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NEEDS OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN RURAL COMMUNITIES OF MOKHOTLONG, LESOTHO

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Abstract

Caregivers of children with cerebral palsy (CwCP) experience multiple challenges leading to various needs. Other caregivers have managed to continue caring for their children despite having these needs, while some have struggled significantly. This study explored the needs of caregivers of CwCP in rural communities of Mokhotlong Lesotho. Understanding needs of caregivers of CwCP in rural communities, is essential for determining the support needed by these caregivers to effectively cope and improve their quality of life and care for their children and informing policy. A qualitative approach was used. Snowballing was used to recruit participants, with the first participant referred to the author by South African organization that worked with parents from Lesotho. The snowballing process yielded 19 caregivers, with only 12 meeting the criteria for inclusion in the study. The 12 caregivers were informed about the study and voluntarily participated. Semi-structured interview was used to collect data. Data was analysed using thematic analysis. The following needs were identified - need for information, social support, decentralized health and social services, financial support, employment and training on caring for CwCP. The study recommended several interventions to address these needs - provision of psychosocial support, community rehabilitation programs, financial and social support.

Keywords

Cerebral palsy, caregivers, Lesotho, needs, rural communities.

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1. Introduction

Cerebral palsy (CP) is a childhood disorder that occurs two to three per 1000 children globally (Wu *et al.*, 2017). Children diagnosed with CP, depend on their caregivers for assistance with a variety of things. Caregivers often devote much of their resources (time, financial and material) to the care of these children, so much that they neglect their own needs. The condition itself gives raise to multiple needs for these caregivers, which are essential to giving the optimal care needed by these children. Literature points out that caregivers of children with cerebral palsy (CwCP), have variety of needs- emotional, social, financial, informational, health and psychological, which often remain unmet during their lives (Aduful *et al.*, 2023; Bertule & Vetra, 2014).

Specific statistics on the prevalence of cerebral palsy in Lesotho is not available, making it difficult to determine the severity of this condition in Lesotho. The 2016 Lesotho population and housing census revealed that out of 847, 300 aged up to 19 years

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old, 5,802 children had at least one type of disability children. In Lesotho, majority of caregivers in rural areas are grandparents (Ministry of Social Development, 2014) because of increased rural-urban migration and the rapid death of the young generation (Ngozwana, 2019; MoSD, 2014). The situation of caregivers of children with disability in Lesotho is aggravated by the poverty and other social ills facing the country.

Service availability for caregivers of children with disabilities, especially CwCP in Lesotho are limited especially for rural caregivers. If at all available, these services are in the urban areas of the district or the capital city. These caregivers incur high transport costs to access these services. Poverty is more prevalent in the rural areas, which is the settlement for a vast majority (68.5%) of Lesotho population and a dwelling place of people with disability (Lesotho Bureau of Statistics, 2016). It is among the widespread problems facing many families in Lesotho, poverty estimates indicate that 57 per cent of all households in Lesotho live below the national poverty line (UNICEF, 2018a), thus Pelea (2016) stated that it causes greater hardships among families with children with disability. After the enactment of the Disability Equity Act of 2021, the Government of Lesotho, introduced M1800 (approximately US$96) disability grant, disbursed quarterly, which acted as a cost buffer among families of people with disability. Prior to this, there was no specific grant for children with disabilities, instead children with disabilities fell in the category of orphaned and vulnerable children and received M360 grant (Pelea, 2016).

Mokhotlong is one of the ten districts of Lesotho, a home for 100,442 people, of which 1,898 are people with disability (Lesotho Bureau of Statistics, 2016). According to UNICEF (2018b) children in this district are multidimensionally deprived. In rural communities, more children are under the care of the grandparents, thus, UNICEF (2018b) stated that children living in a household with five or more children are multidimensional deprived, with poverty of 77.4 per cent. Caregivers of children with disability in Lesotho experience various challenges due to different situations, such as low socio-economic status (Pelea, 2016), poor access to health services, community attitudes towards people with disability (Rafoneke, 2017), pervasive poverty, weak economic growth and highly skewed wealth distribution (Government of Lesotho, 2014). The impact of poverty can be felt across different levels of human lives. In Lesotho, majority of caregivers are females, hence Groce and Kett (2014) contended that often, those caring for children or adults with disability are females. The caregivers are reported to mostly relinquish income generating activities to care and provide support to their family members with disability (Cordier, 2014).

