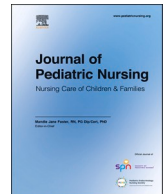




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## Fathers' experiences of caring for children living with cerebral palsy: A qualitative study in a low resourced socioeconomic context, Ghana

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### ABSTRACT

**Background:** In Ghana, little is known about fathers' experiences caring for children with cerebral palsy.

**Purpose:** The purpose of this study is to explore a. the caregiving demand and burden on fathers of children with cerebral palsy and b. describe the caregiving consequences and coping strategies of fathers of children with cerebral palsy.

**Design and methods:** The study utilized an exploratory, descriptive qualitative approach with a sample size of fifteen fathers purposively selected. The study used a semi-structured interview guide to conduct a one-on-one interview with participants. The analysis performed was thematic and content analysis.

**Results:** The results revealed complexities of care demand and burden; thus, meeting the child's needs resulted in physical and mental exhaustion, frequent hospital visits, and substantial financial implications for fathers.

**Conclusions:** We conclude that the family, particularly fathers, need support to embrace the challenging care roles as parents to children with cerebral palsy. It is evident that caring for children is mainly reserved for mothers in the African context. However, the demanding nature of care for a child with a developmental disability requires the involvement of both parents to meet the child's care needs and reduce the caregiver's care burden.

**Practice implications:** Health professionals, particularly nurses must initiate and advocate for fathers' active participation in daily childcare. Tailored supportive care for families with children with disabilities in sub-Saharan Africa is required.

### Background

Cerebral Palsy (CP) is the most frequent childhood neurological and motor impairment, which occurs in approximately 1.5 to 2.5 per 1000 live births globally (Blair et al., 2018). According to 2010 estimates from the Centers for Disease Control and Prevention (CDC), CP affects around 1 in 345 children (3 per 1000 8-year-old children) in the United States (Baio, 2014). A similar report by Cerebral Palsy Alliance Research Foundation indicates that every 20 h, a child is born in Australia with cerebral palsy (Cerebral Palsy Alliance Research Foundation, 2023). In Africa, the prevalence of CP is thought to be 2–10 per 1000 live births (Donald et al., 2014; El-Tallawy et al., 2014; Korzeniewski et al., 2018). Specifically, Uganda has nearly 3 in 1000 children with CP (Kakooza-Mwesige et al., 2015), while Ghana's case of children with CP is

estimated at 1 in 300 births (Graham et al., 2016). It is believed that the severe forms of CP recorded in low and middle-income countries could be attributed to risk factors such as poor or delayed diagnosis and lack of rehabilitation services and education (Jahan, Muhit, Al Imam, et al., 2021; Jahan, Muhit, Hardianto, et al., 2021; Karim et al., 2022).

The impact of CP on the family depends on the degree of disability with associated characteristics (McIntyre et al., 2011). For example, CP is a permanent physical impairment caused by damage to the developing brain and motor impairment, varying from mild to severe (Smithers-Sheedy et al., 2014). It could range from a hand's weakness to nearly no voluntary movement. These features are mainly physical and cognitive functional limitations (Downs et al., 2018) and behavioral problems (Weber et al., 2016), such as poor neck control and motor coordination, stiffness of arms, aggressiveness, inability to recollect information and

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communicate, and drooling. People with severe physical disabilities could need care 24 h of the day. Caring becomes quite complex when the child is entirely dependent on the caregiver (Ribeiro et al., 2016; Yakubu & Schutte, 2018).

Previous studies have shown that parents of disabled children experience stress due to issues like family and societal disruption, weariness, financial hardships, guilt, and parenting discomfort (Graham et al., 2016; Lee, 2013; Nketsia et al., 2019; Obembe et al., 2019). For example, parents of children with cerebral palsy experience tiredness on many social, psychological, and financial levels. Inadequate support from families and society is one of the social difficulties that parents of children with CP face (Nketsia et al., 2019). There are also psychological effects, such as anxiety about being rejected by friends and family. Due to the high cost of the ailment's treatment and the difficulty in having insurance coverage, families with children who have this condition face significant financial hardships (Lee et al., 2019). Inadequate social support systems and, the economic difficulties of poverty, additional costs associated with meeting the child's requirements are additional sources of stress (Graham et al., 2016; Irwin et al., 2019).

