Coping mechanisms of caregivers of children with cerebral palsy in rural communities: The narratives of caregivers of children with cerebral palsy Mokhotlong, Lesotho

**Abstract**

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| --- |
| While many caregivers of children with cerebral palsy experience various long-term challenges, others have coped and continued providing care to their children. Understanding how these caregivers cope and maintain care giving role, can help identify the support needed. However, research on the coping mechanisms of caregivers of children with cerebral palsy in Lesotho is scanty. The objective of this study was to explore the coping mechanisms of caregivers of children with cerebral palsy in Mokhotlong, Lesotho. Data was collected using semi-structured in-depth interviews from 12 caregivers (2 males and 10 females) selected using snowball sampling. Data was analysed using thematic analysis. The findings of the study revealed that caregivers of children with cerebral palsy in Mokhotlong Lesotho, use a variety of coping strategies that complement one another. Religion helped them to accept and positively reinterpreted their children’s disability, which allowed them to find it easy to care. Financial resources, social support from the relatives and government grants helped them to address costs of care associated with cerebral palsy. The findings suggest that caregivers of children with cerebral palsy especially in rural communities, need social and financial support to address their children’s needs, which will lessen the psychosocial and economic burden that comes with caring for children with cerebral palsy. Also, the findings imply that social workers need to intensify the professional support and play an advocacy role for these caregivers.  |

Key words: Cerebral palsy, coping mechanisms, caregivers, rural communities, Lesotho,

1. **Introduction**

Cerebral palsy (CP) is a disorder that affects movement, posture, and motor skills, often accompanied by cognitive, sensory, and communication challenges (Patel at al., 2020). Globally, CP is one of the common causes of physical disability in childhood (Rachamose & Harvey, 2025) and its impact extends beyond the affected child to the family, particularly the primary caregiver. In low- and middle-income countries like Lesotho, studies have revealed that caregiving challenges are compounded and exacerbated by limited health infrastructure, poverty, social stigma, and geographic isolation, particularly in rural communities where access to specialized care is minimal (Pelea, 2016; Takondwa et al., 2010).

Caring for children with disability (CwD) can be a straining task because CwD require special and intensive care, with the situation being more for children with cerebral palsy (CwCP). Caregivers of CwCP, are faced with various economic, psychological, and social challenges (Kyeremateng et al., 2019; Gona et al., 2010). While these caregivers experience these challenges, some have managed to cope with caring for CwCP independently while some require help (Sayed et al., 2020). Research reveals that there are various coping mechanisms used by the caregivers of CwCP (Savage et al., 2021; Ezeonu et al., 2021; Sabetsarvestanie et al., 2023). Understanding these coping mechanisms that caregivers of CwCP employ is essential to informing targeted interventions, strengthening community support systems, and improving the quality of life for both the caregivers and their children.

Caregivers of children with disabilities in Lesotho often assume long-term responsibilities that are physically demanding, emotionally taxing, and financially burdensome (Pelea, 2016; Rafoneke, 2017; Mosia, 2017). The general situation of people with disability in Lesotho and their families remains worrisome, although the government and NGOs are making efforts to rectify it. The lack of formal support systems means that these caregivers must rely on personal, social, and sometimes spiritual resources to navigate the challenges of daily care associated with caring for a CwCP. Lesotho is economically struggling, with unemployment rate of 16.46% as of 2023 (O’Neill, 2024). Parents of children with disabilities are among the most affected people since some cannot secure jobs while some must quit jobs (Wondemu et al., 2023; Cantero-Garlito et al, 2020). Without sustainable financial support, many parents of CwCP are unable to meet their children needs, leading them to experiencing psychological distress and compromised quality of care.

