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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.**

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**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.

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### **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

## 35 Introduction

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

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

66

## 67 **Methods**

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

## 75 **Participants and Setting**

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

## 86 **Sampling and recruitment**

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

## 99 **Data collection**

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

## 109 **Data analysis**

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

## 125 **Ethical considerations**

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

1  
2  
3 131 (CHRPE) of Kwame Nkrumah University of Science and Technology (KNUST), Ghana with  
4  
5 132 reference number CHRPE/AP/231/21 and the Department of Research and Development of the  
6  
7 133 Tamale Teaching Hospital with reference number TTH/R&D/SR/039, who also provided  
8  
9 134 administrative permission for the study setting.

## 11 Findings

12 135  
13  
14 136 We interviewed thirteen (13) family caregivers to generate data for understanding their  
15  
16 137 perspectives of the challenges they face caring for children with CP. All caregivers were  
17  
18 138 women, out of which 12(92%) were biological parents to the child with CP. Majority were  
19  
20 139 middle aged women and ages ranged from 30-68 years, with a mean age of thirty-nine. Most  
21  
22 140 10(77%) of the children were between 2-4 years old. Table 1 presents the detail demographic  
23  
24 141 information of participants.

25 142 *Table 1: Demographic Characteristics of Participants*

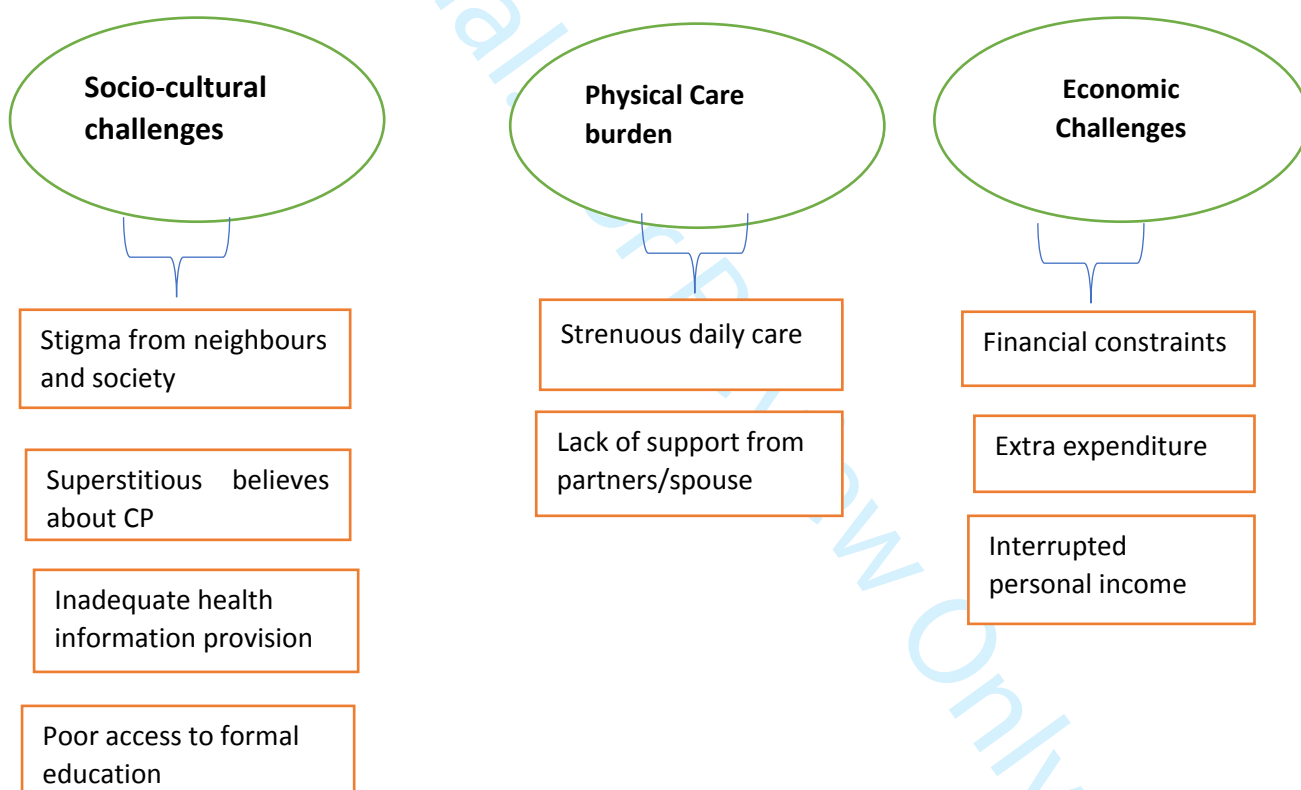
Demographics	Frequency (n)	Percentage (%)
Caregiver relationship		
Mother	12	92
Grandmother	1	8
Age of caregiver		
30-39	10	76
40-49	1	8
50-59	1	8
60-69	1	8
Mean age	39	
Educational level caregiver		
SHS and below	4	31
Tertiary	6	46
No formal education	3	23
Occupation of Caregiver		
Trading	5	38
Nurse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

1  
2  
3 167 socio-cultural viewpoints make the society hostile towards them and living with a child with  
4  
5 168 CP challenging. Salient challenges narrated by caregivers include stigma, misconceptions  
6  
7 169 about CP, inadequate health care services, and problems of accessibility to formal education.  
8

9 170 *Stigma from others:*

10 171 Caregivers recounted how they felt ashamed and humiliated by society because of their child's  
11  
12 172 condition, CP. Caregivers spoke of how their children were described in foul language such as  
13  
14 173 not being human being but as snakes by neighbours and friends. For instance, according to  
15  
16 174 p11, the caregiver of a 2-year-old child with CP, she is unable to attend social gatherings  
17  
18 175 because of the manner in which her child is addressed as shown in their statement.

