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Burden and Coping Mechanisms of Cerebral Palsy Caregivers: Qualitative Evidence from Western Kenya

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Abstract

The purpose of this study was to explore the burden and coping mechanisms of cerebral palsy caregivers in Western Kenya, where the voices of primary caregivers are scarcely documented. Cerebral palsy (CP) is a chronic condition that arises in childhood and is the most common cause of disability globally, with a prevalence rate estimated at 3.6 per 1000 children. Children with CP aged 3 years and above tend to have multiple disabilities; caring for them can lead to considerable burden requiring several coping mechanisms. This qualitative study explored the burden and coping mechanisms of Cerebral Palsy Caregivers (CPC) through data collected via in-depth interviews with 14 caregivers and focus group discussions with social workers. Purposive convenience sampling was used to select caregivers and social workers from a special school for children with CP in Kakamega County, Kenya. Data was audio-recorded, transcribed, and analysed thematically, with presentation done through verbatim excerpts. Results showed that burdens were financial, psychosocio-cultural and physical, while parents coped through religion, social support groups, medical intervention and self-acceptance. In conclusion, caregivers of children with cerebral palsy face multidimensional burdens that are particularly complex in low- and middle-income settings like Western Kenya. The study recommends awareness creation to communities to positively impact caregiver well-being, with quantitative studies needed to support these findings.

Key terms: Burden, care-giving, cerebral palsy, coping.

INTRODUCTION

The purpose of this study was to investigate the burden faced by Cerebral Palsy Caregivers (CPC) and explore how they manage the associated burden in the Kenyan context, where limited evidence exists on this critical issue. Cerebral palsy (CP) refers to a degenerative condition of motion and posture resulting from non-progressive disturbances that take place in the foetal or infant brain, making it the most common cause of disability among chronic conditions that arise in childhood (American Psychological Association, 2022). Caregiver burden is defined as psychological symptoms faced by family members or any non-professional caregiver as an outcome of taking care of persons with mental or physical disorders (American Psychological Association, 2022). Coping involves the behavioural plan of action that caregivers use to decrease the effect of these burdens (Carvalho et al., 2023).

CP begins in early childhood as a group of functional incapabilities that emanate from the central nervous system (Centers for Disease Control and Prevention, 2022). Given CP's clinical variability and elevated prevalence, the condition is regarded as one of the most significant developmental disabilities. The global prevalence rate of CP has been estimated at 3.6 per 1000 children (Monem et al., 2022). Based on population-based research conducted in the United States of America, there is a comparatively constant rate of CP ranging from 1.9 per 1000 in 1985 to 1.8 per 1000 in 2002 (Van Naarden Braun et al., 2016). Research conducted on CP in China for thirty-two years showed an increasing trend of 2.07 per cent among children and adolescents (Shengyi et al., 2021). The neighbouring Uganda reveals a prevalence of 2.7 per 1000 children, which increased to 2.9 per 1000 children subsequently after modification for attrition (Kakooza-Mwesige et al., 2017).

Studies have revealed that the current CP birth prevalence for developed countries stands at 1.6 per 1000 live births, while the prevalence in developing countries cannot presently be determined with accuracy. Despite the under-representation of studies on CP in developing nations, trends show that CP prevalence appears significantly higher in developed countries (Kakooza-Mwesige et al., 2017). This apparent discrepancy likely reflects differences in healthcare infrastructure and diagnostic capabilities rather than true prevalence differences, as developing countries may experience under-reporting due to limited diagnostic capacity and healthcare access.

No matter the risk factor, when CP occurs in a family, caregiving becomes eminently lifelong and burdensome. Despite the fact that care-giving is a natural activity in parenting, high-level and long-term care is taxing for primary caregivers (Vadivelan et al., 2020). The burden of CP is even more pronounced in most African traditional communities since giving birth to children with any form of disability comes with emotional burdens such as stigma, social isolation and negligible societal and government support (Sankombo, 2023).

This introduction provides an overview of the multifaceted burden experienced by CP caregivers, the theoretical framework guiding this investigation, the methodology employed, key findings regarding financial, physical, and psychosocio-cultural burdens, coping mechanisms utilised by caregivers, and recommendations for policy and practice in the Kenyan context.

Theoretical Framework

This study is grounded in Lazarus and Folkman's (1984) transactional model of stress and coping, which provides a comprehensive framework for understanding how caregivers perceive and respond to stressors in their caregiving environment. The model posits that stress arises not merely from external events but from the interactions between individuals and their surroundings, with central importance placed on the process of appraisal (Lazarus & Folkman, 1984).

