

Psychological Distress and Coping Mechanisms among Caregivers of Children Living with Cerebral palsy: A qualitative study

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Abstract

Background

Caring for children with cerebral palsy places considerable emotional, physical, social, and financial strain on caregivers, particularly in low-resource settings such as Ghana where access to rehabilitation services and support systems is limited. Despite increasing awareness of caregiver distress, little qualitative research has explored the lived experiences and coping strategies of caregivers of children with cerebral palsy in Ghana. This study therefore explored the psychological distress and coping mechanisms among caregivers attending a secondary hospital in Ghana.

Methods

This qualitative exploratory study was conducted among 15 purposively selected primary caregivers of children with cerebral palsy attending the paediatric neurology clinic at Holy Family Hospital, Techiman, Ghana. Data were collected through in-depth semi-structured interviews, audio-recorded with consent, transcribed verbatim, and analyzed thematically using the Braun and Clarke approach. Data collection continued until saturation was achieved, while trustworthiness was ensured through measures of credibility, dependability, confirmability, and transferability.

Results

All participants were mothers aged 29–63 years. Three major themes emerged: determinants of psychological distress, manifestations of distress, and coping strategies. Financial strain, caregiving demands, delayed diagnosis, and limited information contributed significantly to distress, which manifested as persistent worry, sadness, emotional withdrawal, fear about the child's future, anger, and frustration. Caregivers coped through acceptance, religious faith, professional and peer support, and reliance on family support systems, with spirituality and family support serving as key sources of resilience.

Conclusion

Caregivers of children with cerebral palsy experience considerable psychological distress due to financial hardship, intensive caregiving demands, delayed diagnosis, and limited access to information. This distress is commonly expressed as anxiety, emotional exhaustion, and uncertainty about their children's future. Despite these challenges, caregivers adopt coping strategies such as acceptance, religious faith, professional guidance, and family support. The findings highlight the need for strengthened caregiver-focused interventions, including psychological support, education, improved social support systems, and better access to early diagnosis and rehabilitation services in Ghana.

Introduction

Caring for a child with cerebral palsy presents profound and often lifelong challenges that extend beyond the child's physical and developmental needs to significantly affect the psychological wellbeing of caregivers (1, 2). Cerebral palsy, a non-progressive neurodevelopmental disorder characterized by impairments in movement, posture, and coordination, frequently coexists with intellectual disability, epilepsy, and sensory impairments, thereby increasing the complexity of care required (3, 4). In many low- and middle-income settings, including Ghana, the burden of care is largely borne by family members, most commonly mothers, within contexts marked by limited access to rehabilitation services, financial constraints, and sociocultural interpretations of disability (5, 6).

The sustained demands of caregiving place caregivers at considerable risk of psychological distress, including symptoms of depression, anxiety, chronic stress, and social isolation (2). Studies across diverse settings have consistently demonstrated higher levels of psychological morbidity among caregivers of children with disabilities compared to caregivers of typically developing children (7, 8). This distress is often compounded by factors such as stigma, inadequate social support, and the economic burden associated with long-term care (9, 10). In Ghanaian and broader African contexts, cultural beliefs surrounding disability, sometimes linked to spiritual or supernatural causes, may further exacerbate caregiver distress by fostering blame, discrimination, and social exclusion (11, 12). Despite these challenges, caregivers do not passively endure their circumstances; rather, they employ a range of coping mechanisms to manage the emotional, social, and practical demands of caregiving. Coping strategies may include problem-focused approaches such as seeking information and accessing healthcare services, as well as emotion-focused strategies such as religious faith, acceptance, and social support seeking (13). In sub-Saharan Africa, spirituality and communal support systems often play a central role in shaping coping responses, although these may vary depending on individual, familial, and contextual factors (14).

Understanding how caregivers experience psychological distress and how they cope is critical for informing culturally appropriate interventions and support systems. However, much of the existing literature has been derived from high-income countries, with limited qualitative exploration of caregiver experiences within Ghanaian healthcare settings. Furthermore, quantitative approaches, while useful in estimating prevalence, may not adequately capture the depth, complexity, and contextual nuances of caregivers' lived experiences.

This study, therefore seeks to explore the psychological distress and coping mechanisms among caregivers of children living with cerebral palsy in a secondary hospital in Ghana using a qualitative approach. By eliciting rich, narrative accounts from caregivers, the study aims to provide a deeper understanding of the emotional and social realities of caregiving within this context. Such insights are essential for guiding the development of responsive mental health services, strengthening caregiver support systems, and informing policy initiatives aimed at improving the well-being of both caregivers and children with cerebral palsy.

Methods

Study setting

The study was conducted at the Holy Family Hospital in Techiman, the capital town of the newly created Bono East Region. The Holy Family Hospital, Techiman, is a very busy 350-bed capacity hospital. The hospital is the main referral health facility for Techiman and other parts of the region and beyond. The hospital has become a preferred training centre for all health professionals in the country and beyond. The facility is also accredited by the Ghana College of Physicians and Surgeons as a centre for specialist training of medical doctors. The hospital is a secondary-level, and a level four safe-care rated health institution. The hospital provides both general and specialised services. The hospital was chosen because it has a specialised paediatric neurology clinic that provides services for individuals with CP.