As part of coping with care related costs, some parents rely on state funded social grants with a few relying on personal income, especially in poor families. For example, the Government of Republic of South Africa provides care dependency grant (CDG) which Trafford and Swartz, (2023) argued that it is inadequate, similarly in Norway, Wondemu et al. (2023) stated that parents of children with disability are provided with monthly financial and care assistance. In the case of Lesotho, the government introduced a quarterly disability grant of M1800 which is approximately US$96; and in Finland, Paajanen, et al (2021) stated that there are two social security grants offered, caregiver and disability allowance, with families eligible to receiving both. While these grants have been able to assist parents of children with disabilities to cope, several studies have highlighted their insufficiency. Participant from a study by Vadivelan et al. (2020) in India, appreciated the government grant but pointed that it is insufficient for providing the quality care to their children. This corroborated with findings of a South African study by Savage et al. (2021) in Umzinyathi district of KwaZulu-Natal, in which the participants expressed that the grants were not enough to cater for the expenses and wished that it could be increased.

Studies have found that social support for parents of CwCP leads to reduced stress and alleviation of psychological and physical burden (Sari & Malini, 2022; Moriwaki et al., 2022). For many caregivers of CwCP, social support is provided by the immediate family, friends and communities and professionals (Dada et al., 2020), therefore this social support becomes a buffer for stress, leading to increased quality of life for caregivers and improved childcare. Although social support is essential for caregivers’ coping, literature have shown that this is a resource that is not available for all caregivers. Fathers of CwCP, are among the most uninvolved people in the care of CwCP. Participants in the South African study by Phumudzo et al. (2021), reported that their children’s fathers were not involved in the upbringing of the children, with other fathers focusing on their nieces instead of their own children, thus this father absence, amplified the challenges that these caregivers experienced (Zuurmond et al., 2019). However, for the supportive spouses, especially fathers of CwCP, research has showed better coping among the mothers of CwCP and the overall care of the CwCP. A study by Siron et al. (2020) which looked at the fathers’ involvement in parenting CwCP, made astonishing findings on the father involvement. Participants in this study, showed that they were involved in different roles in parenting their CwCP, actively meeting the needs of the child, communication with the child, balancing work, and childcare.

Furthermore, given that these caregivers face social isolation from the general community, Carroll (2013) highlighted that they often rely on others with similar circumstances for social support. This association with similar caregivers, has been found to provide numerous benefits to the caregivers. For example, it reduces perceived isolation, provides necessary emotional support, information, resources and increase positive perceptions of caregiving (Carroll, 2013; Niela-Vilen et al., 2014). The significance of associating with parents of children with similar disabilities has been highlighted by Sumbane (2024) in his study on coping mechanisms of caregivers of children with autism in Limpopo province in South Africa. Although participants in this study reported that they did not belong to any support groups, they highlighted that having a support group of parents of children with autism will be helpful for their coping.

The birth of children with disability evokes emotions among parents and families, hence they need to adapt and accept their children. Previous studies have highlighted acceptance of children with disability as an effective mechanism especially for coping with stress (Brown et al., 2020; Sumbane, 2024). Steadman (2015) found that acceptance and inclusion of children with disability resulted in reduced feeling of isolation among the caregivers.

1. **Methodology**

A qualitative research approach guided by phenomenological research design was used in the study. The aim of the study was to explore the coping mechanisms of caregivers of CwCP in Mokhotlong, Lesotho. The study was conducted between February and April 2022, in rural communities of Mokhotlong Lesotho. The study’s population was caregivers of CwCP. Participants were recruited using snowball sampling. The inclusion criteria were- adult caregivers of CwCP less than 18years and resident of Mokhotlong at least a year prior to the study. Nineteen (19) caregivers of CwCP, were yielded by the snowball process and only 12 met the inclusion criteria for participation. All the 12 caregivers consented to participate in the study. The initial caregiver was referred to the author by a South African based organization working also with caregivers of CwCP in Lesotho. Data was collected through one-on-one semi-structured in-depth interviews. Prior to embarking on the full interviews, the researcher began with a small talk to build rapport, explaining the interview procedures and assuring confidentiality to the participants while also ensuring cultural sensitivity, empathy and local context. During the interviews, open-ended questions were asked, while also probing to get full insight into the participants’ situation. Interviews were conducted in Sesotho and audio-recorded, with the shortest interview lasting for 49 minutes and longest interview lasting for 1hr 30minutes. All interviews were transcribed and translated to English language. Thematic analysis was employed to analyse the data. The analysis was guided by the six steps as propounded by Braun and Clarke (2006) that includes- data familiarization, generating initial codes, searching for themes, reviewing themes, defining themes, and writing up. Ethical considerations and the traditional Basotho gate-way approach (i.e meeting with traditional community leaders/chiefs upon entry in the communities) were observed throughout the study. To ensure the trustworthiness of the study, the following constructs developed by Lincoln and Guba (1985) were adhered to; credibility, dependability, conformability, and transferability. These constructs were operationalized through peer debriefing and examination, member checks, and reflexivity (Hendricks, 2006; Earnest, 2020; Birt et al., 2016; Polit and Beck, 2012).

