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A QUALITATIVE EXPLORATION OF THE SUPPORT NEEDS OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN NIGERIA

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ABSTRACT: *Caring for children with cerebral palsy (CP) poses significant emotional, financial, and psychosocial challenges for caregivers, especially in resource-limited settings such as Nigeria. This qualitative phenomenological study explored the lived experiences of 26 caregivers (24 mothers and 2 fathers) in Cross River State, Nigeria, to identify their unmet support needs. Data were gathered through in-depth interviews and analyzed thematically. The findings revealed intense emotional distress among caregivers, including fatigue, anxiety about the future, and social isolation driven by stigma. Many caregivers lacked adequate information about CP management, which contributed to feelings of helplessness. Financial burdens stemming from high medical costs and loss of income, intensified their difficulties. Additionally, institutional barriers such as prolonged wait times and limited expertise within the healthcare system hinder access to appropriate care. Caregivers expressed a strong need for psychosocial support through peer groups and community education to address stigma. The study indicates the urgent need for comprehensive interventions, including financial assistance, improved healthcare services, and the establishment of community-based support systems to reduce caregiver burden and promote family well-being.*

KEYWORDS: Disability, Cerebral palsy, caregivers, support needs, healthcare access.

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INTRODUCTION

Cerebral palsy (CP) is a group of permanent disorders affecting movement and posture, attributed to non-progressive disturbances in the developing fetal or infant brain (Rosenbaum et al., 2007; Oskoui et al., 2013). It is characterized by impairments in movement, posture, and muscle coordination, often accompanied by comorbidities such as intellectual disabilities, epilepsy, visual and auditory impairments, and communication disorders (Oskoui et al., 2013). As the most common cause of childhood physical disability, CP represents a significant public health concern worldwide. While global prevalence rates range between 2–3 per 1,000 live births, the burden is disproportionately higher in low- and middle-income countries (LMICs), including Nigeria, where systemic healthcare challenges exacerbate risk factors and hinder early intervention (Donald et al., 2014; Kakooza-Mwesige et al., 2015).

The etiology of cerebral palsy is multifactorial, involving a complex interaction of prenatal, perinatal, and postnatal risk factors. Prenatal causes include intrauterine infections, maternal malnutrition, exposure to toxins, and genetic mutations (Afolabi et al., 2019). Perinatal factors—particularly birth asphyxia, prolonged or obstructed labor, and preterm birth—remain prominent in LMICs, largely due to inadequate obstetric services, poorly equipped delivery centers, and insufficient skilled birth attendants (Iloeje et al., 1991; Ogunlesi et al., 2008). Postnatal contributors such as neonatal jaundice, meningitis, sepsis, and traumatic brain injuries further increase vulnerability, especially when access to neonatal care is limited (Olusanya et al., 2018). In the Nigerian context, birth asphyxia and severe neonatal hyperbilirubinemia have repeatedly emerged as dominant risk factors for cerebral palsy, often linked to delayed health-seeking behaviors and poor referral systems (Ogunlesi et al., 2008; Afolabi et al., 2019).

The diagnosis of cerebral palsy not only alters the life trajectory of the affected child but also imposes lifelong challenges on the caregivers, most of whom are mothers. These caregivers are thrust into demanding roles that encompass physical assistance with mobility, feeding, toileting, communication, as well as frequent medical visits and therapy appointments (Delgado et al., 2019). Such responsibilities often lead to emotional distress, physical exhaustion, and social exclusion (McManus et al., 2006). In addition, caregivers are frequently confronted with limited support from healthcare systems, government agencies, and community networks (Obembe et al., 2016). The financial implications are also profound, as many families are forced to pay out-of-pocket for physiotherapy, medications, and assistive devices, while simultaneously experiencing income loss due to reduced work hours or job loss (Afolabi et al., 2019).