In sub-Saharan Africa, the dominance of the patriarchal systems usually suggests similar conventional family patterns exist in families of "normal" developing children and families of children with CP (Naami, 2015). This suggests that mothers do most of the work in parenting a child, particularly as the primary caregiver. Women or mothers stay home to nurture the children while the men keep jobs to provide financial support to the family (Poeze, 2019). Consequently, fathers are primarily absent or poorly involved in direct physical caregiving to the child with CP. Mothers get overwhelmed with other home chores and may not fully attend to the child's needs with CP (Dambi et al., 2015; Harmon et al., 2023; Singogo et al., 2015). Maternal stress and depression signs are significantly connected with child behavior difficulties (Nketsia et al., 2019), suggesting that the mother's inadequate care could jeopardize the child's health with CP.

Little is known about the father's caregiver experiences in Ghana (Appelbaum & Smolowitz, 2012), as most studies focused on mothers as caregivers. This study, therefore, explored the experiences of fathers caring for children with CP to gain an understanding of their burden, coping abilities, and health outcomes. Using the caregiving process and caregiver burden among the pediatric population (Raina et al., 2004) as a guiding model, two objectives guided the study. Thus, *a. To explore the caregiving demand and burden on fathers of children with cerebral palsy, b. Describe the caregiving consequences and coping strategies of fathers of children with cerebral palsy.*

## Design and methods

An exploratory, descriptive qualitative approach (Polit & Beck, 2008) was employed to gain insight into the fathers' burden and coping strategies in caring for their children with CP in a resource-limited context in Ghana. We used the conceptual model Caregiving Process and Caregiver Burden among Pediatric Population (Raina et al., 2004) as a guiding framework to understand the phenomenon. The model acknowledges that caring for a child is a normal phenomenon. However, caring for a child with permanent or extended functional limitations can be stressful and impact the caregiver's physical and psychological wellbeing.

The concepts and construct of the Caregiving Process and Caregiver Burden include the *background and context, child characteristics, caregiver strain and stress (psychological), intrapsychic factors, coping factors, and outcomes*. The model illustrates that the caregiver's background, such as educational level and economic status, is directly linked with care and stress. At the same time, the child's characteristics based on the severity of the disability can also lead to stress. This psychological stress will invariably impact the health of the caregiver, in this case, the father, depending on the intrapsychic factors and coping strategies employed in surmounting the stresses the caregiver (father) may encounter (Raina

et al., 2004).

## Study setting

The study was conducted at a military facility, one of the largest specialist hospitals in the capital city, Accra, Ghana. The hospital provides a wide range of services to the public. It is also a training institution for health professionals from a basic professional level to a specialist grade. Participants for the study were recruited from the Pediatric Outpatient Department.

## Sampling and recruitment of participants

Purposive sampling was employed in this study. Before the recruitment, researchers interacted with the healthcare workers at the Neurological clinic and explained the purpose of the study and the inclusion and exclusion criteria to them. The study's inclusion criteria included a father aged 18 years and above with a medically diagnosed child with CP. The father should have spent at least one year with their child. Any father with behavioral and communication difficulties were excluded. It ensured that appropriate participants were identified and recruited. All participants were screened based on the inclusion criteria of the study. Fifteen fathers who cared for their children with CP for over a year consented to participate in the study. These fathers have enough experience to share the phenomenon for in-depth understanding. The fathers were approached one-on-one after being provided care and through the nurses at the clinic.

## Data collection procedure

Interviews were conducted at the convenience of the participants in a quiet conducive space. Participants who could read and comprehend English were provided with an information sheet on the purpose and confines of the study. The information sheet was read to participants who could not read. Participants were allowed to ask questions for clarification before signing or thumb-printing the consent forms. Participants were offered one consent form to keep. All participants signed the consent form voluntarily.

