

‘It shuttered down our hearts’: the mental health of caregivers of children with cerebral palsy in rural Limpopo, South Africa

Ngokwana Rachamose and Clare Harvey 

Abstract

Cerebral palsy is the most prevalent motor disability in childhood, with an estimated prevalence as high as 10 per 1,000 live births in South Africa. Cerebral palsy impacts the mental health of the maternal caregiver, who often assumes the responsibility of the primary caregiver. The current study aimed to explore the mental health of primary caregivers of children living with Cerebral palsy in rural communities of the Limpopo Province, South Africa. The study was conducted in three rural districts of Limpopo (Capricorn, Sekhukhune, and Waterberg). An exploratory qualitative research design was employed. Purposive convenience and snowball sampling were used to recruit 10 maternal primary caregivers of children living with cerebral palsy between the ages of 3 and 18 years. A semi-structured interview was used to collect data. Data were analysed using thematic analysis. The findings of the study include that maternal primary caregivers of children with cerebral palsy experience emotional and social difficulties that impact their mental health. The emotional difficulties include emotional distress, maternal shame and guilt, feelings of lost motherhood aspirations, and feelings of acceptance. The social difficulties include withdrawal and isolation, concern over the family's social well-being, and impact on maintaining a 'normal' life. The study's implications may extend to mental health providers, policymakers within the Departments of Health and Social Development, and other stakeholders invested in the overall health and well-being of children with disabilities and their caregivers.

Keywords

Cerebral palsy, disability, maternal primary caregiver, mental health, rural, South Africa

Department of Psychology, University of the Witwatersrand, South Africa

Corresponding author:

Clare Harvey, Clinical Psychology, Department of Psychology, University of the Witwatersrand, Private Bag 3, Wits, Johannesburg 2050, South Africa.

Email: clare.harvey@wits.ac.za

Cerebral palsy (CP) is a group of permanent conditions caused by disruptions occurring in the developing brain of a foetus that impact the progression of mobility and result in restricted activity (Hallman-Cooper & Rocha Cabrero, 2024). CP is the most prevalent motor disability in childhood; it is estimated to contribute between 0.2% and 0.3% of all international occurrences of childhood disabilities (Mahlaba et al., 2020). Two to three cases of CP per every 1,000 live births were reported in high-income countries, while the figure was five to eight cases per every 1,000 births in low-income countries (Dambi et al., 2015). In rural South Africa (SA), the prevalence of CP has been estimated to be as high as 10 per 1,000 live births due to high-risk factors such as premature birth, intrapartum-related events (primarily intrauterine hypoxia), congenital and postnatal infections including challenges in providing obstetric and neonatal care (Katangwe et al., 2020).

The degree and type of motor impairment and functional capabilities vary depending on the aetiology. CP may be accompanied by various comorbidities, including epilepsy, musculoskeletal issues, cognitive impairment, challenges with nutrition, vision and hearing impairments, and communication difficulties (Hallman-Cooper & Rocha Cabrero, 2024). These additional complications may result in a severe form of CP, in which a child may be incapable of doing tasks independently and consequently rely entirely on a caregiver. Singogo et al. (2015) assert that although the lives of both parents of a child with CP are affected, the maternal caregiver's life changes dramatically as she often assumes the responsibility of the primary caregiver.

Health care practitioners have expressed concerns about the impact of CP on caregivers' mental health, finding that caregivers endure adverse psychological effects throughout their lives (Kouther et al., 2022). According to Nimbalkar et al. (2014), mothers of children with CP experience reduced psychological health marked by shame, hopelessness, frustration, disappointment, and exhaustion; thus, they are particularly susceptible to social isolation, which may lead to anxiety and depression.

In Africa, maternal figures mostly provide care for children with CP. Many mothers, particularly in rural, low-income families, manage the dual responsibilities of family care and caring for a child with CP (Singogo et al., 2015). The interplay of social phenomena such as gender stereotypes, poverty, societal stigma, and the demands of raising a child with disabilities imposes considerable stress on these mothers (Seroke & Mkhize, 2023). Therefore, it is crucial to prioritise the mental health of caregivers to facilitate their ability to manage caregiving demands (World Health Organization, 2022).