Caring for a child with CP in Nigeria is further complicated by sociocultural perceptions of disability. In some regions, conditions like cerebral palsy are attributed to supernatural causes, ancestral punishment, or parental misdeeds, resulting in stigma, discrimination, and shame (Olawale et al., 2013). Mothers in particular may be blamed or abandoned, leading to heightened emotional trauma and social isolation (Afolabi et al., 2019). These sociocultural dynamics not only undermine caregiver well-being but also limit their willingness to seek help or integrate their children into social and educational settings, further perpetuating cycles of marginalization.

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Although numerous studies have quantified the psychological and economic burdens of caregiving, most have employed quantitative designs that fail to capture the lived experiences and nuanced needs of caregivers (Ogunnubi et al., 2020; Aina & Olasoji, 2020). These studies have contributed significantly to understanding the scope of caregiver burden, but they often lack depth in exploring how caregivers cope, what forms of support they value most, and how their unique socio-cultural contexts shape their realities. In Nigeria, where public disability services are limited and few social safety nets exist, a qualitative inquiry is crucial for understanding the support systems that caregivers require—not only to manage their children's conditions but to thrive personally and socially.

Furthermore, evidence from community-based rehabilitation (CBR) models in sub-Saharan Africa has shown that caregiver empowerment and tailored support interventions can improve family functioning, reduce caregiver stress, and enhance child outcomes (World Health Organisation, 2010). Yet such models remain underdeveloped or poorly implemented in many parts of Nigeria. Without an in-depth understanding of caregivers' actual support needs, efforts to improve service delivery risk being ineffective or misaligned with the realities on the ground. This study, therefore, explored the support needs of caregivers of children with cerebral palsy in Nigeria, with a view to generating rich, contextual insights into their lived experiences.

METHOD

Study Design

This study adopted a qualitative phenomenological approach to explore and understand the lived experiences of caregivers of children with cerebral palsy. This approach was appropriate for capturing the depth and meaning of participants' personal experiences as they navigated caregiving challenges and support needs.

Setting

The study was conducted in Calabar South and Calabar Municipal Local Government Areas, Cross River State, Nigeria, a region characterized by diverse cultural backgrounds and varying levels of access to healthcare services. This context provided important insight into the socio-cultural and institutional factors shaping caregivers' experiences.

Participants and Sampling

A total of 26 caregivers participated in the study, including 24 mothers and 2 fathers of children diagnosed with cerebral palsy. Participants were selected using a snowball sampling technique, whereby initial participants referred the researchers to other eligible caregivers within their social networks. This method was effective in reaching participants who might otherwise be difficult to access through formal healthcare or support systems.

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Data Collection

Data were collected through in-depth, semi-structured interviews conducted at locations convenient for the participants to ensure privacy and comfort. The interviews focused on eliciting detailed accounts of caregivers' emotional, informational, financial, institutional, and psychosocial support needs, as well as the challenges they faced. Each interview lasted between 45 and 90 minutes and was audio-recorded with participants' consent.

Data Analysis

Interviews were transcribed verbatim and analyzed using thematic analysis. This involved an iterative process of coding, identifying patterns, and developing themes to elucidate the core aspects of caregivers' lived experiences and support needs within the socio-cultural context of Cross River State.

Ethical Considerations

All participants provided informed consent prior to their involvement in the study, ensuring that they fully understood the purpose, procedures, potential risks, and benefits of participation. They were assured that their identities would be kept confidential and that all data collected would be anonymized to protect their privacy. Participants were also informed of their right to decline to answer any questions they felt uncomfortable with and were free to withdraw from the study at any time without any negative consequences or penalty. These measures were put in place to uphold ethical standards and promote a safe and respectful research environment.

RESULTS

The analysis of the interview data revealed several key themes related to the support needs and lived experiences of caregivers of children with cerebral palsy in Cross River State. These themes include emotional, informational, financial, institutional, and psychosocial dimensions of caregiving.