A semi-structured interview guide was used to elicit information from the participants. Some questions were (1) Kindly share your experiences about the burden of caring for your child. (2) Please describe how you cope with caring for your child. The questions had probes. However, the researchers engaged in further questioning based on the responses from the participants. Each interview lasted between 45 and 60 min. The information gathered was managed for confidentiality and privacy.

## Data analysis

The audio-recorded data collected were transcribed verbatim and checked for completeness by the researchers listening to the audio recordings and reading the transcripts. A deductive analysis approach was adopted by Raina et al. (2004) conceptual model on Caregiving Process and Caregiver Burden among Pediatrics Population. Based on the manageable size of the data, the analysis was done manually without software. Braun and Clark's (2006) approach to thematic analysis was applied to data analysis. Braun and Clark's (2006) approach to Thematic analysis was applied to data analysis. Individually, the researchers read each transcript to familiarize themselves with the experiences the fathers shared. Behaviors that identify with the concepts of the model were labeled; at the same time, other codes were identified based on the content of the data. Similar codes were categorized into potential themes with associated quotes grouped. The themes were reviewed by the researchers and mapped out. The identified themes were compared with the conceptual model to ensure that it resonates with the Caregiving Process and Caregiver Burden constructs.

## Methodological rigor

The following principles of rigor were employed, credibility,

transferability, transferability, and confirmability (Korstjens & Moser, 2018). The strategies offered were prolonged engagement, where participants were provided enough time to respond to questions and share their experiences. Member checking was also done, and findings were returned to participants to confirm the ideas were captured appropriately. Thick descriptions of interpretations and responses were performed while an audit trail was kept on all the processes employed during the study.

**Ethics**

Ethical approval was sought from the Institutional Review Board of 37 Military Hospital's Institutional Review Board (37MH-IRB IPN/MAST/430/2020), and consent was granted by the hospital management, who serves as gatekeepers of the institution. Each participant signed a consent form after comprehending the information sheet and asked questions for clarification where necessary. Participants were made aware of the availability of a clinical psychologist during the interaction. The psychologist was to provide services for emotionally burdened fathers who needed help. None of the participants opted for the services of the clinical psychologist. During the interview, participants who emotionally broke down were offered the space to express their emotions.

**Findings**

*Participants demographic characteristics*

Table 1 presents fifteen fathers, aged between 32 and 51 years, with different ethnic backgrounds were interviewed. All the fathers were married except for one who was divorced. Three married fathers lived separately from their spouses because of job-related demands. Those fathers mostly visited on weekends. Most fathers had two to five children, including a child with CP. Ten children with CP were below five years of age, with five children between ages 6–11. All participants worked in various positions and attained some formal education except for one.

*Three thematic findings*

Table 2 presents the three thematic areas and nine subthemes identified from the participant's interviews. The themes were *care demand and burden*, *fathers' poor health outcomes*, and *coping strategies*. Below are the descriptions of the themes, subthemes, and associated quotes.

**Table 1**  
Demographic Characteristics of Participants.

No.	Age (Yrs)	Tribe	Marital Status	No. of Children	Age Child (Yrs)	Profession	Highest Education
F1	32	Ewe	Married not living together	3	5	Soldier	High School certificate
F2	37	Fante	Married	2	3	Accountant/ Banker	Degree
F3	40	Bono	Married	2	5	Chartered Accountant	Degree
F4	51	Ewe	Married	3	7	Teacher	Degree
F5	36	Ewe	Married not living together	2	4	Police officer	High School certificate
F6	51	Ewe	Married	2	5	Driver	Form 4
F7	40	Grusi – Kasim	Married not living together	2	5	Trader	Tertiary
F8	36	Ewe	Married	2	1	Teacher	Degree
F9	43	Nzema	Married	2	11	Accountant	Postgraduate
F10	37	Ga	Married	2	8	Sales consultant	High school
F11	40	Adangme	Married	3	6	Driver	No Formal Education
F12	50	Akuapem	Married	5	5	Driver	Form 4
F13	42	Ewe	Married	2	5	Receptionist	Tertiary
F14	37	Ewe	Married	3	2	School administrator	Postgraduate Diploma
F15	44	Akan	Divorced	3	9	Carpenter	High school

**Table 2**

Fathers caring for children with cerebral palsy: care demand and burden, fathers' health outcomes and coping strategies.