1. **Results:**

Twelve (10 females and 2 males) aged between 23 years and 73 years participated in the study. Out of the 12, only 1 caregiver was single, 4 were married, 2 separated, 2 were divorced and 3 were widowed. The educational levels of the participants varied, from no school to tertiary. Only 1 participant did not attend school, three participants attained primary level education, 5 participants attained secondary level of education. Two participants attained high school level and only 1 participant attained tertiary education. Only two participants were employed, two were self-employed, while eight were unemployed. Participants were all Christians but had diverse religious affiliation/denomination of Christianity, 7 participants were Catholics, 1 evangelical, while 2 were of salvation and 2 apostolic respectively.

Table 1. Demographic information of participants

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| Participants |  Sex  |  Age | Marital status | Employment status | Educational level | Religious Affiliation |
| CG 1 | $$Female$$ | $$54$$ | Widowed | $$Unemployed$$ | $$Primary$$ | Catholic |
| CG 2 | $$Female$$ | $$23$$ | Separated | $$Unemployed$$ | $$Secondary$$ | Evangelical |
| CG 3 | $$Female$$ | $$31$$ | Divorced | $$Unemployed$$ | $$Secondary$$ | Salvation |
| CG 4 | $$Female$$ | $$29$$ | Married | $$Unemployed$$ | $$Secondary$$ | Catholic |
| CG 5 | $$Female$$ | $$23$$ | Married | $$Unemployed$$ | $$Secondary$$ | Catholic |
| CG 6 | $$Female$$ | $$70$$ | Widowed | $$Unemployed$$ | $$Primary$$ | Salvation  |
| CG 7 | $$Female$$ | $$73$$ | Married | $$Unemployed$$ | $$None$$ | Catholic |
| CG 8 | $$ Male$$ | $$30$$ | Separated | $$ Employed$$ | $$Tertiary$$ | Catholic |
| CG 9 | $$Female$$ | $$52$$ | Single | $$ Selfemployed$$ | $$High School$$ | Catholic  |
| CG 10 | $$Female$$ | $$40$$ | Divorced | $$Unemployed$$ | $$Primary$$ | Apostolic  |
| CG 11 | $$Female$$ | $$32$$ | Married | $$ Employed$$ | $$Secondary$$ | Catholic |
| CG 12 |  $Male$ | $$40$$ | Widowed | $$ Selfemployed$$ | $$High School$$ | Apostolic  |

To explore the caregivers’ coping mechanisms, it was imperative to look at them along the challenges they faced, and how these mechanisms were used to cope with such. The following themes emerged; financial resources, religion (faith in God), association with other caregivers of children with cerebral palsy, use of social media platforms and internet, subsidised health care services, and social support.

**3.1 Financial resources**

Financial resources in form of personal earnings, social grants, loans from microfinance clubs and money received from relatives and other people, helped the caregivers to address their needs and those of their children.