Emotional Support Needs

Emotional support was a prominent and deeply felt need among caregivers of children with cerebral palsy. Many caregivers described the role as physically and emotionally exhausting, with constant demands that left them feeling overwhelmed and stressed. One mother shared her experience of fatigue and the absence of respite:

"Sometimes I feel so tired that I just want to cry, but there is no one to help. It is a full-time job, and I don't get a break." (Mother, 34 years)

Anxiety about the future was also common, with caregivers worrying about their child's well-being long-term, especially in their absence. As another mother explained,

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"I get anxious all the time, worrying about what will happen to my child when I am no longer around." (Mother, 29 years)

The need for empathy and understanding was expressed strongly. Many caregivers felt isolated by family members and the community who did not grasp the challenges they faced. One mother lamented,

"My relatives don't understand what I am going through; they think I am just being weak. I need someone who listens and understands without judging." (Mother, 41 years)

Several caregivers expressed a desire for professional psychological support or counseling, noting that they often kept their feelings bottled up due to a lack of access to such services. A father emphasized this need:

"If there was a counselor or group I could talk to, it would help me a lot. Right now, I just keep everything inside." (Father, 38 years)

Feelings of social isolation were prevalent as well, with caregivers describing reduced social interactions either because of the time-consuming nature of caregiving or due to stigma. One mother recounted,

"I don't go out much anymore because people stare and ask questions I cannot answer. It makes me feel ashamed and isolated." (Mother, 30 years)

The emotional strain from both the demands of caregiving and societal reactions left many caregivers feeling lonely and unsupported. This underscored the critical need for accessible emotional and psychological support tailored to the realities of caregiving in this context.

Informational Needs

Caregivers consistently emphasized a significant gap in accessible and relevant information about cerebral palsy, which hindered their ability to effectively care for their children. Many participants reported feeling confused and uncertain about the causes, management options, and long-term outlook of the condition. One mother expressed her frustration with the lack of clear guidance:

"When my child was diagnosed, no one explained what cerebral palsy really means. I had so many questions, but the doctors were too busy, and I left the hospital feeling lost." (Mother, 37 years)

Several caregivers described struggling to find reliable information tailored to their cultural context and local healthcare resources. The absence of practical advice on everyday care techniques and therapeutic exercises was a recurring concern. As one father noted,

"I searched for ways to help my son, but most of what I found online was not relevant to our situation here. I wished there was someone to teach me how to manage his needs properly." (Father, 40 years)

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Participants also expressed a strong desire for educational programs or workshops that could empower them with knowledge and skills to improve their child's quality of life. One mother stated,

"If there were training sessions or support groups where we could learn from professionals and from each other, it would make a big difference." (Mother, 33 years)

In addition, caregivers pointed to the need for ongoing information updates as their children grew and their needs evolved. The initial diagnosis was only the start of a long journey, and many felt unprepared for the changing demands of care.

The lack of adequate informational support not only affected caregivers' confidence in managing their children's condition but also contributed to feelings of helplessness and anxiety. Addressing these informational gaps was identified as a crucial step toward improving caregiving experiences.

Financial Burden and Support

Financial challenges were a major concern for caregivers, significantly affecting their ability to provide adequate care for their children with cerebral palsy. Many described the high and ongoing costs of hospital bills, therapies, specialized equipment, and transportation to health centers. One mother shared her struggles:

"Hospital expenses are not small. Sometimes, I am not sure whether to pay for the medication or buy food for my children. It is very difficult." (Mother, 36 years)

Most caregivers relied on their limited income or family assistance, with very few receiving any support from the government or community. This lack of external help made the situation even more challenging. A father explained:

"The government does not do anything to help us. We have to pay for everything ourselves. This kind of situation is very tiring." (Father, 42 years)

Some mothers mentioned having to sell their belongings or borrow money just to cover therapy costs. One mother said:

"I even sold a small piece of land I owned just to pay for my child's therapy. It broke my heart, but I had no other option." (Mother, 39 years)

Caregiving responsibilities also forced many to reduce work hours or quit their jobs entirely, leading to a loss of income that could have helped cover expenses. This further intensified the financial strain.

