BMJ Paediatrics Open

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Caring for a child with cerebral palsy: A qualitative exploration of challenges faced by caregivers of children with Cerebral palsy in a resource-constraint environment.

Journal:	*BMJ Paediatrics Open*
Manuscript ID	bmjpo-2022-001807
Article Type:	Original research
Date Submitted by the Author:	04-Dec-2022
Complete List of Authors:	Mwinbam, Mavis Mallory; Nadowli District Hospital, Upper West Region, Ghana, Department of Nursing Suglo, Joseph Ngmenesegre; Presbyterian University College, Department of Nursing and Midwifery Agyeman, Yaa Nyarko; University for Development Studies, Department of Population and Reproductive Health Kukeba, Margaret Wekem; C K Tedam University of Technology and Applied Sciences, Department of Nursing
Keywords:	Qualitative research

Title: Caring for a child with cerebral palsy: A qualitative exploration of challenges faced by caregivers of children with cerebral palsy in a resource-constraint environment.

Authors: Mavis Mallory Mwinbam[1], Joseph Ngmenesegre Suglo[2*], Yaa Nyarko Agyeman[3], Margaret Wekem Kukeba[4]

Institutional affiliations

[1]Department of Nursing, Nadowli District Hospital, Upper West Region, Ghana

[2]Department of Nursing and Midwifery, Presbyterian University, Ghana.

[3]Department of Population and Reproductive Health, School of Public Health, University for Development Studies

[4]Department of Nursing, CK Tedam University of Technology and Applied Sciences

*Correspondence: suglojoseph@gmail.com

Abstract

Introduction

Caring for a child with cerebral palsy could be more emotionally and physically demanding than taking care of a typically growing child. The task could even be more challenging in limited resource settings with insufficient support services. Family caregivers' perspective of this phenomenon needs exploring to facilitate the development of innovative services. The study explored the challenges faced by family caregivers of children with Cerebral palsy in a resource-poor context in Northern Ghana.

Methods:

A qualitative phenomenological approach using content analysis of individual face-to-face in-depth interviews. Participants included family caregivers (n = 13) of children with cerebral palsy seeking health care services in a referral Hospital in Ghana.

Results:

The results show that caregivers encounter challenges that are categorised as socio-cultural, sheer physical care burden and economic challenges. Caregivers describe caring for the child with cerebral palsy as a daunting task. Most caregivers lamented that they encountered social discriminations and lack of family and societal support, as they were isolated, had poor access to health information and education, financial constraints, and loss of businesses and jobs.

Conclusion:

Caregivers have an arduous task of caring for the child with cerebral palsy. They experienced some context-based challenges that warrant that health care systems and policy makers develop support systems that ameliorate the plight of caregivers.

Key words: cerebral palsy; caregivers; family; challenges; Ghana

Introduction

Cerebral palsy (CP) is a major cause of childhood disability affecting function and development (1). CP, a non- progressive lifelong neurodevelopmental disorder results from a brain injury that occurs before the completion of cerebral development in the developing foetus or infant (1). The risk factors associated with the development of CP occurs before, during or after pregnancy. These risk factors may include intrauterine hypoxia, premature rapture of membranes, abnormalities of the placenta, preterm or post-term birth, asphyxia, prolonged labour, meconium aspiration syndrome, infections, hypoglycaemia, intracranial haemorrhage and respiratory distress syndrome (2). CP is estimated to occur in approximately 2.11 per 1000 live births globally (3), affecting males more than females (4) with a greater number in low-income countries (LIC) (1,5,6).

In the Ghanaian context, official statistics on the number of children with CP is lacking, however, Cerebral Palsy Africa (CPA) estimated that one child per 300 births has CP in Ghana (7). The effects of CP on the growing child are enormous ranging from permanent disorders in movement and posture to activity limitation. The motor disorders of CP are frequently accompanied by impaired cognition, communication, sensation, perception, behavioural abnormalities, seizure disorders, or musculoskeletal problems or a combination of these features (8,9). The condition adversely affects children's daily living experiences and limit their self-care functions such as feeding, dressing, bathing, and mobility (10,11). Because of the functional limitations experienced, some children with CP are dependent on others for assistance with daily activities, which leads to long-term caregiving that far exceeds the usual needs of typically developing children (8,12,13). Coping and providing the high level of care required by a child with long-term functional limitations and dependence may be the greatest challenge of caregivers at home. Care provision therefore stands as a burdensome daunting task that impact on the physical and psychological health of the caregiver at home (8,14). The situation could be worse in poor-resourced settings where infrastructural amenities, social support and health care systems are not properly developed to ameliorate the plight of caregivers of children with CP (8,15). Therefore, the study was design to explore the challenges faced by family caregivers of children with Cerebral palsy in a resource-poor context in Northern Ghana. This will serve as basis for developing context relevant support services and policy initiatives to better the lives of caregivers and their children with CP.

Methods

A qualitative phenomenological design was applied in exploring the challenges of caregivers of children with cerebral palsy. Phenomenological principles were used as a better approach for unearthing the experiences of the caregiver in their caregiving role as it provides a better understanding of the caregiver perspective. This also facilitates the development of a composite description of the essence of the experience for the individual (16). The consolidated criteria for reporting qualitative studies (COREQ) was followed to ensure standard reporting of the research findings (17)

Participants and Setting

Thirteen family caregivers of children with CP participated in the study. We included individuals if they resided with and provided care on daily basis for a child less than 18 years of age, diagnosed by a qualified medical doctor, and confirmed in their medical records to have CP. The recruitment of participants took place at a physiotherapy unit of the Tamale Teaching Hospital, the only tertiary hospital in the Northern region of Ghana. The hospital provides specialist care and physiotherapy services for children with diverse needs including CP. Most of the inhabitants in this setting are Muslims, but also practice and revere the traditional African religion as well. Thus, they believe in their ancestors and their supernatural powers (18) and this could sometimes influence their perceptions about disease causation and management. Wholesale, retail and agricultural activities are the main occupation in the area (19).

Sampling and recruitment

Based on the concept of data saturation (20,21), a purposive non-probability sampling technique was adopted to recruit participants for the study. All participants were recruited during their routine physiotherapy clinic appointment days. We observed COVID19 protocols (maintaining of social distancing, wearing of Personal Protective Equipment (PPE) such as nose mask or face shield and use of hand sanitizers) during participants recruitment and data collection. We confirmed participants' inclusion by checking diagnoses from children's hospital records with the help of a physiotherapist to ensure that children had been duly diagnosed by a medical professional. We introduced the study aims and informed potential participants that involvement in the study was voluntary. Participants who expressed interest in joining the study were then provided with further information using the information sheet. We guided participants who consented to take part in the research to sign/thump print the consent form. MMM conducted all recruitment procedures.

Data collection

Completion of demographic information preceded oral interviews for all consenting participants. We conducted individual face-to-face interviews using an in-depth interviews guide. We asked Probing questions based on the responses of each participant. These interviews were either conducted in English language or the native language (Dagbani) at the hospital clinic based on the preferences of participants. All interviews were audio recorded and each lasted for about 35-50 minutes. we wrote additional field notes to cover the observations made on each interviewee and these were considered during analysis for contextual issues. We conducted most interviews in the local Dagbani language, and translated verbatim transcripts were verified by a bilingual expert to ensure accuracy (22)

Data analysis

With the permission of participants, all interviews were audio recorded and verbatim transcription done. Inductive content analysis as described by Elo and colleague (23) was used to analyse the data of this study. Content analysis is a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding. We manually transcribed recorded audio of interviews with participants verbatim into electronic text on a computer, taking cognisance of non-verbal cues captured in the field notes. We translated audio records in the local language (Dagbani) into the English language back-to-back to ensure we did not lose the meaning and was cross-checked between researchers for validation. Participants transcripts were anonymized with letters and numbers such as 'P1', 'P2'. All authors then read the transcripts severally and compared samples with the interview audios files. We generated the codes inductively by highlighting key ideas from data. We then copied these codes and grouped them to form subcategories based on how they were related. We further grouped subcategories with similar meanings to form categories. We reviewed and compared categories and sub-categories with the code and entire dataset to ensure that we captured the meaning of the entire dataset as presented by participants in the interviews.

Ethical considerations

Our study was of low risk to children and the caregivers. However, we observed all relative ethical issues including maintaining privacy and confidential, upholding autonomy of caregivers, occasioning voluntary involvement and obtaining informed consent. We also involved third party to assess our ethical conduct and provide ethical clearance. We therefore obtained ethical approval from the Committee on Human Research, Publication and Ethics

(CHRPE) of Kwame Nkrumah University of Science and Technology (KNUST), Ghana with reference number CHRPE/AP/231/21 and the Department of Research and Development of the Tamale Teaching Hospital with reference number TTH/R&D/SR/039, who also provided administrative permission for the study setting.

Findings

We interviewed thirteen (13) family caregivers to generate data for understanding their perspectives of the challenges they face caring for children with CP. All caregivers were women, out of which 12(92%) were biological parents to the child with CP. Majority were middle aged women and ages ranged from 30-68 years, with a mean age of thirty-nine. Most 10(77%) of the children were between 2-4 years old. Table 1 presents the detail demographic information of participants.

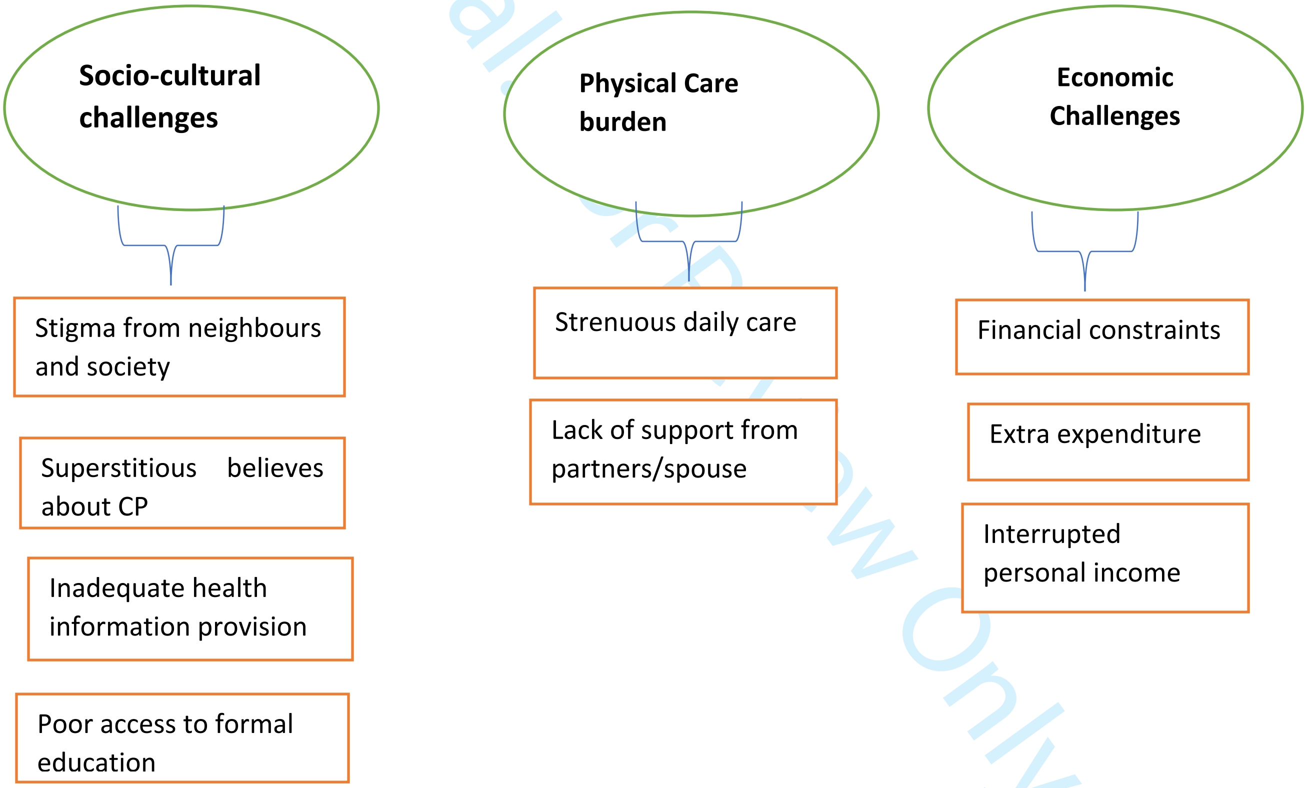
Table 1: Demographic Characteristics of Participants

Demographics	Frequency (n)	Percentage (%)
Caregiver relationship		
Mother	12	92
Grandmother	1	8
Age of caregiver		
30-39	10	76
40-49	1	8
50-59	1	8
60-69	1	8
Mean age	39	
Educational level caregiver		
SHS and below	4	31
Tertiary	6	46
No formal education	3	23
Occupation of Caregiver		
Trading	5	38
Nurse	2	15
Teacher	1	8
Environmental health officer	1	8
Unemployed	4	31
Marital status of caregiver		
Married	11	84

Single	1	8
Widow	1	8
Age of child with CP		
<2 years	2	15
2-4	10	77
5-7	1	8
Type of CP		
Spastic	5	38
Not stated	8	62

Three main categories namely, socio-cultural issues, sheer physical care burden and economic challenges emerged from the data and are detailed in Figure 1.

Fig 1: Categories of challenges faced by caregivers



Socio-cultural challenges

Social cultural challenges emerged as a major category from the data and describing the relationships and difficulties encountered by caregivers as they interact with society and formal institutions on issues related to their child with CP. The results depict the cultural and intuitive beliefs of society about CP and its impact on caregivers. Caregivers also reported how the socio-cultural viewpoints make the society hostile towards them and living with a child with CP challenging. Salient challenges narrated by caregivers include stigma, misconceptions about CP, inadequate health care services, and problems of accessibility to formal education.

Stigma from others:

Caregivers recounted how they felt ashamed and humiliated by society because of their child's condition, CP. Caregivers spoke of how their children were described in foul language such as not being human being but as snakes by neighbours and friends. For instance, according to p11, the caregiver of a 2-year-old child with CP, she is unable to attend social gatherings because of the manner in which her child is addressed as shown in their statement.

> *Whenever there is an 'occasion' (marriage, naming ceremonies and funerals), I do not go because of the way they treat the child, I don't like it. People will just be calling her all sort of names saying she is not human being so I should not waste my time on her (p11, caregiver of a 2year old girl).*

Like p11 account, p6 also demonstrate that the attitudes of society towards their child's CP makes her feel that she is a subject of ridicule. She suggests that even though people in her circles know about her child's condition, suggesting that the child may not be able to walk independently they continue to ask questions about her child not walking just to spite her as she recounts in the quote below;

> *We are now laughing stock to most people, some people know what the child is going through, and they will see you and intentionally ask you, so your child is still not walking 'enh'? Sometimes in a car like this, they do not even want you to sit closer to them or the child should touch them… (P6 caregiver of a 2year boy).*

Other caregivers also felt that there were discriminations against their children, as they were not allowed to associate with other children. Thus, both child and caregiver could not freely relate with others due to the emotional trauma and stigmatisation from others. Such constraints encountered by caregivers observed in their sample narrations are as follows:

> *As for discrimination, it exists. Some relatives do not allow their children closer to my child because they feel that he is not normal (p5 caregiver of a 7year boy).*

A caregiver added that the challenges in caring for a child with CP in the community is compounded by community members believe that CP is a result of punishment from the gods, and others say children with CP were spirits. According to them, such claims provoke emotional pain. It also appears such perceptions compel caregivers to seek cure, and on whether the children were actually spirits or are punished by the gods from spiritualist.