***3.1.1 Help from family***

Seven participants were helped financially by their relatives and were able to meet most of the basic needs of their children. They made the following statement to express the financial help:

*“I am helped by my aunty and uncle, the little money that they give me, I use it to buy whatever we need, especially the child’s needs.” CG 2.*

 *“My mother is the one who gives me money, out of her pension, she sometimes gives me M300.00, to buy things that we need. Also, I have children working in Maseru and South Africa, they are also helping me, if my mother doesn’t give me, they are another source that I depend on” CG 1*

*“I am depending entirely on the money that I receive from my old brother who is working in South Africa, and the money [social grant] I get from [Department of] Social Development.” CG 3.*

*“I made a tuckshop and my siblings also helping me financially.” CG 12*

Two caregivers (grandmothers), were also helped by their daughters (mothers of CwCP) who had to go find jobs due to the financial struggle and the general household destitution they experienced, they said:

 *“I am helped by my daughter,* [the mother of the child with CP]*. We were so struggling so I said that she should go to Maseru and find a job, sometimes she sends M1000.00 or M700,00.” CG 7*

*“I am coping financially through the money that my daughter sends, she had to leave us and go to* [South Africa] *Kwazulu-Natal to search for work, we were really struggling because sometimes we would just have one meal per day, and it was not sitting well with me to see my grandchildren just eating once.” CG 6*

* 1. ***2. Social grants***

Social grants [child grants and old age pension] from the Department of Social Development, were also another source of coping.

*“I get a quarterly child grant of M700,00 given by the [Department of] Social Development, it is the one that also helps with meeting the needs of these children.” CG 3*

*“I am getting the pension from the government, it is the one that I have my greatest hope on, it is helpful; I just wish they can increase it because it is our only hope as old people.” CG 6*

*“I am getting M700,00 from [Ministry of] Social Development. This is the third year receiving it; they give us after every three months.” CG 4*

*“I also get government pension; this is my third year receiving it. Honestly, I don’t know what I would be doing had I not been receiving that pension.” CG 7*

***3.1.3. Loans from community-based microfinance clubs***

Saving and lending of money from community microfinance clubs savings also helped the caregivers to meet their children’s needs. They pointed out that these clubs allow them to borrow money and pay it with some interest.

 *“I have joined a savings and lending society, so the little money that I have, I sometimes save it, then sometime when I need more money, I can just take a loan there and do whatever I need to do, the society is really helpful.” CG 9*

 *“I have joined a stokvel [microfinance club], I easily borrow money whenever I need some to address our needs. That is how I cope with meeting the needs of my grandchildren’’ CG 7*

*“I am also a member of women’s society here in the village. we are saving money and share at the end of each year, so in the year I will still take some loans and address our needs.” CG 3*

*“At my work, we have formed a savings club. It is really helping because anytime I money just call the chairperson and tell him I want to take a loan, ever since I joined that club, truly speaking I have been able to take care of my children especially this one with disability satisfactorily.” CG 8*

***3.1.4. Personal incomes***

Salaries and other personal incomes from microbusinesses, were also helpful in the coping of caregivers. The four caregivers (two self-employed and two employed) are quoted below:

*“My other means of financial survival is the salary I get. I meet most of our needs through that money, basically I cannot do anything huge because of my children’s needs.” CG 8.*

*“My tuckshop is also helping me to survive, it is true it is not generating much, but the little I get, I am able to buy food and some diapers, because though my child is 8 years, he still uses diapers because of this condition.’’ CG 12.*

*“My salary is also helping me with catering for the needs of my children; its little but it is very helpful” CG 11*

*“I brew and sell beer [traditional beer], the little money I get helps me to meet the needs of these children. It is true I don’t make much, but it is better than nothing because I really don’t like depending entirely on people”.” CG 9*

***3.2 Association with other caregivers of children with Cerebral Palsy***

Four caregivers who pointed out that they were part of the support group of caregivers of CwCP at the district hospital.

 *“One thing that helps me to cope is meeting with other parents that have children with this condition. We meet monthly at the hospital.” CG 5*

*“I am a member of support group of parents of children with this disability, that group was really helping me because we exchange ideas; just seeing other parents who are facing similar problem is helping because when they talk of problems they are faced with, honestly I would just thank God that at least my burden is still bearable.” CG 3*

*“I joined a [support] group at the hospital of parents of similar children, since then I have learned a lot and really changed my thinking, I had always been worried about this child, but the group is helping me to cope.” CG 1*

***3.3 Use of social media platforms and internet***

Apart from support groups of caregivers of CwCP, although it was not common among all the caregivers, three caregivers pointed out that they have joined a social media group of caregivers of CwCP, in which they send one another words of encouragement and care-giving tips daily.