The mental health burden of caregivers may be exacerbated if caregivers live in under-resourced areas (Dambi & Jelsma, 2014). According to Neille and Penn (2015), a large number of disabled children reside in rural areas, and about half of SA's population reside in rural areas. However, these rural areas continue to be the most neglected and marginalised concerning mental health resources (Vergunst, 2018). For instance, rural South Africans often lack access to psychiatrists or psychologists, relying on general doctors, occupational therapists, and nurses for mental health interventions. If someone requires a psychologist or psychiatrist, they are frequently referred to a nearby town which may include transportation challenges (Benjamin et al., 2021; Vergunst, 2018). Despite data indicating a high psychological burden on caregivers of children with CP, previous research on CP has paid insufficient attention to the mental well-being of these caregivers (Vadivelan et al., 2020). Therefore, this article explores the mental health of primary maternal caregivers of children with CP in the rural areas of Limpopo, South Africa. The findings are discussed in the context of the Ecological Systems Theory (EST) (Bronfenbrenner, 1977).

Methods

A qualitative exploratory research design was chosen (Saunders et al., 2007). A non-probability purposive sampling technique (Kabir, 2016) was used to recruit the primary maternal caregivers of

children diagnosed with CP aged between 3 and 18 years, living in rural districts (Capricorn, Sekhukhune, and Waterberg) in the Limpopo province of South Africa. Snowball sampling was also used. Participants were recruited through social media pages specifically designed to provide support for mothers of children living with CP, such as Cerebral Palsy South Africa on Facebook, and through non-governmental organisations assisting caregivers of children with CP, such as Malamulele Onwards. Potential participants were excluded if they were not of consenting age (that is, younger than 18 years); they were not the primary caregiver; their child's primary diagnosis was not CP; their child was not aged between 3 and 18, and they did not reside within the Capricorn, Waterberg, and Sekhukhune districts of Limpopo province. Table 1 shows a description of the participants.

Data were collected from the 10 participants via 45- to 60-min semi-structured interviews conducted by the first author. Among other questions, participants were asked: How is your overall physical, mental, and emotional health? What kind of professional assistance for yourself, if any, are you regularly receiving? After interviewing 10 participants, data saturation (Sim et al., 2018) was reached. Prior to conducting the interviews, ethical permission was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Medical) (Protocol number: M231023-B0001). Ethical standards of confidentiality and management of information were adhered to. The process of informed consent was undergone by all participants, who subsequently provided voluntary consent to participate in the study. Anonymity is assured in this article. If the participants encountered significant distress, they were either directed to a free counselling service or provided with the toll-free numbers for Lifeline South Africa and the South African Depression and Anxiety Group (SADAG). The interviews were digitally recorded, transcribed verbatim, and analysed using the six steps of thematic analysis (TA) by the first author (Braun & Clarke, 2019). These included familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and writing a research report (Braun & Clarke, 2019). The second author conducted a cross-checking review of this process to add to the rigour and trustworthiness of the study. The Ecological Systems Theory (EST) (Bronfenbrenner, 1977) was used to make sense of the findings. The EST discusses healthy and unhealthy behaviours as influenced by multiple interconnected systems: micro (individual), meso (interpersonal), macro (community), exo (institutional), and chrono (policy). The microsystem is the nearest to the caregiver and exerts the most significant impact; it includes interactions within their immediate environment (Kilanowski, 2017). The mesosystem extends beyond immediate interactions to include others with whom the caregiver has direct contact, such as colleagues (Kilanowski, 2017). The exosystem includes communal surroundings and social networks which may have indirect positive and negative effects on caregivers (Kilanowski, 2017). The macrosystem encompasses social, religious, and cultural values and influences. Finally, the chronosystem encompasses internal and external time and historical material, including the impact of policies (Bronfenbrenner, 1977). The EST was employed because it can demonstrate how the mental health of mothers can be affected by various factors (Sallis & Owen, 2015). In addition, the model has the potential to identify areas of intervention with regard to maternal mental health (Kilanowski, 2017).

Findings

Table 2 presents two main themes and seven subthemes that provide the mental health experiences of primary caregivers of children with CP. Each theme is presented below with anonymised quotations.

Table 1. Demographic data of the participants.