Research aim	Themes	Subthemes
Fathers' experiences of caring for children living with cerebral palsy	1. Care demand and burden	<ul style="list-style-type: none"> <li>Physical care burden</li> <li>Cost implications</li> <li>Social isolation</li> <li>Stigma</li> </ul>
	2. Coping strategies	<ul style="list-style-type: none"> <li>Social support</li> <li>Positive family functioning</li> <li>Managing personal stress</li> </ul>
	3. Fathers' poor health outcomes	<ul style="list-style-type: none"> <li>Poor physical health</li> <li>Poor psychological health</li> </ul>

*Care demand and burden*

The findings identified that the severity of the disability of children with CP determined their level of dependency on caregivers. The children experiencing CP could not perform most of the basic self-care functions. Thus, parents mostly have the burden of providing complex care to their children to meet their child's care demands. As a result, fathers in this study report the physical, economic, and social burdens emanating from the care they provided.

*Physical care burden*

The father's physical care struggles were enormous, which included lifting and carrying the child and performing activities of daily living such as bathing, feeding, and toileting care. The significant physical burden experienced was lifting and carrying the child, primarily as the child's weight and height increased with age. Excessive lifting and moving without the proper body mechanics can lead to waist pains and posture problems, as evident in the fathers' narratives. Some fathers in this study reported that the total dependency of their children required their constant presence to assist them.

*"I always carry him everywhere I go.... even when you are tired, you still must carry him" F2.*

*"It is a burden, and it takes much energy carrying her around because now she is becoming heavy and heavier" F7.*

The fathers cautioned that special skills are required when caring for the child's daily needs because some children are very aggressive. Sometimes they exert much energy to restrain the child physically.

*"I struggle with feeding him, he will not stay in one place, and he will be struggling and turning his neck. So, we had to exert force on him sometimes; you must know how to feed him; otherwise, you end up putting the food in his*

nose." F6.

*"When you take him to the bath, he is very aggressive; he will be throwing his arm the way the water is pouring on him; if you do not pay careful attention, he can easily get hurt"* F3.

#### Cost implications

According to all the fathers in this study, caring for a child with CP requires enormous sums of money, which drain the family's financial resources. The cost of drugs, special diet, sessions on physiotherapy, and assistive devices, among other costs fathers had to bear. This is because most men in the African context assume the primary responsibility of providing for the family's financial needs. In cases where there is a disability of a family member, one of the parents, mainly the mother, stops work to stay home to provide care to the sick. These understanding compounds the cash inflow in the family, thereby increasing the financial burden on fathers.

*"We go to the physiotherapy clinic twice a month and sometimes four a month. The way he is, you cannot sit on a commercial bus. So, imagine If you want to sit in it then, we have to buy a seat because you cannot sit by somebody while your child is struggling. So, you need to pay for a bus seat for him"* F6.

*"The dieticians also prescribe special diets, which are all expensive"* F8.

#### Social isolation

The fathers narrated that having a child with CP seems like an end to all social engagements. For example, most of them said they had stopped attending social gatherings such as weddings, church, funerals, parties, or visiting friends due to the constant supervision of their CP child. Consequently, the fathers detached themselves from socialization to keep up with the child's care needs. Some deliberately disengage from socialization due to the discrimination meted out to them and their children.

A father also narrated how he felt so traumatized when his child's school attendant refused to feed him. *"This discrimination is inappropriate for a voiceless child who depends on an adult for his livelihood,"* he said. The narrative of this father sends the signal that his child was particularly isolated and neglected due to the difficulties related to his feeding.

*"Last time he went to school, the teacher did not feed him all day. When my wife asked about it, she said she gave the food to him to eat by himself. Meanwhile, she knows the boy cannot eat by himself. The teacher did not bother to help him eat the food; she just left him like that since morning, even without water"* F5.