According to this framework, individuals engage in primary appraisal to determine if an event is harmful, threatening, or challenging, followed by secondary appraisal to assess their ability to cope with the perceived threat (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) identified two main types of coping strategies: problem-focused coping, which involves taking action to address the stressor directly through gathering resources and changing the situation, and emotion-focused coping, which focuses on managing emotional responses when situations are deemed uncontrollable (Folkman & Lazarus, 1985).

This theoretical lens is particularly relevant to understanding CP caregiving experiences, as caregivers continuously appraise their caregiving situations and employ various coping strategies to manage the multidimensional burdens they face. The framework helps explain how caregivers in the Kenyan context navigate between problem-focused strategies (such as seeking medical intervention) and emotion-focused approaches (such as religious coping and acceptance).

LITERATURE REVIEW

Caregivers of children with cerebral palsy (CP) undergo a significant multidimensional burden that encompasses physical, psychological, social, and economic challenges. A systematic review identified five key themes of caregiver experiences: need for convenient healthcare facilities and therapeutic services, need for healthcare information and financial aid, psychological and physical constraints, societal rejection and stigma, and overwhelming caring burden (Baminiwatta & Solangaarachchi, 2023).

Recent systematic reviews have established that caregiver burden among families of children with CP is influenced by both caregiver and child factors, with studies conducted across 11 countries involving over 3,000 caregivers (Liu et al., 2023). The burden is particularly pronounced in low- and middle-income countries (LMICs), where caregivers face unique burdens including an intersection of gender norms, poverty, stigmatisation, and non-inclusive public policy (Raina et al., 2020). Studies conducted in Africa reveal context-specific challenges that differ markedly from Western experiences. In Ghana, physical strain, work-related challenges, and stigma constitute the primary caregiver burden, with coping strategies including emotional coping, displacement/ignoring, seeking knowledge, and religious coping (Kisinna et al., 2025). While Western studies emphasise professional support systems and institutional resources, African studies consistently highlight religious and extended family coping mechanisms, suggesting significant cultural variations in available and preferred support structures.

Similarly, studies from Nigeria demonstrate that problem-focused coping styles are associated with better caregiver well-being, while dysfunctional coping styles correlate with depression (Adegbaju et al., 2019). Additionally, Nigerian research on caregiving burden showed that parents of children with CP commonly experience anxiety, financial problems, time-related stresses, and limited subjective welfare and life satisfaction, leading to insomnia and demotivation (Olagbegi et al., 2021).

African perspectives highlight unique cultural factors, with 50 per cent of caregivers resorting to religious/spiritual interventions and 29 per cent depending on extended family systems for support (Raina et al., 2013). This contrasts with Western contexts where professional counselling and institutional support are more prominent. Social support and positive coping styles serve as mediating factors between care burden and quality of life, with social support playing particularly significant mediating roles (Zhang et al., 2025).

Limited research exists specifically on CP caregiver experiences in Kenya, though studies on broader disability caregiving provide relevant context. Research in Kilifi, Kenya, found that carers of children with disabilities commonly experience physical health problems while carrying out routine care-giving tasks, particularly musculoskeletal disorders and spinal pain (Geere et al., 2013).

A cross-sectional study in Western Kenya revealed that caregivers of children with disability experience greater parenting stress than caregivers of children with no disability, with this effect not entirely explained by socio-economic differences, suggesting that stressors go beyond financial strain (Rowland et al., 2021).

In Kenya, an estimated 10 per cent (approximately 3.9 million) people have disabilities, with 1.6 per cent (about 554,000) having physical disabilities, yet only 2 per cent of children with disabilities have access to education (Association for the Physically Disabled of

Kenya, 1999). Kenyan studies reveal that discrimination against persons with developmental disabilities occurs partly because they are considered incapable of productive contribution according to societal expectations, with parents sometimes considering migration for better education and healthcare options (Midigo & Njeru, 2019).

Limited research exists specifically on CP caregiver experiences in Kenya, though studies on broader disability care-giving provide relevant context. Research in Kilifi, Kenya, found that carers of children with disabilities commonly experience physical health problems while carrying out routine care-giving tasks, particularly musculoskeletal disorders and spinal pain (Geere et al. 2013).

A cross-sectional study in Western Kenya revealed that caregivers of children with disability experience greater parenting stress than caregivers of children with no disability with this effect not entirely explained by socio-economic differences, suggesting that stressors go beyond financial strain (Rowland et al. 2021).

The scarcity of Kenyan-specific literature on CP caregiver experiences underscores the importance of this study in addressing a significant knowledge gap. Despite growing literature from other African contexts, limited evidence exists specifically on caregivers in Western Kenya, where unique cultural, economic, and healthcare system factors may influence caregiver experiences differently. This study addresses this critical gap by providing contextually grounded insights into the lived experiences of CP caregivers in this region.

