that of Eyong et al. [44], who found that marital conflict in Africa is the consequence of a blame game between partners over the responsibility for their child's disability. However, it is also noteworthy that while caregivers in this study encountered numerous obstacles that complicated the caregiving process, they also identified factors that facilitated their caregiving experiences, including social, financial, and community resources. This is demonstrated in other studies, where caregivers reportedly received assistance, despite the presence of challenges [10,48,49]. Participants reported that familial support was a crucial factor enabling them to adapt to their caring responsibilities since it alleviated the feeling of being overwhelmed [19,50]. Practical support from community members was beneficial for caregivers [10]. In order to enhance the resilience and determination of caregivers, Murphy et al. [51] emphasized the significance of informal support networks. Additionally, it is important to mention that seven caregivers in this study were recruited from a network of support services and associations.

The mothers also reported emotional challenges, including emotional distress due to their difficulty in accepting their child's CP diagnosis. This was exacerbated when their child was diagnosed with additional medical conditions. Mothers thought that since their children were unable to speak, they were presumably in more pain than they perceived, which had an impact on their mental health. Prior studies have shown that a significant proportion of parents with children who have CP express concern over their child's disabilities and associated medical conditions [52]. Furthermore, it has been observed that parents often experience conflicting emotions in response to a diagnosis of CP. They may either be relieved to identify the cause of their child's condition or grieve the loss of the healthy, non-disabled child they had anticipated [15,46,50]. This was also apparent in the present research, in which a significant proportion of women had reached a stage of acceptance due to understanding their child's disability. However, a minority of them were still struggling with the concept of raising a child with this type of disability within their community. From a societal perspective, several African communities have a negative perception of disabled people and may even ostracize them, attributing disability to the influence of supernatural

or evil entities [53]. This indicates the need for the prompt and consistent counselling of the primary caregivers of children with disabilities to ease the emotional burden of coping with negative feelings related to their disabled child.

Spiritual barriers were also commonly reported among the participants. This barrier was often associated with emotional and health challenges. When the mothers were unable to accept their child's diagnosis, they often chose to pursue spiritual remedies because they felt that their child's disability was caused by witchcraft. Consequently, several participants made extra efforts to seek advice from traditional healers or churches to obtain treatment for their children. It appeared that it was crucial for mothers to demonstrate that they were not responsible for their child's disabilities. This may be attributed to the prevailing cultural beliefs in several African nations which assert that mothers are responsible for causing disabilities in their children [54]. Some individuals hold the belief that having a child with a disability is a kind of retribution for women engaging in behaviours that are deemed unacceptable [44]. This finding implies that African communities must be informed about the causes of disabilities to prevent the mothers of these children from being further burdened by care because of stigmatization or discrimination. It is important to note, however, that some of the participants stopped looking for spiritual remedies seemingly not because they had accepted their child's disability, but because they appeared exhausted from attempting various remedies.

Another barrier experienced by the caregivers of this study pertained to healthcare services. Many mothers expressed dissatisfaction with the inadequate or nonexistent provision of medical professional assistance, particularly in the area of mental healthcare and other services available for their children [15,38,50]. Furthermore, when such help was available, it was often disorganized. Consequently, these mothers lacked a complete comprehension of their child's diagnoses, which hindered their ability to establish a collaborative relationship with their child's healthcare providers. This is comparable to Ghanaian research that found that all the parents of disabled children who attended health institutions to learn about their child's disability were dissatisfied with the engagements with health experts [17]. Hemming and Akhurst [55] argue that parents often encounter a predicament due to how experts communicate their child's disability and the time it takes to assist parents in coping with the difficulties associated with having a disabled child. This was evident in the current study since most mothers disclosed that it took them over a year to confirm their child's diagnosis. Upon doing so, they believed that it was too late to obtain help for their child, and many had given up on obtaining assistance. Consequently, a significant number of them discontinued their attendance at physiotherapy. Furthermore, participants reported that challenges related to transportation hindered caregivers living in rural locations from receiving healthcare treatments [56]. Caregivers frequently complained about the challenges they faced while bringing their children to follow-up appointments, which included lengthy, expensive, and unreliable transportation [10,56]. This finding supports the notion that taking care of a disabled child in a rural community might be more physically strenuous compared to the experiences of caregivers in urban settings, where healthcare resources are concentrated and more readily available [57].

