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The mental health of maternal caregivers of children with cerebral palsy in rural, low-income parts of Southern Africa

NGOKWANA Rachamose and CLARE Harvey

ABSTRACT

Maternal primary caregivers of children living with cerebral palsy (CP) bear a significant burden that has the potential to impact their mental health. There is a paucity of research on the mental health of maternal caregivers of children with CP in rural areas of Southern Africa, highlighting the need for further exploration in this area. Specifically, there is a need to explore the multifaceted factors that influence the mental health of maternal primary caregivers of children with CP living in rural, low-income areas. The paper aimed to identify the various factors that influence the mental health of maternal primary caregivers of children living with CP who reside in rural, low-income areas of Southern Africa. Additionally, the paper sought to enhance the understanding of healthcare practitioners and stakeholders engaged in the care and support of these maternal primary caregivers and their children living with CP, therefore increasing awareness of this issue. This is a theoretical paper discussing the existing literature on the mental health of maternal caregivers of children living with CP in Southern Africa. The review was conducted by searching for published and grey literature in Google Scholar, PubMed, and EBSCOhost. The mental health of such caregivers is influenced by several factors, including the economic situation, physical demands, environmental conditions, insufficient information, experiences of stigma and marginalisation, interpersonal relationships, and emotional challenges. The social-ecological model is used to make sense of these factors in the mental health of maternal primary caregivers of children living with CP.

KEY TERMS: *cerebral palsy, disability, low-income, maternal primary caregivers, mental health, mothers, rural*

NAGANWAGO (Sepedi/Northern Sotho)

Bahlokomedi ba mathomo ba bomma ba bana bao ba phelago ka bolwetši bja go golofala ga bjoko (CP) ba rwala morwalo wo mogolo wo o nago le bokgoni bja go ama maphelo a bona a monagano. Go na le go fokola ga dinyakišišo mo lefelong le, go gatelela taba ye, go nyakega ga nyakišišo ye ntši ka ga maphelo a monagano a bahlokomedi. Ka go lebanya, go na le tlhokego ya go hlahloba mabaka a mahlakore a mantši ao a amago maphelo a monagano a bahlokomedi ba mathomo ba bomma ba bana bao ba nago le CP bao ba dulago dinagamagaeng, mafelong a letseno la fase. Pampiri e be e ikemišeditše go šupa mabaka a go fapafapana ao a tutuetšago maphelo a monagano a bahlokomedi ba mathomo ba bomma ba bana bao ba phelago le CP bao ba dulago dinagamagaeng, mafelong a letseno la fase. Go tlaleletša, pampiri ye e be e nyaka go godiša kwešišo ya bašomi ba tlhokomelo ya maphelo le bakgathatema bao ba tsenetšego tlhokomelo le thekgo ya bahlokomedi ba ba mathomo ba bomma le bana ba bona bao ba phelago le CP, ka fao e oketša temošo ya taba ye. Ye ke lengwalo la teori leo le ahlaahlago dingwalo tše di lego gona ka ga maphelo a monagano a bahlokomedi ba bomme ba bana bao ba phelago le CP ka Borwa bja Afrika. Tekolo e dirilwe ka go tsoma dingwalo tše di gatišitšwego le tša ka ntle ga dikanale tša setšo tša go phatlalatša go Google Scholar, PubMed, le EBSCOhost. Bophelo bjo bobotse bja monagano bja bahlokomedi ba mathomo ba bomma ba bana bao ba nago le CP dinagamagaeng le mafelong a letseno la fase bo tutuetšwa ke mabaka a mmalwa. Mabaka a a akaretša maemo a ekonomi, ditlhohlo tša maikutlo, dinyakwa tša mmele, maemo a tikologo, dikamano tša magareng ga batho, tshedimošo ye e sa lekanego le maitemogelo a kgethollo, gammogo le go kgaphelwa thoko le go kgaphelwa. Mohlala wa ikholotši ya leago o šomišwa go dira gore mabaka a a kwagale bophelong bjo bobotse bja monagano bja bahlokomedi ba mathomo ba bomma ba bana bao ba phelago le CP.