Participant pseudonym	Participant ID	Age	Relationship with child	Relationship status	Employment status	Child's age	Child's gender	Age of diagnosis	Diagnosis
Anna	Waterberg 1	36	Mother	Married	Self-employed	13	Female	Birth	Self-employed
Eve	Waterberg 2	45	Mother	Married	Employed	5	Male	9 months	Spastic quadriplegia CP
Diana	Sekhukhune 1	36	Mother	Single	Unemployed volunteers	14	Male	1 year	Spastic CP
Elisa	Waterberg 3	41	Mother	Married	Self-employed	7	Female	2 years	Dyskinetic CP
Maria	Sekhukhune 2	40	Mother	Single	Unemployed volunteers	15	Male	1 year 6 months	Choreoathetoid CP
Johana	Sekhukhune 3	45	Mother	Single	Self-employed	8	Female	3 months	Unknown
Esther	Sekhukhune 4	39	Mother	Single	Unemployed	6	Female	5 months	Unknown
Abigail	Capricorn 1	34	Mother	Married	Employed	9	Female	1 year 6 months	Unknown
Ruth	Capricorn 2	42	Mother	Separated	Unemployed	3	Male	5 months	Unknown
Magdeline	Capricorn 3	38	Mother	Married	Self-employed	10	Female	Birth	Spastic diplegia CP

Table 2. Findings: Themes and subthemes.

Theme	Subtheme
Emotional well-being	Emotional distress Maternal shame and guilt Feelings of loss Feelings of acceptance
Social well-being	Withdrawal and isolation Concern over family's social well-being Impact on maintaining a normal life

Emotional well-being

The findings indicated that all the mothers felt anxious, overly critical of themselves, fearful, and preoccupied with self-doubt. They expressed a range of emotions, including shame, guilt, anger, frustration, despair, heartbreak, the loss of motherhood aspirations, and some acceptance.

Emotional distress

Anna expressed how she constantly worries about others' reactions towards, and comments about, her child's appearance:

...when she is around normal kids who don't know her. . .they would look at her like somehow, and you know as a parent, you would feel somehow inside, you understand, like what are they seeing, what are they saying about my child?

A common worry among mothers was about their child's future. Anna explained how the stress of having a child with CP can be mentally draining, especially when thinking about her child's future. She questioned the purpose of her child's existence because her child depended entirely on her. She further revealed how this has led to feeling unwell and worried. This emotional strain is overwhelming:

Emotionally. . .it's so stressful, I don't want to lie, emotionally its stressing, emotionally its draining. . .you will be thinking what is going to be of her two years to come from now, so emotionally its draining, you are asking yourself okay, next year, what is going to happen to this child?. . .you will be asking yourself, after five years, hai [no] this child, what is the purpose of this child being here on earth? Because she doesn't do anything, you are the one doing, who is everything for her. . .emotionally, I am not fine, I am not okay. . .like now I am starting to, my mind is now like oh, how about a time when she starts to menstruate, you know all those things start to run in my mind even if I try to ignore. . .it's very difficult.

Moreover, Eve expressed concern about her child's seizures and the resulting constant care, as well as worrying about their future:

...we had hoped that this year we would take him to crèche, but having observed that at home we hold him 24 hours, we ask ourselves if they will be able to cope with him. . .even the creche teachers will not be able to cope. . .one day his father will get a job, so we constantly think about what we are going to do with him, because his father can't just sit at home for his whole life, looking after him. . .we were hopeful that he would get better, be able to sit and at least go to school, but hey we do not see any changes.

Eight mothers expressed fear of having more children after having a child with CP, particularly because they did not know the cause of their child's CP, which increased their anxiety. The mothers' fear was exacerbated by the belief that their partners and others were blaming them for their child's CP:

Cause even with baby number two. . . I was even worried I am going to have another child with cerebral palsy, I was scared because I couldn't look after two children with CP. I was more worried because I did not know what caused CP in the first child. . .so with the second pregnancy it was hard. . . (Diana).

. . . I was scared because I gave birth to a disabled child, it was hard, the way people look at you it's like it's your fault (Maria).

Anger and frustration are two other common emotional experiences that mothers reported. These were linked to feeling helpless to change their child's disability. They also expressed feeling robbed by health practitioners who delayed assisting them during labour and that God had not healed their child:

. . .there is nothing that you can do, but sometimes when I look at my child, I feel angry, I feel angry, I can feel that those people [doctors] have robbed me. . .you start to think a lot of things, it has hurt me a lot, because this thing, it has affected me a lot, it's making me feel angry (Anna).

I get frustrated. . .and we trusted the Lord to heal her, and even after seven years it still has not happened. . .it's just very very frustrating (Elisa).