These financial struggles forced caregivers to make difficult decisions and sacrifices, highlighting the urgent need for improved financial support and assistance for families caring for children with cerebral palsy.

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Institutional and Healthcare System Challenges

Caregivers faced numerous challenges within the healthcare system that made it difficult to access timely and appropriate care for their children with cerebral palsy. Long waiting times at hospitals and clinics were a frequent source of frustration. Many caregivers described spending several hours in crowded waiting rooms, often without adequate comfort for their children, which sometimes discouraged them from returning for follow-up visits. One mother shared:

"Sometimes we waited for hours before the doctor could see us. By the time we entered, I was already tired, and my child was uncomfortable. It was very stressful, and sometimes I felt like giving up." (Mother, 33 years)

A major concern was the lack of healthcare professionals with specialized knowledge about cerebral palsy. Caregivers often felt that medical staff did not fully understand their child's condition, which resulted in inadequate explanations and limited guidance on care. One mother explained:

"The doctors and nurses did not seem to know much about my child's condition. When I asked questions, they could not explain well. I had to manage many things on my own because I did not receive enough support." (Mother, 38 years)

Some caregivers also reported feeling ignored or rushed by healthcare workers, which made them reluctant to seek medical assistance or follow-up treatment. A father recounted:

"Sometimes, the health workers rushed through appointments and did not listen carefully to our concerns. It made me hesitant to go back to the hospital because I felt they did not really care." (Father, 40 years)

For caregivers living in rural or remote areas, the challenges were even greater. Many had to travel long distances on poor roads, often with limited or expensive transportation options, to reach healthcare facilities that provided even basic services. The journey was often exhausting, costly, and sometimes unsafe, further restricting access to consistent care.

These institutional and healthcare system challenges added to the burden experienced by caregivers. They underscored the urgent need for improvements in healthcare infrastructure, specialized training for healthcare providers on cerebral palsy and related disabilities, and the adoption of a more compassionate, patient-centered approach. Addressing these issues is essential for improving the health outcomes of children with cerebral palsy and providing better support to their families within the Nigerian healthcare context.

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Psychosocial and Community Support

Caregivers consistently emphasized the critical role of psychosocial and community support in coping with the demands of raising a child with cerebral palsy. Many reported experiencing profound feelings of isolation, which stemmed not only from the heavy caregiving responsibilities but also from a lack of understanding and acceptance within their local communities. The persistent stigma surrounding disability often led to social exclusion and judgment, which further intensified the emotional strain on caregivers. As one mother expressed:

"People in my community do not understand my child's condition, so they keep their distance. Sometimes I feel like I am carrying this burden alone. It is very painful when even your neighbors avoid you because of your child's disability." (Mother, 35 years)

This social isolation was compounded by limited opportunities for caregivers to connect with others facing similar challenges. Many participants expressed a strong desire for peer support groups where they could share their experiences, exchange practical advice, and find emotional comfort. A father explained:

"If there was a support group or community where we could meet others like us, it would help a lot. We need to know we are not alone in this struggle and that others understand what we are going through." (Father, 43 years)

Beyond emotional support, caregivers highlighted the importance of community-based education programs that could raise awareness about cerebral palsy. They believed that increased knowledge among community members would reduce misconceptions and negative attitudes, fostering a more inclusive and supportive environment. One mother observed:

"When people learn about cerebral palsy, they will stop judging and begin to accept us. That will make life easier for both us and our children. Awareness can change how people see and treat us." (Mother, 39 years)

Caregivers also noted the value of practical community support, such as assistance with daily tasks, respite care, and access to resources or services closer to home. The absence of such support often left them overwhelmed and exhausted.

The narratives of these caregivers underscored that psychosocial and community support are essential components in enhancing their resilience and capacity to provide effective care. Building strong, culturally sensitive support networks and implementing community outreach programs are necessary steps to foster understanding, reduce stigma, and improve the overall well-being of families affected by cerebral palsy in Nigeria.