> *Others make insulting remarks like, this your child is not a human being. We have even visited a shrine on several occasions because of that... They will give herbal preparation to bath the child and if he is really not human, then he will die after bathing*

> *those herbs. But after bathing him, it is clear that he is not what they were thinking of (p3 caregiver of a 4year, 9months boy)*

Inadequate health information provision:

Adequate information on CP and optimal care strategies could reduce the challenges caregivers face. However, the data show that caregivers did not feel they were given enough information by health care professional to enable them to understand, cope and care for their child. The lack of information appeared to make some caregivers believe in the community's claims about their child and confused the exact nature of their child condition. As shown by p5, even though health workers took history from them about their child's condition, the health workers failed to give them information about the condition. Indeed, due to this limited information giving, it appears caregivers with English literacy and could surf the internet resorted to finding information about their child's condition themselves as demonstrated by caregiver p6.

They asked me questions some time ago about the child's condition which they wrote down, but I have not been given any information regarding his condition since then… they only said we should come to this place (referring to physio unit) and do the exercise (p5, caregiver of a 7year boy).

Meanwhile, caregivers appeared to suggest that they had to persistently demand for information about their child's condition without success. Even though P6 reports show that the internet has helped them to understand their child's condition better, finding information from the internet that is not censored could be misleading as there are sources that may not be credible. Thus, lack of adequate information from health workers could compel caregivers to sources of information that may lead to practices harmful to the child.

> *At first, I didn't know what was wrong with him, because the doctors will not give you more information about this condition…Now I'm beginning to understand because I just browse and read about it. . .. (p6, caregiver of a 2year boy).*

Poor access to formal education:

Another challenge encountered by caregivers was the fact that they could not find a suitable school that would render quality education for their children. Some mothers felt their children would not be accepted into the mainstream due to their condition, and special schools were not also available for them. It thus appears all schools that were within the reach of caregivers were not resourced to admit children with special needs like CP. Some community members who seem not to know the depth of the child schooling problem kept recommending that the child be taken to school. See the following expressions of p11.

They said I should take her to school but in our place, they won't admit her. They said she cannot sit, and she cannot walk… When you send her to these normal schools, they will not *take her. And there is no school too in our area that train such children (p11, caregiver of a 3year old girl).*

Sheer physical care burden:

Caregivers also recounted the challenges with providing activities of daily living such as the bathing, dressing, and moving their child among others, whilst maintaining their routine responsibilities to themselves and other members of the family such as other children mostly without support from others.

Strenuous daily care

Caregivers lamented about the exhausting nature of caring for a child with CP. Due to the physical and neurological incapacities of the child, they depend exclusively on their caregivers to meet all their needs. Most participants of this study experienced struggles in meeting the demands of children's daily care. Caregivers' reports appear to indicate that lifting and moving their children were particularly challenging as it affected their wellbeing as stated by p3 and p5.

> *I usually feel tired due to carrying him always. It is actually a problem lifting him. I sometimes get some body pains as a result of carrying him because he will not sit, so all the time am carrying him. I pray he is able to walk someday, if not, he will be a burden while he is growing up because I can't be carrying him (p3, caregiver of a 4year, 9months boy).*

> *I feel so tired of taking care of him because he has a younger sibling who I equally have to cater for. At his age (7years), he should have been able to bath and move about, but I have to still be doing it (p5, caregiver of a 7year boy).*

Caregivers expressed experiencing pains and having to depend on pain medications to relieve themselves due to the strenuous nature of the care they have to provide for their child with CP. Caregivers also commented that the care became more challenging as their child grew older, as younger children were easier to manage. It appears as seen in the statement of p8, that the difficulty with the care is associated with having to lift and move the children, as the grow physically and increase in size and weight. Indeed, increase in size and weight would make the care of a child more demanding, however, for the child with CP who have neurodevelopment challenges normally limp and with flappy body parts, and involuntary movements that they may not be able to control as seen in p8 submission suggests that their care become more complicated without any support or physical aides.

> *At times when you are going to wear him his clothes, you will struggle with him. He won't relax his hands; he will just stiffen them and make himself hard. You will be struggling, and he will continue to make his hands like that. . .. Am fed-up 'koraa.' (p8, caregiver of 4year old boy)*

Inadequate support from social networks:

Besides the challenges involve in the care, caregivers also indicated that they received very minimal or no support from family members and others in providing care for their child. Most caregivers expressed concerns that their children may be abandoned in the absence of the primary caregiver.

> *It is not easy to get someone to provide care for him especially when I am not feeling so well, I have to still manage and care for him because, the way he is, who will have time to take care of him? (p3, caregiver of a 4year, 9months boy).*

As shown in the demographics, majority of the caregivers were females and mothers to the children. Although, the caregiving role is traditionally a woman's role, and thus consistent with the findings of this study, considering the additional needs of the child with CP and also the emerging trend that women have more roles than the caregiving, it would be expected the caregivers received care, at least from the spouses. However, the statement from p3 captures those experiences of most of the caregivers in terms of support from their spouses.

> *With this one that my husband is not helping me take care of him, do you think I will try to give birth again? He doesn't mind us any longer, at least once a while he should also pick him, and I will also rest but he doesn't. (p3, caregiver of a 4year, 9months boy)*

Economic challenges

The cost of care globally is a challenging issue as it requires constant flow of money. The special needs of children with disability such as CP increases the financial burden both in the amount required for the care, as well as the loss of hours for family to work and gain their normal income. The caregivers in this study demonstrated in the submission that the sources of income were interrupted, and they had financial limitations in meeting all the care needs of the child.

Financial limitations:

Having a child with CP means having an expenditure line that is not consistent with routine households' expenses, and thus raising cost of family budget. Most caregivers employed and unemployed described their experience of having increased expenditures due to buying of medications, assistive devices, transportation costs, laboratory investigations, and buying of foods. The latter definitely placed an extra financial burden of caregivers who may not also receive financial support as there are no clear, steady formal support for the vulnerable in Ghana, and as indicated earlier the relationships of the caregiver and the child are not supportive enough to consider providing the caregiver with monetary support for caregiving. See the submission of p6 and p10.

> *…I am supposed to be coming for review once every week, but because of the cost of transportation, I have made it once every two weeks (p6 caregiver of a 2year boy).*

> *This place (referring to physio unit) I was told that health insurance will cover some part and you will also pay the rest after … sometimes. 'Hmmm' …. Is not easy . . . I have even stopped the neurological consult because you have to pay for the consultation and still buy the drugs because the hospital is not always having them (p10, caregiver of a 4year boy).*

Interrupted personal income:

Besides the increased expenditure, the economic situation of caregivers was reportedly made worst when they could no longer engage in income earning activities. Participants reports show that caregiving demands of their child led to them abandoning their employments as the could not combine the care of the child which is a full-time job with their income generating activities as shown in the quotes from participants, p10 and p3.

> *I am no longer employed, cannot do any work again. I was working in a private hospital before I gave birth, but now this child is like this, I have stopped my employment because he has this problem (cerebral palsy) (p10, caregiver of a 4year boy).*

> *I am no longer in business because I can't be holding him while preparing my local drinks and there is no one to help. Where will I be getting money for his care? (p3, caregiver of a 4year, 9months boy).*

Many of the caregivers who were initially engaged in personal businesses for income had their businesses collapsed because they did not have time to continue trading. Other caregivers simply stopped because of the level of stress in juggling between childcare and business. Caregivers were then left to deal with the effects of these income cuts and rising expenditures.

Discussion

Care for children with special needs such as CP is challenging in even advanced jurisdictions with better societal literacy and technologically derived assistive devices for care (24–26). Our findings show that caregivers encounter sociocultural, physical, and economic challenges associated with the care of their child with CP. This study findings resonate with existing evidence and signpost key contextual and global issues that need consideration to develop support systems and relevant interventions. Our finding indicates that caregivers of children with CP face physical care burden. Due to the muscle spasticity, weakness and uncoordinated motor control, children with CP rely mainly on their caregivers for physical care irrespective of their age (27). Indeed, motor dysfunction may become worst due to weight as children with CP grow (28). Although there are assistive devices for aiding in the care of sick individuals with neuromuscular inadequacies and selfcare deficit (29), the caregivers in this study had to lift and move their children manually without such devices, resulting in caregivers altered wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the wellbeing of caregivers is critical considering that most children with CP depend solely on them for their care (30,31). It might therefore be useful to not only solicit the support of the social networks to assist primary caregivers, but it might be more sustainable for health professionals to assist caregivers to learn manual handling and body mechanics to empower them to lift and move children with minimal impact on the health of caregivers (32,33).

Cerebral palsy is an old age neurological condition with scientifically generated evidence on its course. Despite this, the relations of children with CP and caregivers misunderstand CP in many contexts especially in settings with limited general literacy(34), leading to attribution of the condition to supernatural causes, such as punishment from the gods and witchcraft as reported in this study and others (34,35). The setting of the study as shown in the demographics has majority of the people being superstitions about health and other societal issues as played out in the reports of caregivers, that their children with CP were allegedly perceived as being spirit children and being punished by the gods. The perceptions were translated into the level of engagement members of the community had with the caregivers and the children. Existing evidence show that beliefs of witchcraft and punishment by the gods lead to labelling, stigmatisation and discrimination against families and children with CP (35). Lack of support for caregivers resulting from stigma has been reported in the existing literature (9,14). This limited support could compound the innate challenges associated with having a child requiring special needs. Thus, society's understanding of CP is critical in reducing stigmatisation and discrimination against families with children with CP, and the associated cyclical effect on the child and caregivers. It is therefore critical that health information on CP is intensified to ensure that communities understand the causes and course of CP, therefore promoting empathy and involvement of support systems in providing care for the child to improve their life quality.

In Ghana, the health service and other interested groups such as faith-based institutions and churches are critical in providing service users and communities with health information. However, the findings of the study suggests that even primary caregivers of children with CP receive limited information about the condition. Limited information on health issues and services is a global challenge (36–38) However, challenging settings such as Ghana with limited economic independence are worst in this regard (13,39–43). Anecdotal evidence from the study setting suggests that health professionals provide ad hoc health education to caregivers of children with CP and other disabilities, using medical terms that caregivers and their support systems may not understand. Yet, there is evidence that adequate caregiver's knowledge may promote better care for children with CP (41,44) and provision of health information to health services users is expected to be acknowledged as a right (45–47). Indeed, the trend to breaching the gap in service users understanding of health issues and thus contribute effectively to services provision is through deliberate efforts of ensuring public participation (48). Therefore, to forestall the challenges community's encounter with their health management, conscious efforts must be made to utilize evidence such as that identified in this study and introduce appropriate interventions at every level of the health service.

Existing evidence suggests that children with CP without cognitive impairment could benefit from formal education (49), and caregivers reported that one of their challenges was finding school placement for their children with CP. Besides providing children with CP to explore their potential and contribute to their development, formal school systems health programmes have been a strategy health professionals use to deliver information on health issues to children, and could be a means for delivering health information to children with CP. Nevertheless, accessibility to educational infrastructure was a challenge for caregivers. Although Ghana has an all-inclusive education policy (50), it thus appear most schools in this setting do not have the capacity in terms of human resource and space to admit children with CP. Lack of formal education opportunities have also been reported by parents in studies conducted in India and Kenya where parents lamented their inability to find appropriate schools for their children with disability (40,51,52). Besides contributing to health care and the child's growth and development, formal education reduces the time children have to spend with their caregivers. This provide caregivers the opportunity to engage in income generating activities that could lessen the financial burden of having a child with cerebral palsy (40,53,54). Ghana's National Health Insurance Scheme, meant to lessen the burden of health care cost on service users currently operates a cost sharing system and patients must do out-of-pocket payment to obtain some critical services (55). The latter indicates that the health financial burden on caregivers in this study's setting could be more than communicated by the caregivers. Even though the economic challenges for caregivers in this study are unavoidable considering that the setting is generally a deprived area, the absence or limited financial support could limit caregivers ability to access all necessities such as rehabilitation services for the care of their child as reported in other studies (53).

Conclusively, contextual issues that relates to child physical care, cultural perceptions, health information needs, and education create problems for caregivers, and need to be translated into appropriate community and health system response. Findings suggest that caregivers have a candid idea on challenges they face on daily basis, and they should be appropriately involved in designing appropriate innovative services or health care interventions.

Funding statement: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests' statement: No competing interests to declare.

Author contribution: MMM and YNA and MWK conceptualize the study, methodology and literature review. MMM and JNS undertook the data collection, transcription, and analysis. YNA reviewed transcript compared with audios, JNS and MWK drafted the manuscript. MWK and MMM reviewed manuscript for intellectual content. All authors read and approved the final manuscript for publication.

Data Availability: All data relevant to the study are included in the article

What is already known on this topic

- Having a child with cerebral palsy negatively impact the physical and psychological health of the caregiver at home
- Children with cerebral palsy may have functional limitations and be dependent on others for assistance with activities daily living.
- Coping and providing daily care required by a child with cerebral palsy may be the greatest challenge of caregivers at home.

What this study adds:

- There is a cultural and intuitive belief about cerebral palsy that create social isolation and stigma against caregivers and their children with the condition
- Provision of health information on cerebral palsy is limited, and caregivers remain doubtful of the cause and course of the condition

- Caring for a child with cerebral palsy leads to high health care related cost and loss of businesses and jobs that worsens the financial situation of caregivers.
- Accessibility to formal education for children with cerebral palsy is limited.

How this study might affect research, practice or policy:

- It is a critical moment for health service and interested parties to intensify health information on cerebral palsy to ensure that communities understand its causes and course.
- Pragmatic steps and policy initiatives that offset the cost of accessing health care services for children with cerebral palsy could be beneficial in this context.
- The already existing "all-inclusive educational policy" should be operationalised by the relevant authorities to make formal education accessible to children with cerebral palsy.
- The findings of this study should serve as foundational research for empirical studies that seeks to develop interventions for caregivers of children with CP.
- Caregivers of children with cerebral palsy could benefit from training on manual handling and body mechanics to empower them to lift and move children with minimal impact on their health.

Patient and Public Involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research

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BMJ Paediatrics Open

Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana

Journal:	*BMJ Paediatrics Open*
Manuscript ID	bmjpo-2022-001807.R1
Article Type:	Original research
Date Submitted by the Author:	15-Mar-2023
Complete List of Authors:	Mwinbam, Mavis Mallory; Nadowli District Hospital, Upper West Region, Ghana, Department of Nursing Suglo, Joseph; Presbyterian University College, Department of Nursing and Midwifery Nyarko Agyeman, Yaa; University for Development Studies, Department of Population and Reproductive Health Kukeba, Margaret Wekem; C K Tedam University of Technology and Applied Sciences, Department of Nursing
Keywords:	Qualitative research, Rehabilitation

Title: Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana

Authors: Mavis Mallory Mwinbam[1], Joseph Ngmenesegre Suglo[2*], Yaa Nyarko Agyeman[3], Margaret Wekem Kukeba[4]

Institutional affiliations

[1]Department of Nursing, Nadowli District Hospital, Upper West Region, Ghana

[2]Department of Nursing and Midwifery, Presbyterian University, Ghana.

[3]Department of Population and Reproductive Health, School of Public Health, University for Development Studies

[4]Department of Nursing, CK Tedam University of Technology and Applied Sciences

[*]Correspondence: suglojoseph@gmail.com

Credentials and occupation of Researchers

[1]MPN - Paediatric Nurse Specialist; [2]PhD student - Lecturer; [3]PhD – Senior Lecturer; [4]PhD – Senior Lecturer

Abstract

Introduction

Caring for a child with cerebral palsy could be more emotionally and physically demanding than caring for a typical growing child. The task could be more challenging in resource-limited settings with insufficient support services. Family caregivers' perspective of this phenomenon needs exploring to facilitate the development of innovative services. The study explored the challenges family caregivers face of children with cerebral palsy in a resource-limited context in northern Ghana.