2. Literature review

2.1. Informational needs

CP is a complex condition to understand, with the situation harder for illiterate caregivers. Information on CP is one key need for caregivers of CwCP. Studies show that when these caregivers have information and/or knowledge about CP, they are better at coping with caring for their children. These caregivers need an array of information about caring for themselves and their children. Lack of information on CP, is a barrier to care (Vadivelan *et al.*, 2020). The informational need relates to social and health service acquisition for themselves and their children, support system available and the general care of CwCP. Results from Vadivelan et al. (2020) revealed that lack of knowledge on CP was a major contributing factor for stress experienced by the participants in the study who were mothers of CwCP. Furthermore, a study conducted by Bertule and Vetra (2014) among 227 parents of preschool CwCP in revealed that unmet needs of the children was information about services available and services that children might receive in the future, financial aid to pay for therapy and paying for special equipment of their children.

Information need is the most cited need for among parents of CwCP (Palisano *et al*., 2010; Bertule &Vetra, 2014; Wang & Michaels, 2009). For example, findings from studies revealed that parents of CwCP, felt that health care workers were not knowledgeable about CP, which made it hard for them to inform them about the diagnosis of their children hence parents felt somehow lost (Wise & Gellasch, 2022; Williams *et al*., 2021). The greatest lamentation from parents of CwCP, is the need to get adequate information about CP including the outmost support from the health professionals. In some studies, parents report that not having knowledge about CP, makes them unable to identify early signs that a child may have CP (Wise & Gellasch, 2022; Khan *et al*., 2022). Majority of studies looking at the information needs of parents of CwCP, highlight the need for information about diagnosis as the greatest informational need (Wise & Gellasch, 2022; Williams *et al*., 2021).

2.2. Social needs

While the birth of children brings joys to families, the diagnosis of CP evokes mixed feelings in parents of CwCP. During this, parents’ greatest need is the social and emotional support. Studies reveal that lack of social and emotional support for parents of CwCP, leads to feeling of loneliness (Hosokawa & Katsura, 2024) which in turn affects the overall health and quality of care rendered to children. CwCP are mostly cared for by their mothers, with evidence from various studies explaining that fathers are mostly not involved in the care of CwCP (Phumudzo *et al*., 2021). Caregivers of CwCP have a vast social need across their life. These needs relate to participation in social activities, social support from relatives and community. Studies revealed link between inadequate social support and experiences of psychological challenges among caregivers of CwCP (Hosokawa & Katsura, 2024; Cheshire *et al*., 2010, Park & Kim, 2020).

2.3. Financial needs

Despite the available financial aid, in various studies parents of CwCP have echoed a need for financial assistance. This need has been explained by various studies that have found that majority of parents of CwCP are unemployed (Singogo *et al*., 2015; Bertule & Vetra, 2014; Chibvongodze, 2018; Seroke & Mkhize, 2023). While most countries provide financial support for people with disabilities, this amount falls short to cover the costs associated with disability. The care of CwCP is associated with high costs, with the situation being too detrimental to caregivers in rural areas. These caregivers need money to cater for the various needs of their children and for their families (Dlamini *et al*., 2023). Due to the care demands, majority of caregivers of CwCP are unemployed (Wondemu *et al*., 2022), with some having limited and inflexible working hours (Brannan *et al*., 2022; Pizano-Vega *et al*., 2020) and finding it hard to save money for future use (Vadivelan *et al*., 2020).

3. Methodology

The study was conducted from February to April 2022. Qualitative approach guided by phenomenological design was used to explore the needs of caregivers of CwCP in rural communities in Mokhotlong Lesotho (Creswell & Creswell, 2017). The population of the study was caregivers of CwCP aged 18 years and above, living in Mokhotlong district. The study used snowballing sampling to recruit participants. Strydom (2005) stated snowballing involves approaching a single case that is involved in the phenomenon to be investigated to gain information on other similar persons, in turn, this person is requested to identify further people who could make up the sample. Thus, the first caregiver was linked to the author by a South African organization working with parents of CwCP from Lesotho, who then referred the author to the next caregiver. The snowball process yielded 19 caregivers, of which 12 met the study's criteria for inclusion and voluntarily participated in the study.