*“There is a group I joined on WhatsApp of parents of children with this [CP], so normally there will be sharing of words of encouragement and some caregiving tips, so that helps me cope emotionally.” CG 8*

*“There is a Facebook group of parents of children with this condition I am following their page, and I usually search on internet some of the parenting tips for children with this condition, making it easy for me to cope.” CG 11*

*“We are living in a world full of technology, so if I don’t know something, I just check it there [on the internet]. So, the use of internet is helping to cope, because I even found about the food that I can give to him to lessen him having problems when passing faeces.” CG 3*

***3.4 Subsidised health care services***

Participants reported that the free health care services provided at the clinics have also eased their financial burden and their only worry is when they are referred to the district hospital as they have to incur transport costs and the M15 that is charged for consultation.

*“For medical fees, I don’t worry much because we only pay M15.00 at the hospital, so I think knowing that I don’t have to spend more for his health, allows me to cope, I can just walk to the hospital because it isn’t far.” CG 3.*

*“We don’t pay at the clinic. The greatest stress is when I am told I must go to Mokhotlong hospital, because the transport is expensive from here to town.” CG 12*

*“In relation to health, I think one good thing that the government did is to make medical fees cheap, so I really don’t worry much about paying for the medical check-ups, the only time I spend more money is when I go to the hospital.” CG 8*

***3.5 Social support from family and friends.***

Participants highlighted the nuclear and extended family as first and most important social support when one has a child with disability, hence stated that both their nuclear and extended families offered them social support.

 *“My husband is very supportive, emotionally and financially, he usually tells me that he will always be by my side, and that is really making cope, because I know I have a strong support system.” CG 4.*

*“My family and people in the community offer me the greatest support, and for me that is one thing that helps me most, because people can give you their money but if they are not available emotionally that is as good as nothing.” CG 1*

*“My friends and co-workers are also offering the greatest social support, their support means so much to me, I don’t think I would be able to wake up every day looking forward to each day with hope had they not been this supportive to me.” CG 8*

***3.6 Religion (Faith in God)***

Three caregivers pointed out that after diagnosis, they were in denial and saddened by their children’s conditions, but their religion gave them faith, courage, and strength to make sense of their children’s situation and that functioned as a resource that enabled them to accept their child with special needs and to manage the challenges that came with having a child with Cerebral Palsy.

 *“I was in denial when I knew of my child’s condition, but because of my faith, I ended up accepting that I have a child with disability and nothing with change that. I face the next day with courage because I have accepted my child.” CG 12*

*“I really did not believe that I have a child with disability but the faith I have in God is really helping and it has helped me so much to accept my child, even the challenges that I faced, I submit them to God in prayer I am still living.” CG 2*

*“My bible says what is impossible for man is possible for God. When I learned of this child, I was in so much denial, but because of the faith I have in God I am still up and caring for my children. It is not an easy task, but God is forever giving me the strength” CG 5*

Some participants, prayed, sang hymns and read the bible, which made it possible for the to have faith in God. Their faith offered them strength to care for their children, with some positively interpreting their children’s condition.

*“My faith is the one that helps me cope, because I have faith in God, I am still succeeding, I always sing hymns and pray.” CG 3.*

*“Honestly what keeps me up is my religion, I know when things get tough, I go down on my knees and pray to God to give me power to press on, I know my God is faithful, and he can never give me a load that he sees I can’t carry.” CG 6*

*“Prayer is powerful, and I always pray and read my bible just like an Apostolic person, because there are verses that usual sooth my spirit in difficult times, so I can say my faith is what helps me to cope.” CG 12.*

*“My faith helps me to look at this child as a gift from God because even the bible says that children are a gift from God, and because of that I know my child is a gift that I have to embrace, I don’t see him as a burden.” CG 8.*

**Discussions**

The study was carried out to explore the coping mechanisms of caregivers of CwCP in Mokhotlong Lesotho. The findings reveal a multidimensional coping mechanism rooted in financial strategies, personal belief systems, social networks, and structural support systems. Caring for CwCP brings about various psychological, social, financial challenges (Manyuma et al., 2023; Katumba et al., 2023; Wondemu et al., 2023). However, caregivers of CwCP have different coping mechanisms that they use to overcome or lessen these challenges. The findings of study revealed that coping mechanisms of caregivers of CwCP in Mokhotlong are: religion (faith in God), association with other caregivers of CwCP, social media platforms and internet, financial assistance, subsidised health care services, and social support. Of these coping mechanisms, financial resources, social support and religion were the widely used coping mechanisms among all caregivers.