19  
20 176 *Whenever there is an 'occasion' (marriage, naming ceremonies and funerals), I do not*  
21 177 *go because of the way they treat the child, I don't like it. People will just be calling her*  
22 178 *all sort of names saying she is not human being so I should not waste my time on her*  
23 179 *(p11, caregiver of a 2year old girl).*

25 180 Like p11 account, p6 also demonstrate that the attitudes of society towards their child's CP  
26 181 makes her feel that she is a subject of ridicule. She suggests that even though people in her  
27 182 circles know about her child's condition, suggesting that the child may not be able to walk  
28 183 independently they continue to ask questions about her child not walking just to spite her as  
29 184 she recounts in the quote below;

32 185 *We are now laughing stock to most people, some people know what the child is going*  
33 186 *through, and they will see you and intentionally ask you, so your child is still not*  
34 187 *walking 'enh'? Sometimes in a car like this, they do not even want you to sit closer to*  
35 188 *them or the child should touch them... (P6 caregiver of a 2year boy).*

37 189 Other caregivers also felt that there were discriminations against their children, as they were  
38 190 not allowed to associate with other children. Thus, both child and caregiver could not freely  
39 191 relate with others due to the emotional trauma and stigmatisation from others. Such constraints  
40 192 encountered by caregivers observed in their sample narrations are as follows:

45 193 *As for discrimination, it exists. Some relatives do not allow their children closer to my*  
46 194 *child because they feel that he is not normal (p5 caregiver of a 7year boy).*

48 195 A caregiver added that the challenges in caring for a child with CP in the community is  
49 196 compounded by community members believe that CP is a result of punishment from the gods,  
50 197 and others say children with CP were spirits. According to them, such claims provoke  
51 198 emotional pain. It also appears such perceptions compel caregivers to seek cure, and on whether  
52 199 the children were actually spirits or are punished by the gods from spiritualist.

57 200 *Others make insulting remarks like, this your child is not a human being. We have even*  
58 201 *visited a shrine on several occasions because of that... They will give herbal*  
59 202 *preparation to bath the child and if he is really not human, then he will die after bathing*

1  
2  
3 203 *those herbs. But after bathing him, it is clear that he is not what they were thinking of*  
4 204 *(p3 caregiver of a 4year, 9months boy)*

6 205 *Inadequate health information provision:*

8 206 Adequate information on CP and optimal care strategies could reduce the challenges caregivers  
9 207 face. However, the data show that caregivers did not feel they were given enough information  
10 208 by health care professional to enable them to understand, cope and care for their child. The lack  
11 209 of information appeared to make some caregivers believe in the community's claims about  
12 210 their child and confused the exact nature of their child condition. As shown by p5, even though  
13 211 health workers took history from them about their child's condition, the health workers failed  
14 212 to give them information about the condition. Indeed, due to this limited information giving, it  
15 213 appears caregivers with English literacy and could surf the internet resorted to finding  
16 214 information about their child's condition themselves as demonstrated by caregiver p6.

24 215 *They asked me questions some time ago about the child's condition which they wrote down,*  
25 216 *but I have not been given any information regarding his condition since then... they only said*  
26 217 *we should come to this place (referring to physio unit) and do the exercise (p5, caregiver of a*  
27 218 *7year boy).*

29 219 Meanwhile, caregivers appeared to suggest that they had to persistently demand for information  
30 220 about their child's condition without success. Even though P6 reports show that the internet  
31 221 has helped them to understand their child's condition better, finding information from the  
32 222 internet that is not censored could be misleading as there are sources that may not be credible.  
33 223 Thus, lack of adequate information from health workers could compel caregivers to sources of  
34 224 information that may lead to practices harmful to the child.

40 225 *At first, I didn't know what was wrong with him, because the doctors will not give you*  
41 226 *more information about this condition...Now I'm beginning to understand because I*  
42 227 *just browse and read about it. . . . (p6, caregiver of a 2year boy).*

45 228 *Poor access to formal education:*

46 229 Another challenge encountered by caregivers was the fact that they could not find a suitable  
47 230 school that would render quality education for their children. Some mothers felt their children  
48 231 would not be accepted into the mainstream due to their condition, and special schools were not  
49 232 also available for them. It thus appears all schools that were within the reach of caregivers were  
50 233 not resourced to admit children with special needs like CP. Some community members who  
51 234 seem not to know the depth of the child schooling problem kept recommending that the child  
52 235 be taken to school. See the following expressions of p11.

58 236 *They said I should take her to school but in our place, they won't admit her. They said she*  
59 237 *cannot sit, and she cannot walk... When you send her to these normal schools, they will not*

238 *take her. And there is no school too in our area that train such children (p11, caregiver of a*  
239 *3year old girl).*

240 **Sheer physical care burden:**

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

245 **Strenuous daily care**

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

252 *I usually feel tired due to carrying him always. It is actually a problem lifting him. I*  
253 *sometimes get some body pains as a result of carrying him because he will not sit, so*  
254 *all the time am carrying him. I pray he is able to walk someday, if not, he will be a*  
255 *burden while he is growing up because I can't be carrying him (p3, caregiver of a*  
256 *4year, 9months boy).*

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

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

1  
2  
3 270 *At times when you are going to wear him his clothes, you will struggle with him. He*  
4 271 *won't relax his hands; he will just stiffen them and make himself hard. You will be*  
5 272 *struggling, and he will continue to make his hands like that. . . . Am fed-up 'koraa.'* (p8,  
6 273 *caregiver of 4year old boy)*

#### 9 274 **Inadequate support from social networks:**

10 275 Besides the challenges involve in the care, caregivers also indicated that they received very  
11 276 minimal or no support from family members and others in providing care for their child. Most  
12 277 caregivers expressed concerns that their children may be abandoned in the absence of the  
13 278 primary caregiver.

17 279 *It is not easy to get someone to provide care for him especially when I am not feeling*  
18 280 *so well, I have to still manage and care for him because, the way he is, who will have*  
19 281 *time to take care of him?* (p3, caregiver of a 4year, 9months boy).