The study was conducted in rural communities in Mokhotlong district, where access to health and other specialized services for CwCP is limited. The study observed various ethical considerations for studies involving human subjects. The following ethics were considered, informed consent, voluntary participation, confidentiality, anonymity and privacy (Goredema-Braid, 2010; Barrow *et al*., 2021). All participants were provided with all relevant information about the study, in the local language (Sesotho) to ensure that all they were adequately informed prior to participation in the study. Furthermore, the study upheld no deception and the no harm ethics, throughout the study by ensuring that no participants were either emotionally or physically harmed. Data was collected using semi-structured interview guide and all interviews conducted in Sesotho and were recorded, transcribed and translated to English. The longest interview lasted for 1-hour 30min and the shortest for 49 minutes. The thematic analysis was used to analyse the data and all the steps of thematic analysis as propounded by (Braun & Clarke, 2006) were followed.

4. Findings of the study

Table 1. Demographic information of participants

CG 1	Female	54	Widowed	Unemployed	Primary
CG 2	Female	23	Separated	Unemployed	Secondary
CG 3	Female	31	Divorced	Unemployed	Secondary
CG 4	Female	29	Married	Unemployed	Secondary
CG 5	Female	23	Married	Unemployed	Secondary
CG 6	Female	70	Widowed	Unemployed	Primary
CG 7	Female	73	Married	Unemployed	None
CG 8	Male	30	Separated	Employed	Tertiary
CG 9	Female	52	Single	Selfemployed	High School
CG 10	Female	40	Divorced	Unemployed	Primary
CG 11	Female	32	Married	Employed	Secondary
CG 12	Male	40	Widowed	Selfemployed	High School

Twelve caregivers (10 females and 2 males) voluntarily participated in this study. Their ages ranged from 23 to 73 years, with majority (10/12) falling between 23 and 54 years. The oldest caregivers aged 54, 70 and 73, were the maternal grandparents of the CwCP. Majority (8/12) were unemployed. For educational attainment, only 1 caregiver did not attend school, five attained secondary education, three primary and only 1 other caregiver had attained tertiary education. In relation to marital status, only 1 caregiver was single, 4 were married, 2 separated, 2 were divorced and 3 were widowed. All participants were Basotho.

The following themes emerged during the data analysis; need for information, need for social support, need for decentralized services (health and social services), need for financial support and need for employment and establishment of income generating activities and need for training on caring for CwCP.

4.1. Need for information

All caregivers reported the need for information as their greatest need. This need related to diagnosis, services for CwCP. Biological parents who participated in this study, voiced having had mixed emotions during diagnosis and needed to be informed more by the health professionals.

> "*I really didn't understand this condition at all because the doctor just told me that a child had 'problems' during birth so that is the reason why he this [cerebral palsy] We need to get more information about this condition" CG4.*
> *"I need more information about this condition, because it was first time seeing a child like this. I need to know how to care for this child, there is a whole lot to learn" CG 1.*
> *"It was my first time to have a child with this condition and I have never seen anyone with it, so for me I needed the doctors to tell me more about it, but it was like they also didn't know much about it. There is so much to know about this condition, as parents we need so much information" CG 3.*

Lack of knowledge also led to other caregivers being worried about the future of their children due to uncertainties of what will happen next.

> *"I wonder if in the coming years I will still be able to care for him in a manner that he needs, because I am getting old. This condition needs someone who can keep up with the demands it raises in child, I sometimes just can't cope" CG 7.*
> *"It's true now I am still able to care for her, but I am worried about whether I will be able to care for her as she grows older than she is now, this condition brings up new challenges as the child grows old. I need to know more about it" CG 11.*
> *"For a male person like me who is caring for a child, I need to be given more information about, because I am worried what will happen next, but if I have information, I can be provide the needed care" CG 12.*

Moreover, none of the children under the participants care were in school, due to lack of knowledge about special schools for CwCP.