According to some fathers, their paid jobs were the only social interaction place. However, not all participants related to their workplace as a source of socialization. Few of them attended church occasionally.

*"Many social functions that we used to attend were affected, so we no longer attend any social gatherings. The only social gathering we sent him was the church"* F9.

*"Apart from work, I am unable to go anywhere. She has become familiar with and attached to me, so if I am to go somewhere without her, then it becomes a problem. She starts to cry when I leave the house. That is a major problem for me, and so I am unable to go anywhere"* F12.

#### Stigma

It was revealed that people's attitudes toward a child with CP insinuated some form of stigma. Fathers recounted stigma from either external family or people in their local communities. This was evidenced as parents observed that other parents openly stopped their children from going near the child with CP. Some healthy children also exhibited tendencies to bully children with CP. One father said, *"As a parent, you need to be mentally tough"* to manage any form of discrimination acts when they must go out with the CP child.

*"Sometimes you will go out, and a child would like to play with him, and the other mothers will move their kids away. People mock or ridicule him"* F9.

A father recounted that he and his family were neglected by their

extended families because they have a child with CP. Their families never visited or supported them.

*"In terms of a helping hand, we do not get it from family; the family is not ready to help; they keep giving excuses. Even during our times at the hospital, no family member has come to support"* F8.

The severity of the stigma was such that some participants reported that their businesses were affected. For example, a father narrated that he had a small convenience store where he sold items. However, because of the child's condition, whenever he receives a customer and sees the child, they leave without purchasing any item.

*I have opened a little grocery shop where my wife sells stuff. But because of the child's condition, when she even gets a customer, and they see the child's condition, it makes them leave. Other community members in similar businesses use our child's condition as a negative advertisement against us, so people don't buy from us"* F12.

According to some of the fathers, the gazes from onlookers when they step out of the house are evident and stigmatizing.

#### Fathers' poor health outcomes

Almost all the fathers who participated in this study reported adverse physical and psychological health outcomes.

#### Poor physical health

Most fathers reported daily physical exhaustion because of caregiving. Several of them said they had developed chronic lower back pains over the years due to their child's constant lifting and carrying. They complained of physical exhaustion and inadequate rest and sleep.

*"Normally, at times, I carry her. Because of her weight now, she is becoming heavy. My waist, I feel these chronic pains in my waist and back"* F7.

*"I am always tired and sleepy. I sleep when I even get onto my car to work"* F8.

Most fathers complained that they had lost physical intimacy with their spouses. A few of the fathers attributed the intimacy loss to low sexual drive or libido since the birth of their child.

*"I do not have sexual urges like before; I felt it was the intimacy that brought about this situation. So, I ask myself why I should go into that again; psychologically, I am not there. The stress is so much"* F8. To some of the fathers, the loss of sexual drive was due to both physical and psychological consequences of the duties of caring.

#### Poor psychological health

The fathers described their psychological health as emotionally traumatic and hopeless. According to them, they battled psychologically with the fear of the unknown future for their children living with CP. They were emotionally overwhelmed with daily feelings of empathy for the child. Their thoughts were mainly filled with how the child could improve.

*"You will see your child struggle all the time. It is painful"* F14.

*"I cannot predict the future; her education is the most important thing. I want her to improve before she moves to the next class, but since there is no improvement, I keep repeating her in the same class. Until she can speak, that is when I will know the steps ahead"* F1.

Some fathers felt their world had halted, and they could no longer plan as long as the child lived. Others felt embarrassed to be seen with a disabled child.

*"It is embarrassing telling people that you have this kind of child; I would not feel okay telling people about it. I feel so bad for having a child of that kind, you know, in the sight of my friends and families, my firstborn is like that. His behavior is odd; he would turn his neck some ways and then the way the saliva flows, so during those periods, I feel so ashamed of carrying him outside"* F5.

*"I do not feel so confident. The world has crashed on me like plans have been stuck, like I cannot make any major plans due to the situation. Yes, like a stagnated state"* F8.