Study design

This study employed a qualitative exploratory design to examine the psychological distress and coping mechanisms among caregivers of children living with cerebral palsy in a secondary hospital in Ghana. A qualitative approach was deemed appropriate as it facilitates an in-depth understanding of caregivers' lived experiences, perceptions, and contextual realities, particularly in relation to the complex and subjective nature of psychological distress (15).

The qualitative design prioritised depth and contextual relevance, providing detailed insights into caregivers' experiences that can inform the development of culturally appropriate interventions and support systems.

Study population

The study population comprised primary caregivers of children diagnosed with cerebral palsy who were receiving care at a secondary hospital in Ghana. Caregivers included parents, guardians, or close family members who were primarily responsible for the child's daily care. Inclusion criteria were caregivers aged 18 years and above who had provided care for a child with cerebral palsy for at least six months, were actively involved in caregiving at the time of the study, and were willing and able to provide informed consent. Exclusion criteria included caregivers who had provided care for less than six months, individuals who were not the primary caregivers, those who were unable to give informed consent, and caregivers who were too ill to participate at the time of the study.

Sampling method

A purposive sampling technique was employed to recruit participants for this study. This approach is appropriate in qualitative research as it allows for the deliberate selection of individuals who have direct experience with the phenomenon under investigation and can provide rich, relevant, and detailed information (15).

Sample size

The sample size for this study consisted of 15 participants. In qualitative research, sample size is not predetermined by statistical power considerations but is guided by the principle of data saturation, which refers to the point at which no new themes or insights emerge from the data (16). The selection of 15 caregivers was therefore considered adequate to achieve sufficient depth and richness of information relevant to the study objectives.

Sampling procedure

Participants were recruited using a purposive sampling approach at the pediatric neurology clinic of the selected secondary hospital. On clinic days, caregivers of children diagnosed with cerebral palsy were identified with the assistance of attending healthcare professionals. The researcher approached potential participants, provided detailed information about the study, and screened them against the inclusion criteria. Eligible caregivers who expressed willingness to participate were enrolled after providing written informed consent. Recruitment was conducted sequentially during routine clinic visits to ensure that participants had direct and relevant caregiving experience. Efforts were made to include caregivers with diverse backgrounds and caregiving experiences to capture a range of perspectives. A total of 15 participants were recruited. Recruitment continued until data saturation was achieved, defined as the point at which no new themes or significant insights were emerging from subsequent interviews, consistent with established qualitative research principles.

Data collection instrument

Data were collected using a semi-structured interview guide designed to facilitate an in-depth exploration of caregivers' psychological distress and coping mechanisms. The interview guide was structured around key domains relevant to the study objectives, including caregivers' emotional and psychological experiences, daily caregiving challenges, and the impact of caregiving on their personal and social lives. Additional probes explored perceived sources of stress, experiences of psychological distress, and coping strategies employed in managing caregiving demands. The open-ended nature of the questions allowed participants to freely express their perspectives and highlight issues of personal and cultural significance. (See *Supplementary File 1*).

Data Collection Process

Data were collected from September to November 2025 through in-depth semi-structured interviews with primary caregivers of children living with cerebral palsy attending the selected secondary hospital. The interviews were conducted by the first author, a psychologist with experience in qualitative research and interviewing techniques. Prior to the commencement of the main study, the interview guide was piloted with two caregivers to assess the clarity, relevance, and appropriateness of the questions.

Following the pilot interviews, minor modifications were made to improve the interview guide; however, data obtained from the pilot interviews were not included in the final analysis.

Eligible participants were identified during routine clinic visits and were provided with detailed information regarding the purpose and procedures of the study. Caregivers who voluntarily agreed to participate and provided informed consent were recruited into the study. All interviews were conducted in a quiet, private, and conducive environment within the hospital premises to ensure confidentiality and encourage participants to freely share their experiences and perceptions. Each interview lasted approximately 30 to 60 minutes and was conducted in the participant's preferred language to facilitate effective communication and rich data generation.

During the interviews, open-ended questions were used to explore caregivers' experiences, psychological distress, coping strategies, and challenges associated with caring for children with cerebral palsy. Probing and iterative questioning techniques were employed to obtain clarification and deeper understanding of participants' responses. Adequate time was given to participants to comprehensively express their views and lived experiences. With participants' permission, all interviews were audio-recorded to ensure accurate capture of information, while field notes were simultaneously taken to document contextual details, non-verbal expressions, and observations made during the interviews.

Data collection and preliminary analysis were conducted concurrently, allowing emerging issues and insights to guide subsequent interviews and facilitate deeper exploration of relevant themes. Interviews continued until no new information or themes emerged from the data. Saturation was reached after the fifteenth interview, and no participant was interviewed more than once. Participants were purposively selected to ensure variation in caregiving experiences and socio-demographic characteristics, thereby enhancing the richness and diversity of perspectives captured in the study.

All audio-recorded interviews were transcribed verbatim. Interviews conducted in local languages were translated into English prior to analysis. To maintain confidentiality and anonymity, all identifying information was removed from the transcripts, and data were securely stored in password-protected files accessible only to the research team. This systematic and rigorous data collection process ensured the generation of rich, credible, and contextually grounded data suitable for thematic analysis.