KEY TERMS: *bahlokomedi ba mathomo ba bomma, bogole, bolwetši bja go golofala ga bjoko, bomma, bophelo bjo bobotse bja monagano metsemagae, Borwa bja Afrika, letseno la fase*

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INTRODUCTION

Cerebral palsy (CP) is a collective term used to refer to a set of persistent conditions that affect the development of movement and posture, resulting in limitations in activity. These conditions are caused by non-progressive disruptions that take place in the developing brain of a foetus. *Go golofala ga bjoko* (cerebral palsy) is often accompanied by other medical conditions including epilepsy, intellectual impairment, sensory abnormalities, and behavioural issues. The exact cause of CP is unclear, however, the most prevalent causes include genetics, foetal brain deformity, maternal illness during pregnancy, and foetal birth injury. Cerebral palsy ranges in severity from moderate to severe, and several subtypes exist depending on the brain regions affected, including spastic, athetoid, ataxic, hypotonic, and mixed. Although there is no cure for CP, motor abilities may be improved with therapies, medicine, and surgery. This paper presents a comprehensive theoretical review of the current body of literature pertaining to the mental health of maternal caregivers of children living with CP in Southern Africa. The review aimed to explore the various factors that have an impact on the mental health of these caregivers.

BACKGROUND

Cerebral palsy remains the most prevalent *bogole bja mosepelo* (motor disability) among children (Katangwe *et al*., 2020). In 2019, it was predicted that 8.1% of the world's 662.8 million children under the age of five years had CP (Katangwe et al., 2020), implying an increasing population of children living with CP globally, necessitating increased consideration for this particular disability. Various global population-based studies report that the incidence rate of CP during childbirth ranges from 1.5 to 4 per 1000 live births (Katangwe *et al*., 2020). 2 to 3 cases of CP per every 1000 live births were reported in high-income countries, while the figure was more than double, 5 to 8 cases per every 1000 births, in low-income countries (Dambi *et al*., 2015). *Dinaga tša letseno la fase* (low-income countries) are defined as nations with the most economically disadvantaged conditions, as assessed by the World Bank (World Population Review, 2023). The low-income continent of Africa has the highest rates of CP worldwide, with prevalence estimates ranging from 2 to 10 per 1000 live births (Katangwe *et al*., 2020). This statistic demonstrates a significant disparity in the prevalence of CP between low and high-income countries, highlighting the need for increased attention in this area. Furthermore, a significant proportion of children living with disabilities reside in rural areas, resulting in caregivers having restricted access to knowledge about the rehabilitation, training, and nutritional needs of their children (Zuurmond et al., 2019). Arguably, caregivers of children with CP residing in rural, low-income areas may encounter distinct barriers when it comes to accessing support services because resource-constrained environments differ considerably from those in developed nations (Sodi & Kgopa, 2016).

Children diagnosed with CP require a substantial degree of physical assistance and emotional nurturing from their primary caregivers, necessitating a heightened allocation of time and resources (Kyeremateng *et al*., 2019). Providing individualised support that is specifically designed to accommodate the unique needs of a person with disabilities is an integral aspect of a parent's obligations. While it is widely recognised that the responsibility of caring for children is no longer exclusive to women and that men are progressively assuming this role, gender stereotypes and gendered caregiving practises continue to prevail, particularly in low-income contexts, designating *basadi* (women) as the primary caregivers for children (Harvey, 2015). Often, the maternal figure withdraws from her professional commitments to prioritise nurturing her child, significantly influencing her day-to-day existence (Kyeremateng *et al*., 2019). In the African context, children diagnosed with CP are often cared for within a familial environment, mostly by close relatives. This trend is especially prevalent in rural regions of the continent (Olawale *et al*., 2013). These individuals are considered caregivers, although they often lack formal training in caring for children with disabilities. Given the paucity of research on familial female caregivers of children living with CP in rural, low-income areas, this paper will focus on maternal primary caregivers – referred to as *'bahlokomedi'* ('caregivers') – including biological mothers, grandmothers, aunts, as well as legal female parents such as adoptive or foster mothers. The paper will focus on those who provide full-time care for children with CP. The area of interest includes exploring the factors affecting the *bophelo bjo bobotse bja monagano* (mental health) of these maternal primary caregivers who reside in rural, low-income areas of Southern Africa. The next section will answer the research question: What are the various factors that have an impact on the mental health of caregivers of children with CP in rural, low-income Southern Africa?