The findings of this study were also found to align with other research on the caregivers of children with various developmental disabilities. For example, Cooke and Harvey [58] discovered that the caregivers of children with communication disorders experienced obstacles in obtaining services, feelings of helplessness, a misunderstanding of their child's impairment, and a sense of relinquished control. Another study in rural SA involving the caregivers of children with severe intellectual disabilities, autism, and spina bifida revealed that caregivers faced several challenges including distress, difficulties in providing care, insufficient external support, coping issues, and inadequate acceptance by the commu-

nity [42]. While the current research provides valuable insights into the barriers to caring for a child with CP in rural settings, it is important to note that the findings were derived exclusively from the experiences of ten mothers residing in three districts within a single province. Due to the same cultural, social, and economic backgrounds of these mothers, it is not possible to generalize these results to apply them to all primary caregivers of children with CP in rural contexts.

5. Conclusions

The study referred to here demonstrated that mothers who care for children with CP in rural areas of SA experience a significant burden in terms of physical, financial, emotional, social, and spiritual aspects, as well as in accessing healthcare services. Consequently, there is a need for education or training expressly designed to mitigate the stigma around disability occurring at familial, communal, and institutional levels. Interventions involving caregiver support groups should be explored since they have shown the potential to enhance outcomes for both caregivers and children with disabilities in low- and middle-income countries [59]. Additional interventions that have been proven to be beneficial in assisting the caregivers of children with disabilities that can be explored include mental health support, financial assistance for caregivers, aid with assistive equipment such as wheelchairs, including specialized schools, and nutrition.

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Appendix A

Interview Schedule

1. What is your age?
2. Do you work, and if so, what do you do?
3. Who do you live with?
4. How old is your child with cerebral palsy?
5. What is your child's gender?
6. Do you have any other children?
    a. Ages?
7. What was your pregnancy and birth like with your child living with CP?
    a. How was this for you emotionally?

8. When was your child diagnosed with CP?
    a. Can you tell me about this process, including how this diagnosis came about?
    b. What do you remember about this time, including how you felt?
9. What do you understand about CP?
    a. How did you learn about this?
10. What was it like finding out about your child's disability?
11. Who did you talk to after finding out about your child's disability?
    a. What was this like for you?
    b. What were other people's responses towards you and your child?
    c. How did you manage these feelings and reactions?
12. How is the relationship like between you and your child?
13. What is it like raising your child, specifically with regards to their CP?
14. What does your day-to-day routine look like?
15. How has your child's disability impacted your life?
    a. Physically, mentally, emotionally, socially?
16. What are the challenges you face raising your child living with CP?
17. Who is helping you raise your child, if anyone?
    a. What is helpful, unhelpful about this?
18. What other kinds of support systems do you have?
    a. Can you elaborate on these? How did these come about? What is helpful about them?
19. What motivates you to keep looking after your child?
20. How does raising your child in a rural area, specifically, impact your role as a maternal caregiver of a child with a disability, specifically, CP?
    a. What access do you have for support services with regards to raising your child living with CP?
21. How is your overall health?
    a. Physically, mentally and emotionally?
22. What kind of professional assistance for yourself, if any, are you regularly receiving?
    a. Can you elaborate on this?
23. What do you think can be (further) done to help you raise your child?
24. What do you think can be done to make things easier for you?
25. Is there anything else you would like to share that I may not have asked?
26. Do you have any questions?
27. Are you feeling okay to finish the interview now?

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