22 282 As shown in the demographics, majority of the caregivers were females and mothers to the  
23 283 children. Although, the caregiving role is traditionally a woman's role, and thus consistent with  
24 284 the findings of this study, considering the additional needs of the child with CP and also the  
25 285 emerging trend that women have more roles than the caregiving, it would be expected the  
26 286 caregivers received care, at least from the spouses. However, the statement from p3 captures  
27 287 those experiences of most of the caregivers in terms of support from their spouses.

33 288 *With this one that my husband is not helping me take care of him, do you think I will*  
34 289 *try to give birth again? He doesn't mind us any longer, at least once a while he should*  
35 290 *also pick him, and I will also rest but he doesn't.* (p3, caregiver of a 4year, 9months  
36 291 *boy)*

#### 38 292 **Economic challenges**

39 293 The cost of care globally is a challenging issue as it requires constant flow of money. The  
40 294 special needs of children with disability such as CP increases the financial burden both in the  
41 295 amount required for the care, as well as the loss of hours for family to work and gain their  
42 296 normal income. The caregivers in this study demonstrated in the submission that the sources  
43 297 of income were interrupted, and they had financial limitations in meeting all the care needs of  
44 298 the child.

#### 51 299 **Financial limitations:**

52 300 Having a child with CP means having an expenditure line that is not consistent with routine  
53 301 households' expenses, and thus raising cost of family budget. Most caregivers employed and  
54 302 unemployed described their experience of having increased expenditures due to buying of  
55 303 medications, assistive devices, transportation costs, laboratory investigations, and buying of  
56 304 foods. The latter definitely placed an extra financial burden of caregivers who may not also

1  
2  
3 305 receive financial support as there are no clear, steady formal support for the vulnerable in  
4  
5 306 Ghana, and as indicated earlier the relationships of the caregiver and the child are not  
6  
7 307 supportive enough to consider providing the caregiver with monetary support for caregiving.  
8  
9 308 See the submission of p6 and p10.

10  
11 309 *...I am supposed to be coming for review once every week, but because of the cost of*  
12 310 *transportation, I have made it once every two weeks (p6 caregiver of a 2year boy).*

13  
14 311 *This place (referring to physio unit) I was told that health insurance will cover some*  
15 312 *part and you will also pay the rest after ... sometimes. 'Hmmm' .... Is not easy . . . I*  
16 313 *have even stopped the neurological consult because you have to pay for the consultation*  
17 314 *and still buy the drugs because the hospital is not always having them (p10, caregiver*  
18 315 *of a 4year boy).*

19  
20  
21 316 **Interrupted personal income:**

22 317 Besides the increased expenditure, the economic situation of caregivers was reportedly made  
23  
24 318 worst when they could no longer engage in income earning activities. Participants reports show  
25  
26 319 that caregiving demands of their child led to them abandoning their employments as the could  
27  
28 320 not combine the care of the child which is a full-time job with their income generating activities  
29  
30 321 as shown in the quotes from participants, p10 and p3.

31 322 *I am no longer employed, cannot do any work again. I was working in a private hospital*  
32 323 *before I gave birth, but now this child is like this, I have stopped my employment*  
33 324 *because he has this problem (cerebral palsy) (p10, caregiver of a 4year boy).*

34  
35 325 *I am no longer in business because I can't be holding him while preparing my local*  
36 326 *drinks and there is no one to help. Where will I be getting money for his care? (p3,*  
37 327 *caregiver of a 4year, 9months boy).*

38  
39  
40 328 Many of the caregivers who were initially engaged in personal businesses for income had their  
41  
42 329 businesses collapsed because they did not have time to continue trading. Other caregivers  
43  
44 330 simply stopped because of the level of stress in juggling between childcare and business.  
45  
46 331 Caregivers were then left to deal with the effects of these income cuts and rising expenditures.

## 47 48 49 332 **Discussion**

50 333 Care for children with special needs such as CP is challenging in even advanced jurisdictions  
51  
52 334 with better societal literacy and technologically derived assistive devices for care (24–26). Our  
53  
54 335 findings show that caregivers encounter sociocultural, physical, and economic challenges  
55  
56 336 associated with the care of their child with CP. This study findings resonate with existing  
57  
58 337 evidence and signpost key contextual and global issues that need consideration to develop  
59  
60 338 support systems and relevant interventions. Our finding indicates that caregivers of children

1  
2  
3 339 with CP face physical care burden. Due to the muscle spasticity, weakness and uncoordinated  
4 340 motor control, children with CP rely mainly on their caregivers for physical care irrespective  
5 341 of their age (27). Indeed, motor dysfunction may become worst due to weight as children with  
6 342 CP grow (28). Although there are assistive devices for aiding in the care of sick individuals  
7 343 with neuromuscular inadequacies and selfcare deficit (29), the caregivers in this study had to  
8 344 lift and move their children manually without such devices, resulting in caregivers altered  
9 345 wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the  
10 346 wellbeing of caregivers is critical considering that most children with CP depend solely on  
11 347 them for their care (30,31). It might therefore be useful to not only solicit the support of the  
12 348 social networks to assist primary caregivers, but it might be more sustainable for health  
13 349 professionals to assist caregivers to learn manual handling and body mechanics to empower  
14 350 them to lift and move children with minimal impact on the health of caregivers (32,33).