The fathers were traumatized by having a child with CP and expressed regret for getting married. Some also attributed having CP to early childbirth after marriage.

*"I used to think a lot concerning the boy. Sometimes, my mind is carried away, and my wife must touch me before I return to myself. I am going through trauma because of this. Though I regretted giving birth early when I got married, I should have waited for some three years before we started making a baby; maybe this thing would have passed us; that kind of child we gave birth should have passed over us. We should not have given birth to him"* F5.

*"To be frank, I will say I regretted even entering into the marriage, but you cannot give the blame to anybody"* F13.

#### Coping strategies

This finding revealed the resources available to fathers and how much they maximized the resources to function effectively in their caregiving roles. Fathers explored several coping strategies as identified in this study. Their coping strategies included religious practices such as praying to God. Some exercised hope for a cure ignored negative comments (avoiding stress), maintained an optimistic view, and suppressed negative feelings. Others pretended to ignore the child's presence and focused on their other healthy siblings to derive transient joy. The presence of family, friends, and neighbors also enhanced their coping abilities. The following sections give an account of detailed descriptions of how some of these strategies were narrated.

#### Social support

In most instances, the fathers expected support from their extended families, friends, and neighbors. The support was in the form of financial help and physical presence to support the family when the child gets into hospital admissions. According to some, families and friends were helpful during challenging moments. This made the family feel loved and cherished.

*"When the seizure happened, and I was not around, a friend just came in to help. The first night that it occurred, about four people from the neighborhood came to stay with us at the hospital"* F4.

Only a few participants reported support from medical and clinical staff, particularly nurses, doctors, and private foundations.

*Along the line, there was one foundation we came along with; they were around to support and do their best. Even the support from the hospital has been great. I had never encountered it before, and at a point, we did not have to pay for anything because doctors and nurses also supported us financially. It is so relieving"* F8.

Fathers enjoyed support from their immediate family members.

*"But I have my sister and my wife's brother's son with me, so he normally carries him around when he is free"* F6.

*"My mother-in-law also comes every weekend because of the baby, and most of the time, she sends money to take care of him and some of the hospital bills"* F2.

#### Positive family functioning

Spousal support was the foundation of family cohesion and functioning. Most fathers mentioned that their wives' committed care for the sick child helped the family to keep up its functions. Siblings interacting with the child with CP was helpful. The fathers expressed that the care burden shared among family members reduced the negative impact.

*"We [father and spouse] both understand each other; we assist each other. When my wife is to go out, she leaves him at home with me. I know it is my responsibility, so I have to take care of him, feed him, babysit, and do those things"* F10.

*"I always pray for long life for my wife; even if I am not in the house, she takes good care of them. The mother is so helpful. She does not even allow herself to be dirty and is always neat. She ensures that she is always there to give her food when she is supposed to eat. So as for the mother. So as for the mother, I always congratulate her for what she is doing for our child"* F7.

Most fathers mentioned that the sick child's siblings were supported by the care. In this study context, siblings were the immediate source of play and socialization for children with CP.

*"Well, I am now okay because he plays with his sister. When the sister is not in a good mood, he goes around and plays with her and feeds her"* F7.

Few fathers said they did not always enjoy spouses' support, but marital conflicts precipitated unmet needs of both the father and the sick child. *"It was most difficult and disappointing because my woman was always agitating and never appreciative of my support. So, all the time we were engaged in petty quarrels"* F13.

#### Managing personal stress

In managing the stress of caring for a child with CP, the fathers in this study adopted different ways unique to the individual. Mostly, the fathers prioritized their stress over family stress management. Some periodically practiced diversional therapies such as listening to music and enjoying nature. These activities help maintain their psychological sanity and relaxation.

*"Normally, when it happens like this, I do not allow myself to be stressed; I play music, I go out, I have a walk, and go to the park to release all this pressure on me"* F7.

Some of them mentioned that they consciously stopped worrying about the child; this was to prevent sending negative emotions to their spouses, so they could cope better. This meant suppressing emotions and putting up appearances for positive energy.