Trustworthiness

The rigor of this study was ensured using the criteria proposed by Lincoln and Guba (17), namely credibility, dependability, confirmability, and transferability, with attention also given to authenticity. Credibility was enhanced through prolonged engagement with participants during the interview process and the use of probing questions to obtain in-depth and accurate accounts of caregivers' experiences. Data collection and analysis were conducted concurrently, allowing emerging insights to be explored in subsequent interviews. Additionally, member checking was undertaken by clarifying responses during interviews and, where necessary, confirming interpretations with participants to ensure that the findings accurately reflected their perspectives. Dependability was ensured by maintaining a clear and systematic

research process. An interview guide was used consistently across participants, while still allowing flexibility for probing. Detailed documentation of the research procedures, including data collection and analysis steps, was maintained to ensure transparency and consistency throughout the study. Confirmability was achieved by maintaining an audit trail that documented key methodological decisions, coding processes, and theme development. This ensured that the findings were grounded in the data rather than influenced by researcher bias. Field notes and verbatim transcripts further supported the objectivity of the analysis. Transferability was facilitated through the provision of a rich, detailed description of the study setting, participant characteristics, and caregiving context. This allows readers to assess the applicability of the findings to similar settings or populations.

Data Analysis

Data were analyzed using a thematic approach as described by Braun and Clarke (18). This method was considered appropriate for identifying, analyzing, and reporting patterns within qualitative data while allowing for both descriptive and interpretive analysis of participants' experiences. All interviews were transcribed verbatim, and transcripts were read repeatedly to ensure familiarization with the data. The analysis followed an iterative process, beginning with the generation of initial codes from the data. Coding was conducted manually, with segments of text systematically labeled to capture meaningful units related to psychological distress and coping mechanisms among caregivers. The initial codes were then reviewed and grouped into broader categories based on similarities and patterns across the dataset. These categories were further refined into themes and subthemes that reflected shared and divergent experiences among participants. The development of themes was guided by both the study objectives and emerging insights from the data, ensuring that the analysis remained grounded in participants' accounts. To enhance rigor, the coding and theme development process was continuously reviewed and refined through comparison across transcripts. An audit trail was maintained throughout the analytical process to document coding decisions and theme development. Where necessary, discrepancies in interpretation were discussed and resolved to ensure consistency. The final themes were defined and clearly named, and representative verbatim quotations were selected to illustrate each theme. This approach ensured that the findings remained closely linked to participants' narratives while providing a coherent and meaningful interpretation of the data. The report of the findings followed the COREQ checklist.

Ethical Considerations

Ethical approval

for the study was obtained from the Ethical Review Board of the University of Cape Coast, College of Education Studies, with approval number CES/ERB/UCC/EDU/46/22–118. Institutional permission was subsequently sought and granted by the management of Holy Family Hospital prior to the commencement of the study. A senior specialist paediatrician and a child neurologist were designated as on-site supervisors to support the research process. Written informed consent was obtained from all participants before data collection. Participants were fully informed about the purpose of the study, and

their right to voluntary participation and withdrawal at any stage without any consequences. Confidentiality and anonymity were ensured by omitting identifiable information and assigning unique codes to participants. Data collection was conducted in a private room provided by the physiotherapy department to ensure privacy and comfort during interviews and questionnaire administration. The researcher remained available throughout the process to address any concerns or questions raised by participants. The study adhered to the ethical principles outlined in the Declaration of Helsinki (19), ensuring respect for participants' rights, autonomy, confidentiality, and overall protection throughout the research process.

Results

Sociodemographic Characteristics of participants.

A total of 15 primary caregivers participated in the study, all of whom were mothers of children living with cerebral palsy. The ages of the participants ranged from 29 to 63 years. In terms of educational attainment, the majority of caregivers had either basic or secondary education, with a few having no formal education, and only one participant reporting tertiary-level education. Regarding employment status, most caregivers were engaged in unskilled work, while a smaller proportion were unemployed, and only one participant reported formal employment. See Table 1.

Table 1
Demographic Distribution of Participants

Code	Age of Caregiver (Years)	Caregiver Relationship	Educational Level	Employment Status
1	44	Mother	Basic	Unemployed
2	36	Mother	Secondary	Unskilled worker
3	45	Mother	Basic	Unskilled worker
4	63	Mother	None	Unemployed
5	41	Mother	Secondary	Unemployed
6	39	Mother	Secondary	Unskilled worker
7	43	Mother	Basic	Unskilled worker
8	50	Mother	None	Unskilled worker
9	45	Mother	Secondary	Unskilled worker
10	42	Mother	Basic	Unskilled worker
11	34	Mother	Tertiary	Employed
12	47	Mother	Basic	Unskilled worker
13	52	Mother	None	Unemployed
14	38	Mother	Secondary	Unskilled worker
15	29	Mother	Secondary	Unemployed

Three major themes emerged from the data: determinants of psychological distress among caregivers, manifestations of psychological distress, and coping strategies adopted by caregivers with their corresponding subthemes as shown in Table 2.

Theme 1: Determinants of Psychological Distress.

Participants identified factors such as economic burden, Time burden and caregiver demands, delayed diagnosis and late interventions, and limited access to information as the main factors that influenced their psychological distress.

Economic Burden

Participants in this study identified financial strains as the main economic burden posed on them as caregivers of children with cerebral palsy. This burden emanated from healthcare expenses, such as special shoes and physiotherapy, leading to increased distress and, in some cases, adverse health effects on the caregivers.

some care givers lamented as follows:

"Sometimes I feel helpless because all the money we get goes into my child's treatment. The physiotherapy sessions, transportation to the hospital, and buying special shoes are very expensive for us. There are days I even skip my own needs just to make sure my child gets the care he needs." (Caregiver 13)

"Caring for my child has affected us financially in so many ways. I had to stop working regularly because I need to stay with him most of the time. The hospital visits and medications are draining us, and the stress is beginning to affect my own health too." (Caregiver 11)

Time burden and caregiving demands.