Nine mothers reported feeling hopeless as a result of their child's CP. Participants acknowledged the emotional impact of caring for a child with CP, stating that it would be a lifelong struggle. Eight mothers believe that CP confines them, and this has limited their outlook on life. Some mothers described how giving birth to a child with CP has impacted their lives in that they are unable to pursue their dreams or take on some opportunities:

. . .it has shuttered many things in my life, many things in my life were shut down. . .since I knew that he has CP, my life got stuck, he is my full-time job, I was never able to fulfil my dreams. . .There is not even a chance for me to apply for a job or school. I am stuck. . .I have accepted that my whole life I will be working with this disability. . .he is a life commitment. . .I had to drop everything. . .I do not see myself outside this cerebral palsy (Diana).

..It has affected me a lot, even to look for a job, I have some jobs offers but I can't, because I won't trust anyone to leave with my child, I am not sure what that person will do to her because she is not talking, so basically I can say it has shuttered everything for me (Anna).

Maternal shame and guilt

Mothers frequently encountered emotions of shame and guilt. Participants reported that people made them feel negligent, adversely affecting their parental self-esteem. Anna expressed how she feels blamed for her child's CP:

. . .they will ask me what's wrong with the child, they won't ask my husband. . .it made me feel like they see me like a careless person. . .they are seeing me as someone who is careless, who doesn't take care of herself. . .it kills your self-esteem as a parent.

Other mothers blamed themselves for a lack of knowledge about their child's needs due to a lack of information about CP. Abigail expressed feelings of guilt and shame:

They say things like 'she gave birth to a disabled child'. . .they keep reminding me that I gave birth to a disabled child, and what bothers me the most is that in my village I am the only person with a child with a disability, so I ask myself why me, what did I do? It hurts me, I don't mind people swearing at me, but just don't use disability or her as part of that swearing, it hurts me.

Participants described CP as an unexpected tragedy that caused heartbreak and their world to crumble:

It [CP] shuttered down our hearts, our whole world came down, crumbling down on us, it's nothing we expected ever, we didn't expect that ever. . .but we decided to just tackle the disability and give her all the things she needs (Elisa).

Feelings of loss

Participants mentioned feelings of lost motherhood aspirations as frequent emotional experiences. Although the mothers were optimistic about their children's independence, they recognised that the limitations of the CP are beyond their control:

I now know that I have to live with this [CP]. . .I was hopeful that one day I will see her stand up, see her walk, see her talk. . .but now I can see that no, its been nine years, full nine years, I have no choice but to accept (Abigail)

I sometimes look at him and think that by now he would have been going to school, he can do things for himself, feed himself, I thought by now I would be done, he would be independent, but he is still a newborn, he can't do anything. . .Eish [expression of emotional pain], unfortunately its beyond me (Eve).

Acceptance

In contrast, some participants expressed acceptance, asserting that embracing their child's disability alleviated their stress. They explained that knowing about, and understanding, their child's CP led to some acceptance:

I felt better compared to when I did not know what was wrong with my child. . .I just accepted, but also, I was happy for the fact that now I know. . . you just accept, I don't even stress anymore (Maria).

Social well-being

All mothers expressed experiencing detachment and isolation. They conveyed a lack of engagement in social activities and spending time with friends, resulting in isolation and exclusion from social circles. Some mothers perceived that their child's CP affected their family's well-being, while others believed it hindered their capacity to lead a life they had expected.

Withdrawal and isolation

Participants expressed difficulty interacting with others as a result of being isolated because of their child's CP. For example, Elisa expressed:

For a long time, we actually excluded our friends and everybody, so we were alone for a very long time. . .we have excluded ourselves from people because it's just difficult. . .most of the times it's just easier to stay at home.

While Esther and Eve expressed:

I can't visit friends. . .I didn't desire going out, seeing people (Eve).

I don't leave home, except in few circumstances. . . (Esther).

The isolation was further complicated by the association of CP with 'witchcraft' in the participants' villages, leading many mothers to think that their children were 'bewitched':

The first thing I thought of was witchcraft. . .to be honest, like what did they do to my child, why is he in this condition, that's what I thought (Eve).

I knew its witchcraft, because even where I went, they confirmed it, they said I was bewitched when I was pregnant, they said they took my child from my belly when I was pregnant and did things to her and returned her (Abigail).

