



## BEYOND THE DIAGNOSIS: A BIOPSYCHOSOCIAL INQUIRY INTO MATERNAL CAREGIVING IN CEREBRAL PALSY

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**ABSTRACT:** *Cerebral palsy is a chronic neurological condition that affects children's physical and cognitive development, often requiring long-term caregiving. Mothers commonly assume the primary caregiving role and subsequently experience significant challenges that affect their physical, psychological, and social well-being. Understanding these experiences is essential to informing holistic and family-centred care. The study explored the physical, psychological, and social experiences of mothers caring for children living with cerebral palsy, guided by the biopsychosocial model. A qualitative descriptive design was used. Fifteen mothers of children diagnosed with cerebral palsy were purposively selected from a tertiary hospital in Ghana. Data were collected through semi-structured interviews and analyzed using thematic content analysis. Mothers reported delays in developmental milestones, feeding difficulties, and recurrent seizures in their children, which resulted in intense and continuous caregiving demands. Physically, mothers experienced fatigue, back pain, and sleep deprivation. Psychologically, they reported mental stress, worry, and periods of sadness, primarily linked to caregiving responsibilities and financial strain. Socially, mothers encountered stigma, isolation, and strained family relationships. However, some mothers demonstrated resilience through faith, self-motivation, and support from family members. Caring for a child with cerebral palsy significantly affects the physical, emotional, and social well-being of mothers. Holistic, family-centred care is essential to address caregiver needs alongside the child's health needs. Strengthening psychosocial support, improving access to financial and respite resources, and fostering community awareness may enhance the well-being and caregiving capacity of mothers.*

**KEYWORDS:** Biopsychosocial model, Caregiving experiences, Cerebral palsy, Cognitive development, Mothers, Psychosocial support.



## INTRODUCTION

Cerebral palsy (CP) is a non-progressive disorder of movement and posture resulting from injury to the developing brain, most often occurring during the perinatal period (Bulekbayeva et al., 2017). It is one of the most common causes of lifelong physical disability in childhood, with global prevalence estimates ranging from 1.5 to 4 per 1,000 live births (CDC, 2020). In Ghana, CP is estimated to affect approximately 1 in every 300 children (Graham et al., 2016), reflecting a significant public health concern. The higher burden in many low- and middle-income countries (LMICs) is frequently linked to preventable perinatal factors, limited neonatal intensive care capacity, and delayed access to early rehabilitation services (Nelson & Blair, 2015; McLaren, 2014).

Children living with CP experience a wide range of motor impairments, commonly classified as spastic, dyskinetic, or ataxic (Madzhie et al., 2022). These impairments may affect mobility, posture, balance, and coordination, and are often accompanied by associated conditions, including epilepsy, feeding difficulties, sensory and communication challenges, and cognitive limitations (Rudebeck, 2020; Polack et al., 2018). These complex and ongoing needs require long-term and often intensive caregiving.

In Ghana, as in many cultural contexts, mothers typically assume primary responsibility for caregiving. Providing daily care to their children, including feeding, bathing, lifting, positioning, and transporting the child. These can place considerable physical strain on mothers, especially where assistive devices or home modifications are limited (Agyemang-Duah et al., 2019; Nyante & Carpenter, 2019; Chen et al., 2018). The unrelenting nature of caregiving may lead to fatigue, musculoskeletal pain, and neglect of personal health. Psychologically, mothers may experience worry, frustration, sadness, guilt, or uncertainty about their child's future, contributing to stress and emotional exhaustion (Brehaut et al., 2020). Socially, mothers may encounter stigma, discrimination, or misunderstanding surrounding disability, which can result in social withdrawal, strained family relationships, and reduced participation in community or religious activities (Singogo et al., 2015; Smith & Blamires, 2022).

Despite these multidimensional challenges, caregiver support services remain limited in many parts of Ghana. Access to rehabilitation therapy, psychosocial counselling, respite care, mobility aids, and financial or social support systems is inconsistent and often inadequate (Polack et al., 2018). The Pediatric Neuro Clinic at the Greater Accra Regional Hospital serves as a major referral point for children with CP; however, little is known about the everyday caregiving experiences of mothers who attend this clinic. Without a deeper understanding of these experiences, healthcare providers may be limited in their ability to design family-centred, contextually relevant interventions that support both the child and the caregiver.

Guided by the biopsychosocial model, which recognises that health and caregiving experiences are shaped by the interaction of biological, psychological, and social factors, this study aims to explore the physical, psychological, and social experiences of mothers whilst caring for their children living with cerebral palsy at the Pediatric Neuro Clinic of the Greater Accra Regional Hospital.