15 351 Cerebral palsy is an old age neurological condition with scientifically generated evidence on  
16 352 its course. Despite this, the relations of children with CP and caregivers misunderstand CP in  
17 353 many contexts especially in settings with limited general literacy(34), leading to attribution of  
18 354 the condition to supernatural causes, such as punishment from the gods and witchcraft as  
19 355 reported in this study and others (34,35). The setting of the study as shown in the demographics  
20 356 has majority of the people being superstitions about health and other societal issues as played  
21 357 out in the reports of caregivers, that their children with CP were allegedly perceived as being  
22 358 spirit children and being punished by the gods. The perceptions were translated into the level  
23 359 of engagement members of the community had with the caregivers and the children. Existing  
24 360 evidence show that beliefs of witchcraft and punishment by the gods lead to labelling,  
25 361 stigmatisation and discrimination against families and children with CP (35). Lack of support  
26 362 for caregivers resulting from stigma has been reported in the existing literature (9,14). This  
27 363 limited support could compound the innate challenges associated with having a child requiring  
28 364 special needs. Thus, society's understanding of CP is critical in reducing stigmatisation and  
29 365 discrimination against families with children with CP, and the associated cyclical effect on the  
30 366 child and caregivers. It is therefore critical that health information on CP is intensified to ensure  
31 367 that communities understand the causes and course of CP, therefore promoting empathy and  
32 368 involvement of support systems in providing care for the child to improve their life quality.

33 369 In Ghana, the health service and other interested groups such as faith-based institutions and  
34 370 churches are critical in providing service users and communities with health information.  
35 371 However, the findings of the study suggests that even primary caregivers of children with CP

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3 372 receive limited information about the condition. Limited information on health issues and  
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5 373 services is a global challenge (36–38) However, challenging settings such as Ghana with  
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7 374 limited economic independence are worst in this regard (13,39–43). Anecdotal evidence from  
8  
9 375 the study setting suggests that health professionals provide ad hoc health education to  
10  
11 376 caregivers of children with CP and other disabilities, using medical terms that caregivers and  
12  
13 377 their support systems may not understand. Yet, there is evidence that adequate caregiver's  
14  
15 378 knowledge may promote better care for children with CP (41,44) and provision of health  
16  
17 379 information to health services users is expected to be acknowledged as a right (45–47). Indeed,  
18  
19 380 the trend to breaching the gap in service users understanding of health issues and thus  
20  
21 381 contribute effectively to services provision is through deliberate efforts of ensuring public  
22  
23 382 participation (48). Therefore, to forestall the challenges community's encounter with their  
24  
25 383 health management, conscious efforts must be made to utilize evidence such as that identified  
26  
27 384 in this study and introduce appropriate interventions at every level of the health service.

28  
29 385 Existing evidence suggests that children with CP without cognitive impairment could benefit  
30  
31 386 from formal education (49), and caregivers reported that one of their challenges was finding  
32  
33 387 school placement for their children with CP. Besides providing children with CP to explore  
34  
35 388 their potential and contribute to their development, formal school systems health programmes  
36  
37 389 have been a strategy health professionals use to deliver information on health issues to children,  
38  
39 390 and could be a means for delivering health information to children with CP. Nevertheless,  
40  
41 391 accessibility to educational infrastructure was a challenge for caregivers. Although Ghana has  
42  
43 392 an all-inclusive education policy (50), it thus appear most schools in this setting do not have  
44  
45 393 the capacity in terms of human resource and space to admit children with CP. Lack of formal  
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47 394 education opportunities have also been reported by parents in studies conducted in India and  
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49 395 Kenya where parents lamented their inability to find appropriate schools for their children with  
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51 396 disability (40,51,52). Besides contributing to health care and the child's growth and  
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53 397 development, formal education reduces the time children have to spend with their caregivers.  
54  
55 398 This provide caregivers the opportunity to engage in income generating activities that could  
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57 399 lessen the financial burden of having a child with cerebral palsy (40,53,54). Ghana's National  
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59 400 Health Insurance Scheme, meant to lessen the burden of health care cost on service users  
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401 currently operates a cost sharing system and patients must do out-of-pocket payment to obtain  
402  
403 some critical services (55). The latter indicates that the health financial burden on caregivers  
404  
405 in this study's setting could be more than communicated by the caregivers. Even though the  
406  
407 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.

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**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

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3 434 • Caring for a child with cerebral palsy leads to high health care related cost and loss of  
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5 435 businesses and jobs that worsens the financial situation of caregivers.  
6  
7 436 • Accessibility to formal education for children with cerebral palsy is limited.  
8

9 437 **How this study might affect research, practice or policy:**

- 10  
11 438 • It is a critical moment for health service and interested parties to intensify health  
12  
13 439 information on cerebral palsy to ensure that communities understand its causes and  
14  
15 440 course.  
16  
17 441 • Pragmatic steps and policy initiatives that offset the cost of accessing health care  
18  
19 442 services for children with cerebral palsy could be beneficial in this context.  
20  
21 443 • The already existing “all-inclusive educational policy” should be operationalised by the  
22  
23 444 relevant authorities to make formal education accessible to children with cerebral palsy.  
24  
25 445 • The findings of this study should serve as foundational research for empirical studies  
26  
27 446 that seeks to develop interventions for caregivers of children with CP.  
28  
29 447 • Caregivers of children with cerebral palsy could benefit from training on manual  
30  
31 448 handling and body mechanics to empower them to lift and move children with minimal  
32  
33 449 impact on their health.

34 450 **Patient and Public Involvement**

35  
36 451 Patients or the public were not involved in the design, or conduct, or reporting, or dissemination  
37  
38 452 plans of our research  
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42 454 **References**

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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

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**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

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### **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.