Methods

A qualitative phenomenological approach was utilised. Participants were family caregivers (n = 13) of children with cerebral palsy recruited from the physiotherapy unit of Tamale teaching hospital in Ghana. Individual face-to-face, in-depth interviews using a topic guide were conducted. All interviews were audio recorded, and verbatim transcription and translation were carried out before undertaking an inductive content analysis.

Results

Caregivers describe caring for a child with cerebral palsy as a daunting task. The results show that caregivers encounter challenges that are categorised as sociocultural, consisting of the values, attitudes, and belief systems of society, sheer physical care burden and economic challenges. Most caregivers lamented that they encountered social discrimination and lack of family and societal support, as they were isolated, had poor access to health information and education, had financial constraints, and lost businesses and jobs.

Conclusion

Caregivers have the arduous task of caring for a child with cerebral palsy. Social support interventions and policy initiatives that seek to ameliorate caregivers' finances and make formal education accessible to this marginalised child population may be beneficial in this study context.

What is already known on this topic:

- Having a child with cerebral palsy negatively impact the physical and psychological health of the caregiver at home.
- Children with cerebral palsy may have functional limitations and depend on others for assistance with daily living activities.
- Coping and providing daily care required by a child with cerebral palsy may be the greatest challenge of caregivers at home.

What this study adds:

- There is a cultural and intuitive belief about cerebral palsy that create social isolation and stigma against caregivers and their children with the condition.
- Provision of health information on cerebral palsy is limited, and caregivers remain doubtful of the cause and course of the condition.
- Caring for a child with cerebral palsy leads to high health care related cost and loss of businesses and jobs that worsens the financial situation of caregivers.
- Accessibility to formal education for children with cerebral palsy is limited.

How this study might affect research, practice, or policy:

- Pragmatic steps and policy initiatives that offset the cost of accessing health care services for children with cerebral palsy could be beneficial in this context.
- The relevant authorities should operationalise the already existing "all-inclusive educational policy" to make formal education accessible to children with cerebral palsy.
- The findings of this study should serve as foundational research for empirical studies that seeks to develop interventions for caregivers of children with CP.

Introduction

Cerebral palsy (CP) is a major cause of childhood disability affecting function and development (1). CP, a non-progressive lifelong neurodevelopmental disorder, results from a brain injury that occurs before the completion of cerebral development in the developing foetus or infant (1). The risk factors associated with developing CP occur before, during or after pregnancy. These risk factors may include intrauterine hypoxia, the premature rupture of membranes, placenta abnormalities, preterm or post-term birth, asphyxia, prolonged labour, meconium aspiration syndrome, infections, hypoglycaemia, intracranial haemorrhage and respiratory distress syndrome (2). CP is estimated to occur in approximately 2.11 per 1000 live births globally (3), affecting males more than females (4), with a more significant number in low-income countries (LIC) (1,5,6).

In the Ghanaian context, official statistics on the number of children with CP are lacking. However, Cerebral Palsy Africa (CPA) estimated that one child per 300 births has CP in Ghana (7). The effects of CP on the growing child range from permanent disorders in movement and posture to activity limitation. The motor disorders of CP are frequently accompanied by impaired cognition, communication, sensation, perception, behavioural abnormalities, seizure disorders, musculoskeletal problems or a combination of these features (8,9). The condition adversely affects children's daily living experiences and limits their self-care functions such as feeding, dressing, bathing, and mobility (10,11). Because of the functional limitations experienced, some children with CP depend on others for assistance with daily activities, leading to long-term caregiving that far exceeds the usual needs of typically developing children (8,12,13). Coping and providing the high level of care required by a child with long-term functional limitations and dependence may be the greatest challenge for caregivers at home. Care provision, therefore, stands as a burdensome daunting task that impacts the caregiver's physical and psychological wellbeing at home (8,14). The situation could be worse in poor-resourced settings where infrastructural amenities, social support and health care systems are not adequately developed to ameliorate the plight of caregivers of children with CP (8,15). Therefore, the study was designed to explore the challenges faced by family caregivers of children with cerebral palsy in a resource-limited context in northern Ghana. This will serve as a basis for developing context-relevant services and policy initiatives to better the lives of caregivers and their children with CP.

Methods

Design

Essence or truth about the reality of a phenomenon is embodied in people's lived experiences. The principles of phenomenology research approach were employed to underpin the methods of this study as it aimed to describe the lived experiences of individuals caring for children with cerebral palsy. The qualitative research design literature shows that phenomenological principles acknowledge people's ties with their physical, social, and emotional world (16–21). Thus, whilst a descriptive qualitative approach could equally be used to unearth the data required in this study to explain the experiences of carers of children with cerebral palsy, the phenomenological approach fitted in better (16,19). Caring for a child with special needs is unique and has special meaning for the individuals involved. Being a parent of a child with cerebral palsy is emotionally and physically unpleasant as the child cannot live like other children, and the care could be daunting, especially in settings where assistive devices to aid daily living are absent. Sociocultural factors place the child and their family in a disadvantaged position. For instance, beliefs about disabilities like those associated with cerebral palsy are associated with mystical causes such as a curse or punishment by other individuals or the ancestors for disobedience of an inappropriate action that provokes consequences. To understand, interpret and describe the caregiving process of such children as it is to the individuals who live it requires using procedures that ensure that the lived experiences of the individuals are appropriately unearthed.

Participants and Setting

Thirteen family caregivers of children with CP participated in the study. We included individuals who resided with and provided care daily for a child under 18 years of age, diagnosed by a qualified medical doctor and confirmed in their medical records to have CP. The recruitment of participants took place at a physiotherapy unit of the Tamale Teaching Hospital, the only tertiary hospital in the northern region of Ghana. The hospital provides specialist care and physiotherapy services for children with diverse needs, including CP. Most of the inhabitants in this setting are Muslims, but they also practice and revere the traditional African religion. Thus, they believe in their ancestors and supernatural powers (18), which could sometimes influence their perceptions about disease causation and management. Wholesale, retail and agricultural activities are the main occupation in the area (22).

Sampling and recruitment

Based on data saturation (23,24), a purposive non-probability sampling technique was adopted to recruit participants for the study. All participants were recruited during their routine physiotherapy clinic appointment days. We observed COVID-19 protocols (maintaining social distancing, wearing Personal Protective Equipment (PPE) such as a nose mask or face shield and using hand sanitisers) during participant recruitment and data collection. We confirmed participants' inclusion by checking diagnoses from children's hospital records with the help of a physiotherapist to ensure that children had been duly diagnosed by a medical professional. We introduced the study aims and informed potential participants that involvement in the study was voluntary. Participants interested in joining the study were then provided further information using the information sheet. We guided participants who consented to participate in the research to sign/thumb print the consent form. MMM, a paediatric nurse specialist conducted all recruitment procedures and data collection. Though she had no prior relationship with participants in the study area, she was motivated to recruit and gain understanding of issues in this context.

Data collection

Gathering participant demographic information such as caregiver relationship with the child, educational level, child age, marital status, and caregiver occupation preceded oral interviews for all consenting participants. These characteristics were collected to add more context to the study findings as they could diversely influence caregivers' experience. However, they were never used to select participants purposively. For pragmatic reasons and the challenges involved in bringing participants with different medical review dates together for focus group discussion, we conducted individual face-to-face interviews using an in-depth interview topic guide (supplementary file 1) developed by the researchers based on the study's objectives. The open-ended nature of questions in the interview guide, facilitated the exploration of issues based on each participant's responses (25,26). These interviews were either conducted in English language or the native language (Dagbani) at the hospital clinic based on the preferences of participants. All interviews were audio recorded and lasted 35-50 minutes. We wrote additional field notes to cover the observations made on each interviewee, and these were considered during the analysis for contextual issues. We conducted most interviews in the local Dagbani language. We manually transcribed recorded audio of interviews with participants verbatim into electronic text on a computer, taking cognisance of non-verbal cues captured in the field notes. We translated audio records in the local language (Dagbani) into English back-to-back to ensure we did not lose the meaning and were cross-checked between researchers for validation. Translated verbatim transcripts were also verified by a bilingual expert not part of the research team to ensure accuracy (27).

Data analysis

Inductive content analysis, as described by Elo and colleagues (28), was used to analyse the data of this study. Content analysis is a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit coding rules. Participants' transcripts were anonymised with letters and numbers such as 'P1'and 'P2'. All authors then read the transcripts repeatedly and compared samples with the interview audio files. We generated the codes inductively by highlighting critical ideas from the data. We then copied these codes and grouped them into subcategories based on their relationship. We further grouped subcategories with similar meanings to form categories. We reviewed and compared categories and subcategories with the code and the entire dataset to ensure that we captured the meaning of the entire dataset as presented by participants in the interviews.

Ethical considerations

Our study was of low risk to children and caregivers. However, we observed all relative ethical issues, including maintaining privacy and confidentiality, upholding the autonomy of caregivers, occasioning voluntary involvement and obtaining informed consent. We also involved a third party to assess our ethical conduct and provide ethical clearance. We, therefore, obtained ethical approval from the Committee on Human Research, Publication and Ethics (CHRPE) of Kwame Nkrumah University of Science and Technology (KNUST), Ghana, with reference number CHRPE/AP/231/21 and the Department of Research and Development of the Tamale Teaching Hospital with reference number TTH/R&D/SR/039, who also provided administrative permission for the study setting.

Findings

We interviewed thirteen (13) family caregivers to generate data for understanding their perspectives on the challenges they face caring for children with CP. All caregivers were women, 12 being biological parents to the child with CP. The majority were middle-aged women aged 30-68 years, with a mean age of thirty-nine. Most 10(77%) of the children were between 2-4 years old. Table 1 presents the detailed demographic information of participants.

Table 1: Demographic Characteristics of Participants

Demographics	**Frequency (n)**	**Percentage (%)**
Caregiver relationship		
Mother	12	92

Grandmother	1	8
Age of caregiver		
30-39	10	76
≥ 40-49	3	24
Mean age	39	
Educational level caregiver		
SHS and below	4	31
Tertiary	6	46
No formal education	3	23
Occupation of Caregiver		
Trading	5	38
Nurse	2	15
Teacher	1	8
Environmental health officer	1	8
Unemployed	4	31
Marital status of the caregiver		
Married	11	84
Single	1	8
Widow	1	8
Age of child with CP		
<2 years	2	15
2-4	10	77
5-7	1	8
Type of CP		
Spastic	5	38
Not stated	8	62

Three main categories, namely, sociocultural issues, sheer physical care burden and economic challenges, emerged from the data and are detailed in Figure 1.

Sociocultural challenges

The results depict society's cultural and intuitive beliefs about CP and its impact on caregivers. Social cultural challenges emerged as a significant category from the data, describing the relationships and difficulties caregivers encounter as they interact with society and formal institutions on issues related to their child with CP. Caregivers also reported how the sociocultural viewpoints make society hostile towards them and challenging living with a child with CP. Salient challenges narrated by caregivers included stigma, misconceptions about CP, inadequate health care services, and problem of accessibility to formal education.

Stigma from others:

Caregivers recounted how they felt humiliated by society because of their child's condition, CP. For instance, according to p11, the caregiver of a 2-year-old child with CP, she cannot attend social gatherings because of how her child is addressed as shown in their statement. Caregivers spoke of how their children were described in foul language, such as not being a human being but as snakes by neighbours and friends.

> *Whenever there is an 'occasion' (marriage, naming ceremonies and funerals), I do not go because of how they treat the child; I do not like it. People will just be calling her all sorts of names, saying she is not human, so I should not waste my time on her (p11, caregiver of a 2year old girl).*

Like the p11 account, p6 also demonstrates that society's attitudes towards their child's CP make her feel that she is a subject of ridicule. She suggests that even though people in her circles know about her child's condition, suggesting that the child may not be able to walk independently, they continue to ask questions about her child not walking to spite her, as she recounts in the quote below.

> *We are now laughing stock to most people, some people know what the child is going through, and they will see you and intentionally ask you, so your child is still not walking 'Penh'? Sometimes in a car like this, they do not even want you to sit closer to them, or the child should touch them… (P6 caregiver of a 2year boy).*

Other caregivers also felt discrimination against their children, as they were not allowed to associate with other children. Thus, the child and caregiver could not freely relate with others due to emotional trauma and stigmatisation from others. Such constraints encountered by caregivers observed in their sample narrations are as follows:

> *As for discrimination, it exists. Some relatives do not allow their children closer to my child because they feel he is not normal (p5 caregiver of a 7year boy).*

A caregiver added that the challenges in caring for a child with CP in the community are compounded by community members believing that CP results from punishment from the gods, and others say children with CP are spirits. According to them, such claims provoke emotional pain. It also appears such perceptions compel caregivers to seek a cure and on whether the children were spirits or are punished by the gods from spiritualists.

> *Others make insulting remarks like this your child is not a human being. We have even visited a shrine on several occasions because of that... They will give herbal preparation to bathing the child; if he is not human, he will die after bathing those*

> *herbs. But after bathing him, it is clear that he is not what they were thinking of (p3 caregiver of a 4year, 9months boy)*

Inadequate health information provision:

Adequate information on CP and optimal care strategies could reduce caregivers' challenges. However, the data show that caregivers did not feel healthcare professionals gave them enough information to understand, cope and care for their children. The lack of information made some caregivers believe in the community's claims about their child and confuse the exact nature of their child's condition. As shown by p5, even though health workers took the history of their child's condition, the health workers failed to give them information about the condition. Indeed, due to this limited information given, caregivers with English literacy who could surf the Internet resorted to finding information about their child's condition, as demonstrated by caregiver p6.

They asked me questions some time ago about the child's condition, which they wrote down, but I have not been given any information regarding his condition since then… they only said we should come to this place (referring to the physio unit) and do the exercise (p5, caregiver of a 7year boy).

Meanwhile, caregivers appeared to suggest that they had to demand information about their child's condition without success persistently. Even though P6 reports show that the Internet has helped them to understand their child's condition better, finding information from the Internet that is not censored could be misleading as there are sources that may not be credible. Thus, a lack of adequate information from health workers could compel caregivers to sources of information that may lead to practices harmful to the child.

> *At first, I did not know what was wrong with him because the doctors would not give me more information about this condition…Now I am beginning to understand because I browse and read about it. . .. (p6, caregiver of a 2year boy).*

Poor access to formal education:

Another challenge caregivers encountered was that they could not find a suitable school that would render quality education for their children. Some mothers felt their children would not be accepted into the mainstream due to their condition, and special schools were unavailable. Thus, all schools within reach of caregivers were not resourced to admit children with special needs like CP. Some community members who seem not to know the depth of the child schooling problem kept recommending that the child be taken to school. See the following expressions of p11.

They said I should take her to school, but in our place, they will not admit her. They said she could not sit, and she could not walk… When you send her to these regular schools, they will *not take her. Moreover, no school in our area trains such children (p11, caregiver of a 3year old girl).*

Sheer physical care burden:

Caregivers also recounted the challenges with providing activities of daily living such as bathing, dressing, and moving their child, among others, whilst maintaining their routine responsibilities to themselves and other family members, such as other children, mostly without support from others.

Strenuous daily care

Caregivers lamented about the exhausting nature of caring for a child with CP. Due to the physical and neurological incapacities of the child, they depend exclusively on their caregivers to meet all their needs. Most participants of this study experienced struggles in meeting the demands of children's daily care. Caregivers' reports indicate that lifting and moving their children were particularly challenging as it affected their wellbeing, as stated by p3 and p5.