## **METHODS**

### **Study Design**

This study employed a qualitative exploratory descriptive design. This design was appropriate because it enabled an in-depth exploration of mothers' physical, psychological, and social experiences while caring for their children living with CP. The biopsychosocial model guided the conceptual framing and informed the areas of inquiry during data collection and analysis.

### **Study Setting**

The study was conducted at the Pediatric Neurology Clinic of the Greater Accra Regional Hospital, Ghana. The clinic is a major referral centre for children with neurodevelopmental conditions, including cerebral palsy, and provides medical review, physiotherapy, and counselling support for affected families.

### **Study Population and Sampling**

The study population consisted of mothers who had children diagnosed with CP and who attended follow-up care at the Pediatric Neurology Clinic. Purposive sampling was used to recruit mothers who had direct caregiving experience and were able and willing to provide rich descriptions of their caregiving situations. Nurses at the clinic facilitated initial contact between the researcher and potential participants.

A total of 15 mothers were included in the study. Sample adequacy was determined through data saturation, which was reached when no new information or meaning emerged from the interviews by the 15th participant.

### **Data Collection**

Data were collected through a semi-structured interview guide developed based on the biopsychosocial model (Engel, 2012), covering physical caregiving demands, emotional and psychological responses, and social interactions and support systems. Interviews were conducted face-to-face in a private room at the hospital. For participants who were unavailable at the clinic, appointments were scheduled to conduct interviews in their homes at their convenience.

Each interview lasted between 45 to 60 minutes and was audio-recorded with participants' permission. Field notes were taken to capture relevant non-verbal cues and contextual observations, which helped enrich interpretation.

### **Data Management and Analysis**

Data were analysed using reflexive thematic analysis, following the six -step approach outlined by Braun and Clarke (2006). Thus, a structured and iterative process was used. Recorded interviews were transcribed verbatim immediately after data collection. The transcripts were read repeatedly to ensure familiarity with the data, and to achieve immersion. Initial open coding was conducted manually, line-by-line to identify meaningful units of text. Codes were then compared and grouped into categories, from which sub-themes were inductively developed. These sub-themes were subsequently reviewed and refined into overarching themes aligned with the biosychosocial framework (physical, psychological, and social domains).



That is, similar codes were grouped to form sub-themes. The sub-themes were subsequently organised under the main constructs of the biopsychosocial model (Engel, 2012). The overarching themes under the model are physical, psychological, and social experiences.

The analytical process involved constant comparisons across the transcripts to ensure consistency and depth. Themes were reviewed for internal coherence and distinctiveness, and discrepancies were resolved through discussion with research supervisor. Also, to enhance rigour and minimise researcher bias, coding and theme development were independently reviewed and cross-checked with the research supervisor. Field notes were used to support interpretation and add contextual depth.

### Trustworthiness

Credibility was enhanced through prolonged engagement with the data and member checking, whereby summaries of the findings were returned to participants to verify accuracy and resonance with their experiences. An audit trail documenting coding decisions and theme development was maintained to enhance dependability, confirmability, and transparency.

### Ethical Considerations

Ethical approval was obtained from Ghana Health Service Ethics Review Committee (GHS-ERC: 03703/23), and permission was granted by the management of the Greater Accra Regional Hospital before data collection. Informed consent was obtained from all participants, who were assured of voluntary participation and the right to withdraw at any time, without penalty. Privacy, confidentiality, and anonymity were strictly maintained throughout data collection, analysis, and reporting. Participants were also informed that while no physical harm was anticipated, some questions could evoke emotional distress; therefore, the researcher allowed breaks and offered referral to support services when needed.

## RESULTS

### Demographic Characteristics of Participants

Fifteen mothers of children living with CP participated in the study (Table 1). Participants were aged between 19 and 39 years. Five had completed junior high school, six had senior high school education, and four had tertiary education. Seven participants were traders; others included a nurse assistant, a pharmacy assistant, an administrator, and a seamstress, while four were unemployed. Most participants were Christians ( $n = 11$ ), three were Muslims, and one was a Pagan. Twelve participants were married, and three were single, as indicated in Table 1.