LITERATURE REVIEW METHODOLOGY

The review was conducted by the first author searching for published and grey literature (peer-reviewed journal articles, dissertations, policies, and government documents) in the databases of Google Scholar, PubMed, and EBSCOhost. The search terms were 'cerebral palsy', 'disability', 'mental health', 'carers', 'Africa', 'rural', 'low-income', 'challenges', 'quality of life', and 'barriers'. We did not stipulate a time frame for the literature given that the topic is so understudied. Both qualitative and quantitative studies were included. The review began by

looking at the definition and types of CP, then moving on to the prevalence of CP in Africa and Southern Africa. Then we looked at papers about the barriers, obstacles, and challenges of caring for a child with CP in Africa, as well as papers addressing the mental health of caregivers. Following that, we provided a theoretical framework to contextualise and emphasise the interconnected relationship between individuals and their social contexts, allowing us to examine caregivers' challenges and resources at both the individual and broader social levels.

Caregiving of children living with CP in rural, low-income Southern Africa

Research indicates that caregivers of children living with CP are at significant risk for mental health issues (Seroke & Mkhize, 2023). The prevalence of mental health issues among these caregivers residing in rural areas of Africa is further exacerbated by substantial obstacles in obtaining healthcare services and limited resources (Seroke & Mkhize, 2023). This is particularly relevant in African communities where impairments are still often seen as unfortunate circumstances (Rohwerder, 2018). The experience of becoming a mother to a child with a disability has the potential to result in social isolation, stigmatisation, and marginalisation, potentially contributing to the onset of depression and other mental health issues (Brandt *et al*., 2022). The World Health Organisation (WHO) highlights that various factors – individual, societal, and structural – exert influence on an individual's mental health (Allen *et al*., 2014). These factors interact with one another, either facilitating or hindering mental well-being. In low-income countries, various socioeconomic and environmental factors, including poverty, violence, inequality, and environmental deprivation, significantly contribute to the heightened likelihood of individuals experiencing mental health issues (Allen *et al*., 2014). Thus, a comprehensive understanding of the social determinants of mental disorders may be crucial for developing effective strategies aimed at promoting mental health.

In low-income settings caregivers are often *imetšwe* (burdened) with the care of the family, earning a livelihood, as well as caring for the child with CP (Vadivelan *et al*., 2020). Further, caregivers often experience stress and depression (Seroke & Mkhize, 2023). The caregiver's degree of stress and despair is negatively linked to their self-esteem and social support (Nuri et al., 2019). Along with psychological issues, caregivers experience social isolation, are unable to engage in social life, and are ostracised, causing family and societal disputes (Thrush & Hyder, 2014). Additionally, they experience bodily stress, including sleep deprivation, musculoskeletal problems, and hypertension (Resch *et al*., 2010). The burden associated with caring for children living with CP, particularly in rural, low-income areas is a neglected phenomenon and therefore, it is necessary to recognise and address the experience to better both the lives of the caregivers and subsequently of the children cared for. The following sections examine the factors that influence the mental health of primary maternal carers of children with CP in rural, low-income areas.