Concern for family's social well-being

Some mothers expressed how caring for their children with CP has affected their social well-being. They described how relying on family members resulted in feelings of worry that they were burdening their children:

My children help me, but I can tell I am burdening them because this is a woman's job. . .my husband and I take turns in looking after him [child with CP]. . .and sometimes the kids must remain and I feel like I am abusing them because they also have their own plans. . .I have not taken him anywhere in the community (Eve).

Abigail conveyed that her child's constant need to sleep in the middle of her and her husband has affected their intimacy:

For my husband, it is still hard for him to accept because also we sleep with her on our bed in the middle, we are not enjoying anything, always she is in the middle.

Impact on maintaining a 'normal' life

Diana expressed feeling stuck in child care duties, constantly occupied, and disinterested in social interactions:

Some of my friendships ended because I would turn down all invites to go out, I am always occupied, and I am not even enjoying anything. . .I am still stuck.

All mothers reported that the presence of CP in their children had an impact on their ability to live a 'normal' life. They described how their lives were disrupted by their child's constant need for care:

It's tiring, you don't have a normal life, through every planning you have. . .just going out for dinner has to revolve around her. . .it's very difficult, tiring (Elisa).

Discussion

This article has explored the mental health of maternal primary caregivers of children with CP in the rural province of Limpopo, SA. The findings are contextualised through the EST, understanding the themes according to various systems (Bronfenbrenner, 1977). The themes are also discussed in relation to previous literature.

The findings indicated that the interplay of multiple systems, from the conditions surrounding childbirth to diagnosis and subsequent integration of children into the caregivers' lives and society, results in emotional and social challenges for maternal caregivers. The findings on emotional and social difficulties are consistent with previous local and international studies conducted in rural and urban areas. For example, a meta-synthesis conducted by Dlamini et al. (2023) found that caring for children with CP is emotionally overwhelming, resulting in caregivers feeling stress and chronic sorrow. These authors also found that caregivers of children with CP are uncertain about their child's future and have mixed emotions regarding taking care of their disabled child. This illustrates a microsystem in which emotional challenges relate to individual factors such as the caregivers' abilities to manage stressors.

Providing care for children, in general, greatly impacts a caregiver. However, when a child has a disability, the act of caregiving takes on additional complexities. Children with CP may have limitations in functionality that may lead to long-term dependency on the caregiver. This exemplifies a mesosystem where interpersonal relationships may be affected by one individual, the caregiver, assuming multiple roles without assistance, consequently impacting their mental health and destabilising the family unit (Rachamose & Harvey, 2024). Further, as an illustration of the interdependence between the meso and macro systems, Dantas et al. (2012) highlighted that caregivers often have a burden to provide comprehensive and ongoing primary care, encompassing activities such as ensuring the child's nutrition, mobility, hygiene, seizure management, and transporting the child to medical examinations. This is atypical because usually children gradually become increasingly independent. The long-term dependency of children diagnosed with CP on caregivers to meet their daily needs may have profound consequences on caregivers' mental well-being while caregivers seek interventions to enhance their child's capabilities (Wati et al., 2020).

Deepthi and Krishnamurthy (2011) found that caregivers experience stress because of the ongoing demands of caring for children with disabilities. This was apparent in the findings of this study as all participants expressed concern and anxiety regarding their child's inability to communicate their needs. In addition, mothers who provide care for children with severe forms of CP expressed stress about not being able to leave their children with others because they fear potential complications that may arise in their absence. Moreover, the participants reported elevated stress, which is attributed to microsystem or individual factors such as the child's behaviour and cognitive difficulties, inadequate self-efficacy among caregivers, and limited familial and societal support (Dambi et al., 2015; Pousada et al., 2013).

Although the findings of this study indicate that maternal primary caregivers of children with CP in the Limpopo province of SA face mental health challenges, it is evident from prior research that geographic location, rural or urban, does not exempt caregivers from psychological distress (Madzhie et al., 2022; Ni et al., 2022; Seroke & Mkhize, 2023; Vadivelan et al., 2020). However, in the rural areas of SA, children with CP are cared for in the home by immediate relatives (Ni et al., 2022). These close family members are considered caregivers but lack the necessary training to provide care for children with special needs. All mothers in the current research indicated considerable distress due to their lack of knowledge about their child's disability and uncertainty about where to seek information and help. Many of the women admit to relying on intuition when it comes to making decisions for their children.