**38 Conclusion**

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

**42 What is already known on this topic:**

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

**49 What this study adds:**

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

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

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

64

## 65 Introduction

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

76 In the Ghanaian context, official statistics on the number of children with CP are lacking.  
77 However, Cerebral Palsy Africa (CPA) estimated that one child per 300 births has CP in  
78 Ghana (7). The effects of CP on the growing child range from permanent disorders in  
79 movement and posture to activity limitation. The motor disorders of CP are frequently  
80 accompanied by impaired cognition, communication, sensation, perception, behavioural  
81 abnormalities, seizure disorders, musculoskeletal problems or a combination of these features  
82 (8,9). The condition adversely affects children's daily living experiences and limits their self-  
83 care functions such as feeding, dressing, bathing, and mobility (10,11). Because of the  
84 functional limitations experienced, some children with CP depend on others for assistance  
85 with daily activities, leading to long-term caregiving that far exceeds the usual needs of  
86 typically developing children (8,12,13). Coping and providing the high level of care required  
87 by a child with long-term functional limitations and dependence may be the greatest  
88 challenge for caregivers at home. Care provision, therefore, stands as a burdensome daunting  
89 task that impacts the caregiver's physical and psychological wellbeing at home (8,14). The  
90 situation could be worse in poor-resourced settings where infrastructural amenities, social  
91 support and health care systems are not adequately developed to ameliorate the plight of  
92 caregivers of children with CP (8,15). Therefore, the study was designed to explore the  
93 challenges faced by family caregivers of children with cerebral palsy in a resource-limited  
94 context in northern Ghana. This will serve as a basis for developing context-relevant services  
95 and policy initiatives to better the lives of caregivers and their children with CP.

## 96 **Methods**

### 97 **Design**

98 Essence or truth about the reality of a phenomenon is embodied in people's lived experiences. The  
99 principles of phenomenology research approach were employed to underpin the methods of this  
100 study as it aimed to describe the lived experiences of individuals caring for children with cerebral palsy.  
101 The qualitative research design literature shows that phenomenological principles acknowledge  
102 people's ties with their physical, social, and emotional world (16–21). Thus, whilst a descriptive  
103 qualitative approach could equally be used to unearth the data required in this study to explain the  
104 experiences of carers of children with cerebral palsy, the phenomenological approach fitted in better  
105 (16,19). Caring for a child with special needs is unique and has special meaning for the individuals  
106 involved. Being a parent of a child with cerebral palsy is emotionally and physically unpleasant as the  
107 child cannot live like other children, and the care could be daunting, especially in settings where  
108 assistive devices to aid daily living are absent. Sociocultural factors place the child and their family in  
109 a disadvantaged position. For instance, beliefs about disabilities like those associated with cerebral  
110 palsy are associated with mystical causes such as a curse or punishment by other individuals or the  
111 ancestors for disobedience of an inappropriate action that provokes consequences. To understand,  
112 interpret and describe the caregiving process of such children as it is to the individuals who live it  
113 requires using procedures that ensure that the lived experiences of the individuals are appropriately  
114 unearthed.

### 115 **Participants and Setting**

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

### 126 **Sampling and recruitment**

127 Based on data saturation (23,24), a purposive non-probability sampling technique was adopted  
128 to recruit participants for the study. All participants were recruited during their routine

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2  
3 129 physiotherapy clinic appointment days. We observed COVID-19 protocols (maintaining social  
4 130 distancing, wearing Personal Protective Equipment (PPE) such as a nose mask or face shield  
5 131 and using hand sanitisers) during participant recruitment and data collection. We confirmed  
6 132 participants' inclusion by checking diagnoses from children's hospital records with the help of  
7 133 a physiotherapist to ensure that children had been duly diagnosed by a medical professional.  
8 134 We introduced the study aims and informed potential participants that involvement in the study  
9 135 was voluntary. Participants interested in joining the study were then provided further  
10 136 information using the information sheet. We guided participants who consented to participate  
11 137 in the research to sign/thumb print the consent form. MMM, a paediatric nurse specialist  
12 138 conducted all recruitment procedures and data collection. Though she had no prior relationship  
13 139 with participants in the study area, she was motivated to recruit and gain understanding of  
14 140 issues in this context.

#### 141 **Data collection**

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



## 162 **Data analysis**

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

## 173 **Ethical considerations**

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

## 183 **Findings**

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

189 *Table 1: Demographic Characteristics of Participants*

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

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

190

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

### 193 **Sociocultural challenges**

194 The results depict society's cultural and intuitive beliefs about CP and its impact on caregivers.  
 195 Social cultural challenges emerged as a significant category from the data, describing the  
 196 relationships and difficulties caregivers encounter as they interact with society and formal  
 197 institutions on issues related to their child with CP. Caregivers also reported how the  
 198 sociocultural viewpoints make society hostile towards them and challenging living with a child

199 with CP. Salient challenges narrated by caregivers included stigma, misconceptions about CP,  
200 inadequate health care services, and problem of accessibility to formal education.

201 *Stigma from others:*

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

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

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

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

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

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

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

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

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

236 *Inadequate health information provision:*

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

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

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

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

259 *Poor access to formal education:*

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

267 *They said I should take her to school, but in our place, they will not admit her. They said she*  
268 *could not sit, and she could not walk... When you send her to these regular schools, they will*

269 *not take her. Moreover, no school in our area trains such children (p11, caregiver of a 3year*  
270 *old girl).*

271 **Sheer physical care burden:**

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

276 **Strenuous daily care**

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

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

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

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

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

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3 303 **Inadequate support from social networks:**

4 304 Besides the challenges involved in the care, caregivers also indicated that they received  
5  
6 305 minimal or no support from family members and others in providing care for their child. Most  
7  
8 306 caregivers expressed concerns that their children may be abandoned without the primary  
9  
10 307 caregiver.

11  
12 308 *It is not easy to get someone to care for him, especially when I am not feeling well. I*  
13 309 *still have to manage and care for him because, the way he is, who will have time to take*  
14 310 *care of him? (p3, caregiver of a 4year, 9months boy).*

15  
16 311 As shown in the demographics, most caregivers were females and mothers to the children.  
17  
18 312 Although the caregiving role is traditionally a woman's role, and thus consistent with the  
19  
20 313 findings of this study, considering the additional needs of the child with CP and also the  
21  
22 314 emerging trend that women have more roles than caregiving, it would be expected the  
23  
24 315 caregivers received care, at least from the spouses. However, the statement from p3 captures  
25  
26 316 the experiences of most of the caregivers in terms of support from their spouses.