Some participants also expressed as distressing for them the hefty amount of time they had to spend caring for their children with Cerebral Palsy. They worried that this demand on their time made it difficult for them to undertake any other important activities for their well beings. Therefore sitting and watching other responsibilities unattended to make them distressed.

They explained as below:

"I spend almost the whole day taking care of my child. From bathing him, feeding him, carrying him around, and taking him to the hospital, I hardly get time for myself. Sometimes I look at the house chores and other responsibilities left undone, and it makes me feel overwhelmed." (Caregiver 4)

"Caring for my child takes all my time and energy. I cannot work like I used to, and I barely have time to rest or even attend to my other children. It worries me because there are so many things I need to do, but I cannot leave my child alone." (Caregiver 1)

Delayed diagnosis and late intervention

Another major cause of psychological distress experienced by caregivers was that delay in diagnosis of their children and hence the late interventions. They explained that provided their childrens' conditions were identified earlier and the appropriate interventions instituted, they believed their situation would have been better than the current situation they suffer. Anytime they think about this, they feel more devastated.

"We moved from one hospital to another before they finally told us what was wrong with my child. By the time we started treatment and physiotherapy, his condition had already worsened. Sometimes I keep thinking that if we had known earlier, things might have been very different for him." (Caregiver 11)

"The delay in finding out my child's condition still pains me. We did not understand what was happening, and no one explained it to us early enough. Whenever I see other children improving with early treatment, I feel devastated and wonder if my child would have been better if help had come sooner." (Caregiver 6))

Limited access to information

Some participants believed that their distress experienced in their caregiving roles were as a result of lack of information about the condition their children were suffering. They opined that with the right information, they would have understood the condition and how to help the children which would have eased their stress.

At the beginning, I did not really understand my child's condition or what I was supposed to do to help him. Nobody explained things clearly to us, and that made me very anxious and confused. I believe if I had the right information earlier, caring for him would not have been this stressful." (Caregiver 9)

"Sometimes the distress comes from not knowing what exactly is wrong or what to expect in the future. We were just trying different things without proper guidance. If we had enough education about the condition and how to manage it, I think it would have reduced a lot of the stress we go through." (Caregiver 14)

Theme 2:Manifestations of Psychological Distress

Another theme that emerged from the analysis of the data was "Manifestation of Psychological distress". Under this theme, participants who had experienced psychological distress as a result of their caregiving responsibilities narrated how the distress was manifested. They mentioned persistent worry and anticipatory anxiety, feelings of sadness and emotional withdrawal, fear regarding child's future and prognosis, anger and frustration as how their distresses are manifested.

Persistent worry and anticipatory anxiety

Participants mentioned that their lives were filled with worries and persistent fear of the unknown. Some wondered what will happen to the children if they died in their sleep. Some also complained about developing hypertension as a result of their persistent worry because of the burden of caregiving responsibilities on them.

"When I wake up every morning, I pray for God to give me strength to be able to carry him, however what really saddens me and it's the biggest problem for me is who takes care of this child when I sleep today and don't wake up" (Caregiver 4).

"...it has left me worrying and anxious. I started having symptoms like palpitations, general malaise and numbness in my fingers and I took a lot of herbal medications but I wasn't relieved. I therefore went to Abrafi Hospital and a doctor diagnosed me of hypertension after recording BP of 180/106 mmHg" (Caregiver 5).

This notwithstanding, some caregivers worried about the future independence of these children. Caregivers expressed doubts about whether their children would achieve meaningful functional improvement. These worries were often compounded by limited access to rehabilitation services and the unpredictable progression of the condition, resulting in emotional distress, and difficulty planning for the future.

"Sometimes I cannot sleep because I keep thinking about what will happen to my child when I am no longer alive. Who will take care of him the way I do?" (Caregiver 10)

"I worry a lot about her future because I don't know whether she will ever walk, go to school properly, or be able to live independently." (Caregiver 15)

Feelings of sadness and emotional withdrawal

Participants described feelings of sadness and emotional withdrawal as common emotional experiences associated with caring for children with cerebral palsy. Caregivers expressed persistent sadness, emotional exhaustion, and a tendency to isolate themselves from social interactions and activities they previously enjoyed. Some participants explained that the continuous demands of caregiving, coupled with worries about their children's conditions, left them feeling overwhelmed and emotionally drained. Others reported withdrawing from friends, family gatherings, and community activities because they felt misunderstood or unable to cope emotionally with their circumstances. These experiences of sadness and social withdrawal contributed significantly to their psychological distress.

"There are times I just sit alone and cry because everything feels too heavy for me. I no longer enjoy being around people like I used to, and sometimes I avoid gatherings because I feel emotionally drained." (Caregiver 8)

"Caring for my child has made me very sad at times. I keep many things to myself and prefer staying indoors because I feel people do not really understand what I am going through. Slowly, I have withdrawn from friends and even some family members." (Caregiver 3)

Anger and frustration

Caregivers described feelings of anger toward the situation, health system delays, and lack of adequate information, as well as frustration due to the ongoing caregiving burden, financial pressures, and limited improvement in their child's condition. These emotions were often intensified by social misunderstanding and stigma, contributing to significant psychological strain.