Caring for a child with CP in rural regions places an enormous caregiving burden on those involved, which can lead to severe mental health issues (Rachamose & Harvey, 2024). First, CP continues to be associated with witchcraft, curses, and misfortunes (Dako-Gyeke et al., 2021). Various caregivers in this study believed that they had given birth to a child with CP due to ‘witchcraft’, displeased ancestors, someone’s curse, or God’s will. Beyond the microsystem, African communities frequently hold unfavourable views and even reject those with disabilities on the grounds that evil spirits afflict them (Singogo et al., 2015; Wegner & Rhoda, 2015). The widespread cultural belief in witchcraft exacerbates the social isolation, discrimination, and stigmatisation of those with disabilities and their families (Groe & McGeown, 2013). This implies that maternal caregivers of children with CP face mental health challenges in the macrosystem due to shared community values and beliefs, as well as constant concerns about how others perceive them and their children, affecting both social and psychological dimensions of their experience.

Second, according to the Department of Statistics South Africa (2023), the Limpopo province has a 48.6% unemployment rate. This includes all caregivers who participated in this study. The majority of the participants rely on government disability grants for financial support, which serves as the family’s income because many of their partners are unemployed or do not have stable jobs. This means that the funds for their child’s needs, such as special food, nappies, and transportation to hospitals (frequently located faraway in towns), are also used for family needs. This suggests that the mental health challenges encountered by the caregivers in this study are highly likely to have been influenced by their socioeconomic backgrounds.

All caregivers originate from previously disadvantaged households and reside in rural villages, mostly stemming from the chronosystem, including limited access to resources, high unemployment rates, and dependence on government financial aid for sustenance (Pretorius & Steadman, 2018). Lack of adequate financial support may cause mothers to be constantly distressed about the demands of caring for a child with CP, especially if they are unable to work, a finding consistent with Rachamose and Harvey (2024).

Finally, rural areas like the Limpopo province offer minimal or non-existent mental health services. Despite the fact that rural areas in SA account for nearly half of the country’s population, mental health remains a neglected priority in these regions (Vergunst, 2018). Mental health services might be inaccessible to these caregivers due to various obstacles, including financial constraints, limited transportation options, considerable distances to the nearest facility, and insufficient availability of resources. In the absence of support and feelings of hopelessness, the mental health of these maternal caregivers may consequently deteriorate. In summary, this study’s findings support prior research on caregiving for a child with CP, emphasising the impact of a complex array of systems and interrelated environmental factors on caregivers’ mental health. This encompasses an interplay of individual factors, including the timing and circumstances surrounding the birth of their child, family dynamics, social networks, community value systems, institutional factors, and policies (Deepthi & Krishnamurthy, 2011; Gilson et al., 2018; Guillamón et al., 2013; Kouther et al., 2022; Rachamose & Harvey, 2024; Seroke & Mkhize, 2023). This implies the need for a multifaceted approach to caregivers’ mental health, one that is cognisant of the various systems in which they typically engage.

Conclusion

This study demonstrated that maternal primary caregivers of children with CP in rural areas of SA encounter mental health issues and require support. Thus, the article contributes to the dearth of literature in the field of the experience of caregivers and disability – specifically CP – in rural SA. Community education and awareness programmes are recommended to inform rural communities

about the causes, treatment, and management of CP. These programmes should also guide how to effectively support caregivers and their children with CP. In addition, medical professionals attending to these children must provide mothers with accurate information regarding the nature of their child's disability, as well as promptly enrol them in ongoing therapies. Furthermore, it is essential to provide primary maternal caregivers with supplementary financial assistance, such as the South African Social Security Agency (SASSA) caregiver grant, to reduce the burden of care.

This study's limitation is that it did not include any other types of female caregivers (grandmothers, aunts, etc.); only biological mothers participated. Although the participants provided valuable insights, the findings cannot be generalised to encompass the experiences of all maternal primary caregivers responsible for children with CP in the province. In addition, no mental health assessments were conducted with the participants. Consequently, future research could explore maternal mental health using standardised assessments. Moreover, future research could also involve male primary caregivers such as fathers, since this study found that fathers also care for children living with CP. Finally, future research could explore factors that facilitate the mental health of primary caregivers for children with special needs. This will help develop caregivers' mental health interventions.