*"I do not want to worry about certain things because if those things start worrying me, it will also worry the mom because I have to be the man [being strong in the Ghanaian context]. If you are found being sad, how do you want the people around you to be? When you are downcast, and your spirit is down, definitely the people around you their spirit will be down you will worry them as well"* F10.

Through self-care, other fathers maintained a positive view while avoiding and suppressing negative feelings and comments. However, it was not easy for these fathers to experience some form of temporal relief.

*"When the whole thing started, I tried to have a positive view of the whole issue"* F8.

Few of the fathers did cope by accepting the situation and bracing themselves, but they were of hope that God could grant them a miracle. This kept them at peace with the care of the child.

*One great strategy is that I believe in miracles. God can do anything. Even if the situation does not change, this is the reality. I have come to terms with the situation on the ground. Because even doctors tell us there is nothing they can do. So, I have come to accept that this is the condition, and we can only do our best. I think that is one of the ways we have adopted"* F8.

*"It has been tough, but I realized this is the challenge, so I must brace up to face it. So, I have psyched my mind to endure whatever comes my way. I have just braced up to the task with the help of God to overcome all the challenges"* F14.

However, in one instance, a father had abandoned his child with CP, who is his youngest son, which he narrated as;

*"A man said he can cure the child, and so I should bring him; he said he has cured a similar illness before, and so he can cure him of this sickness. Someone came all the way to cure the child, but he refused to bring the child, so after that, I made up my mind not to bother myself about anything that had to do with the child except the elder ones. As for the elder ones, they are my responsibility, so I cater to them. But the youngest one, no"* F15.

#### Discussion

The study extensively explored the demands and burdens on fathers caring for children with CP. The needs and responsibilities were predominantly physical, psychological, social, and economic. The physical burden was derived based on the degree of disability where the child had a loss of motor function and coordination, inability to talk, comprehend, and recollect, as well as hyperactivity and inappropriate behavior like

excessive crying. The fathers' experiences of physical discomforts such as waist pains, headaches, back pains, exhaustion, and frequent ill health have been widely reported in the literature (Lee et al., 2019; Nimbalkar et al., 2014; Terzi & Tan, 2016). However, according to the literature, back pain is the chief physical pain reported in Africa (Patel et al., 2017). This could probably result from the cultural approach to carrying children in some parts of Africa, where assistive devices (adaptable strollers) are not routinely used for carrying children as in Western countries (Dogbe et al., 2022).

The economic implications on fathers in this current study were enormous, with little to no external support. Studies allude that care for children with CP is expensive (Tonmukayakul et al., 2018; Umar et al., 2020). The cost of care spans from the child's basic needs to special education, constant transportation for medical treatment (Kyeremateng et al., 2019), and specific nutritional needs. For example, Jahan, Muhit, Al Imam, et al. (2021), Jahan, Muhit, Hardianto, et al. (2021) argue that different levels of function, the capacity to feed by mouth, and tolerance for various food types and textures hamper nutrition in children with CP. These translate into the high cost of meeting the nutritional needs as caregivers must consider the type, texture, and concentration of food or formula and any fluid supplementation, vitamin, and mineral supplementation. Also, the presence of a child with disabilities makes it challenging for fathers to cater to the basic needs of the other family members, as in most cases, their female spouses may be unemployed and supporting the child's care at home (Kyeremateng et al., 2019).

The informal social support system is primarily non-existent due to the consequences of stigma-related issues. Generally, stigma concerns caregivers caring for children with CP (Kassah et al., 2014; Naami, 2015; Opoku et al., 2018). Typically, as evidenced in the findings, the fathers were embarrassed to inform friends and families about their children's medical conditions. In instances where family members were aware, some were not ready to help or visit the family. According to McNally and Mannan (2013), children with CP experience discrimination from parents preventing their children from playing with CP children, staring, pointing fingers, and laughing at them. Social stigma compounded their worries and psychological stress, which impacted the fathers, therefore, their isolation from social activities. Avoidance is the only means of coping with such acts (Mavi et al., 2021; Nimbalkar et al., 2014) and keeping the child at home.