"Sometimes I get angry because I feel like no one really understands what I go through every day taking care of this child." (Caregiver 6)

"I become frustrated when I see that despite all the effort and hospital visits, there is still very little improvement in my child's condition." (Caregiver 12)

Theme 3: Coping Strategies Adopted by Caregivers

Under this theme, participants expressed how they coped with the challenges of caregiving. Strategies such as psychological acceptance and adaptation, religious faith and spiritual coping, utilisation of support groups and professional guidance and reliance on family and informal social support systems.

Psychological acceptance and adaptation

Participants explained that despite the initial reactions, over time, they often give way to acceptance, where caregivers recognize the condition as long-term and focus on managing care rather than seeking cure. This shift is accompanied by practical and emotional adaptation. Although challenges persist, acceptance helps caregivers achieve better emotional stability and improves their ability to manage caregiving demands.

"At first I was devastated and kept asking why this happened, but with time I have accepted it and now I just focus on taking care of my child the best way I can." (Caregiver 9)

"I have learned to live with it. It is not easy, but I have accepted that this is how my child is, and I have adjusted my life around his needs." (Caregiver 5)

Religious faith and spiritual coping

Many caregivers interpreted their child's condition within a spiritual framework, viewing it as part of God's will or a test of faith, which provided meaning and helped reduce feelings of despair. Religious practices such as prayer, attending church services, and seeking support from faith leaders were commonly used as coping strategies. This reliance on spirituality often provided emotional comfort, hope for improvement, and resilience in the face of ongoing caregiving challenges. For some caregivers, faith served as a stabilizing force that helped them endure uncertainty and maintain caregiving responsibilities despite financial, physical, and psychological strain.

"...All what I say is that God is my helper, so in everything I leave it to God's hands, that He should come to my aid in every situation, and I can't fight this battle except Him the sovereign lord who will fight for me, so I don't really mind what people were saying..." (Caregiver 7).

"...so I always ask God to give me strength so I don't say I'm tired...this is what I strengthen myself with, that God should always be with me so that every day I will get the strength to do everything I need to do for him" (Caregiver 15).

Utilisation of support groups and professional guidance

Caregivers mentioned that they relied on both formal healthcare providers and informal peer networks to cope with the demands of caring for a child with cerebral palsy. Guidance from health professionals was valued for providing practical caregiving knowledge, reassurance, and improved confidence in managing the child's condition. Similarly, engagement with support groups or other caregivers offered emotional relief, shared understanding, and reduced feelings of isolation. These sources of support helped caregivers better adapt to their roles, although access to structured and consistent support was sometimes limited.

"When the therapist explains things to me and shows me how to care for my child, I feel more confident and less worried." (Caregiver 1)

"Talking to other parents like me in similar situations makes me feel I am not alone, and it gives me strength to continue caring for my child." (Caregiver 3)

Reliance on Family and Informal Social Support Systems

Some caregivers in this study explained that they depended on spouses, parents, siblings, and other family members for practical assistance such as caregiving tasks, financial help, and occasional respite, as well as emotional encouragement that reduced feelings of isolation. This informal support often filled gaps left by limited formal health and social services, particularly in resource-constrained settings. However, the level and consistency of support varied, with some caregivers receiving strong assistance while others experienced limited help, contributing to increased burden and emotional strain.

"My husband and my mother help me a lot, especially when I am tired or overwhelmed with taking care of the child. My mother sometimes stays with the child so I can rest or attend to other responsibilities, and my husband tries to support me financially and emotionally, which makes the burden easier to carry." (Caregiver 5)

"Without my family's support, I don't think I would have been able to manage this situation alone. There are times when I feel completely exhausted, but knowing that my relatives are willing to step in, even if only occasionally, gives me strength and helps me continue caring for my child." (Caregiver 3)

Table 2
Thematic Structure of Caregivers' Psychological Distress and Coping Experiences in Caring for Children with Cerebral Palsy

Major Themes	Sub-Themes
1. Determinants of Psychological Distress among Caregivers	1. Economic burden 2. Time burden 3. Delayed diagnosis and late intervention 4. Limited access to information
2. Manifestations of Psychological Distress	1. Persistent worry and anticipatory anxiety 2. Sadness and emotional withdrawal 3. Fear regarding child's future and prognosis 4. Anger and frustration
3. Coping Strategies Adopted by Caregivers	1. Psychological acceptance and adaptation 2. Religious faith and spiritual coping 3. Utilisation of support groups and professional guidance 4. Reliance on family and informal social support systems

Discussion

The findings of this study provide important insights into the multidimensional nature of psychological distress among caregivers of children with cerebral palsy (CP). The study demonstrates that caregivers experience significant emotional, social, and economic challenges that arise not only from the child's physical condition but also from broader structural and contextual realities. Similar to findings from previous studies conducted in low- and middle-income countries, the experiences of caregivers in this study highlight how caregiving responsibilities extend beyond routine childcare and often become physically exhausting, emotionally draining, and financially disruptive (1, 20).