These coping mechanisms were a positive predictor of quality of life and enhanced children’s care. For all participants, faith in God emerged as a central pillar of emotional resilience, and psychological anchor. This aligns with findings from similar studies in sub-Saharan Africa. Like findings of Sabik et al. (2024); Halabi-Elshiekh, (2012); Pelea (2016), the study found that religion was used by participants in this study to cope with caring for CwCP, and it provided meaning, hope, and strength to accept their children. Prayer, singing hymns, reading bible were mostly used strategies. While religion did not practically solve their problems, it provided them with a soothing feeling and spiritual comfort that helped them to overcome their problems as well as positively reinterpreting their children’s disability. Mikołajczuk and Zielińska-Król (2023), have also explored the use of religion in the life of the families of children with disability, participants in this study revealed the enormous benefits of religion. The study concluded that religion helps families cope with moments of difficulty and strengthening acceptance. These findings are like those of the present study, which found that praying, singing hymns and reading the bible, allowed the participants to cope and look forward to other days with hope including looking at their children as a gift instead of a burden.

Financial resources played a vital role in the participants’ coping. While the caregivers could not meet all their needs and those of children, the financial assistance from relatives and loans from community microfinance clubs, helped them to meet the basic needs of the children. Additionally, financial assistance from government in the form of grants and pensions, played a vital role, especially in households where caregiving responsibilities limited employment opportunities. Similar findings were found by Maronga- Feshete (2022) among caregivers of CwCP in Diepsloot, Gauteng, South Africa. Although caregivers in the present study appreciated the grants from the government, they still voiced concerns that the grants were not enough to cater for the needs of their children and wished that it could be increased. The same view was echoed by Trafford (2023) regarding the care dependency grant in South Africa, as well as participants in studies conducted by Vadivelan et al. (2020); Savage et al. (2021).

Extended family members, friends, and community members and other caregivers of children with cerebral palsy provided instrumental and emotional support, lightening the caregiving burden. Similar findings have been echoed by (Maronga-Feshete, 2022; Liu et al., 2025). While access to health services remains a challenge in Lesotho, especially in rural area, the subsidized health care services has alleviated the financial burden for the caregivers and enabled regular medical checkups for the CwCP. However, caregivers still reported challenges such as transportation costs, especially if they were referred to the district hospital. Although access to technology and signal connectivity remains uneven especially in rural communities, caregivers who could access social media and the internet reported significant benefits. These social media platforms enabled them to gather information on caring for CwCP, to connect with other caregivers and find emotional support.

1. **Conclusion**

Coping with caring for CwCP can be hard when resources are not available, despite this, caregivers of CwCP have coped. The general situation of caregivers and parents of children with disability in Lesotho is of great concern and of great promise if the right measures are taken to address challenges they face for their full latitude. The coping mechanisms employed by caregivers in rural communities of Lesotho reflect both individual resilience and collective support, and their situation is a call for help that needs to be addressed through policy and community-based programs and interventions that will enable these them to meet their psychosocial needs, to provide the best care for their children.

**Consent**

As per international standards or university standards, Participants’ written consent has been collected and preserved by the author(s).

**COMPETING INTERESTS DISCLAIMER:**

Author(s) have declared that they have no known competing financial interests OR non-financial interests OR personal relationships that could have appeared to influence the work reported in this paper.

**Disclaimer (Artificial intelligence)**

Author(s) hereby declares that NO generative AI technologies such as Large Language Models (ChatGPT, COPILOT, etc.) and text-to-image generators have been used during the writing or editing of this manuscript.

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