> *I usually feel tired due to carrying him always. It is a problem lifting him. I sometimes get some body pain due to carrying him because he will not sit, so I do all the time I am carrying him. I pray he can walk someday. If not, he will be a burden while growing up because I cannot carry him (p3, caregiver of a 4year, 9months boy).*

> *I feel so tired of caring for him because he has a younger sibling I have to cater. At his age (7 years), he should have been able to bathe and move about, but I still have to do it (p5, caregiver of a 7year boy).*

Caregivers expressed experiencing pain and having to depend on pain medications to relieve themselves due to the strenuous nature of the care they provide for their child with CP. Caregivers also commented that the care became more challenging as their child grew older, as younger children were easier to manage. As seen in the statement of p8, the difficulty with the care is associated with having to lift and move the children, as they grow physically and increase in size and weight. Indeed, an increase in size and weight would make caring for a child more demanding. However, the child with CP who has neurodevelopment challenges, normally limp and with flappy body parts, and involuntary movements that they may not be able to control, as seen in p8 submission, suggests that their care becomes more complicated without any support or physical aides.

> *When you wear him his clothes, you will struggle with him. He won't relax his hands; he will just stiffen them and make himself hard. You will struggle, and he will continue to make his hands like that. . .. I Am fed up with 'koraa.' (p8, caregiver of 4year old boy)*

Inadequate support from social networks:

Besides the challenges involved in the care, caregivers also indicated that they received minimal or no support from family members and others in providing care for their child. Most caregivers expressed concerns that their children may be abandoned without the primary caregiver.

> *It is not easy to get someone to care for him, especially when I am not feeling well. I still have to manage and care for him because, the way he is, who will have time to take care of him? (p3, caregiver of a 4year, 9months boy).*

As shown in the demographics, most caregivers were females and mothers to the children. Although the caregiving role is traditionally a woman's role, and thus consistent with the findings of this study, considering the additional needs of the child with CP and also the emerging trend that women have more roles than caregiving, it would be expected the caregivers received care, at least from the spouses. However, the statement from p3 captures the experiences of most of the caregivers in terms of support from their spouses.

> *With this one, my husband is not helping me care for him. Do you think I will try to give birth again? He does not mind us any longer. At least once in a while, he should also pick him, and I will also rest, but he doesn't. (p3, caregiver of a 4year, 9months boy)*

Economic challenges

The cost of care globally is a challenging issue as it requires a constant flow of money. The special needs of children with a disability such as CP increase the financial burden in the amount required for the care and the loss of hours for the family to work and gain their normal income. The caregivers in this study demonstrated in the submission that their sources of income were interrupted, and they had financial limitations in meeting the child's care needs.

Financial limitations:

Having a child with CP means having an expenditure line inconsistent with routine household expenses, thus raising the cost of a family's budget. Most caregivers employed and unemployed, described their experience of having increased expenditures due to buying medications, assistive devices, transportation costs, laboratory investigations, and food buying. The latter placed an extra financial burden on caregivers who may not also receive financial support as there is no clear, steady formal support for the vulnerable in Ghana. As indicated earlier, the relationships of the caregiver and the child are not supportive enough to consider providing the caregiver with monetary support for caregiving. See the submission of p6 and p10.

> *...I am supposed to be coming for review once every week, but because of the cost of transportation, I have made it once every two weeks (p6 caregiver of a 2year boy).*

> *In this place (referring to the physio unit), I was told that health insurance would cover some part and you would also pay the rest after ... sometimes. 'Hmmm'.... It is not easy . . . I have even stopped the neurological consult because you have to pay for the consultation and still buy the drugs. After all, the hospital does not always have them (p10, caregiver of a 4year boy).*

Interrupted personal income:

Besides the increased expenditure, caregivers' economic situation was reportedly made worse when they could no longer engage in income-earning activities. Participants' reports show that the caregiving demands of their children led to them abandoning their employments as they could not combine the care of the child who is a full-time job with their income-generating activities, as shown in the quotes from participants, p10 and p3.

> *I am no longer employed and cannot do any work again. I worked in a private hospital before I gave birth, but now this child is like this. I have stopped my employment because he has this problem (cerebral palsy) (p10, caregiver of a 4year boy).*

> *I am no longer in business because I can't be holding him while preparing my local drinks, and there is no one to help. Where will I be getting money for his care? (p3, caregiver of a 4year, 9months boy).*

Many of the caregivers who were initially engaged in personal businesses for income had their businesses collapse because they did not have time to continue trading. Other caregivers stopped because of the stress of juggling childcare and business. Caregivers were then left to deal with the effects of these income cuts and rising expenditures.

Discussion

Care for children with special needs such as CP is challenging in even advanced jurisdictions with better societal literacy and technologically derived assistive devices for care (29–31). Our findings show that caregivers encounter sociocultural, physical, and economic challenges associated with caring for their child with CP. This study's findings resonate with existing evidence and signpost critical contextual and global issues that need consideration to develop support systems and relevant interventions. Our finding indicates that caregivers of children with CP face physical care burdens. Due to muscle spasticity, weakness and uncoordinated motor control, children with CP rely mainly on their caregivers for physical care, irrespective of age (32). Indeed, motor dysfunction may worsen due to weight as children with CP grow (33). Although there are assistive devices for aiding in the care of sick individuals with neuromuscular inadequacies and self-care deficit (34), the caregivers in this study had to lift and move their children manually, without such devices, resulting in caregivers' altered wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the wellbeing of caregivers is critical, considering that most children with CP depend solely on them for their care (35,36). It might therefore be useful to not only solicit the support of social networks to assist primary caregivers, but it might be more sustainable for health professionals to assist caregivers in learning manual handling and body mechanics to empower them to lift and move children with minimal impact on the health of caregivers (37,38).

Cerebral palsy is an old-age neurological condition with scientifically generated evidence on its course. Despite this, the relations of children with CP and caregivers misunderstand CP in many contexts, especially in settings with limited general literacy(39), leading to attribution of the condition to supernatural causes, such as punishment from the gods and witchcraft, as reported in this study and others (39,40). The setting of the study, as shown in the demographics, has the majority of the people being superstitious about health and other social issues, as played out in the reports of caregivers, that their children with CP were allegedly perceived as being spirit children and being punished by the gods. The perceptions were translated into the level of community engagement with the caregivers and the children. Existing evidence shows that beliefs of witchcraft and punishment by the gods lead to labelling, stigmatisation and discrimination against families and children with CP (40). Lack of support for caregivers resulting from stigma has been reported in the existing literature (9,14). This limited support could compound the innate challenges of having a child with special needs. Thus, society's understanding of CP is critical in reducing stigmatisation and discrimination against families with children with CP and the associated cyclical effect on the child and caregivers. It is therefore critical that health information on CP is intensified to ensure that communities understand the causes and course of CP, promoting empathy and involvement of support systems in providing care for the child to improve their quality of life.

In Ghana, the health service and other interested groups, such as faith-based institutions and churches, are critical in providing service users and communities with health information. However, the study's findings suggest that even primary caregivers of children with CP receive limited information about the condition. Limited information on health issues and services is a global challenge (41–43). However, challenging settings such as Ghana, with limited economic independence, are worst in this regard (13,44–48). Anecdotal evidence from the study setting suggests that health professionals provide ad hoc health education to caregivers of children with CP and other disabilities, using medical terms that caregivers and their support systems may not understand. Yet, there is evidence that adequate caregiver knowledge may promote better care for children with CP (46,49) and the provision of health information to health services users is expected to be acknowledged as a right (50–52). Indeed, the trend of breaching the gap in service users' understanding of health issues and thus contributing effectively to service provision is through deliberate efforts to ensure public participation (53). Therefore, to forestall the challenges communities encounter with their health management, conscious efforts must be made to utilise evidence such as that identified in this study and introduce appropriate interventions at every health service level.

Existing evidence suggests that children with CP without cognitive impairment could benefit from formal education (54), and caregivers reported that one of their challenges was finding school placement for their children with CP. Besides providing children with CP to explore their potential and contribute to their development, formal school systems health programmes have been a strategy health professionals use to deliver information on health issues to children and could be a means for delivering health information to children with CP. Nevertheless, accessibility to educational infrastructure was a challenge for caregivers. Although Ghana has an all-inclusive education policy (55), it thus appears most schools in this setting do not have the capacity in terms of human resources and space to admit children with CP. Parents have also reported lack of formal education opportunities in studies conducted in India and Kenya, where parents lamented their inability to find appropriate schools for their children with disability (45,56,57). Besides contributing to health care and the child's growth and development, formal education reduces children's time with their caregivers. This allows caregivers to engage in income-generating activities that could lessen the financial burden of having a child with cerebral palsy (45,58,59). Ghana's National Health Insurance Scheme, meant to lessen the burden of health care costs on service users, currently operates a cost-sharing system, and patients must make out-of-pocket payments to obtain some critical services (60). The latter indicates that the caregivers could more than communicate the health financial burden on caregivers in this study's setting. Even though the economic challenges for caregivers in this study are unavoidable, considering that the setting is generally a deprived area, the absence or limited financial support could limit caregivers' ability to access all necessities, such as rehabilitation services for the care of their child as reported in other studies (58).

Conclusively, contextual issues related to child physical care, cultural perceptions, health information needs, and education created problems for caregivers, and these must be translated into appropriate community and health system response. The findings suggest that caregivers have a candid idea of daily challenges, and they should be appropriately involved in designing innovative services or health care interventions.

Funding statement: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests' statement: No competing interests to declare.

Author contribution: MMM, YNA and MWK conceptualise the study, methodology, and literature review. MMM and JNS undertook the data collection, transcription, and analysis. YNA reviewed transcript compared with audios, JNS and MWK drafted the manuscript. MWK and MMM reviewed manuscript for intellectual content. All authors read and approved the final manuscript for publication.

Data Availability: All data relevant to the study are included in the article

Patient and Public Involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

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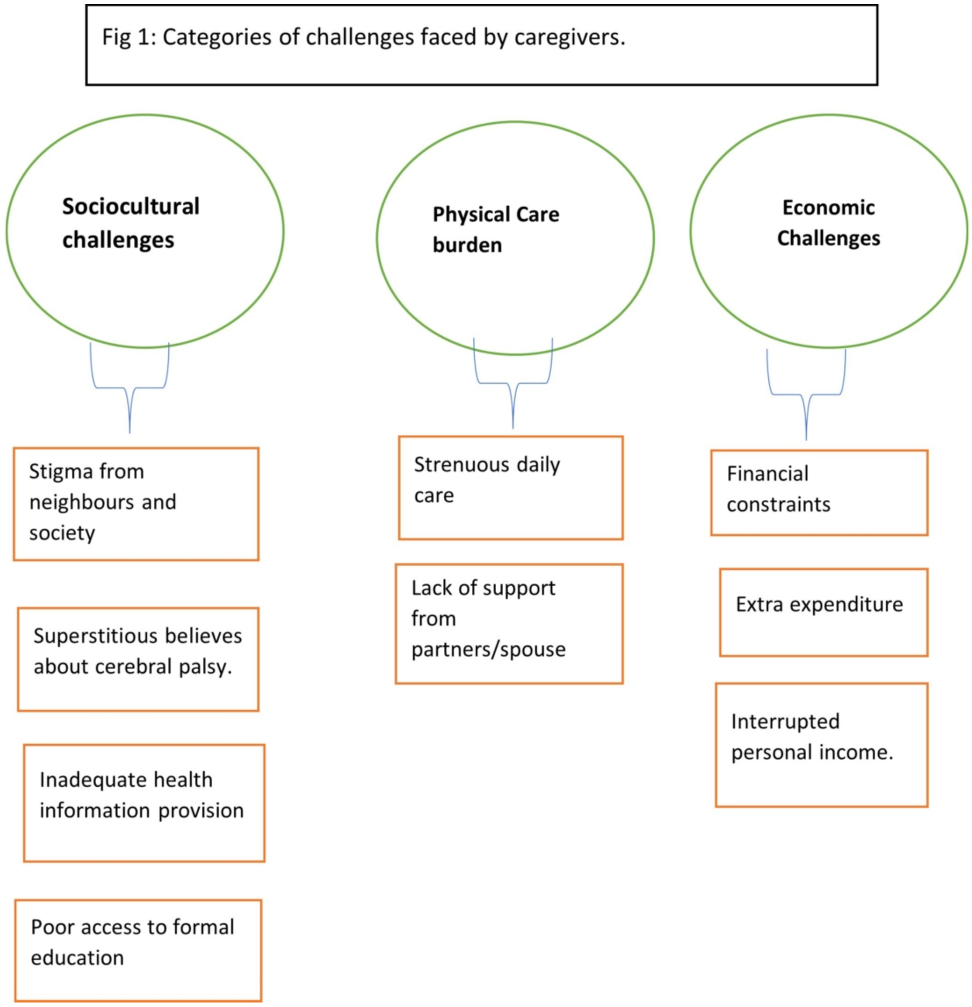

Categories of challenges

569x568mm (96 x 96 DPI)

Supplementary File 1: Interview guide

	A. Demographic data child and caregiver	
		Comment/ details
	- Relationship of caregiver to child - Age of caregiver - Educational level of caregiver - Occupation of Caregiver - Marital status of Caregiver - Age of child - Type of cerebral palsy	
	Interview guide	
	1. Tell me about your experience of caring for a child with cerebral palsy? Probes: Ask probing questions base on response of each participant. 2. Tell me about any challenges that you experience in your role as a caregiver. Probes: Ask probing question to explore details of challenges mentioned by caregivers.	

BMJ Paediatrics Open

Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana

Journal:	*BMJ Paediatrics Open*
Manuscript ID	bmjpo-2022-001807.R2
Article Type:	Original research
Date Submitted by the Author:	09-May-2023
Complete List of Authors:	Mwinbam, Mavis Mallory; Nadowli District Hospital, Upper West Region, Ghana, Department of Nursing Suglo, Joseph; Presbyterian University College, Department of Nursing and Midwifery Nyarko Agyeman, Yaa; University for Development Studies, Department of Population and Reproductive Health Kukeba, Margaret Wekem; C K Tedam University of Technology and Applied Sciences, Department of Nursing
Keywords:	Qualitative research, Rehabilitation

Title: Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana

Authors: Mavis Mallory Mwinbam[1], Joseph Ngmenesegre Suglo[2*], Yaa Nyarko Agyeman[3], Margaret Wekem Kukeba[4]

Institutional affiliations

[1]Department of Nursing, Nadowli District Hospital, Upper West Region, Ghana

[2]Department of Nursing and Midwifery, Presbyterian University, Ghana.

[3]Department of Population and Reproductive Health, School of Public Health, University for Development Studies

[4]Department of Nursing, CK Tedam University of Technology and Applied Sciences

*Correspondence: suglojoseph@gmail.com

Credentials and occupation of Researchers

[1]MPN - Paediatric Nurse Specialist; [2]PhD student - Lecturer; [3]PhD – Senior Lecturer; [4]PhD – Senior Lecturer

Abstract

Introduction

Caring for a child with cerebral palsy may be more emotionally and physically exhausting than caring for a typical growing child. The task could be more challenging in resource-limited settings with insufficient support services. Family caregivers' perspective of this phenomenon needs exploring to facilitate the development of innovative services. The study explored the challenges family caregivers face with children with cerebral palsy in a resource-limited context in northern Ghana.

Methods

We conducted a qualitative study underpinned by phenomenological principles where it is believed that the reality of a phenomenon is tied to caregivers' experiences. In this study, we unearthed caregivers' experiences/challenges from their own perspective. The method of data analysis used was to allow the issues emerge from the data (Inductive process) using the content analysis approach. This analysis approach appears acceptable from the qualitative studies literature. We recruited 13 caregivers of children with cerebral palsy from the physiotherapy unit at Tamale teaching hospital, Ghana and conducted individual in-depth interviews supported by an open-ended topic guide. Interviews were audio recorded, transcribed, and translated and were then coded inductively prior to conducting a content analysis of the data when grouped into themes.