Economic burden emerged as one of the most dominant determinants of psychological distress among caregivers. Participants described the overwhelming costs associated with physiotherapy, transportation, medications, and assistive devices such as special shoes. In addition, some caregivers reported losing employment opportunities or reducing work hours in order to provide constant care for their children. These findings are consistent with studies conducted in Ghana, Nigeria, and other sub-Saharan African countries where caregivers of children with disabilities often experience catastrophic financial strain and reduced household productivity (21, 22). The narratives presented by caregivers in this study reflect the broader relationship between disability and poverty, where limited financial

resources worsen caregiving stress while caregiving responsibilities simultaneously reduce income-generating opportunities. The emotional consequences of this economic burden were evident in caregivers' descriptions of helplessness, sacrifice, and deteriorating personal wellbeing.

The findings further revealed that time burden and caregiving demands significantly contributed to caregivers' distress. Caregivers described spending most of their day feeding, bathing, carrying, and supervising their children, leaving little time for rest, employment, social activities, or self-care. Similar findings have been reported by Dehghan et al., (23) in Iran, who observed that caregivers of children with CP frequently experience physical exhaustion and social restriction due to the intensive nature of caregiving. The inability to attend to other responsibilities often generated feelings of frustration, guilt, and emotional overwhelm among participants in this study. In many African contexts where caregiving responsibilities largely fall on women, such burdens may be amplified by cultural expectations surrounding motherhood and caregiving roles (24, 25).

Delayed diagnosis and late intervention also emerged as major contributors to psychological distress. These findings are consistent with previous literature demonstrating that delayed diagnosis contributes to parental anxiety, uncertainty, and hopelessness (2, 21, 26). In many low-resource settings, limited availability of specialist services, poor referral systems, and inadequate public awareness about developmental disorders contribute to delayed intervention and poorer functional outcomes for children with CP (27, 28). The emotional distress associated with delayed diagnosis in this study reflects caregivers' ongoing attempts to make sense of their children's condition and their feelings of missed opportunity.

Another important finding was the role of limited access to information in worsening psychological distress. Caregivers explained that insufficient education about CP left them confused, anxious, and uncertain about how to manage their children's condition. This finding aligns with studies suggesting that lack of knowledge about disability often increases caregiver stress and reduces confidence in caregiving abilities (29, 30). Inadequate communication from healthcare providers may further intensify misconceptions, fear, and emotional instability. These findings highlight the importance of caregiver education and continuous counselling in improving psychological adjustment and caregiving competence (31).

The study also revealed several manifestations of psychological distress among caregivers, including persistent worry, anticipatory anxiety, sadness, emotional withdrawal, anger, and frustration. These findings are consistent with previous research showing that uncertainty regarding long-term prognosis and future caregiving responsibilities contributes significantly to caregiver anxiety (32). Some caregivers in this study even reported developing physical symptoms such as palpitations and hypertension, illustrating the close relationship between chronic psychological stress and physical health outcomes (33, 34).

Feelings of sadness and emotional withdrawal were also common. Participants described social isolation, emotional exhaustion, and reduced participation in social activities. These findings mirror

studies indicating that caregivers of children with disabilities often experience depressive symptoms, loneliness, and reduced social functioning (35). Social withdrawal may partly result from perceived stigma, lack of understanding from others, and the overwhelming nature of caregiving responsibilities. Similarly, expressions of anger and frustration reflected caregivers' emotional responses to ongoing stress, financial hardship, limited improvement in the child's condition, and perceived lack of support. Such emotional reactions are understandable within the context of chronic caregiving stress and align with Lazarus and Folkman's (36) stress and coping framework, which emphasizes the psychological consequences of prolonged caregiving demands.

Despite these challenges, caregivers demonstrated remarkable resilience through a range of coping strategies. Psychological acceptance and adaptation emerged as important coping mechanisms, with many caregivers describing a gradual process of coming to terms with their child's condition. Acceptance appeared to facilitate emotional adjustment and improved caregivers' ability to manage caregiving responsibilities. Similar findings have been reported in studies showing that acceptance-based coping is associated with reduced psychological distress among caregivers of children with chronic illnesses (37, 38).

Religious faith and spiritual coping also played a central role in caregivers' adaptation. Participants frequently relied on prayer, faith in God, and spiritual interpretations of their experiences to sustain hope and emotional strength. In many African societies, spirituality serves as an important coping resource during periods of adversity and illness (38, 39). While spirituality provided emotional comfort and resilience, it also reflected broader cultural meanings attached to suffering, caregiving, and disability.

Furthermore, caregivers relied heavily on support groups, professional guidance, and family support systems. Emotional encouragement from relatives and practical assistance from spouses and parents helped reduce caregiving burden and feelings of isolation. This finding supports existing literature emphasizing the protective role of social support in buffering caregiver stress and improving psychological wellbeing (40, 41). However, the variability in support availability observed in this study also suggests that caregivers without strong family networks may be particularly vulnerable to psychological distress.

Overall, the findings of this study reinforce the understanding that caregiving for children with cerebral palsy is a deeply complex and emotionally demanding experience shaped by interconnected economic, social, cultural, and health-system factors. The findings underscore the need for holistic interventions that move beyond biomedical management to include psychological support, caregiver education, social protection policies, accessible rehabilitation services, and community-based support systems.