METHODOLOGY

This study was undertaken based on the constructivist paradigm using the naturalist philosophy (Cutler et al., 2021). The researcher conducted the study among selected parents of children with CP enrolled at Daisy Special School in Kakamega. Purposive convenience sampling was used to select the 14 caregivers from the special school who were followed up at their homes. This two-stage sampling approach was employed, where participants were first purposively selected based on specific criteria (being primary caregivers of CP children), then convenience sampling was applied within this purposive framework for practical accessibility. Convenience sampling was appropriate for this sensitive topic as it allowed recruitment of willing participants from a trusted institution (special school) where rapport had already been established, facilitating more open discussions about personal care-giving experiences. The researcher stopped at 14 participants after reaching the saturation point, where no new themes were identified.

Data collection methods included in-depth interviews for caregivers of children with CP and a focus group discussion with social workers from the special school. Fundamental trigger questions were formulated prior to each session. Respondents signed consent forms and accepted audio recording. All data were audio-recorded and transcribed verbatim, with the research team reviewing written accounts for quality purposes.

Through a repetitive procedure of listening, discussions, and re-listening, researchers identified and agreed on emerging themes. Portions of discussions supporting projected themes were then identified. Transcripts of interviews and focused group discussions were thematically analysed and presented verbatim in the form of excerpts. Triangulation was employed to diversify the in-depth information on the burdens and coping mechanisms.

Informed consent was obtained from all participants prior to their inclusion in the study. Participant names were coded, and transcription was done professionally. Only the lead researcher had the right to the raw data. Reflexivity was preserved through analysis, note-taking, tape recording, discussions and challenging entrenched assumptions.

FINDINGS AND DISCUSSION

The findings were grouped into themes with dominant themes highlighted. Themes identified on burdens experienced by caregivers of children with CP were categorised as financial, psychosocio-cultural and physical. Themes on coping mechanisms were medical, psychological, and social. Results are presented thematically below.

Financial Burdens Faced by CPC

CPC acknowledged that hospital attendance costs, caregiver employment costs, special education fees, health specialist consultations, and caregiving materials represented significant lifetime expenditures. Multiple participants highlighted the compounding nature of these expenses:
"If I employed a caregiver for a child, I have to pay eight thousand Kenyan shillings. And if the caregiver finds out that the child is living with any disability, they want double pay" (IDI 2).

Medical expenses proved particularly burdensome, with participants spending substantial amounts on medications and treatments. One participant noted spending 2,500 Kenyan shillings for medication lasting only two weeks, plus 1,500 shillings for other medication, during challenging economic times when employment was unavailable.

Even financially stable participants struggled with long-term planning due to caregiving costs. As one participant explained, investment became impossible since *"all money is lost through child care... you cannot lie that you can invest any cent" (IDI 4).* Physiotherapy requirements added further financial strain, with participants accessing services irregularly due to cost constraints rather than following recommended twice-weekly sessions.

Financial pressures often forced families into debt cycles, with caregivers taking loans to meet medical requirements. Registration costs for government support cards (6,000 shillings) compete with basic needs like diapers and epilepsy medication. Comorbidities created additional expenses, including surgical procedures requiring specialised equipment replacement every four months, alongside frequent hospital visits costing at least 5,000 shillings per session.

Physical Burdens Faced by CPC

CPC experienced significant physical problems resulting from assisting children with functional activities and daily living tasks. Caregivers reported fatigue from feeding, cleaning, and managing challenging behaviours. One participant described how *"feeding him, cleaning him and putting him to bed is not easy... by the time you are done with him, you are extremely fatigued" with sleep often delayed past midnight* (IDI 6).

Health impacts included weight loss and emotional pain, particularly when children's developmental delays became apparent. Public transportation presented additional physical challenges, with caregivers forced to pay for multiple seats in overcrowded vehicles yet unable to access appropriate seating for their children, who cannot sit independently.

Psychosocio-cultural Burdens faced by CPC

Results revealed significant social isolation among CPC due to a lack of support from family, friends, and community members. Fear of social judgment prevented participation in community events, with caregivers avoiding gatherings due to staring and misconceptions about contagious disease transmission.

Marital relationships suffered strain after children's births, with participants reporting relationship deterioration and blame attribution. Extended family rejection emerged as a significant burden, with some families associating CP children with bad omens and family misfortunes. One participant shared: *"The entire family said it is the birth of my child that brought the bad omen to the family. None of my husband's family wants me"* (IDI 7).

Social workers confirmed patterns of spousal abandonment and child abandonment to schools to preserve marriages. Even educated individuals sometimes rejected CP children due to social stigma, highlighting the pervasive nature of discrimination across educational levels.