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ORCID iD

Clare Harvey  <https://orcid.org/0000-0001-6598-8038>

References

- Benjamin, F., Vickerman-Delpont, S. A., & Roman, N. V. (2021). Mental health care services in rural South Africa: A human capabilities approach. *Social Work in Mental Health, 19*(5), 365–380. <https://doi.org/10.1080/15332985.2021.1927283>
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health, 11*(4), 589–597.
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist, 32*(7), 513–531. <https://doi.org/10.1037/0003-066X.32.7.513>
- Dako-Gyeke, M., Boateng, D. A., Mills, A. A., Kodom, R. B., & Appiah-Kubi, J. (2021). Known by the children's condition: Associative stigma among family carers of children with Cerebral Palsy. *Global Social Welfare, 8*, 379–392.
- Dambi, J. M., & Jelsma, J. (2014). The impact of hospital-based and community based models of Cerebral Palsy rehabilitation: A quasi-experimental study. *BMC Pediatrics, 14*(1), 301. <https://doi.org/10.1186/s12887-014-0301-8>
- Dambi, J. M., Jelsma, J., & Mlambo, T. (2015). Caring for a child with Cerebral Palsy: The experience of Zimbabwean mothers. *African Journal of Disability, 4*(1), 168. <https://doi.org/10.4102/ajod.v4i1.168>

- Dantas, M. S., d, A., Pontes, J. F., de Assis, W. D., & Collet, N. (2012). Family's abilities and difficulties in caring for children with Cerebral Palsy. *Revista gaucha de enfermagem*, 33, 73–80.
- Deepthi, N., & Krishnamurthy, A. (2011). Mental health and quality of life of caregivers of individuals with Cerebral Palsy in a community based rehabilitation programme in rural Karnataka. *Disability, CBR & Inclusive Development*, 22(3), 29–38.
- Department of Statistics South Africa. (2023). *Quarterly labour force survey*. <https://www.statssa.gov.za/publications/P0211/Presentation%20QLFS%20Q1%202023.pdf>
- Dlamini, M. D., Chang, Y.-J., & Nguyen, T. T. B. (2023). Caregivers' experiences of having a child with Cerebral Palsy. A meta-synthesis. *Journal of Pediatric Nursing*, 73, 157–168. <https://doi.org/10.1016/j.pedn.2023.08.026>
- Gilson, K. M., Johnson, S., Davis, E., Brunton, S., Swift, E., Reddihough, D., & Williams, K. (2018). Supporting the mental health of mothers of children with a disability: Health professional perceptions of need, role, and challenges. *Child: Care, Health and Development*, 44(5), 721–729. <https://doi.org/10.1111/cch.12589>
- Groce, N., & McGeown, J. (2013). *Witchcraft, wealth and disability: Reinterpretation of a folk belief in contemporary urban Africa* [Leonard Cheshire Disability and Inclusive Development Centre Working Paper Series].
- Guillamón, N., Nieto, R., Pousada, M., Redolar, D., Muñoz, E., Hernández, E., Boixadós, M., & Gómez-Zúñiga, B. (2013). Quality of life and mental health among parents of children with Cerebral Palsy: The influence of self-efficacy and coping strategies. *Journal of Clinical Nursing*, 22(11–12), 1579–1590. <https://doi.org/10.1111/jocn.12124>
- Hallman-Cooper, J. L., & Rocha Cabrero, F. (2024). *Cerebral Palsy*. StatPearls Publishing.
- Kabir, S. M. S. (2016). Basic guidelines for research: An introductory approach for all disciplines. *Book Zone Publication*, 4(2), 168–180.
- Katangwe, T. J., Van Toorn, R., Solomons, R. S., Donald, K., Steel, S., Springer, P. E., & Kruger, M. (2020). A South African Cerebral Palsy registry is needed. *South African Medical Journal*, 110(5), 353–354. <https://doi.org/10.7196/SAMJ.2020.v110i5.14504>
- Kilanowski, J. F. (2017). Breadth of the socio-ecological model. *Journal of Agromedicine*, 22(4), 295–297. <https://doi.org/10.1080/1059924X.2017.1358971>
- Kouther, D. A., Shakir, M. O., Alhumaidah, R. A., Jamaluddin, H. A., Jaha, A. Y., Alshumrani, M. J., & Hakami, A. Y. (2022). Factors influencing the mental health of caregivers of children with Cerebral Palsy. *Frontiers in Pediatrics*, 10, Article 920744. <https://doi.org/10.3389/fped.2022.920744>
- Madzhie, M., Mphephu, K., Baloyi, V., & Chueng, M. (2022). The challenges experienced by mothers with children suffering from Cerebral Palsy: A study conducted at mutale municipality, South Africa. *Cogent Psychology*, 9(1), 2043020.
- Mahlaba, N., Nakwa, F. L., & Rodda, J. R. (2020). A descriptive study of children with Cerebral Palsy at Chris Hani Baragwanath Academic Hospital. *South African Journal of Child Health*, 14, 4–9. http://www.scielo.org.za/scielo.php?script=sci_arttext&pid=S1999-76712020000100002&nrm=iso
- Neille, J., & Penn, C. (2015). Beyond physical access: A qualitative analysis into the barriers to policy implementation and service provision experienced by persons with disabilities living in a rural context. *Rural and Remote Health*, 15(3), 149–162.
- Ni, Z. H., Ding, S., Wu, J. H., Zhang, S., & Liu, C. Y. (2022). Family caregivers' experiences of caring for children with Cerebral Palsy in China: A qualitative descriptive study. *Inquiry*, 59, 469580221121510. <https://doi.org/10.1177/00469580221121510>
- Nimbalkar, S., Raithatha, S., Shah, R., & Panchal, D. A. (2014). A qualitative study of psychosocial problems among parents of children with Cerebral Palsy attending two tertiary care hospitals in Western India. *ISRN Family Medicine*, 2014, 769619. <https://doi.org/10.1155/2014/769619>
- Pousada, M., Guillamón, N., Hernández-Encuentra, E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B. (2013). Impact of caring for a child with Cerebral Palsy on the quality of life of parents: A systematic review of the literature. *Journal of Developmental and Physical Disabilities*, 25, 545–577.
- Pretorius, C., & Steadman, J. (2018). Barriers and facilitators to caring for a child with Cerebral Palsy in rural communities of the Western Cape, South Africa. *Child Care in Practice*, 24(4), 413–430. <https://doi.org/10.1080/13575279.2017.1347146>