Economic factors

Caring for children with CP is commonly related to *kgatelelo ya ditšhelete* (economic strain) (Donald *et al*., 2014; Thrush & Hyder, 2014). Children with disabilities residing in low-income areas are statistically more prone to reside with caregivers who encounter financial hardships and elevated levels of psychological distress in comparison to able-bodied children (Goudie *et al*., 2014; Moosa-Tayob & Risenga, 2022; Thrush & Hyder, 2014). When caregivers have to simultaneously fulfil the responsibilities of regular employment and the care of their children living with CP they may be predisposed to mental health difficulties (Goudie *et al*., 2014). Rural areas present a significant deficiency in support services for caregivers to provide the adequate care required by children. One of the problems highlighted in the literature for caregivers is transportation challenges in accessing rehabilitation services in rural areas, manifesting in lengthy travel durations and financial implications (Sodi & Kgopa, 2016). In this context, financial hardship poses a significant barrier to the development of resilience and serves as an additional stressor for families with children who have disabilities (Sodi & Kgopa, 2016). Consequently, having access to financial assistance and healthcare services improves the mental health of caregivers.

Physical factors

During the caregiving process women endure tremendous *mošomo wa mmele* (physical labour), involving repositioning, washing, feeding, playing with, and giving the child physical treatment (Vadivelan et al., 2020). Furthermore, women are usually responsible for home chores and the care of other family members. The compromise of physical health may have an additional impact on the mental health of caregivers. Caring for children living with CP has been found to have an adverse impact on the caregiver's physical and mental well-being, as well as the potential to induce psychiatric disorders as a consequence of their caregiving responsibilities (Albayrak *et al*., 2019). Moreover, in many circumstances, it is difficult to get relief services, as many caregivers in rural, low-income communities may not afford them, and these may be inaccessible.

Environmental factors

Various environmental factors place caregivers under duress (Vadivelan *et al*., 2020). The environment, particularly in low-income contexts, is a significant impediment to the active participation of people with disabilities in society, and for the purposes here, of those who care for them (Vadivelan *et al*., 2020). Disability-inclusive environments (specialised educational institutions and recreational areas) are infrequently encountered in rural, low-income areas. Visagie *et al*. (2013) noted that wheelchairs in rural areas are limited mainly because of the long process of application as well as the lack of adequate funding, and that a lack of assistive technologies for children in rural, low-income areas hinders their rehabilitation. Thus, there seems to be a lack of desire to include children with CP leaving caregivers in these contexts holding negative attitudes towards raising children with disabilities.

Inadequate knowledge

One of the most prevalent difficulties experienced by caregivers of children with disabilities is a lack of access to essential disability-related information (Donald *et al*., 2014). In low-income, rural contexts, caregivers frequently encounter a lack of comprehensive guidelines for the management of disabilities, primarily because of insufficient training of healthcare workers in the necessary skills required to provide care for children with CP. The absence of expertise leads to a sense of mistrust towards healthcare professionals (Donald *et al*., 2014). According to Sadiki (2022), cooperation and communication between caregivers and medical personnel in rural areas are insufficient. *tshedimošo ye e sa lekanego* (inadequate information) available to caregivers may present a mental health challenge, since it may result in a lack of confidence in providing adequate support to their children, potentially leading to feelings of hopelessness, misplaced optimism, and isolation. Sadiki (2022) postulated that in Southern Africa, a middle to low-income context, there exists a lack of effective collaboration among the education, health, and social development sectors leading to inadequate knowledge about various resources at caregivers' disposal.