27 317 *With this one, my husband is not helping me care for him. Do you think I will try to give*  
28 318 *birth again? He does not mind us any longer. At least once in a while, he should also*  
29 319 *pick him, and I will also rest, but he doesn't. (p3, caregiver of a 4year, 9months boy)*

30  
31  
32 320 **Economic challenges**

33 321 The cost of care globally is a challenging issue as it requires a constant flow of money. The  
34  
35 322 special needs of children with a disability such as CP increase the financial burden in the  
36  
37 323 amount required for the care and the loss of hours for the family to work and gain their normal  
38  
39 324 income. The caregivers in this study demonstrated in the submission that their sources of  
40  
41 325 income were interrupted, and they had financial limitations in meeting the child's care needs.

42 326 **Financial limitations:**

43 327 Having a child with CP means having an expenditure line inconsistent with routine household  
44  
45 328 expenses, thus raising the cost of a family's budget. Most caregivers employed and  
46  
47 329 unemployed, described their experience of having increased expenditures due to buying  
48  
49 330 medications, assistive devices, transportation costs, laboratory investigations, and food buying.  
50  
51 331 The latter placed an extra financial burden on caregivers who may not also receive financial  
52  
53 332 support as there is no clear, steady formal support for the vulnerable in Ghana. As indicated  
54  
55 333 earlier, the relationships of the caregiver and the child are not supportive enough to consider  
56  
57 334 providing the caregiver with monetary support for caregiving. See the submission of p6 and  
58  
59 335 p10.  
60

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

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

#### 343 Interrupted personal income:

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

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

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

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

## 359 Discussion

360 Care for children with special needs such as CP is challenging in even advanced jurisdictions  
361 with better societal literacy and technologically derived assistive devices for care (29–31). Our  
362 findings show that caregivers encounter sociocultural, physical, and economic challenges  
363 associated with caring for their child with CP. This study's findings resonate with existing  
364 evidence and signpost critical contextual and global issues that need consideration to develop  
365 support systems and relevant interventions. Our finding indicates that caregivers of children  
366 with CP face physical care burdens. Due to muscle spasticity, weakness and uncoordinated  
367 motor control, children with CP rely mainly on their caregivers for physical care, irrespective  
368 of age (32). Indeed, motor dysfunction may worsen due to weight as children with CP grow  
369 (33). Although there are assistive devices for aiding in the care of sick individuals with  
370 neuromuscular inadequacies and self-care deficit (34), the caregivers in this study had to lift

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2  
3 371 and move their children manually, without such devices, resulting in caregivers' altered  
4  
5 372 wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the  
6  
7 373 wellbeing of caregivers is critical, considering that most children with CP depend solely on  
8  
9 374 them for their care (35,36). It might therefore be useful to not only solicit the support of social  
10  
11 375 networks to assist primary caregivers, but it might be more sustainable for health professionals  
12  
13 376 to assist caregivers in learning manual handling and body mechanics to empower them to lift  
14  
15 377 and move children with minimal impact on the health of caregivers (37,38).

16 378 Cerebral palsy is an old-age neurological condition with scientifically generated evidence on  
17  
18 379 its course. Despite this, the relations of children with CP and caregivers misunderstand CP in  
19  
20 380 many contexts, especially in settings with limited general literacy(39), leading to attribution of  
21  
22 381 the condition to supernatural causes, such as punishment from the gods and witchcraft, as  
23  
24 382 reported in this study and others (39,40). The setting of the study, as shown in the  
25  
26 383 demographics, has the majority of the people being superstitious about health and other social  
27  
28 384 issues, as played out in the reports of caregivers, that their children with CP were allegedly  
29  
30 385 perceived as being spirit children and being punished by the gods. The perceptions were  
31  
32 386 translated into the level of community engagement with the caregivers and the children.  
33  
34 387 Existing evidence shows that beliefs of witchcraft and punishment by the gods lead to labelling,  
35  
36 388 stigmatisation and discrimination against families and children with CP (40). Lack of support  
37  
38 389 for caregivers resulting from stigma has been reported in the existing literature (9,14). This  
39  
40 390 limited support could compound the innate challenges of having a child with special needs.  
41  
42 391 Thus, society's understanding of CP is critical in reducing stigmatisation and discrimination  
43  
44 392 against families with children with CP and the associated cyclical effect on the child and  
45  
46 393 caregivers. It is therefore critical that health information on CP is intensified to ensure that  
47  
48 394 communities understand the causes and course of CP, promoting empathy and involvement of  
49  
50 395 support systems in providing care for the child to improve their quality of life.

51 396 In Ghana, the health service and other interested groups, such as faith-based institutions and  
52  
53 397 churches, are critical in providing service users and communities with health information.  
54  
55 398 However, the study's findings suggest that even primary caregivers of children with CP receive  
56  
57 399 limited information about the condition. Limited information on health issues and services is a  
58  
59 400 global challenge (41–43). However, challenging settings such as Ghana, with limited economic  
60  
401 independence, are worst in this regard (13,44–48). Anecdotal evidence from the study setting  
402  
403 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



1  
2  
3 404 may not understand. Yet, there is evidence that adequate caregiver knowledge may promote  
4  
5 405 better care for children with CP (46,49) and the provision of health information to health  
6  
7 406 services users is expected to be acknowledged as a right (50–52). Indeed, the trend of breaching  
8  
9 407 the gap in service users' understanding of health issues and thus contributing effectively to  
10  
11 408 service provision is through deliberate efforts to ensure public participation (53). Therefore, to  
12  
13 409 forestall the challenges communities encounter with their health management, conscious  
14  
15 410 efforts must be made to utilise evidence such as that identified in this study and introduce  
16  
17 411 appropriate interventions at every health service level.