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DISCUSSION

This study sheds light on the multifaceted challenges faced by caregivers of children with cerebral palsy (CP) in Cross River State, Nigeria, revealing profound emotional distress, financial hardship, institutional barriers, and social isolation. These findings align with global research on caregiver burden, yet they also highlight unique socio-cultural and systemic obstacles that intensify struggles in low-resource settings like Nigeria. For instance, while studies worldwide recognize the emotional toll of caregiving (McManus et al., 2006; Delgado et al., 2019), participants in this study faced compounded distress due to the near-total absence of mental health support and pervasive stigma tied to disability—a reality less documented in high-income contexts. Similarly, the financial strain described here surpasses observations in other LMICs (Afolabi et al., 2019), with caregivers resorting to selling assets or abandoning livelihoods, underscoring the dire need for economic safety nets.

Moreover, the study exposes critical gaps in healthcare systems that exacerbate caregiver vulnerability. Unlike settings with structured early-intervention programs (Rosenbaum et al., 2007), Nigerian caregivers navigate a fragmented system marked by long wait times, limited provider expertise, and minimal guidance, forcing them to rely on informal networks or unreliable information. This aligns with prior work on healthcare deficiencies in LMICs (Donald et al., 2014) but emphasizes the urgency of training healthcare workers in CP management and expanding services to rural areas. At the same time, caregivers' resilience shines through their calls for peer support groups, mirroring the success of community-based rehabilitation (CBR) models in sub-Saharan Africa (WHO, 2010). Their demand for such networks, coupled with community education to combat stigma, presents an actionable pathway to reduce isolation and foster inclusion.

IMPLICATIONS OF THE STUDY

The insights gained from this study have significant implications for improving the support systems available to caregivers of children with cerebral palsy in Nigeria. This study highlights the critical need for policies and programs that are deeply informed by caregivers' lived experiences, ensuring interventions align with the real-world challenges they face daily. Beyond systemic support, the findings stress the transformative power of community awareness and social inclusion in dismantling stigma and creating environments where caregivers and their children feel genuinely valued. By centering caregivers' voices, the study calls for a paradigm shift in healthcare planning and social services—one that prioritizes caregiver wellbeing as foundational to improving outcomes for children with cerebral palsy. Such an approach would not only enhance quality of life but also promote equitable access to resources, bridging gaps in current support structures. These findings advance the understanding of caregiving in resource-limited settings like Nigeria, providing a vital evidence base for future research. They also lay the groundwork for comprehensive, culturally responsive frameworks that address the intersecting emotional, financial, and social needs of caregivers—a necessary step toward sustainable change.

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RECOMMENDATIONS

Based on the findings of this study, several recommendations are proposed to enhance the support structures available to caregivers of children with cerebral palsy in Nigeria:

Government bodies, in partnership with non-governmental organizations, should develop and implement comprehensive support frameworks that address the financial, emotional, and psychosocial needs of caregivers. These frameworks should include provisions for regular financial aid, subsidized therapy sessions, and access to essential assistive devices.

Improving the healthcare system for children with cerebral palsy requires a deliberate investment in the training of health professionals in developmental disabilities, alongside expanding the availability of specialized services. Priority should be given to extending these services to rural and hard-to-reach communities where access remains limited.

Efforts should be made to establish and sustain community-based peer support networks where caregivers can freely share their experiences, receive emotional support, and exchange practical coping strategies. Such platforms offer a valuable source of encouragement and solidarity among caregivers.

Public awareness campaigns are needed to address widespread misinformation and stigma associated with cerebral palsy. Leveraging the influence of community leaders, faith-based organizations, and local media can help shift negative societal attitudes and foster greater acceptance and inclusion.

There is also an urgent need for the government to enact and enforce policies that prioritize the welfare of families of children with cerebral palsy. Such policies should promote inclusive healthcare services, support access to education for children with disabilities, and provide employment protections and flexibility for caregivers.

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