> *"I have never heard of any orphanage or school that can accommodate children with this condition, so I am forced to take care of this child here at home, we don't know of places that can accommodate our children, so that they can also get education also" CG 8.*
> *"We live in a district where developments are just a wish, we don't have schools or some facilities that can accommodate our children, I am sure even if we did, they will all be in town not anywhere near where I can just walk daily" CG 10.*

> *"There are no schools that can accommodate children of this kind in Mokhotlong, the problem is that my child has other limitation that don't need this primary school we have here, they need special schools" CG 12.*
> *"This district isn't like Maseru, no schools or whatsoever that can assist our children, the unavailability of such things is the greatest barrier, imagine a 17-year-old girl not in school, what's going to happen in future? She will forever be a burden to us" CG 9.*

4.2. Need for social support

The care for CwCP is emotionally draining hence the need for social support. Some caregivers especially mothers of CwCP, lamented the need for social support especially from the children's father, who were not so involved in the children upbring.

> *"In as much as his father still gives me support, he doesn't do that fully he is not so involved as one would expect, I need him the most" CG 4.*
> *"My husband still helps me, but he is just so not involved. I need the greatest support from him in this journey" CG 11.*
> *"It is true we are no longer married with this child's father, but he doesn't do anything for him. I wish he can support me in taking care of this child since he is working" CG 3.*

For some caregivers, their extended families, friends and the community were not supportive, instead blamed and made insensitive comments about them and their children, hence wish that they can be support.

> *"I still have "friends", but most of the time I hear them speaking negative things that discourage me about my child, that hurts me so much. I need them to be therefore me because the care of this child is so draining" CG 5.*
> *"Instead of supporting me, they will be asking me if I never feel like my son can die considering how much I struggle, I so wish they can be there for me, I need to have a strong social support" CG 3.*
> *"All I need is for people to support me in caring for this child, I need people who are there for me emotionally, nothing is more important than having a strong support" CG 6.*

4.3. Need for decentralized health and social services

As parents navigate the health and social services system, they are confronted by systemic barriers hindering them to access services for themselves and for their children. Many caregivers were faced with unique health related problems. They endured worries, leading to psychological stress, burnout and other illness that demand medical attention. Often than not, their needs remained unattended to for a long period of time, hence needed services to be decentralized. Explaining this, the caregivers made the following:

> *"As parents we have so much stress because of this condition, I think having regular community health visits by nurses will help because we cannot reach there [health centers] easily because of our children" CG 11.*

> *"In as much as the clinic is near, most services needed by my child are at the district hospital, so I need them to bring these services to us, instead of having to go there [district hospital] because it is costly" CG 5.*
> *"I wasn't aware that we have people [Auxiliary Social Workers] from social development at our council office, so I only learned when I went to the office in town, so we need to have services coming to us because we really can't afford traveling to them with these children" CG 3.*
> *"It is high time services come to us because we are in rural areas, having to access these services, which are mostly in town or Maseru, it is costly, so service providers must come to us" CG 8.*

4.4. Need for financial support

Although there was financial support in terms of social grants, help from other relatives, all caregivers echoed the need for financial support, arguing that their needs and those of the children they care for surpass the money they have.

> "*Caring for a child like this [CwCP] demands so much money, of which I don't have it. I need money to buy things that he needs" CG 5.*
> *"I need more [financial] support. My daughter [mother of CwCP] even had to go to Maseru for work because we were struggling" CG 7.*

Even caregivers who were receiving government grants [child grant and old age pension] echoed a need for the grants to be increased.

> *"I appreciate getting the M700.00 for child grants that is given by the [Ministry] of social development, but the problem is that it too little and it comes after a long time, I so wish they can increase it" CG 3.*
> *"The problem with the money from the government, is given after three months, I wish they can increase it, our needs are just too much" CG 4.*

4.5. Need for employment and establishment of income generating activities

Majority (8/12) were not employed, among these some had disengaged in income generating activities because they had to stay home to care for their CwCP. These caregivers stated that one of their needs is employment which will enable them to have a sustainable income.

> *"I need some startup capital if I can't get employed, I used to sell at the taxi rank, when my mother was still around, I believe I can meet some of my needs if I have a stable income" CG 9.*
> *"I used to do some piece-jobs, but that is no longer something I do now because of this child, I am in need of a job or get some money to start my own business" CG 1.*
> *"All I need is a job to provide for my child, it is true I am getting the [child] grant, but it is not enough given my needs and those of the children I care for, especially this one [CwCP]" CG 3.*
> *"I need a job, caring for a child like this, need someone with lots of money, but then I just can't find any because of staying in rural areas" CG 4.*

4.6. *Need for training on caring for CwCP*

All caregivers expressed the need for training on caring for a CwCP, to acquire knowledge on caring, throughout the lifetime of their children.