**Table 1: Demographic characteristics of participants**

ID	Age (Years)	Level of Education	Employment Status	Religion	Marital Status
CP1	39	Junior High School	Trader	Muslim	Married
CP2	29	Senior High School	Trader	Christian	Married
CP3	37	Tertiary	Nursing Assistant	Christian	Married
CP4	19	Junior High School	Unemployed	Pagan	Single
CP5	34	Tertiary	Administrator	Christian	Married



CP6	34	Tertiary	Pharmacy Assistant	Christian	Married
CP7	39	Junior High School	Trader	Muslim	Married
CP8	27	Senior High School	Trader	Christian	Married
CP9	30	Tertiary	Trader	Christian	Single
CP10	34	Senior High School	Unemployed	Christian	Married
CP11	33	Junior High School	Seamstress	Christian	Married
CP12	27	Senior High School	Trader	Christian	Married
CP13	34	Junior High School	Unemployment	Muslim	Single
CP14	26	Senior High School	Trader	Christian	Married
CP15	20	Senior High School	Unemployed	Christian	Married

Data analysis generated three main themes and thirteen sub-themes (Table 2) guided by the biopsychosocial framework:

1. Physical Experiences (5 sub-themes)
2. Psychological Experiences (4 sub-themes)
3. Social Experiences (4 sub-themes)

The three themes with their sub-themes are shown in Table 2.

**Table 2: Themes and Sub-themes**

Themes	Sub-themes
Physical experiences	(1) Developmental delay (2) Seizures (3) Physical stress (4) Rest and sleep (5) Physical support
Psychological experiences	(1) Mental burden (2) Financial problems (3) Acceptance of the condition (4) Resilience
Social experiences	(1) Stigma and discrimination (2) Social pressure (3) Isolation (4) Social support

### Physical Experiences

This theme describes the physical impact of caring for children with cerebral palsy on both the children and their mothers. The description of physical experiences focuses on developmental delays, seizures, stress, physical support, and finally rest and sleep.



### ***Developmental Delay***

Mothers reported noticeable delays in milestones such as neck control, sitting, crawling, walking, and speech. Many children learned to sit or walk years beyond expected developmental timelines. One mother indicated:

*“My child took a longer time to be able to gain neck control, sitting, and even crawling.” (CP6)*

Another mother said:

*“He crawled for 4 years before being able to walk.” (CP7)*

### ***Seizures***

Seizures were one of the experiences of children with CP, as stated by the mothers. It was described as frightening and sudden, often beginning within months after birth. The unpredictable and recurring nature of seizures caused distress for mothers.

*“My baby was fine until 4 months when... the seizure disorder started.” (CP14)*

### ***Physical Stress***

According to the mothers, daily caregiving demands, including feeding, positioning, and hospital visits, resulted in back pain and weight loss.

*“I have back pain because of carrying him almost all the time.” (CP6). “Because of him, I have lost weight” (CP7).*

### ***Rest and Sleep***

Mothers experienced sleep disruptions due to caregiving needs, which sometimes extend into nighttime.

*“I have sleepless nights sometimes. I wake up at night to feed him.” (CP5)*

### ***Physical Support***

Some mothers received assistance from spouses, grandparents, siblings, in-laws, or hired caregivers, which provided temporary relief.

*“Sometimes when I’m going to work, I leave him with my mother-in-law.” (CP5). “My husband supports me when he is at home” (CP 6). “Yes, my husband’s family supports me. ... Yes. They support” (CP 2).*

### ***Psychological Experiences***

This theme captures mothers’ emotional and mental responses to caring for a child with CP.

### ***Mental Burden***

Mothers described caregiving as emotionally overwhelming, associated with spiritual and mental worry.

*“The struggle has been both spiritual and mental, and it has not been easy.” (CP10)*



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### ***Financial Problems***

Caring responsibilities limited mothers' ability to work and meet medical expenses, leading to financial strain.

*"I had to stop working so that I could be at home... I became broke." (CP1)*

### ***Acceptance of the Condition***

Acceptance was gradual and often followed initial denial, emotional distress, and questioning.

*"It hurts... but you have to just accept." (CP5)*

### ***Resilience***

Despite challenges, mothers developed coping strengths, often grounded in faith, self-encouragement, and hope for future improvement.

*"It's been God. I put my trust in Him, and that's why I am still standing." (CP3)*

### ***Social Experiences***

This third theme reflects mothers' interactions with family, community, and society.

### ***Stigma and Discrimination***

Mothers and children were ridiculed, labelled, or treated unfairly.

*"They (society) said he is an animal and we have to transform him into a human being." (CP4)*

### ***Social Pressure***

Some mothers faced pressure to pursue traditional or harmful remedies, or even to abandon the child.

*"They told me to kill him, but I tell them God created him." (CP4)*

### ***Isolation***

Care demands and stigma led to social withdrawal, relationship breakdowns, and abandonment by partners.