Results

Barriers that emerged from the data, to managing a child with cerebral palsy included those at the level of socio-cultural barriers (values, attitudes and belief systems within society), economic challenges with looking after a child as well as the immediate physical care burdens. Societal barriers included discrimination and isolation, lack of family and societal support with poor access to health information and formal education.

Conclusion

Caregivers have the arduous task of caring for a child with cerebral palsy. Social support interventions and policy initiatives that seek to ameliorate caregivers' finances and make formal education accessible to this marginalised child population may be beneficial in this study context.

What is already known on this topic:

- Caring for a child with cerebral palsy may impact on caregivers physical and psychological health.
- Children with cerebral palsy may have functional limitations and depend on others for assistance with daily living activities.
- How caregivers cope or adapt to caregiving responsibility vary and may depend on contextual factors.

What this study adds:

- Parents of children with cerebral palsy in Ghana describe experiences of social isolation and stigma within their communities.
- Caregivers of children with cerebral palsy in Tamale Hospital in Ghana perceive that they have limited information on the cause and course of the condition.
- Caregivers describe high levels of spending on health care as well as the loss of businesses and jobs.
- There is a need to tackle how to prevent stigma and social isolation for caregivers of children with cerebral palsy.
- Provision of better information for caregivers on the health-related issues, cause, and prognosis for children with cerebral palsy may enable parents to feel more empowered to help their children in the future.

How this study might affect research, practice, or policy:

- Pragmatic steps and policy initiatives that offset the cost of accessing health care services for children with cerebral palsy could be beneficial in this context.
- The relevant authorities should operationalise the already existing "all-inclusive educational policy" to make formal education accessible to children with cerebral palsy.
- The findings of this study should serve as foundational research for empirical studies that seeks to develop interventions for caregivers of children with cerebral palsy.

Introduction

Cerebral palsy (CP) is a lifetime physical disability due to non-progressive injuries to the immature or developing brain (1–3). The risk factors associated with developing CP occur before, during or after pregnancy and include but not limited to intrauterine hypoxia, premature rupture of membranes, placenta abnormalities, preterm or post-term birth, asphyxia, prolonged labour, infections, hypoglycaemia, intracranial haemorrhage and respiratory distress syndrome (4,5). CP is estimated to occur in approximately 2.11 per 1000 live births globally (6), affecting males more than females (7), with more living in resource-limited settings (5,8,9).

In the Ghanaian context, official statistics on the number of children with CP are lacking. However, Cerebral Palsy Africa (CPA) estimated that one child per 300 births has CP in Ghana (10). The effects of CP on the growing child range from permanent disorders in movement and posture to activity limitation. The motor disorders of CP are frequently accompanied by impaired cognition, communication, sensation, perception, behavioural abnormalities, seizure disorders, musculoskeletal problems or a combination of these features (11,12). The condition adversely affects children's daily living experiences and limits their self-care functions such as feeding, dressing, bathing, and mobility (13,14). Because of the functional limitations experienced, some children with CP depend on caregivers for assistance with daily activities, leading to long-term caregiving that far exceeds the usual needs of typically developing children (11,15,16). For some caregivers, provision of care can be a burdensome, daunting task that can impact on their physical and psychological well-being (11,17). This is often worse in resource-limited settings where infrastructural amenities, social support and health care systems are not adequately developed to ameliorate the plight of caregivers (11,18). This study was designed to evaluate the challenges faced by family caregivers of children with CP in a resource-limited context in northern Ghana. This will serve as a basis for developing context-relevant services and policy initiatives to better the lives of caregivers and their children with CP.

Methods

Design

Phenomenological research methods have been employed in underpinning this study as it aims to describe the lived experience of individuals caring for children with CP. The qualitative research design literature shows that phenomenological principles acknowledge people's ties with their physical, social, and emotional world (19–24), suggesting that truth about the reality of a phenomenon is embodied in peoples lived experiences (20,24). Thus, whilst a descriptive qualitative approach could equally be used to unearth the data required in this study to explain the experiences of carers of children with cerebral palsy, the phenomenological approach fitted in better (19,22). Caregivers vary in how they adapt to caregiving demands and the process is unique with a special meaning for the individual involved (25). The study design adapted enabled us to account for the variability in caregivers' interpretations of their experience of care (26).

Participants and Setting

Thirteen family caregivers of children with CP participated in the study. We included individuals who resided with and provided care daily for a child under 18 years of age, diagnosed by a qualified medical doctor and confirmed in their medical records to have CP. The recruitment of participants took place at the physiotherapy unit of the Tamale Teaching Hospital, the only tertiary hospital in the northern region of Ghana. The hospital provides specialist care and physiotherapy services for children with diverse needs, including CP. Most of the inhabitants in this setting are Muslims, but they also practice and revere the traditional African religion. Thus, they believe in their ancestors and supernatural powers which could sometimes influence their perceptions about disease causation and management. Wholesale, retail and agricultural activities are the main occupation in the area (27). The first author, a female paediatric nurse specialist has an extensive knowledge of the study area through her residency program. Anecdotal observations she made at this setting motivated the conduct of the study. However, she had no prior relationship with study participant.

Sampling and recruitment

We undertook a purposive non-probability sampling technique where we concluded once we met data saturation (28,29). All participants were recruited during their routine physiotherapy clinic appointment days. We observed COVID-19 protocols (maintaining social distancing, wearing Personal Protective Equipment (PPE) such as a nose mask or face shield and using hand sanitisers) during participant recruitment and data collection. We confirmed participants' inclusion by checking diagnoses from children's hospital records with the help of a physiotherapist to ensure that children had been duly diagnosed by a medical professional. We introduced the study aims and informed potential participants that involvement in the study was voluntary. Participants interested in joining the study were then provided further information using the information sheet by the researcher. We guided participants who consented to participate in the research to sign/thumb print the consent form before commencing data collection.

Data collection

We gathered participants demographic information such as caregiver relationship with the child, educational level, child age, marital status, and caregiver occupation from all consenting participants. These characteristics were collected to add more context to the study findings as they could diversely influence caregivers' experience. However, experience were not used to select participants purposively. For pragmatic reasons and the challenges involved in bringing participants with different medical review dates together for focus group discussion, we conducted individual face-to-face interviews using an in-depth interview topic guide (supplementary file 1) developed by the researchers based on the study's objectives. Our topic guide provided open ended questions which were then probed based on the participant's response (30,31). These interviews were either conducted in English language or the native language (Dagbani) at the hospital clinic based on the preferences of participants. All interviews were audio recorded and lasted 35-50 minutes. We wrote additional field notes to cover the observations made on each interviewee, and these were considered during the analysis for contextual issues. We conducted most interviews in the local Dagbani language. We manually transcribed recorded audio of interviews with participants verbatim into electronic text on a computer, taking cognisance of non-verbal cues captured in the field notes. We translated audio records in the local language (Dagbani) into English back-to-back to ensure we did not lose the meaning and were cross-checked between researchers for validation. Translated verbatim transcripts were also verified by a bilingual expert not part of the research team to ensure accuracy (32).

Data analysis

Inductive content analysis, as described by Elo and colleagues (33), was used to analyse the data of this study. Content analysis is a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit coding rules. Participants' transcripts were anonymised with letters and numbers such as 'P1'and 'P2'. All authors then read the transcripts repeatedly and compared samples with the interview audio files. We generated the codes inductively by highlighting critical ideas from the data. We then copied these codes and grouped them into subcategories based on their relationship. We further grouped subcategories with similar meanings to form categories. We reviewed and compared categories and subcategories with the code and the entire dataset to ensure that we captured the meaning of the entire dataset as presented by participants in the interviews.

Ethical considerations

We observed all relative ethical issues, including maintaining privacy and confidentiality, upholding the autonomy of caregivers, occasioning voluntary involvement and obtaining informed consent. We also involved a third party to assess our ethical conduct and provide ethical clearance. We, therefore, obtained ethical approval from the Committee on Human Research, Publication and Ethics (CHRPE) of Kwame Nkrumah University of Science and Technology (KNUST), Ghana, with reference number CHRPE/AP/231/21 and the Department of Research and Development of the Tamale Teaching Hospital with reference number TTH/R&D/SR/039, who also provided administrative permission for the study setting.

Findings

All caregivers interviewed were women, 12 being biological parents to the child with CP. The majority were middle-aged women aged 30-68 years, with a mean age of 39. Most of the children (n = 10) were between 2-4 years old. Table 1 presents the detailed demographic information of participants.

Table 1: Demographic Characteristics of Participants

Demographics	Frequency (n)	Percentage (%)
Caregiver relationship		
Mother	12	92
Grandmother	1	8
Age of caregiver		
30-39	10	76
≥ 40-49	3	24
Mean age	39	
Educational level caregiver		
Senior High School and below	4	31
Tertiary	6	46
No formal education	3	23
Occupation of Caregiver		
Trading	5	38
Nurse	2	15
Teacher	1	8
Environmental health officer	1	8
Unemployed	4	31

Marital status of the caregiver		
Married	11	84
Single	1	8
Widow	1	8
Age of child with CP		
<2 years	2	15
2-4	10	77
5-7	1	8
Type of CP		
Spastic	5	38
Not stated	8	62

The interview data generated findings that embodied caregivers' sociocultural issues, accessibility to health information and formal education, physical care burden and economic factors. These themes mirrored three constructs of the multidimensional model of caregiving process and caregiver burden proposed by Raina and colleagues (25). Thus, the model's constructs of "background/context", "caregiver strain" and "coping/supportive factors" were represented in the interview data. Generally, the model comprises of constructs and factors that facilitate the understanding of caregiving and processes affecting caregivers' health (25). Guided by this framework our study findings are presented in Figure 1.

Figure 1: Multidimensional experiences and challenges of caregivers

Background/context factors

The first domain, background/context relates more to the social and economic characteristics of the setting where caregiving takes place. Our findings depicted contextual sociocultural issues and economic status of caregivers impacting their caregiving experience as described in subsequent sections.

Sociocultural Challenges:

The sociocultural issues pertain to society's cultural and intuitive beliefs about CP and its impact on caregivers. Caregivers reported how the sociocultural viewpoint make society hostile towards them, and challenging living with a child with CP. Salient challenges narrated by caregivers included stigma and misconceptions about CP. For example, one caregiver of a 2-

year-old child with CP explained how attending social gatherings was a challenge due to the negative language used to describe her child as not human but animal:

> *Whenever there is an 'occasion' (marriage, naming ceremonies and funerals), I do not go because of how they treat the child; I do not like it. People will just be calling her all sorts of names, saying she is not human, so I should not waste my time on her (p11, caregiver of a 2year old girl).*

Furthermore, one mother described her feeling like she was the subject of ridicule with the belief that some members of the community might even intentionally push her why her child is not walking:

> *We are now laughing stock to most people, some people know what the child is going through, and they will see you and intentionally ask you, so your child is still not walking 'Penh'? Sometimes in a car like this, they do not even want you to sit closer to them, or the child should touch them… (P6 caregiver of a 2year boy).*

Other caregivers felt discrimination against their children was obvious which scare them from associating with others. Thus, the child and caregiver could not freely relate with others due to emotional trauma and stigmatisation from others. Such constraints encountered by caregivers observed in their sample narrations are as follows:

> *As for discrimination, it exists. Some relatives do not allow their children closer to my child because they feel he is not normal (p5 caregiver of a 7year boy).*

A caregiver added that the challenges in caring for a child with CP in the community are compounded by community members believing that CP results from punishment from the gods, and others say children with CP are spirits. According to them, such claims provoke emotional pain. It also appears such perceptions compel caregivers to seek a cure and on whether the children were spirits.

> *Others make insulting remarks like this your child is not a human being. We have even visited a shrine on several occasions because of that... They will give herbal preparation to bathing the child; if he is not human, he will die after bathing those herbs. But after bathing him, it is clear that he is not what they were thinking of (p3 caregiver of a 4year, 9months boy)*

Economic status

The caregivers in this study demonstrated in their submission that their sources of income were interrupted, and they had financial limitations in meeting the child's care needs. Having a child with CP means having an expenditure line inconsistent with routine household expenses, thus raising the cost of a family's budget. Most caregivers employed and unemployed, described their experience of having increased expenditures due to buying medications, assistive devices, transportation costs, laboratory investigations, and food buying. The latter placed an extra financial burden on caregivers who may not also receive financial support as there is no clear, steady formal support for the vulnerable in Ghana. See the submission of some participants:

> *…I am supposed to be coming for review once every week, but because of the cost of transportation, I have made it once every two weeks (p6 caregiver of a 2year boy).*

> *In this place (referring to the physio unit), I was told that health insurance would cover some part and you would also pay the rest after … sometimes. 'Hmmm'…. It is not easy . . . I have even stopped the neurological consult because you have to pay for the consultation and still buy the drugs. After all, the hospital does not always have them (p10, caregiver of a 4year boy).*

Besides the increased expenditure, caregivers' economic situation was reportedly made worse when they could no longer engage in income-earning activities. Participants' reports show that the caregiving demands of their children led to abandoning their employments as they could not combine the care of the child who is a full-time job with their income-generating activities, as shown in the quotes from participants:

> *I am no longer employed and cannot do any work again. I worked in a private hospital before I gave birth, but now this child is like this. I have stopped my employment because he has this problem (cerebral palsy) (p10, caregiver of a 4year boy).*

> *I am no longer in business because I can't be holding him while preparing my local drinks, and there is no one to help. Where will I be getting money for his care? (p3, caregiver of a 4year, 9months boy).*

Many of the caregivers who were initially engaged in personal businesses for income had their businesses collapse because they did not have time to continue trading. Other caregivers stopped because of the stress of juggling childcare and business. Caregivers were then left to deal with the effects of these income cuts and rising expenditures.

Caregiver Strain Factors:

The second domain of factors, caregiver strain, denotes caregiving demands and perception on family centeredness of formal healthcare services. Some participants narratives generally reflected the sheer physical care burden and inadequate formal health information as detailed below.

Physical care burden

Caregivers recounted the challenges with providing activities of daily living such as bathing, dressing, and moving their child whilst maintaining their routine responsibilities to themselves and other family members. They lamented about the exhausting nature of caring for a child with CP. Due to the physical and neurological incapacities of the child, they depend exclusively on their caregivers to meet all their needs. Most participants of this study experienced struggles in meeting the demands of children's daily care. Caregivers' reports indicate that lifting and moving their children were particularly challenging as it affected their wellbeing, as stated in their narratives below:

> *I usually feel tired due to carrying him always. It is a problem lifting him. I sometimes get some body pain due to carrying him because he will not sit, so I do all the time I am carrying him. I pray he can walk someday. If not, he will be a burden while growing up because I cannot carry him (p3, caregiver of a 4year, 9months boy).*

> *I feel so tired of caring for him because he has a younger sibling I have to cater. At his age (7 years), he should have been able to bathe and move about, but I still have to do it (p5, caregiver of a 7year boy).*

Caregivers also expressed experiencing body pains and having to depend on pain medications to relieve themselves due to strenuous nature of the care they provide for their child with CP. Caregivers also commented that the care became more challenging as their child grew older. As seen in the verbatim quotations below, the complains of body pains is associated with having to lift and move the children, as they grow physically and increase in size and weight.