Stigmatisation and marginalisation

According to Resch *et al*. (2010), the integration of children with disabilities into communities is a key concern for mothers. In low-income, rural areas special schools are often lacking. Hence, caregivers rely on mainstream schools for their children with CP, leaving them feeling helpless because they cannot supervise their children. Moreover, the community's negative attitude towards the child is typically cited as one of the most difficult obstacles to manage for caregivers (Resch *et al*., 2010). According to Rohwerder (2018), cultural and religious beliefs contribute to the formation of inaccurate ideas on the aetiology of disabilities in many low-income nations. A prevalent belief among some African cultures is that disabilities are attributed to ancestral transgressions, parental misconduct and supernatural beings such as demons or spirits. Caregivers of a child with a visible disability such as CP are subjected to public scrutiny and feel shamed and alienated, often being excluded from social occasions as a result of the ignorance of others (Resch et al., 2010). Notably, caregivers' persistent emotional anguish is not caused by the degree of their child's disability, but rather by *go kgetholla* (stigmatisation) by community members (Brandt *et al*., 2022). Additionally, family members stigmatise mothers since they gave birth to a child with a disability and are perceived as the cause of the disability, especially in low-income, rural areas where a lack of education into disabilities is prevalent (Polaha *et al*., 2015).

Interpersonal factors

Caregivers' interpersonal relationships may serve as stress buffers in their caregiving duties, however, they may occasionally lead to stress (Vadivelan *et al*., 2020). Thrush and Hyder (2014) found that social disengagement from various activities and a constrained social life are two of the largest social disadvantages of caring for children with CP. Caregivers report spending the vast majority of their time on their caregiving responsibilities (Arasu & Shanbhag, 2021). Consequently, it is challenging for caregivers to maintain friendships because their lives seem so dissimilar to those of their acquaintances, and their friends do not always know how to engage with their children. Thus, caregivers report feeling isolated when caring for children with CP, since they often feel they have no one to talk to about the challenges they face (Albayrak *et al*., 2019; Arasu & Shanbhag, 2021). *Thekgo ya leago* (social support) has been demonstrated to effectively alleviate the stress experienced by caregivers of children living with CP (Nuri *et al*., 2019).

Emotional factors

The General Health Questionnaire-28 study found a significant proportion of caregivers of children with disabilities exhibited a vulnerability to the onset of *malwetši a monagano* (mental disorders) (Kouther *et al*., 2022).

Similarly, a study conducted by Arasu and Shanbhag (2021) revealed that caregivers are susceptible to experiencing stress as well as cognitive and emotional difficulties. Caregivers experience *kgatelelo ya monagano* (stress) because of the ongoing demands associated with caring for children with disabilities, specifically in relation to communication constraints and difficulties in performing everyday duties and self-care activities, as is the case with CP. Further, mothers of disabled children have reportedly suffered from mental health issues including depression and anxiety (Vadivelan *et al*., 2020). It was found that having a child with a neurological impairment represented failure for mothers, leaving them feeling accountable and guilty. The absence of adequate maternal services provided by both governmental and non-governmental entities in rural areas is a contributing factor to these emotional difficulties (Sadiki, 2022; Tigere & Makhubele, 2019). Mothers are in particular need of psychological support since they assume the majority of the responsibility of caring for their children living with CP (Olawale *et al*., 2013). Concerns regarding the effects of CP on caregivers' mental health status have been raised by healthcare providers. However, studies report on the challenges related to the treatment of mental illness in resource-poor countries (Polaha *et al*., 2015), including caregivers' limited recognition of the need for treatment, societal stigmatisation, financial feasibility, availability of healthcare services, and scarcity of mental health professionals. According to the Rural Health Information Hub (2017), individuals residing in rural areas face limited availability of service providers, with some rural regions completely lacking healthcare services. Individuals in rural areas frequently encounter the need to cover substantial distances to access necessary services. Individuals residing in rural regions with limited financial resources frequently exhibit a tendency to postpone the initiation of mental health interventions until their symptoms have reached a heightened level of severity. Consequently, these individuals are more prone to experiencing hospitalisation compared to their counterparts residing in urban settings (Stewart et al., 2015). The presence of mental illness stigma has been identified as a contributing factor to challenges in identifying mental health symptoms, accepting diagnoses, and pursuing timely and continuous treatment (Polaha *et al*., 2015).