*"Because of this, her father divorced me and never came back." (CP1)*

### ***Social Support***

Despite challenges, some mothers received emotional support and inclusive interactions from family and community members.

*"People love to play with him because he smiles a lot." (CP5)*



## SUMMARY OF FINDINGS

The findings of this study indicate that mothers caring for their children with CP described multiple caregiving experiences across a range of interrelated physical, psychological, and social challenges, based on the biopsychosocial framework guiding the study. Physically, mothers reported on strain due to the demanding nature of daily caregiving tasks, frequent hospital visits, sleep disruptions, and the emotional toll of managing seizures and developmental delays. Psychologically, mothers described emotional stress, and financial strain; however, many also demonstrated resilience and gradually developed acceptance of their child's condition. Socially, participants reported experiences of stigma, isolation, discrimination, and with relationship challenges, as well as varying levels of social support.

### Discussion of Findings

This study explored the physical, psychological, and social experiences of mothers caring for children with CP at the Greater Accra Regional Hospital, using the biopsychosocial model as a guiding framework. The findings reveal that caregiving for a child with CP is a demanding experience affecting multiple dimensions of mothers' lives. Overall, the caregiving experience was characterised by both considerable challenges and adaptive coping mechanisms, underscoring the need for strengthened family-centred support services within health and community systems.

Within the Ghanaian context, caregiving experiences are shaped by limited access to specialised rehabilitation services, financial constraints, and strong sociocultural beliefs surrounding disability. Public health infrastructure for long-term neurodevelopmental care remains uneven, placing a disproportionate burden on families, especially mothers. In addition, cultural interpretations of childhood disability, including spiritual or moral explanations, may contribute to stigma and influence help-seeking behaviours.

Consistent with findings from Singogo et al. (2015) and Eyong et al. (2017), the mothers in this study were predominantly young and within the reproductive age range. Most were married and had attained at least secondary education, which suggests a relatively high level of literacy. Unlike a study from Zambia (Singogo et al., 2015), where the majority of mothers were unemployed, most mothers in this study reported being employed, though many eventually had to stop working due to caregiving demands. This shows how caregiving responsibilities often alter mothers' social and economic participation.

The themes are interrelated and reflect the interconnected nature caregiving within the biopsychosocial framework. Physical caregiving demands often influenced psychological well-being, while both physical and emotional experiences shaped social interactions and support systems.

### *Physical Experiences*

This theme captures the embodied demands of caregiving, highlighting how children's clinical conditions translate into physical strain for mothers. Mothers described significant developmental delays in their children, including difficulties in neck control, sitting, walking, and speech, suggesting that CP connected to impaired motor functioning and delayed milestone acquisition (Madzhie et al., 2022). Seizures, reported to begin as early as four months, were frightening and unpredictable, intensifying mothers' fears and caregiving vigilance. As in prior



studies (McLaren, 2014; Baba et al., 2017), seizures contributed substantial emotional strain and influenced frequent hospital visits.

The physical demands of caregiving, for example, lifting, feeding, carrying, attending appointments, and constant supervision, led to fatigue, back pain, poor sleep, and in some cases, weight loss. These findings echo studies in Iran, India, Ghana, and Zambia (Mokhtari & Abootorabi, 2019; Vadivelan et al., 2020; Nyante & Carpenter, 2019; Singogo et al., 2015), which posit the global nature of the caregiving burden. Feeding difficulties further increased stress and risked nutritional deficits in children, confirming reports of malnutrition among children with cerebral palsy (Graham et al., 2016; Polack et al., 2018).

### ***Psychological Experiences***

This theme covers the psychological demands of caregiving, describing the emotional stress of mothers. Psychologically, mothers experienced emotional distress, worry, and sadness linked to the chronic nature of the condition. The constant caregiving demands and uncertainty about their children's futures led to symptoms resembling depression, similar to findings by Esposito et al. (2018) and Brehaut et al. (2020). Financial strain intensified psychological distress, as mothers struggled with treatment costs and often lost income due to caregiving responsibilities (Mukushi, 2018).

Acceptance of the child's condition was not immediate. Mothers initially experienced denial before gradually adjusting emotionally. Their eventual acceptance was supported by personal reflection, social support, and spiritual coping, demonstrating resilience. Faith emerged as a major source of emotional strength, contrary to studies suggesting that cerebral palsy is sometimes interpreted as divine punishment (Mohammed et al., 2019; Nyante & Carpenter, 2019). Instead, mothers in this study used faith as a sustaining coping resource, aligning with resilience frameworks (Ko et al., 2018; Findler et al., 2019).