> *…she doesn't want anyone to carry her, only me…so every day I have to be taking pain medications, now she has reduced in weight… at first, she was heavy so when you carry her hmmm my waist. Sometimes when I am in the room I cry because of the pains (P11 caregiver of a 2years old girl).*

Inadequate health information:

The data show that caregivers felt that healthcare professionals did not give them enough information to enable them to understand, cope and care for their children. The lack of health information made some caregivers believe in the community's claims of such children being spirits or animals. For instance, some participants suggested that even though health workers took the history of their child's condition, the health workers failed to give them information about the condition. Caregivers with English literacy who could surf the internet resorted to finding information about their child's condition, as demonstrated below.

They asked me questions some time ago about the child's condition, which they wrote down, but I have not been given any information regarding his condition since then… they only said we should come to this place (referring to the physio unit) and do the exercise (p5, caregiver of a 7year boy).

Even though participants report show that the internet has helped them to understand their child's condition better, finding information from the internet that is not censored could be misleading as there are sources that may not be credible. Thus, a lack of adequate information from health workers could compel caregivers to sources of information that are not helpful.

> *At first, I did not know what was wrong with him because the doctors would not give me more information about this condition…Now I am beginning to understand because I browse the internet and read about it. . .. (p6, caregiver of a 2year boy).*

Coping/Supportive Factors

The factors included in this third and final construct consist of social support, family function and accessibility to formal education. The social support comprises of the informal support from immediate family members, friends, neighbours, and the community, while function describes the extent to which the family function as a unit in supporting caregivers. The findings related to these are described further below.

Inadequate support from social networks

Some caregivers indicated that they received minimal or no support from family members and others in providing care for their child. Most caregivers expressed concerns that their children may be abandoned in the event of their absence as represented in the following statement:

> *It is not easy to get someone to care for him, especially when I am not feeling well. I still have to manage and care for him because, the way he is, who will have time to take care of him? (p3, caregiver of a 4year, 9months boy).*

As shown in the demographics, most caregivers were females and mothers to the children. Although caregiving role is traditionally a woman's role, and thus consistent with the findings of this study, considering the additional care needs of the child with CP, it would be expected the caregivers received support, at least from their spouses. However, the statement below captures the experiences of most of the caregivers in terms of support from their spouses.

> *With this one, my husband is not helping me care for him. Do you think I will try to give birth again? He does not mind us any longer. At least once in a while, he should also pick him, and I will also rest, but he doesn't. (p3, caregiver of a 4year, 9months boy)*

Inadequate access to formal education

Another challenge caregivers encountered was that they could not find a suitable school that would render quality education for their children. Some mothers felt their children would not be accepted into the mainstream schools due to their condition, and special schools were unavailable. Thus, all schools within reach of caregivers were not resourced to admit children with special needs like CP. Some community members who seem not to know the depth of the child schooling problem kept recommending that the child be taken to school. See the following expressions of participants.

They said I should take her to school, but in our place, they will not admit her. They said she could not sit, and she could not walk… When you send her to these regular schools, they will not take her. Moreover, no school in our area trains such children (p11, caregiver of a 3year old girl).

Discussion

Our findings show that caregivers in this context encounter sociocultural, physical, and economic challenges in caring for their children with CP. The study's findings resonate with existing evidence and signpost critical contextual and global issues that need consideration to develop support systems and relevant interventions. To support policy makers, practitioners, and researchers in the design of interventions, key findings of this study are discussed in three domains: (i) individual level issues (ii) community level and (iii) formal health care system (See figure 2). The study findings in these areas according to existing literature impact on caregivers' physical health, psychological health and general wellbeing (25,34–36).

Figure 2: Contextual Framing of Caregivers experiences and challenges

Individual level Issues

Our finding indicates that caregivers of children with CP faced physical care burdens and economic pressures. Due to muscle spasticity, weakness and uncoordinated motor control, children with CP rely mainly on their caregivers for physical care, irrespective of age (37). Although there are assistive devices for aiding in the care of sick individuals with neuromuscular inadequacies and self-care deficit (38), the caregivers in this study had to lift and move their children manually, without such devices, resulting in caregivers' altered wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the wellbeing of caregivers is critical, considering that most children with CP depend solely on them for their care (39,40). Therefore, though it might be useful to solicit the support of social networks to assist primary caregivers, it might even be more beneficial for health professionals to assist caregivers in learning manual handling and body mechanics to empower them to safely lift and move children (41,42).

Also at the individual level was the income cuts and increased expenditures of caregivers and their families. The loss of jobs, businesses and increased health care expenditures consequence of caring for a child with CP necessitate the need for employers and policy makers to create a more flexible work culture that allows caregivers to engage in income-generating activities to lessen their financial burden (43–45). Even though the economic challenges for caregivers in this study are unavoidable, considering that the setting is generally a deprived area, the absence or limited financial support could limit caregivers' ability to access health care such as rehabilitation services for the care of their child as reported in other studies (43). Specific to this study's setting and similar populations, it might be beneficial if the current cost-sharing system of the National Health Insurance Scheme (46) is re-evaluated to meet the health financing needs of this marginalise populations with CP.

Community level

Cerebral palsy is an old-age neurological condition with scientifically generated evidence on its course (4,5). Despite this, the relations of children with CP and caregivers misunderstand CP in many contexts, especially in settings with limited general literacy (47), leading to attribution of the condition to supernatural causes, such as punishment from the gods and witchcraft, as reported in this study and others (47,48). Children with CP in this context were perceived as being spirit children and punished by the gods. These perceptions were translated into the level of community engagement with the caregivers and the children. Existing evidence shows that beliefs on witchcraft and punishment by the gods lead to labelling, stigmatisation and discrimination against families and children with CP (48). Lack of support for caregivers resulting from stigma has been reported in the existing literature (12,17). This limited support could compound the innate challenges of having a child with special needs. Thus, society's understanding of CP is critical in reducing stigmatisation and discrimination against families with children with CP and the associated cyclical effect on the child and caregiver. It is therefore critical that health information on CP is intensified to ensure that communities understand the causes and course of CP, promoting empathy and involvement of support systems in providing care for the child to improve their quality of life.

Furthermore, existing evidence suggest that children with CP without cognitive impairment could benefit from formal education (49). Nevertheless, caregivers reported that one of their challenges was finding school placement for their children with CP. Although Ghana has an all-inclusive education policy (50), it thus appear most schools in this setting do not have the capacity in terms of human resources and space to admit children with CP. This situation resonates with other study findings in India and Kenya reporting lack of formal education opportunities (45,51,52). This suggests the need to operationalise educational policies that makes formal education more accessible to all including children with CP.

Health System

The study's findings suggest that primary caregivers received limited or no health information about their child's condition. Limited information on health issues and services is a global challenge (53–55). However, challenging settings such as Ghana, with limited economic independence, are worst in this regard (16,45,56–59). Anecdotal evidence from the study setting suggests that health professionals provide ad hoc health education to caregivers of children with CP and other disabilities, using medical terms that caregivers and their support systems may not understand. Yet, there is evidence that adequate caregiver knowledge may promote better care for children with CP (57,60). Indeed, the trend of breaching the gap in service users' understanding of health issues and contributing effectively to service provision is through deliberate efforts to ensure public participation (61). Therefore, to forestall the challenges communities encounter with their health management, conscious efforts must be made to utilise evidence such as that identified in this study and introduce appropriate interventions at every health service level.

Conclusively, though the study findings might not be generalisable, it raises issues related to child physical care, cultural perceptions, health information, and educational needs that must be translated into appropriate community, health system and individual level response.

Funding statement: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests' statement: No competing interests to declare.

Author contribution: MMM, YNA and MWK conceptualise the study, methodology, and literature review. MMM and JNS undertook the data collection, transcription, and analysis. YNA reviewed transcript compared with audios, JNS and MWK drafted the manuscript. MWK and MMM reviewed manuscript for intellectual content. All authors read and approved the final manuscript for publication.

Data Availability: All data relevant to the study are included in the article and its supplementary.

Patient and Public Involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

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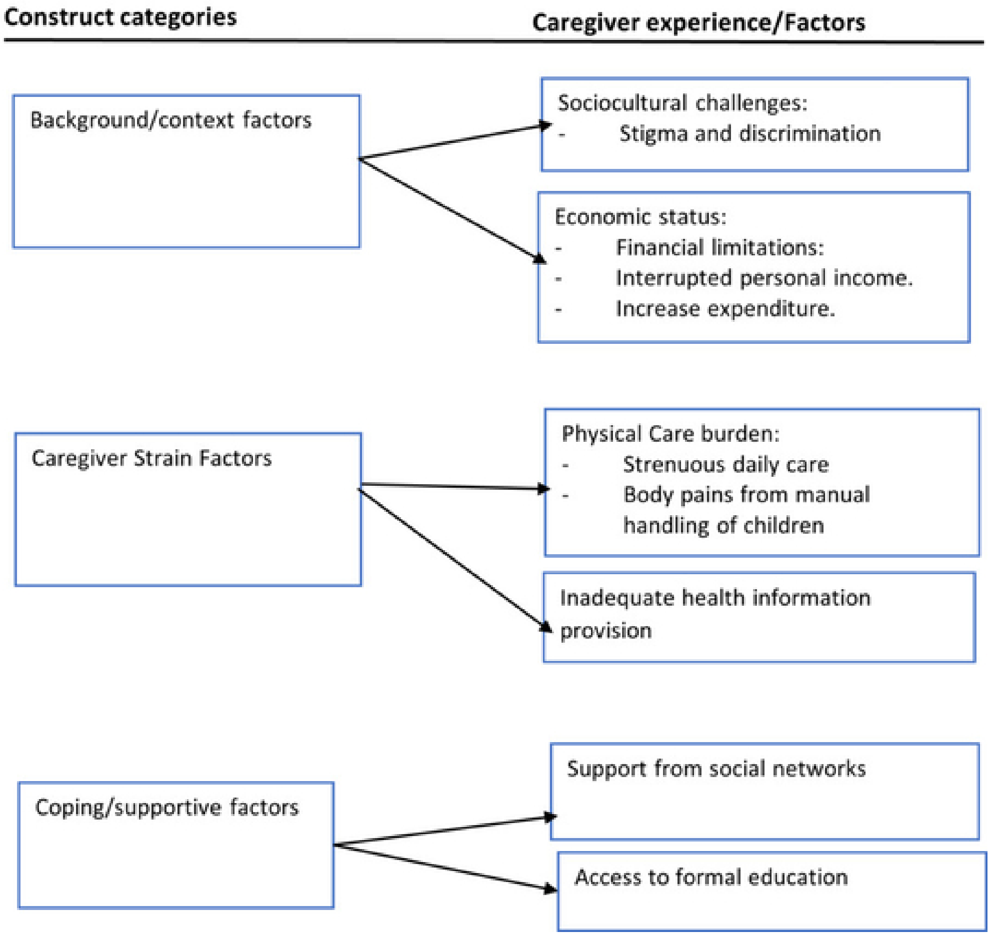
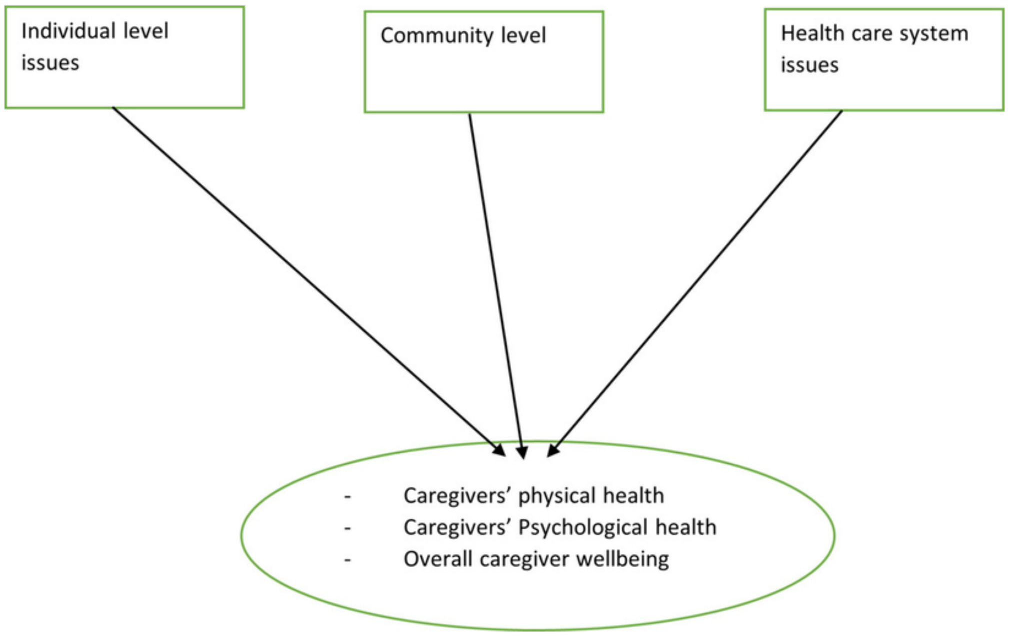


Multidimensional experiences and challenges of caregivers

45x43mm (300 x 300 DPI)



Contextual Framing of Caregivers experiences and challenges

69x43mm (300 x 300 DPI)

Supplementary File 1: Interview guide

	A. Demographic data child and caregiver	
		Comment/ details
	- Relationship of caregiver to child - Age of caregiver - Educational level of caregiver - Occupation of Caregiver - Marital status of Caregiver - Age of child - Type of cerebral palsy	
	Interview guide	
	1. Tell me about your experience of caring for a child with cerebral palsy? Probes: Ask probing questions base on response of each participant. 2. Tell me about any challenges that you experience in your role as a caregiver. Probes: Ask probing question to explore details of challenges mentioned by caregivers.	

BMJ Paediatrics Open

Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana

Journal:	*BMJ Paediatrics Open*
Manuscript ID	bmjpo-2022-001807.R3
Article Type:	Original research
Date Submitted by the Author:	10-Jun-2023
Complete List of Authors:	Mwinbam, Mavis Mallory; Nadowli District Hospital, Upper West Region, Ghana, Department of Nursing Suglo, Joseph; Presbyterian University College, Department of Nursing and Midwifery Nyarko Agyeman, Yaa; University for Development Studies, Department of Population and Reproductive Health Kukeba, Margaret Wekem; C K Tedam University of Technology and Applied Sciences, Department of Nursing
Keywords:	Qualitative research, Rehabilitation

Title: Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana

Authors: Mavis Mallory Mwinbam[1], Joseph Ngmenesegre Suglo[2*], Yaa Nyarko Agyeman[3], Margaret Wekem Kukeba[4]

Institutional affiliations

[1]Department of Nursing, Nadowli District Hospital, Upper West Region, Ghana

[2]Department of Nursing and Midwifery, Presbyterian University, Ghana.

[3]Department of Population and Reproductive Health, School of Public Health, University for Development Studies

[4]Department of Nursing, CK Tedam University of Technology and Applied Sciences

[*]Correspondence: suglojoseph@gmail.com

Credentials and occupation of Researchers

[1]MPN - Paediatric Nurse Specialist; [2]PhD student - Lecturer; [3]PhD – Senior Lecturer; [4]PhD – Senior Lecturer

Abstract

Introduction

Caring for a child with cerebral palsy may be more emotionally and physically exhausting than caring for a typical growing child. The family caregivers' perspective of this phenomenon needs exploring to facilitate the development of services. Our study explored the challenges family caregivers face with children with cerebral palsy in a resource-limited context in northern Ghana.

Methods

We conducted a qualitative study underpinned by phenomenological principles where it is believed that the reality of a phenomenon is tied to caregivers' perspectives of their own experiences. In this study, we unearthed caregivers' experiences/challenges from their own perspectives. The method of data analysis used was to allow the issues to emerge from the data (Inductive process) using the content analysis approach. We recruited 13 caregivers of children with cerebral palsy from the physiotherapy unit at Tamale teaching hospital, and conducted individual in-depth interviews supported by an open-ended topic guide. Interviews were audio recorded, transcribed, and translated and coded inductively before conducting a content analysis of the data when grouped into themes.