- Rachamose, N., & Harvey, C. (2024). The mental health of maternal caregivers of children with Cerebral Palsy in rural, low-income parts of Southern Africa. *African Journal of Social Work*, 14(4), 217–224. <https://dx.doi.org/10.4314/ajsw.v14i3.2>
- Sallis, J. F., & Owen, N. (2015). Ecological models of health behavior. In K. Glanz, B. K. Rimer, & K. V. Viswanath (Eds.), *Health behavior: Theory, research, and practice* (5th ed., pp. 43–64). Jossey-Bass/Wiley.
- Saunders, M., Lewis, P., & Thornhill, A. (2007). *Instructor's manual: Research methods for business students*. FT Prentice Hall.
- Seroke, S., & Mkhize, S. W. (2023). Psychosocial experiences of mothers caring for children with Cerebral Palsy in the eThekweni district. *Health SA Gesondheid*, 28, 1–11.
- Sim, J., Saunders, B., Waterfield, J., & Kingstone, T. (2018). Can sample size in qualitative research be determined a priori? *International Journal of Social Research Methodology*, 21(5), 619–634. <https://doi.org/10.1080/13645579.2018.1454643>
- Singogo, C., Mweshi, M., & Rhoda, A. (2015). Challenges experienced by mothers caring for children with Cerebral Palsy in Zambia. *South African Journal of Physiotherapy*, 71(1), 274. <https://doi.org/10.4102/sajp.v71i1.274>
- Vadivelan, K., Sekar, P., Sruthi, S. S., & Gopichandran, V. (2020). Burden of caregivers of children with Cerebral Palsy: An intersectional analysis of gender, poverty, stigma, and public policy. *BMC Public Health*, 20(1), 645. <https://doi.org/10.1186/s12889-020-08808-0>
- Vergunst, R. (2018). From global-to-local: Rural mental health in South Africa. *Global Health Action*, 11(1), 1413916. <https://doi.org/10.1080/16549716.2017.1413916>
- Wati, R. S., Purwati, N. H., & Permatasari, T. A. E. (2020). Caring for Cerebral Palsy children: Indonesian parents' experience. *The International Journal of Social Sciences World*, 2(2), 117–121.
- Wegner, L., & Rhoda, A. (2015). The influence of cultural beliefs on the utilisation of rehabilitation services in a rural South African context: Therapists' perspective: Original research. *African Journal of Disability*, 4(1), 1–8. <https://doi.org/doi:10.4102/ajod.v4i1.128>
- World Health Organization. (2022). *World mental health report: Transforming mental health for all*.