### ***Social Experiences***

This theme describes the social experiences of mothers providing caregiving to children with cerebral palsy. Mothers faced stigma, judgment, and discriminatory attitudes from some community members, including hurtful comments and pressure to seek spiritual explanations or harmful cultural practices. This aligns with evidence that stigma contributes to social exclusion and emotional suffering among caregivers of children with disabilities (Vadivelan et al., 2020; Mokhtari & Abootorabi, 2019). Some mothers experienced relationship strain, separation, or abandonment by partners, which further increased their caregiving burden.

However, not all experiences were negative. Some mothers reported meaningful social support from spouses, family members, neighbours, and hired caregivers. Such support provided emotional relief and caregiving assistance and fostered coping, reflecting the protective value of support networks (Nimbalkar et al., 2014).

Putting all the experiences of participants together, the findings illustrate that mothers' experiences are shaped by the dynamic interaction of physical, psychological, and social factors. Physical caregiving such as lifting and managing seizures contributed to fatigue and sleep deprivation, which in turn influenced psychological stress. Financial strain and social stigma further intensified emotional burden, while social support and spirituality served as



moderating factors. This interconnected pattern reflects the biopsychosocial model, where challenges in one domain often reinforce difficulties in others.

### **Implications for Nursing and Healthcare Practice**

The findings of this study have several important implications for nursing practice, health service delivery, and policy in Ghana.

First, the study indicates the physical and emotional demands placed on mothers caring for children with CP. Nurses and other healthcare providers should therefore adopt a more holistic care approach, where the needs of caregivers are assessed alongside those of the child. Routine caregiver assessments during clinic visits could help identify stress, fatigue, and burnout, enabling timely referrals to counselling or support services.

Second, the chronic nature of caregiving responsibilities, there is need for structured caregiver education on feeding, positioning, and seizure care. Healthcare teams at paediatric neurology clinics should provide ongoing education on feeding techniques, positioning, seizure management, and home-based physiotherapy exercises. Such training would enhance mothers' caregiving confidence and reduce physical strain and anxiety. Health facilities could consider forming support groups at the clinic level, where mothers can share experiences, encourage one another, and strengthen coping strategies.

Third, the study reveals the financial challenges associated with long-term caregiving. This calls for intersectoral collaboration between the health sector and the Department of Social Welfare to ensure caregivers are linked to available social support programmes, including the Livelihood Empowerment Against Poverty (LEAP) programme and disability support grants. Improved communication about eligibility and referral processes could help mothers access resources that ease financial strain. The ministry of health should invest into community-based rehabilitation to enhance access of caregivers.

Fourth, the findings suggests that stigma and social isolation continue to affect mothers. Ministry of Health can engage in national disability awareness campaigns to reduce stigma. Nurses also can play a major role in disability awareness and community sensitisation to challenge misconceptions and promote inclusion.

Finally, the study brought to light the value of spirituality and resilience as coping mechanisms. Integrating mental health and psychosocial support, including faith-based or culturally aligned counselling where appropriate, may improve maternal wellbeing. Nurses should therefore collaborate with psychologists, social workers, and chaplaincy units to provide holistic care aligned with the biopsychosocial framework. There should be an integration of caregiver support into health policy frameworks.

### **Limitation of the Study**

This study has some limitations. The qualitative design limits generalisability of findings beyond the study context. Also, the sample size is relatively small although adequate for in-depth exploration. Further, the study was conducted in a single tertiary facility which may not reflect experiences of mothers in rural or less resource settings. Besides, nurse-mediated recruitment may introduce selection bias. Despite these limitations, the study provides valuable insights into maternal caregiving experiences within this context.



## CONCLUSION

This study explored the physical, psychological, and social experiences of mothers caring for children with cerebral palsy using the biopsychosocial model. The findings suggest that caregiving places considerable physical demands on mothers, including fatigue and back pain. Additionally, mothers often encounter social isolation and stigma, which further intensifies the caregiving burden. Despite these challenges, many mothers showed resilience and coping strength, often drawing on faith, personal motivation, and support from family members.

These findings underscore the need for a holistic approach to care that recognizes and responds to the needs of both the child and the mother. Strengthening caregiver education, enhancing psychosocial support, improving access to assistive devices, and fostering community awareness are essential steps toward improving the well-being of mothers and their children. Addressing these needs requires coordinated efforts among healthcare providers, social workers, and policy makers to ensure equitable, family-centred support within health and community settings.

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