> *"I also need to get some training on how to care for this child [CwCP], because sometimes I worry that I may worsen his condition because of not knowing how to care for him" CG 12.*
> *"As parents, we need to be taught about this [cerebral palsy], especially when we are pregnant be will then know when to prevent the chances of our children having this" CG5.*
> *"I think we need to have many workshops to learn how to care for children with this disability, so that as they age, we know how what to do" CG 3.*
> *"I have never cared for a child with disability, so I need some training on how to care, especially because I am the sole caregiver of this child since her mother died" CG 1.*

5. Discussion

The study has found a common occurrence of needs, which underscored the living experiences of caregivers of CwCP in rural communities of Mokhotlong Lesotho. Often, these needs remained unmet, consequently impacting on participants' living conditions and the overall care for their children. While these caregivers had diverse needs as revealed by the findings, informational, financial and social needs stood out as the top needs. These findings were consistent with findings from Almasri et al. (2013), Palisano et al. (2010), Bertule and Vetra (2014) and Wang and Michaels (2010). Compared to other needs, the need for information was voiced by all caregivers, this related to need for information about cerebral palsy and services available for themselves and their children. These caregivers hope is on health and social service professionals for acquisition of these information. Thus, if they do not have this information, it limits them in several ways, such as services acquisition for themselves and their children, especially services that can help to improve the care for their children.

The need for social support was mostly voiced by the female participants (3, 4, 11) who were the biological parents of CwCP, whose husband and relatives were wholly not available to support them. While other studies have shown friends and families as a social support system aiding the caregivers coping (Pelea 2016; Wang *et al*., 2020), the findings of the study revealed that not all caregivers enjoyed the support from the friends and family. For example, participants (3, 5, 7) in this present study, reported that their friends and family were not supportive instead blamed them for having children with cerebral palsy.

Consistent with findings of (Eloreidi *et al*., 2021; Dlamini *et al*., 2023) the study has also found that financial support is a need for caregivers of CwCP, especially because majority of them are unemployed and those engaging in income generating activities had to disengage in such to care for their children. As expressed by participants in studies conducted in South Africa (Savage *et al*., 2021) and in India (Vadivelan *et al*., 2020) on the need to increase the grants, participants in this study who received social grants also shared the same sentiment as they felt that the grants were insufficient to cater for the needs of their children and themselves. The participants' need for financial support was exacerbated by several factors, high cost associated with care, transports costs to access services at the district hospital and that majority (8/12) were unemployed. Despite the lack of training on caring for CwCP, the caregivers have managed to develop their own means of care through trial and error. It remains critical that services are decentralized to meet the needs of caregivers of CwCP.

6. Recommendation

While the needs of caregivers of CwCP are diverse, the study recommends the following:

6.1. The increase and digitalizing of social grants (child grants and disability grants) and do monthly disbursement.

6.2. Provision of targeted mental health and psychosocial support to caregivers of children with disabilities.

6.3. Provision of community-based rehabilitation and positive parenting programmes to improve caregivers' ability and resiliency to care for their children.

6.4. Introduction of social work with people with disabilities as a special field in social work training to ensure social workers has a thorough understanding of issues of disability, to holistically help people with disabilities and their families.

7. Implication for social work practice

The implications that this study has for social work practice are intense, especially when the social work practice still has its own challenges in Lesotho, particularly its regulation. Social Workers need to intensify the advocacy for support of families of children with disabilities across different fields of practice, especially in the health settings. Furthermore, social workers need to engage in psychosocial preparations of families/parents and communities to offer support to people with disabilities and their families. Social workers need to advocate for the mainstreaming of disability issues across a broad range of policies, including lobbying the private sector to address these needs, as the government cannot do it all by itself.

8. Conclusion

The study aimed to explore the needs of caregivers of CwCP in rural communities of Mokhotlong Lesotho. This was achieved through looking at these needs across individual, family, community and institutional level. The conclusion made from this study is that caregivers of CwCP in rural communities have diverse needs, which are exacerbated by the family relations, lack of knowledge on the availability of services and the inadequate policy frameworks on disability issues. The study calls for multisectoral approach to addressing these needs, prominently access to financial resources and social support.

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