DISCUSSION

This paper aimed to explore various factors that have an impact on the mental health of primary maternal caregivers of children with CP in rural, low-income areas of Southern Africa. The review identified several factors including the economic situation, physical demands, environmental conditions, insufficient information, experiences of stigma and marginalisation, interpersonal relationships, and emotional challenges. This review supports the theoretical framework of the Social Ecological Model (SEM) (Bronfenbrenner, 1977). While this model was originally developed in the Western, high-income world context, it has relevance in the Southern, low-income context (Tarkang & Amu, 2023). Furthermore, while the SEM refers to health in general, we can use it to make sense of mental health. The SEM proposes that health is affected by five levels of influence: individual factors (e.g., caregivers' emotional challenges, knowledge), interpersonal processes (e.g., caregivers' relationships, societal attitudes), institutional factors (e.g., health care and social services), community factors (e.g., community support), as well as social policy, structures, or systems (Bronfenbrenner, 1977). Through the interdependence of these five levels, changes in one level have far-reaching consequences that extend beyond the immediate individual. This is apparent in the exploration of the literature in the current paper. Studies included in this review demonstrated that the mental health of caregivers of children with CP residing in rural areas of Southern Africa is predominantly impacted by a variety of factors, the majority of which occur at the social level, exerting diverse effects on various aspects of this caregiving experience. At the broader social level, the African continent, excluding some parts of East Africa, contributes 24% to the global burden of disease while only receiving 1% of the world's health budget (WHO, 2019). Additionally, resources are often allocated towards costly medical interventions rather than prioritising health education and preventative measures. These services often spotlight the management and prevention of communicable diseases, omitting non-communicable diseases, such as disabilities, including psychosocial disabilities affecting one's mental health (WHO, 2019). This may explain the dominant influence of broader social factors on the mental well-being of caregivers of children with CP in the Southern African region. The caregivers of children with CP who reside in rural, low-income areas face specific barriers, such as institutional factors, in accessing support services due to their residence in resource-limited environments, which significantly differ from those found in high-income areas.

Hence, a variety of strategies and interventions are necessary to enhance the mental health of caregivers of children with CP in the Southern African region. These include understanding the impact exerted by various contexts, systems, and environments on the maternal primary caregiver, children, and their family units. These interventions may encompass the provision of *thekgo ya leago* (social support) to the primary caregivers, their children, and their families; the establishment of dedicated mental health services for these caregivers; the cultivation of collaborative relationships among all stakeholders involved in providing service or support to these caregivers to facilitate their well-being; and the provision of *thekgo ya ditšhelete* (financial support) to ensure that they have the necessary resources to effectively care for their children. Thus, a call is made to allocate funds

towards enhancing health systems; providing training and building capacity for health professionals; as well as increasing resources that would alleviate the burden on these maternal caregivers.

One limitation of this review is the scarcity of literature specifically addressing the mental health of caregivers of children with CP in rural, low-income Southern Africa. Consequently, the findings of this review may not be fully representative of the region. The lack of prioritisation of mental health in numerous African countries and other low-income nations may account for this problem.

CONCLUSION

This paper examined the factors affecting the mental health of primary maternal caregivers of children with CP in rural, low-income Southern African settings. The focus is on female caregivers since it is widely accepted that women are traditionally expected to be the primary caregivers for their children, especially in rural, low-income contexts. There is a paucity of research that comprehensively examines the factors that impact the mental health of caregivers of a child with CP. The paper demonstrated that maternal primary caregivers of children with CP who reside in rural, low-income areas encounter a range of factors that impact their mental well-being. These factors include economic circumstances, physical demands, environmental conditions, limited access to information, experiences of stigma and marginalisation, interpersonal relationships, and emotional difficulties. The consideration of these factors is crucial in comprehending the challenges associated with providing care for a child with CP, particularly in rural, low-income African areas. Furthermore, these factors serve as a framework for determining the maternal mental health interventions that should be prioritised. Future studies should prioritise an in-depth, individual exploration of these factors, delving further into their intricacies, and aim to identify practical and contextually feasible supportive measures specifically tailored to the rural, low-income Southern African setting.

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