Coping Strategies of CPC

The study found that CPC employ various coping methods, including psychosocial strategies, medical interventions, self-acceptance, and, in some cases, neglect and abandonment.

Psychosocial Coping included acceptance and time management adjustments. Participants described accepting their situations while occasionally wishing for different outcomes, recognising children with CP as gifts requiring care. Time restructuring involved waking earlier to complete household tasks before children awakened.

Social support emerged through support groups providing advice and shared experiences. Family support, particularly from spouses and mothers, provided crucial assistance during illness episodes. Sibling support also proved valuable, with older children learning to assist and provide respite.

Medical Coping involved managing personal health impacts through pain medication and, in severe cases, depression treatment and hospitalisation for suicidal ideation. Spiritual coping represented a significant strategy, with participants "leaving everything to God" and hoping for miraculous improvements while accepting ongoing challenges (IDI 4).

Discussion

Findings demonstrate that parents of children with CP face substantial financial burdens consistent with previous research, indicating children with daily living challenges require two to three times higher medical examination costs than those without (Newacheck et al., 1994). Current Malaysian studies support these findings, identifying highly development-related direct and indirect healthcare costs (Ismail et al., 2022). Nigerian research in resource-strained contexts confirms that the economic burden transcends normal child-rearing costs, resulting in physical, emotional, and financial strain (Umar et al., 2020).

Parents of CP children experienced psychological challenges, supported by Sankombo's (2023) findings that CP children may be seen as sources of disappointment and stress to families. The psychological burdens reflect high stresses due to medical and social support needs (Al-Gamal & Long, 2013), with African contexts showing care burden impacts on all family members as probable depression candidates due to restricted social interaction possibilities (Olagbegi et al., 2021).

In traditional Kenyan communities, disability is often attributed to supernatural causes or family curses, leading to shame and social isolation. The patriarchal family structure contributes to mothers being blamed for children's conditions, while communal decision-making processes can result in extended family rejection, as observed in our findings. These cultural factors create unique burdens beyond those documented in Western contexts, where professional support systems are more readily available.

Physical burdens emerged from performing daily living activities, corroborated by Indian research showing caregivers bearing huge burdens of moving, bathing, feeding, and recreation activities, lacking time for rest and experiencing body aches and pains (Vadivelan et al., 2020). CP comorbidities requiring diversified health needs create additional physical demands (Al-Gamal & Long, 2013).

Parents employed various coping mechanisms, including psychosocial support and medical interventions. Well-coping families demonstrated acceptance, new information acquisition, optimistic attitudes, good family cohesion, open communication, social support, self-confidence, and flexibility. Low-coping families showed serious disagreements in disability acceptance between parents, with coping strategies used only by mothers, poor marital relationships, negative feelings, and sibling problems.

Research suggests that good social support networks benefit mothers by alleviating caregiving stress (Lima et al., 2016). Many CPC felt inadequate medical professional support, affecting long-term coping abilities, suggesting that medical support and clear disability information would facilitate problem-focused coping strategies. The frequent use of reframing strategies appears encouraging as it helps parents make grave situations more acceptable.

Limitations of the Study

Several limitations should be acknowledged. Focus group discussions revealed social workers' perceptions rather than their direct realities, though this was addressed through data triangulation. The over-representation of women in the sample, while reflecting caregiving patterns, might have influenced results, although gender differences in perceptions were not identified in the data. The study's strength lies in including caregivers across the various CP spectrum. AI assistance (Claude, Anthropic) was used to help locate and organise relevant literature sources, but all analyses and interpretations represent the author's own work.

CONCLUSION AND RECOMMENDATIONS

Conclusion: Caregivers of children with cerebral palsy face unique burdens in the Kenyan context controlled by an intersection of patriarchy, poverty, stigmatisation, and lack of awareness. This qualitative study reveals that caregivers face multidimensional burdens, particularly complex in low- and middle-income settings like Western Kenya. Data demonstrates that caregiver burden encompasses physical strain, psychological stress, social stigma, and financial challenges, with cultural components playing important roles in both burden experience and coping strategies. Social support and problem-focused coping mechanisms are connected to better caregiver outcomes, while religious and spiritual coping strategies are particularly prevalent in the Kenyan context.

Recommendations: There is an urgent need to create awareness to reduce stigma and allay misconceptions about cerebral palsy. Community education programs should address supernatural attributions and promote understanding of CP as a medical condition. Healthcare systems require strengthening to provide affordable, accessible services for children with CP and their families. Support groups should be established to provide peer support and information sharing among caregivers. Policy recommendations include developing disability-inclusive social protection programs, subsidising healthcare and assistive devices for CP families, and training healthcare providers in family-centred care approaches. Quantitative studies should be conducted to support these qualitative findings and inform evidence-based interventions for CP caregivers in Kenya.

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