Results

We have identified barriers to managing a child with cerebral palsy, including; socio-cultural barriers (values, attitudes and belief systems within society), economic challenges and immediate physical care burdens. Specific barriers included; discrimination and isolation, lack of family and societal support, with poor access to health information and formal education. Others were lack of information on the cause and course of CP, caregivers' loss of jobs, increased healthcare expenditure and struggles in lifting and moving children, which resonates with evidence-based multidimensional model of caregiving process and caregiver burden.

Conclusion

Caregivers have the arduous task of caring for a child with cerebral palsy. Social support interventions and policy initiatives that seek to ameliorate caregivers' finances and make formal education accessible to this marginalised child population may be beneficial in this context.

What is already known on this topic:

- Caring for a child with cerebral palsy may impact caregivers' physical and psychological health.
- Children with cerebral palsy may have functional limitations and depend on others for assistance with daily living activities.
- How caregivers cope or adapt to caregiving responsibility varies and may depend on contextual factors.

What this study adds:

- Parents of children with cerebral palsy in Ghana describe experiences of social isolation and stigma within their communities.
- Caregivers of children with cerebral palsy in Tamale Hospital in Ghana perceive that they have limited information on the cause and course of the condition.
- Caregivers describe high levels of spending on health care as well as the loss of businesses and jobs.
- There is a need to tackle how to prevent stigma and social isolation for caregivers of children with cerebral palsy.
- Provision of better information for caregivers on the health-related issues, cause, and prognosis for children with cerebral palsy may enable parents to feel more empowered to help their children in the future.

How this study might affect research, practice, or policy:

- Pragmatic steps and policy initiatives that offset the cost of accessing health care services for children with cerebral palsy could be beneficial in this context.
- The relevant authorities should operationalise the already existing "all-inclusive educational policy" to make formal education accessible to children with cerebral palsy.
- The findings of this study should serve as foundational research for empirical studies that seeks to develop interventions for caregivers of children with cerebral palsy.

Introduction

Cerebral palsy (CP) is a lifetime physical disability due to non-progressive injuries to the immature or developing brain (1–3) The risk factors associated with developing CP occur before, during or after pregnancy and include but not limited to intrauterine hypoxia, premature rupture of membranes, placenta abnormalities, preterm or post-term birth, asphyxia, prolonged labour, infections, hypoglycaemia, intracranial haemorrhage and respiratory distress syndrome (4,5). CP is estimated to occur in approximately 2.11 per 1000 live births globally (6), affecting males more than females (7), with more living in resource-limited settings (5,8,9).

In the Ghanaian context, official statistics on the number of children with CP are lacking. However, Cerebral Palsy Africa (CPA) estimated that one child per 300 births has CP in Ghana (10). CP causes permanent brain damage, limiting the child's ability to have full postural control, mobility and complete activities of daily living. The motor disorders of CP are frequently accompanied by impaired cognition, communication, sensation, perception, behavioural abnormalities, seizure disorders, musculoskeletal problems or a combination of these features (11,12). The condition adversely affects children's daily living experiences and limits their self-care functions such as feeding, dressing, bathing, and mobility (13,14). Because of the functional limitations experienced, some children with CP depend on caregivers for assistance with daily activities, leading to long-term caregiving that far exceeds the usual needs of typically developing children (12,15,16). For some caregivers, providing care can be a burdensome, daunting task impacting their physical and psychological well-being (12,17). This is often worse in resource-limited settings where infrastructural amenities, social support and health care systems are not adequately developed to ameliorate the plight of caregivers (12,18). This study was designed to evaluate the challenges family caregivers face of children with CP in a resource-limited context in northern Ghana. This will serve as a basis for developing context-relevant services and policy initiatives to better the lives of caregivers and their children with CP.

Methods

Design

Phenomenological research methods have been employed in underpinning this study as it aims to describe the lived experience of individuals caring for children with CP. The qualitative research design literature shows that phenomenological principles acknowledge people's ties with their physical, social, and emotional world (19–24), suggesting that truth about the reality of a phenomenon is embodied in people's lived experiences (20,24). Thus, whilst a descriptive qualitative approach could equally be used to unearth the data required in this study to explain the experiences of carers of children with cerebral palsy, the phenomenological approach fitted in better (19,22). Caregivers vary in how they adapt to caregiving demands, and the process is unique with a special meaning for the individual involved (25). The study design adapted enabled us to account for the variability in caregivers' interpretations of their experience of care (26).

Participants and Setting

Thirteen family caregivers of children with CP participated in the study. We included individuals who resided with and provided care daily for a child under 18 years of age, diagnosed by a qualified medical doctor and confirmed in their medical records to have CP. The recruitment of participants took place at the physiotherapy unit of the Tamale Teaching Hospital, the only tertiary hospital in the northern region of Ghana. The hospital provides specialist care and physiotherapy services for children with diverse needs, including CP. Most of the inhabitants in this setting are Muslims, but they also practice and revere the traditional African religion. Thus, they believe in their ancestors and supernatural powers which could sometimes influence their perceptions about disease causation and management. Wholesale, retail and agricultural activities are the main occupation in the area (27). The first author, a female paediatric nurse specialist has an extensive knowledge of the study area through her residency program. Anecdotal observations she made at this setting motivated the conduct of the study. However, she had no prior relationship with study participant.

Sampling and recruitment

We utilised a purposive (non-probability) sampling technique to identify and recruit participants. Once we met data saturation, we did not recruit further participants (28,29). All participants were recruited during their routine physiotherapy clinic appointment days. We observed COVID-19 protocols (maintaining social distancing, wearing Personal Protective Equipment (PPE) such as a nose mask or face shield and using hand sanitisers) during participant recruitment and data collection. We confirmed participants' inclusion by checking diagnoses from children's hospital records with the help of a physiotherapist to ensure that a medical professional had duly diagnosed children. We introduced the study aims and informed potential participants that involvement in the study was voluntary. Participants interested in joining the study were then provided further information using the information sheet by the researcher. Participants who consented then signed or printed their thumbprint on the consent form prior to data collection.

Data collection

We gathered participants' demographic information such as caregiver relationship with the child, educational level, child age, marital status, and caregiver occupation from all consenting participants. These characteristics were collected to add more context to the study findings as they could diversely influence caregivers' experience. For pragmatic reasons and the challenges involved in bringing participants with different medical review dates together for focus group discussion, we conducted individual face-to-face interviews using an in-depth interview topic guide (supplementary file 1) developed by the researchers based on the study's objectives. Our topic guide provided open-ended questions which were then probed based on the participant's responses (30,31). These interviews were either conducted in English language or the native language (Dagbani) at the hospital clinic based on the preferences of participants. All interviews were audio recorded and lasted 35-50 minutes. We wrote additional field notes to cover the observations made on each interviewee, and these were considered during the analysis for contextual issues. We conducted most interviews in the local Dagbani language. We manually transcribed recorded audio of interviews with participants verbatim into electronic text on a computer, taking cognisance of non-verbal cues captured in the field notes. We translated audio records in the local language (Dagbani) into English back-to-back to ensure we did not lose the meaning and were cross-checked between researchers for validation. Translated verbatim transcripts were also verified by a bilingual expert not part of the research team to ensure accuracy (32).

Data analysis

Inductive content analysis, as described by Elo and colleagues (33), was used to analyse the data of this study. Content analysis is a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit coding rules. Participants' transcripts were anonymised with letters and numbers such as 'P1'and 'P2'. All authors then read the transcripts repeatedly and compared samples with the interview audio files. We generated the codes inductively by highlighting critical ideas from the data. We then copied these codes and grouped them into subcategories based on their relationship. We further grouped subcategories with similar meanings to form categories. We reviewed and compared categories and subcategories with the code and the entire dataset to ensure that we captured the meaning of the entire dataset as presented by participants in the interviews.

Ethical considerations

We observed all relative ethical issues, including maintaining privacy and confidentiality, upholding the autonomy of caregivers, occasioning voluntary involvement and obtaining informed consent. We also involved a third party to assess our ethical conduct and provide ethical clearance. We, therefore, obtained ethical approval from the Committee on Human Research, Publication and Ethics (CHRPE) of Kwame Nkrumah University of Science and Technology (KNUST), Ghana, with reference number CHRPE/AP/231/21 and the Department of Research and Development of the Tamale Teaching Hospital with reference number TTH/R&D/SR/039, who also provided administrative permission for the study setting.

Findings

All caregivers interviewed were women, 12 being biological parents to the child with CP. The majority were middle-aged women aged 30-68 years, with a mean age of 39. Most of the children (n = 10) were between 2-4 years old. Table 1 presents the detailed demographic information of participants.

Table 1: Demographic Characteristics of Participants

Demographics	**Frequency - n (%)**
Caregiver relationship	N = 13
Mother	12 (92)
Grandmother	1 (8)
Age of caregiver	N = 13
30-39	10 (76)
≥ 40-49	3 (24)
Mean age	39
Educational level caregiver	N = 13
Senior High School and below	4 (31)
Tertiary	6 (46)
No formal education	3 (23)
Occupation of Caregiver	N = 13
Trading	5 (38)
Nurse	2 (15)
Teacher	1 (8)

Environmental health officer	1 (8)
Unemployed	4 (31)
Marital status of the caregiver	N = 13
Married	11 (84)
Single	1 (8)
Widow	1 (8)
Age of child with CP	N = 13
<2 years	2 (15)
2-4	10 (77)
5-7	1 (8)
Type of CP	N = 13
Spastic	5 (38
Not stated	8 (62)

The interview data generated findings that embodied caregivers' sociocultural issues, accessibility to health information and formal education, physical care burden and economic factors. These themes mirrored three constructs of the multidimensional model of caregiving process and caregiver burden proposed by Raina and colleagues (25). Thus, the model's constructs of "background/context", "caregiver strain" and "coping/supportive factors" were represented in the interview data. Generally, the model comprises of constructs and factors that facilitate the understanding of caregiving and processes affecting caregivers' health (25). Guided by this framework our study findings are presented in Figure 1.

Figure 1: Multidimensional experiences and challenges of caregivers

Background/context factors

The first domain, background/context relates more to the social and economic characteristics of the setting where caregiving takes place. Our findings depicted contextual sociocultural issues and economic status of caregivers impacting their caregiving experience as described in subsequent sections.

Sociocultural Challenges:

The sociocultural issues pertain to society's cultural and intuitive beliefs about CP and its impact on caregivers. Caregivers reported how they perceived that individuals within society were often hostile to them, challenging their ability to live with their children with CP. In particular, caregivers mentioned how other members within their community often stigmatised them and had misconceptions about CP, including how it might have been caused. For example, one caregiver of a 2-year-old child with CP explained how attending social gatherings was a challenge due to the negative language used to describe her child as not human but animal:

> *Whenever there is an 'occasion' (marriage, naming ceremonies and funerals), I do not go because of how they treat the child; I do not like it. People will just be calling her all sorts of names, saying she is not human, so I should not waste my time on her (p11, caregiver of a 2year old girl).*

One mother enunciated how she felt the subject of ridicule - describing how she believed that some members of the community intentionally questioned her on things they knew her child could not do." Furthermore, this same mother recounted how she and her child were even seen as having something that might be "caught" or infectious with others purposely not sitting near her on public transport:

> *We are now laughing stock to most people, some people know what the child is going through, and they will see you and intentionally ask you, so your child is still not walking 'Penh'? Sometimes in a car like this, they do not even want you to sit closer to them, or the child should touch them… (P6 caregiver of a 2year boy).*

Similarly, some caregivers mentioned how they felt discriminated against even by their relatives who would not allow their own children to interact with a child with a disability in case it might be infectious. Thus, the child and caregiver could not freely relate with others due to emotional trauma and stigmatisation from others. Such constraints encountered by caregivers observed in their sample narrations are as follows:

> *As for discrimination, it exists. Some relatives do not allow their children closer to my child because they feel he is not normal (p5 caregiver of a 7year boy).*

It was shocking to hear that one caregiver even described how much community members stigmatised children with CP – believing that CP results as a punishment from "the Gods" and furthermore, that children with CP are "spirits and not human. This emerged in caregiver's verbatim as emotionally very painful, leading some caregivers to seek cures through traditional healers to better understand whether their children were "spirits" or "possessed".

> *Others make insulting remarks like this your child is not a human being. We have even visited a shrine on several occasions because of that... They will give herbal preparation to bathing the child; if he is not human, he will die after bathing those*

> *herbs. But after bathing him, it is clear that he is not what they were thinking of (p3 caregiver of a 4year, 9months boy)*

Economic status

The caregivers in this study described through their interviews that their sources of income were interrupted, and they had financial limitations in meeting the child's care needs. Having a child with CP means having an expenditure line inconsistent with routine household expenses, thus raising the cost of a family's budget. Most caregivers employed and unemployed, described their experience of having increased expenditures due to buying medications, assistive devices, transportation costs, laboratory investigations, and food buying. The latter placed an extra financial burden on caregivers who may not also receive financial support as there is no clear, steady formal support for the vulnerable in Ghana. An example of experiences that were enunciated by caregivers include:

> *...I am supposed to be coming for review once every week, but because of the cost of transportation, I have made it once every two weeks (p6 caregiver of a 2year boy).*

> *In this place (referring to the physio unit), I was told that health insurance would cover some part and you would also pay the rest after ... sometimes. 'Hmmm'.... It is not easy . . . I have even stopped the neurological consult because you have to pay for the consultation and still buy the drugs. After all, the hospital does not always have them (p10, caregiver of a 4year boy).*

Besides the increased expenditure, caregivers' economic situation was reportedly worsened when they could no longer engage in income-earning activities. Participants' reports show that the caregiving demands of their children led to abandoning their employment as they could not combine the care of the child who is a full-time job with their income-generating activities, as shown in the quotes from participants:

> *I am no longer employed and cannot do any work again. I worked in a private hospital before I gave birth, but now this child is like this. I have stopped my employment because he has this problem (cerebral palsy) (p10, caregiver of a 4year boy).*

> *I am no longer in business because I can't be holding him while preparing my local drinks, and there is no one to help. Where will I be getting money for his care? (p3, caregiver of a 4year, 9months boy).*

Many of the caregivers who were initially engaged in personal businesses for income had their businesses collapse because they did not have time to continue trading. Other caregivers stopped because of the stress of juggling childcare and business. Caregivers were then left to deal with the effects of these income cuts and rising expenditures.

Caregiver Strain Factors:

The second domain of factors, caregiver strain, denotes caregiving demands and perception of family centeredness of formal healthcare services. Some participants narratives generally reflected the sheer physical care burden and inadequate formal health information, as detailed below.

Physical care burden

Caregivers recounted the challenges with providing activities of daily living such as bathing, dressing, and moving their child whilst maintaining their routine responsibilities to themselves and other family members. They lamented about the exhausting nature of caring for a child with CP. Due to the physical and neurological incapacities of the child, they depend exclusively on their caregivers to meet all their needs. Most participants of this study experienced struggles in meeting the demands of children's daily care. Caregivers' reports indicate that lifting and moving their children were particularly challenging as it affected their wellbeing, as stated in their narratives below:

> *I usually feel tired due to carrying him always. It is a problem lifting him. I sometimes get some body pain due to carrying him because he will not sit, so I do all the time I am carrying him. I pray he can walk someday. If not, he will be a burden while growing up because I cannot carry him (p3, caregiver of a 4year, 9months boy).*

> *I feel so tired of caring for him because he has a younger sibling I have to cater. At his age (7 years), he should have been able to bathe and move about, but I still have to do it (p5, caregiver of a 7year boy).*

Caregivers expressed how they often experienced body pains - depending on medications to relieve the pain from the strenuous nature of the care they provide for their child with CP. Caregivers also commented that care became more challenging as their children grew older and particularly mentioned how body pains were related to having to lift and move the children manually.