18 412 Existing evidence suggests that children with CP without cognitive impairment could benefit  
19  
20 413 from formal education (54), and caregivers reported that one of their challenges was finding  
21  
22 414 school placement for their children with CP. Besides providing children with CP to explore  
23  
24 415 their potential and contribute to their development, formal school systems health programmes  
25  
26 416 have been a strategy health professionals use to deliver information on health issues to children  
27  
28 417 and could be a means for delivering health information to children with CP. Nevertheless,  
29  
30 418 accessibility to educational infrastructure was a challenge for caregivers. Although Ghana has  
31  
32 419 an all-inclusive education policy (55), it thus appears most schools in this setting do not have  
33  
34 420 the capacity in terms of human resources and space to admit children with CP. Parents have  
35  
36 421 also reported lack of formal education opportunities in studies conducted in India and Kenya,  
37  
38 422 where parents lamented their inability to find appropriate schools for their children with  
39  
40 423 disability (45,56,57). Besides contributing to health care and the child's growth and  
41  
42 424 development, formal education reduces children's time with their caregivers. This allows  
43  
44 425 caregivers to engage in income-generating activities that could lessen the financial burden of  
45  
46 426 having a child with cerebral palsy (45,58,59). Ghana's National Health Insurance Scheme,  
47  
48 427 meant to lessen the burden of health care costs on service users, currently operates a cost-  
49  
50 428 sharing system, and patients must make out-of-pocket payments to obtain some critical services  
51  
52 429 (60). The latter indicates that the caregivers could more than communicate the health financial  
53  
54 430 burden on caregivers in this study's setting. Even though the economic challenges for  
55  
56 431 caregivers in this study are unavoidable, considering that the setting is generally a deprived  
57  
58 432 area, the absence or limited financial support could limit caregivers' ability to access all  
59  
60 433 necessities, such as rehabilitation services for the care of their child as reported in other studies  
61  
62 434 (58).

63 435 Conclusively, contextual issues related to child physical care, cultural perceptions, health  
64  
65 436 information needs, and education created problems for caregivers, and these must be translated

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3 437 into appropriate community and health system response. The findings suggest that caregivers  
4  
5 438 have a candid idea of daily challenges, and they should be appropriately involved in designing  
6  
7 439 innovative services or health care interventions.

8  
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14  
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16  
17 444 literature review. MMM and JNS undertook the data collection, transcription, and analysis.  
18  
19 445 YNA reviewed transcript compared with audios, JNS and MWK drafted the manuscript. MWK  
20  
21 446 and MMM reviewed manuscript for intellectual content. All authors read and approved the  
22  
23 447 final manuscript for publication.

24  
25 448 **Data Availability:** All data relevant to the study are included in the article

#### 26 27 449 **Patient and Public Involvement**

28  
29  
30 450 Patients or the public were not involved in the design, or conduct, or reporting, or dissemination  
31  
32 451 plans of our research.

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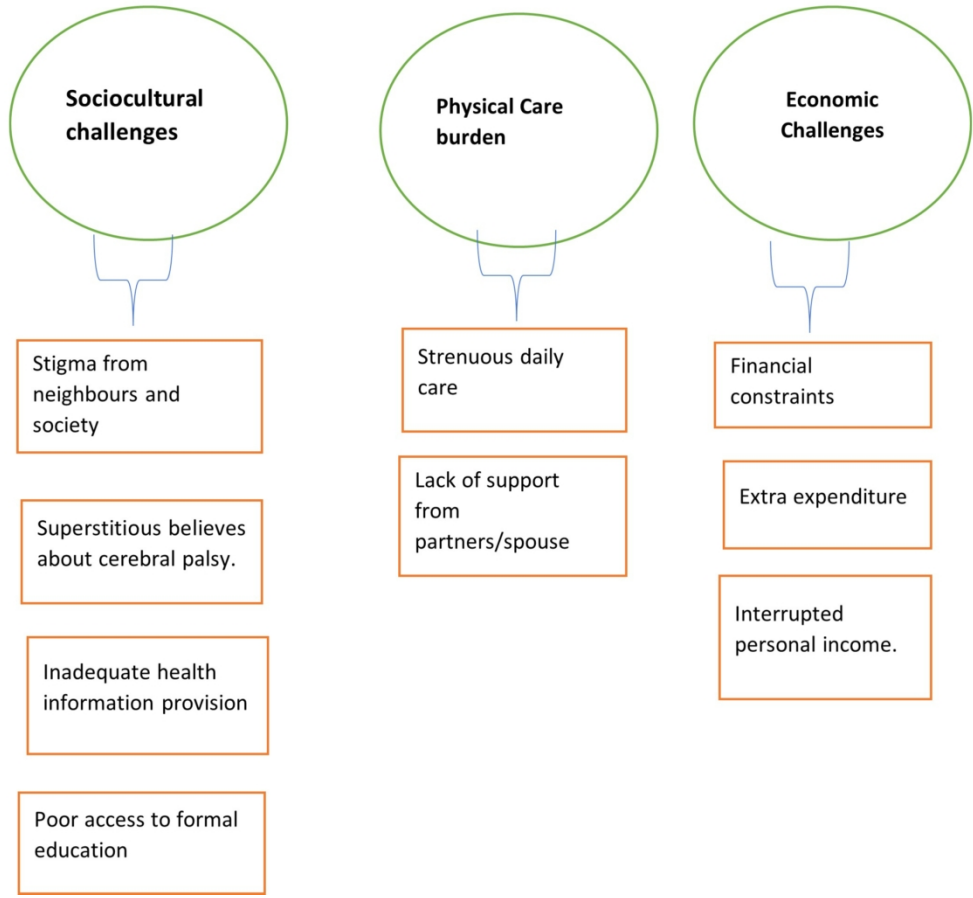
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Fig 1: Categories of challenges faced by caregivers.