Caregivers adopt several coping strategies to deal with physical exhaustion and psychological stress. Some use acceptance of a child's condition (Silva et al., 2015), avoidance, prayers, and solace in God (Mavi et al., 2021; Nimbalkar et al., 2014). Others also control negative emotions such as crying, sadness, anger, and helplessness as coping strategies to maintain positive views to deal with stresses from caring for a child with CP (Olwit et al., 2018). Parents support each other to cater to the child's needs with CP and other family members. Family functioning influences the family's situation, more importantly when a family needs to cope with a debilitating disease. Thus, healthy family functioning plays a valuable and essential role in having a healthy family lifestyle (Schroeder, 2014).

In the literature on support systems for families of children with CP, nurses form one of the core networks of professional groups that advocate for the health and wellbeing of the children and their primary carers (Polita & Tacla, 2014). For example, nurses have positively contributed to families' psychological and emotional wellbeing by promoting a Family-Centered Care (FCC) approach to medical and rehabilitation intervention services (King et al., 2004). The Ghanaian nurses have not fully operationalized the family-centered care concept yet (Ohene et al., 2020). Introducing the FCC approach to care services for children with CP could be an excellent way to start, as this will provide psychological support to the families of children with CP in Ghana. It is also essential that special attention is paid to fathers' involvement in childcare, as evidence shows that even within the concept of FCC, nurses pay less attention to fathers (Khajeh et al., 2017) as they are often perceived as secondary caregivers instead of primary caregivers (Buek et al., 2021).

When FCC is well implemented, it helps fathers to know that their families are being well cared for, resulting in contentment with care.

### Limitations

This study is one of the few studies on fathers as family caregivers from the Ghanaian context. A limitation of the study was the inability to provide some fundamental interventions, such as education and counseling sessions, as strategies to relieve fathers' stress and burden. It was also apparent that most of the fathers needed financial and other support, which was beyond the scope of this study. Future research should consider interventional strategies to assist fathers and family caregivers in meeting some of their primary care needs.

### Implications

Caring for children is mainly reserved for mothers in the African context. However, the demanding nature of care for a child with a developmental disability requires the involvement of both parents to meet the child's care needs and reduce the caregiver's care burden. Health professionals must advocate for active fathers' participation in daily childcare, particularly in Africa. Families of children with disabilities require funding through a social support system. Based on the unique care needs of children with CP, periodic parental competence assessments will be required to identify needs and support systems. Also, a comprehensive healthcare system may consider regular medical screening for parents and family caregivers of children with CP to assess and improve their overall health and quality of life.

### Conclusions

As much as Ghanaian society is concerned, parents are solely responsible for the basic and medical care of children with disabilities such as CP. Parenting a child with CP in the sociocultural context of Ghana attracts negative public sentiments and behaviors such as discrimination, social isolation, and stigma. This study further reports the childcare demand and burden on fathers who care for children with CP. Parents, especially fathers, need education and awareness of living with a condition associated with physical, social, and intellectual disabilities. A tailored support system should include the self-care needs of the parents, especially the primary caregiver, to ensure they are less physically and psychologically burdened. It is also essential to explore holistic support systems both formally and informally to cater to the needs of families with children living with CP.

### Authors' contributions

LSB and LAO conceptualized the study. LSB conducted all interviews, and all authors (LSB, LAO, VAA, LL, and MOA) participated in the data analysis. VAA produced the initial draft, and all the authors took turns reviewing and finalizing the final draft.

### Ethics approval

Ethics approval was gained from the Institutional Review Board of 37 Military Hospital's Institutional Review Board (37MH-IRB IPN/MAST/430/2020).

Informed consent to participate in the study was obtained from all participants.

All methods were carried out by relevant guidelines and regulations.

### Consent for publication

Not applicable to this study.

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## Declaration of Competing Interest

The authors declare that they have no competing interests.

## Data availability

The datasets generated and analyzed during the study are available from the corresponding author upon reasonable request.

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