…she doesn't want anyone to carry her, only me…so every day I have to be taking pain medications, now she has reduced in weight… at first, she was heavy so when you carry her hmmm my waist. Sometimes when I am in the room I cry because of the pains (P11 caregiver of a 2years old girl).

Inadequate health information:

The data show that caregivers felt that healthcare professionals did not give them enough information to enable them to understand, cope and care for their children. The lack of health information made some caregivers believe in the community's claims of such children being spirits or animals. For instance, some participants suggested that even though health workers took the history of their child's condition, they failed to give them information about the condition. Caregivers with English literacy who could surf the internet resorted to finding information about their child's condition, as demonstrated below.

They asked me questions some time ago about the child's condition, which they wrote down, but I have not been given any information regarding his condition since then… they only said we should come to this place (referring to the physio unit) and do the exercise (p5, caregiver of a 7year boy).

Even though participants reported that the internet helped them to understand their child's condition, finding information from the internet that is not censored could be misleading as there are sources that may not be credible. Thus, a lack of adequate information from health workers could compel caregivers to sources of information that are not helpful.

> *At first, I did not know what was wrong with him because the doctors would not give me more information about this condition…Now I am beginning to understand because I browse the internet and read about it. . .. (p6, caregiver of a 2year boy).*

Coping/Supportive Factors

The factors included in this third and final construct consist of social support, family function and accessibility to formal education. Social support comprises of the informal support from immediate family members, friends, neighbours, and the community, while function describes the extent to which the family function as a unit in supporting caregivers. The findings related to these are described further below.

Inadequate support from social networks

Some caregivers indicated that they received minimal or no support from family members and others in providing care for their children. Most caregivers expressed concerns that their children may be abandoned in the event of their absence:

> *It is not easy to get someone to care for him, especially when I am not feeling well. I still have to manage and care for him because, the way he is, who will have time to take care of him? (p3, caregiver of a 4year, 9months boy).*

As shown in the demographics, most caregivers were females and mothers to the children. Although caregiving roles in Ghana are traditionally female, considering the additional care needs of a child with CP, many mothers might benefit from support from spouses. It was clear, however in the statements of most of the caregivers that we interviewed that spouses were unsupportive and unhelpful most of the time – almost in rejecting the child with CP and their caregiver.

> *With this one, my husband is not helping me care for him. Do you think I will try to give birth again? He does not mind us any longer. At least once in a while, he should also pick him, and I will also rest, but he doesn't. (p3, caregiver of a 4year, 9months boy)*

Inadequate access to formal education

Another challenge caregivers encountered was that they could not find a suitable school that would render quality education for their children. Some mothers felt their children would not be accepted into the mainstream schools due to their condition, and special schools were unavailable. Thus, all schools within reach of caregivers were not resourced to admit children with special needs like CP. Some community members who seem not to know the depth of the child schooling problem kept recommending that the child be taken to school. See the following expressions of participants.

They said I should take her to school, but in our place, they will not admit her. They said she could not sit, and she could not walk… When you send her to these regular schools, they will not take her. Moreover, no school in our area trains such children (p11, caregiver of a 3year old girl).

Discussion

Our findings show that caregivers in this context encounter sociocultural, physical, and economic challenges in caring for their children with CP. The study's findings resonate with existing evidence and signpost critical contextual and global issues that need consideration to develop support systems and relevant interventions. To support policymakers, practitioners, and researchers in the design of interventions, key findings of this study are discussed in three domains: (i) individual level issues, (ii) community level and (iii) National level (See figure 2). The study findings in these domains, according to existing literature, impact caregivers' physical health, psychological health and general wellbeing (25,34–36).

Figure 2: Contextual Framing of Caregivers' Experiences and Challenges

Individual level Issues

Our finding indicates that caregivers of children with CP face physical care burdens and economic pressures. Due to muscle spasticity, weakness and uncoordinated motor control, children with CP rely mainly on their caregivers for physical care, irrespective of age (37). Although there are assistive devices for aiding in the care of sick individuals with neuromuscular inadequacies and self-care deficit (38), the caregivers in this study had to lift and move their children manually, without such devices, resulting in caregivers' altered wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the wellbeing of caregivers is critical, considering that most children with CP depend solely on them for their care (39,40). Therefore, though it might be useful to solicit the support of social networks to assist primary caregivers, it might even be more beneficial for health professionals to assist caregivers in learning manual handling and body mechanics to empower them to safely lift and move children (41,42).

Also, at the individual level were the income cuts and increased expenditures of caregivers and their families. The loss of jobs, businesses, and increased healthcare expenditures for a child with CP necessitate employers and policymakers to create a more flexible work culture that allows caregivers to engage in income-generating activities to lessen their financial burden (15,43,44). Even though the economic challenges for caregivers in this study are unavoidable, considering that the setting is generally a deprived area, the absence or limited financial support could limit caregivers' ability to access health care such as rehabilitation services for the care of their child as reported in other studies (15). Specific to this study's setting and similar populations, it might be beneficial if the current cost-sharing system of the National Health Insurance Scheme (45) is re-evaluated to meet the health financing needs of these marginalised populations with CP.

Community level

The relations of children with CP, the general public and caregivers misunderstand CP especially in settings with limited general literacy (46), leading to the attribution of the condition to supernatural causes, such as punishment from the gods and witchcraft, as reported in this study and others (46,47). In our study context, Children with CP were perceived as spirit children and punished by the gods. These perceptions were translated into the level of community engagement with the caregivers and the children. Existing evidence shows that beliefs in witchcraft and punishment by the gods lead to labelling, stigmatisation and discrimination against families and children with CP (47). Lack of support for caregivers resulting from stigma has been reported in the existing literature (11,17). This limited support could compound the inherent challenges of having a child with special needs. Thus, society's understanding of CP is critical in reducing stigmatisation and discrimination against families with children with CP and the associated cyclical effect on the child and caregiver. It is therefore critical that health information on CP is intensified to ensure that communities understand the causes and course of CP, promoting empathy and involvement of support systems in providing care for the child to improve their quality of life.

National level

The study's findings suggest that primary caregivers received limited or no health information about their child’s condition. Limited information on health issues and services is a global challenge (48–50). However, challenging settings such as Ghana, with limited economic independence, are worst in this regard(43,51–55). Anecdotal evidence from the study setting suggests that health professionals provide ad hoc health education to caregivers of children with CP and other disabilities, using medical terms that caregivers and their support systems may not understand. Yet, there is evidence that adequate caregiver knowledge may promote better care for children with CP (55,56). Indeed, the trend of breaching the gap in service users' understanding of health issues and contributing effectively to service provision is through deliberate efforts to ensure public participation (57). Therefore, to forestall the challenges communities encounter with their health management, conscious efforts must be made to utilise evidence such as that identified in this study and introduce appropriate interventions that ensure optimal public participation in health care at every health service level.

Furthermore, existing evidence suggest that children with CP without cognitive impairment could benefit from formal education (58). Nevertheless, caregivers reported that one of their challenges was finding school placement for their children with CP. Although Ghana has an all-inclusive education policy (59), it thus appear most schools in this setting do not have the capacity in terms of human resources and space to admit children with CP. This situation resonates with other study findings in India and Kenya reporting lack of formal education opportunities (43,60,61). This suggests the need to operationalise educational policies that makes formal education more accessible to all including children with CP.

Conclusively, though the study findings might not be generalisable, it raises issues related to child physical care, cultural perceptions, health information, and educational needs that must be translated into appropriate individual, community and national level response.

Funding statement: This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests' statement: No competing interests to declare.

Author contribution: MMM, YNA and MWK conceptualise the study, methodology, and literature review. MMM and JNS undertook the data collection, transcription, and analysis. YNA reviewed transcript compared with audios, JNS and MWK drafted the manuscript. MWK and MMM reviewed manuscript for intellectual content. All authors read and approved the final manuscript for publication.

Data Availability: All data relevant to the study are included in the article and its supplementary.

Patient and Public Involvement

Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research.

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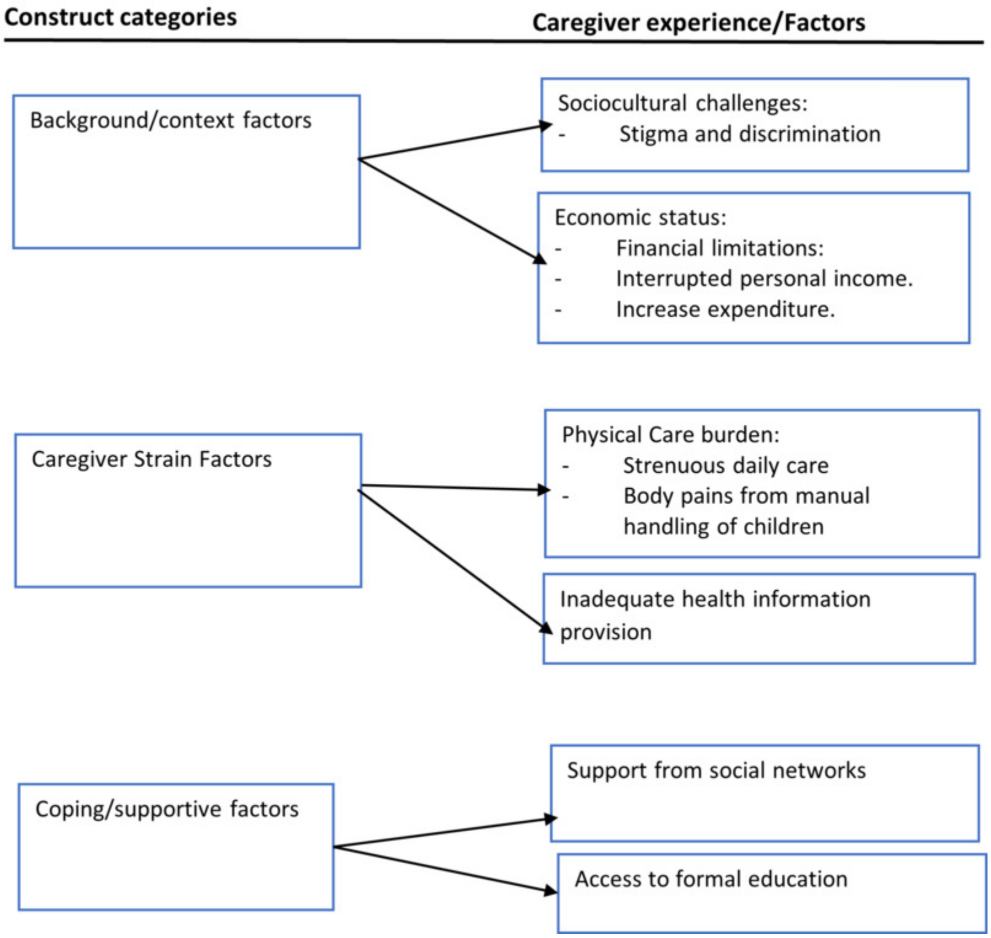
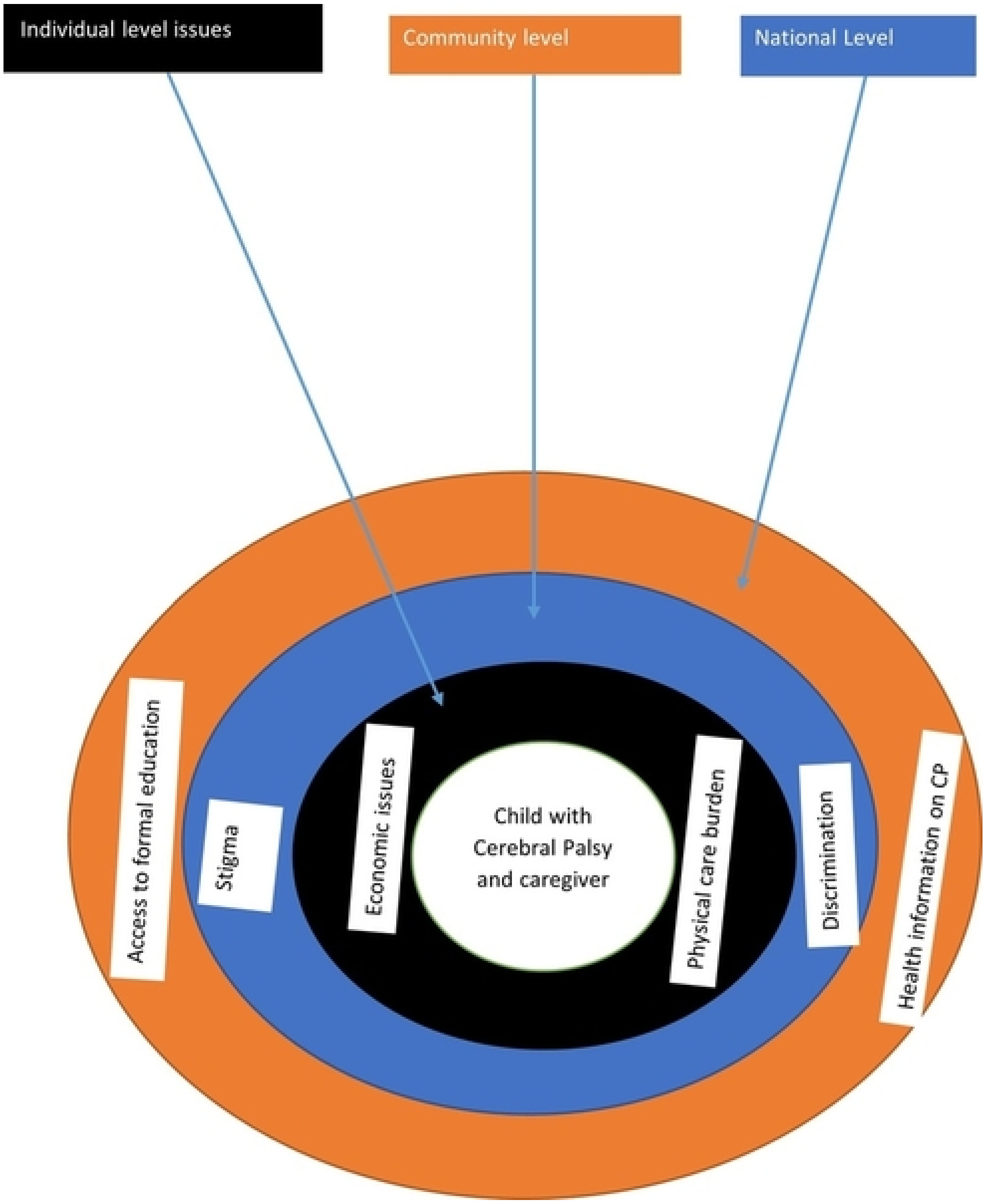


Multidimensional experiences and challenges of caregivers

45x43mm (450 x 450 DPI)



Contextual Framing of Caregivers' Experiences and Challenges

41x50mm (300 x 300 DPI)

Supplementary File 1: Interview guide

	A. Demographic data child and caregiver	
		Comment/ details
	- Relationship of caregiver to child - Age of caregiver - Educational level of caregiver - Occupation of Caregiver - Marital status of Caregiver - Age of child - Type of cerebral palsy	
	Interview guide	
	1. Tell me about your experience of caring for a child with cerebral palsy? Probes: Ask probing questions base on response of each participant. 2. Tell me about any challenges that you experience in your role as a caregiver. Probes: Ask probing question to explore details of challenges mentioned by caregivers.	