Implications for Practice and Research

The findings highlight the need for holistic and family-centred care for children with cerebral palsy, with attention given to both the child and the psychological wellbeing of caregivers. Healthcare professionals should integrate psychological screening, counselling, and caregiver education into routine paediatric

and rehabilitation services. Improved access to information, affordable rehabilitation services, and community-based support systems may help reduce caregiver distress. Establishing caregiver support groups and implementing culturally sensitive interventions that incorporate family and spiritual support may further enhance caregivers' emotional wellbeing and coping abilities.

Future research should further explore the psychological wellbeing and coping experiences of caregivers of children with cerebral palsy, particularly in low- and middle-income settings. Longitudinal and mixed-methods studies are needed to understand how caregiver distress changes over time and to identify effective interventions for reducing psychological burden. Further studies should also examine predictors of caregiver distress, evaluate psychosocial and rehabilitation interventions, and explore the experiences of other family members involved in caregiving. Comparative studies across different cultural and geographical contexts may also improve understanding of factors influencing caregiving experiences and coping strategies.

Limitations of the Study

The study employed a qualitative design with a relatively small sample size, which may limit the generalisability of the findings. Participants were recruited from a single health facility, potentially excluding caregivers who do not access formal care services. The findings were also based on self-reported experiences, which may have been influenced by recall bias or social desirability bias due to the nature of the sensitive experiences. In addition, the study mainly reflected the perspectives of primary caregivers, particularly mothers, and may not represent the experiences of other family members involved in caregiving. Finally, the findings may be context-specific due to the sociocultural and geographical setting of the study.

Conclusion

This study revealed that caring for children with cerebral palsy places considerable psychological, emotional, financial, and social burdens on caregivers. Caregivers experienced distress arising from financial difficulties, demanding caregiving responsibilities, delayed diagnosis and intervention, and limited access to information about the condition. These challenges were often accompanied by feelings of sadness, worry, frustration, and fear about the future of their children. Despite these difficulties, caregivers adopted various coping strategies, including acceptance of the child's condition, reliance on religious faith, support from family members, and seeking guidance from healthcare professionals and support networks.

The findings highlight the need for healthcare systems to pay greater attention not only to the needs of children with cerebral palsy but also to the well-being of their caregivers. Providing psychological support, caregiver education, accessible rehabilitation services, and stronger social support systems may help reduce caregiver distress and improve their overall quality of life. Overall, the study emphasizes the importance of compassionate, family-centred, and culturally sensitive approaches in the care and support of families living with cerebral palsy.

Declarations

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Authors Contributions

DJK led the conceptualization and development of the study topic and research questions, and contributed to data collection, analysis, and manuscript drafting. DBD supported the conceptualization of the study, supervised data collection and analysis, and critically revised the manuscript. KK contributed to data analysis and review of themes. GPA was involved in manuscript writing and revision. SAA contributed to manuscript writing and editing. All authors read and approved the final manuscript.

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Data availability

Data for the study can be found in the study as excerpts. Full data will be available from the corresponding author upon reasonable request.

Ethical Considerations

Ethical approval for the study was obtained from the Ethical Review Board of the University of Cape Coast, College of Education Studies, with approval number CES/ERB/UCC/EDU/46/22-118. Institutional permission was subsequently sought and granted by the management of Holy Family Hospital prior to the commencement of the study.

Consent to Publish

Written informed consent to participate and publish was obtained from all participants prior to data collection.

Competing interests

The authors declare no competing interests.

Clinical Trial Number

Not Applicable

References

1. Raina P, O'Donnell M, Rosenbaum P, Brehaut J, Walter SD, Russell D, et al. The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*. 2005;115(6):e626–36.
2. Hasan A, Dubey AK. Addressing psychological challenges of caregivers and children living with cerebral palsy. *Int J Psychol*. 2025;7(1):26–32.
3. Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol Suppl*. 2007;109(suppl 109):8–14.
4. Sadowska M, Sarecka-Hujar B, Kopyta I. Cerebral Palsy: Current Opinions on Definition, Epidemiology, Risk Factors, Classification and Treatment Options. *Neuropsychiatr Dis Treat*. 2020;16:1505–18.
5. Kisinna AA, Ohene LA, Attafuah PA. Family caregivers' burden and coping with caring for children with cerebral palsy: A qualitative study in a low-resourced context. *Ghana Child: Care Health Dev*. 2025;51(4):e70141.
6. Torres MA, Ohajunwa CO. Care perspectives: Mothers of children with disabilities in a peri-urban setting in South Africa. *Afr J Disabil*. 2025;14:1463.
7. Olsson MB, Hwang CP. Depression in mothers and fathers of children with intellectual disability. *J Intellect Disabil Res*. 2001;45(6):535–43.
8. Parkes J, Caravale B, Marcelli M, Franco F, Colver A. Parenting stress and children with cerebral palsy: A European cross-sectional survey. *Dev Med Child Neurol*. 2011;53(9):815–21.
9. Le Roux R. Caregivers' perceptions of caregiver burden, quality of life and support needs in caring for a child with cerebral palsy with feeding and/or swallowing difficulties within the context of the Western Cape, South Africa. 2023.
10. Davis E, Shelly A, Waters E, Boyd R, Cook K, Davern M. The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child Care Health Dev*. 2010;36(1):63–73.
11. Hughes C, Avoke SK. The elephant in the room: Poverty, disability, and employment. *Research and Practice for. Persons Severe Disabil*. 2010;35(1–2):5–14.
12. Mfoafo-M'Carthy M, Moasun F, Grischow J. Experiencing disability stigma in Ghana: Impact on individuals and caregivers. 2024.
13. Folkman S, Lazarus RS. Coping as a mediator of emotion. *J Personal Soc Psychol*. 1988;54(3):466.
14. Oti-Boadi M. Exploring the lived experiences of mothers of children with intellectual disability in Ghana. *Sage Open*. 2017;7(4):2158244017745578.
15. Creswell JW, Poth CN. *Qualitative inquiry and research design: Choosing among five approaches*. Sage; 2016.
16. Guest G, Bunce A, Johnson L. How Many Interviews Are Enough? *Field Methods*. 2006;18:59–82.
17. Alexander AP. Lincoln and Guba's quality criteria for trustworthiness. *IDC Int J*. 2019;6(4):1–6.

18. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Res Psychol.* 2006;3(2):77–101.
19. Goodyear MD, Krleza-Jeric K, Lemmens T. The Declaration of Helsinki. *BMJ.* 2007;335(7621):624–5.
20. Pelentsov LJ, Fielder AL, Esterman AJ. The supportive care needs of parents with a child with a rare disease: a qualitative descriptive study. *J Pediatr Nurs.* 2016;31(3):e207–18.
21. Nketsia W, Edusei A, Hammond C, Dogbe JA, Afriyie SA, Opoku MP, et al. Experiences of primary caregivers of children with cerebral palsy across the trajectory of diagnoses in Ghana. *Afr J Disabil.* 2019;8(1):1–11.
22. Adama EA, Adua E, Bayes S, Mörelius E. Support needs of parents in neonatal intensive care unit: An integrative review. *J Clin Nurs.* 2022;31(5–6):532–47.
23. Dehghan A, Hosseini SA, Rassfiani M, Dalvand H. Exploring perceptions of health caregivers on the causes of caregivers' occupational burnout in institutes of children with cerebral palsy: A qualitative study. *Electron physician.* 2017;9(6):4516.
24. Evans R. Children's caring roles and responsibilities within the family in Africa. *Geogr Compass.* 2010;4(10):1477–96.
25. Oppong C. Familial roles and social transformations: Older men and women in sub-Saharan Africa. *Res Aging.* 2006;28(6):654–68.
26. Whittingham K, Wee D, Sanders MR, Boyd R. Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. *Disabil Rehabil.* 2013;35(17):1447–52.
27. Oguntade HA, Nishath T, Owusu PG, Papadimitriou C, Sakyi KS. Barriers to providing healthcare to children living with cerebral palsy in Ghana: A qualitative study of healthcare provider perspectives. *PLOS Global Public Health.* 2022;2(12):e0001331.
28. Mwangi LW, Abuga JA, Cottrell E, Kariuki SM, Kinyanjui SM, Newton CR. Barriers to access and utilization of healthcare by children with neurological impairments and disability in low-and middle-income countries: a systematic review. *Wellcome Open Res.* 2022;6:61.
29. Chen Y, Cai T, Le P, Zhang L, Chen Y, Wu L, et al. Family caregivers' perceptions and challenges in the care of pressure injuries in daily life: a qualitative study. *BMC Geriatr.* 2025;25(1):490.
30. Abeasi DA, Nkosi NG, Badoe E, Adjeman J. Caring by default: experiences of caregivers of children with developmental disabilities in Ghana mirrored in the context of the stress process model. *BMC Nurs.* 2024;23(1):482.
31. Tang SH, Chio OI, Chang LH, Mao HF, Chen LH, Yip PK, et al. Caregiver active participation in psychoeducational intervention improved caregiving skills and competency. *Geriatr Gerontol Int.* 2018;18(5):750–7.
32. Rentinck I, Ketelaar M, Jongmans M, Gorter J. Parents of children with cerebral palsy: a review of factors related to the process of adaptation. *Child Care Health Dev.* 2007;33(2):161–9.
33. Saban KL, Sherwood PR, DeVon HA, Hynes DM. Measures of psychological stress and physical health in family caregivers of stroke survivors: a literature review. *J Neurosci Nurs.* 2010;42(3):128–

- 38.
34. Dimsdale JE. Psychological stress and cardiovascular disease. *J Am Coll Cardiol*. 2008;51(13):1237–46.
35. Peer JW, Hillman SB. Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *J policy Pract Intellect Disabil*. 2014;11(2):92–8.
36. Lazarus R, Folkman S. *Stress and coping*. New York. 1985;18(31):34–42.
37. Feliciano A, Feliciano E, Palompon D, Gonzales F. Acceptance theory of family caregiving. *Belitung Nurs J*. 2022;8(2):86.
38. Daliri DB, Aninanya GA, Laari TT, Abagye N, Afaya A. Coping strategies used by informal family caregivers of individuals living with mental illness in the Upper East Region of Ghana: a qualitative study. *BMJ Open*. 2024;14(7):e084791.
39. Mhaka-Mutepfa M, Maundeni T. The role of faith (spirituality/religion) in resilience in sub-Saharan African children. *Int J Community Social Dev*. 2019;1(3):211–33.
40. Zuurmond M, Nyante G, Baltussen M, Seeley J, Abanga J, Shakespeare T, et al. A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers. *Child Care Health Dev*. 2019;45(1):45–53.
41. Zuurmond M, O'Banion D, Gladstone M, Carsamar S, Kerac M, Baltussen M, et al. Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana. *PLoS ONE*. 2018;13(9):e0202096.

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