Categories of challenges

569x568mm (96 x 96 DPI)

## Supplementary File 1: Interview guide

A. Demographic data child and caregiver		Comment/ details
	<ul style="list-style-type: none"> <li>• Relationship of caregiver to child</li> <li>• Age of caregiver</li> <li>• Educational level of caregiver</li> <li>• Occupation of Caregiver</li> <li>• Marital status of Caregiver</li> <li>• Age of child</li> <li>• Type of cerebral palsy</li> </ul>	
	Interview guide	
	<p>1. Tell me about your experience of caring for a child with cerebral palsy?</p> <p>Probes: Ask probing questions base on response of each participant.</p> <p>2. Tell me about any challenges that you experience in your role as a caregiver.</p> <p>Probes: Ask probing question to explore details of challenges mentioned by caregivers.</p>	

# 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

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**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

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### **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.

## 39 Conclusion

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

### 43 What is already known on this topic:

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

### 50 What this study adds:

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

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

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



## 70 Introduction

71 Cerebral palsy (CP) is a lifetime physical disability due to non-progressive injuries to the  
72 immature or developing brain (1–3). The risk factors associated with developing CP occur  
73 before, during or after pregnancy and include but not limited to intrauterine hypoxia, premature  
74 rupture of membranes, placenta abnormalities, preterm or post-term birth, asphyxia, prolonged  
75 labour, infections, hypoglycaemia, intracranial haemorrhage and respiratory distress syndrome  
76 (4,5). CP is estimated to occur in approximately 2.11 per 1000 live births globally (6), affecting  
77 males more than females (7), with more living in resource-limited settings (5,8,9).

78 In the Ghanaian context, official statistics on the number of children with CP are lacking.  
79 However, Cerebral Palsy Africa (CPA) estimated that one child per 300 births has CP in  
80 Ghana (10). The effects of CP on the growing child range from permanent disorders in  
81 movement and posture to activity limitation. The motor disorders of CP are frequently  
82 accompanied by impaired cognition, communication, sensation, perception, behavioural  
83 abnormalities, seizure disorders, musculoskeletal problems or a combination of these features  
84 (11,12). The condition adversely affects children's daily living experiences and limits their  
85 self-care functions such as feeding, dressing, bathing, and mobility (13,14). Because of the  
86 functional limitations experienced, some children with CP depend on caregivers for  
87 assistance with daily activities, leading to long-term caregiving that far exceeds the usual  
88 needs of typically developing children (11,15,16). For some caregivers, provision of care can  
89 be a burdensome, daunting task that can impact on their physical and psychological well-  
90 being (11,17). This is often worse in resource-limited settings where infrastructural amenities,  
91 social support and health care systems are not adequately developed to ameliorate the plight  
92 of caregivers (11,18). This study was designed to evaluate the challenges faced by family  
93 caregivers of children with CP in a resource-limited context in northern Ghana. This will  
94 serve as a basis for developing context-relevant services and policy initiatives to better the  
95 lives of caregivers and their children with CP.

## 96 Methods

### 97 Design

98 Phenomenological research methods have been employed in underpinning this study as it aims to  
99 describe the lived experience of individuals caring for children with CP. The qualitative research design  
100 literature shows that phenomenological principles acknowledge people's ties with their physical,  
101 social, and emotional world (19–24), suggesting that truth about the reality of a phenomenon is

1  
2  
3 102 embodied in peoples lived experiences (20,24). Thus, whilst a descriptive qualitative approach could  
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5 103 equally be used to unearth the data required in this study to explain the experiences of carers of  
6  
7 104 children with cerebral palsy, the phenomenological approach fitted in better (19,22). Caregivers vary  
8  
9 105 in how they adapt to caregiving demands and the process is unique with a special meaning for the  
10  
11 106 individual involved (25). The study design adapted enabled us to account for the variability in  
12  
13 107 caregivers' interpretations of their experience of care (26).

## 14 108 **Participants and Setting**

15  
16 109 Thirteen family caregivers of children with CP participated in the study. We included  
17  
18 110 individuals who resided with and provided care daily for a child under 18 years of age,  
19  
20 111 diagnosed by a qualified medical doctor and confirmed in their medical records to have CP.  
21  
22 112 The recruitment of participants took place at the physiotherapy unit of the Tamale Teaching  
23  
24 113 Hospital, the only tertiary hospital in the northern region of Ghana. The hospital provides  
25  
26 114 specialist care and physiotherapy services for children with diverse needs, including CP. Most  
27  
28 115 of the inhabitants in this setting are Muslims, but they also practice and revere the traditional  
29  
30 116 African religion. Thus, they believe in their ancestors and supernatural powers which could  
31  
32 117 sometimes influence their perceptions about disease causation and management. Wholesale,  
33  
34 118 retail and agricultural activities are the main occupation in the area (27). The first author, a  
35  
36 119 female paediatric nurse specialist has an extensive knowledge of the study area through her  
37  
38 120 residency program. Anecdotal observations she made at this setting motivated the conduct of  
39  
40 121 the study. However, she had no prior relationship with study participant.

## 41 122 **Sampling and recruitment**

42  
43 123 We undertook a purposive non-probability sampling technique where we concluded once we  
44  
45 124 met data saturation (28,29). All participants were recruited during their routine physiotherapy  
46  
47 125 clinic appointment days. We observed COVID-19 protocols (maintaining social distancing,  
48  
49 126 wearing Personal Protective Equipment (PPE) such as a nose mask or face shield and using  
50  
51 127 hand sanitisers) during participant recruitment and data collection. We confirmed participants'  
52  
53 128 inclusion by checking diagnoses from children's hospital records with the help of a  
54  
55 129 physiotherapist to ensure that children had been duly diagnosed by a medical professional. We  
56  
57 130 introduced the study aims and informed potential participants that involvement in the study  
58  
59 131 was voluntary. Participants interested in joining the study were then provided further  
60  
132 information using the information sheet by the researcher. We guided participants who  
133 consented to participate in the research to sign/thumb print the consent form before  
134 commencing data collection.

## 135 Data collection

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

## 156 Data analysis

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

## 167 **Ethical considerations**

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

## 176 **Findings**

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

181 *Table 1: Demographic Characteristics of Participants*

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

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

182

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

### 191 **Figure 1: Multidimensional experiences and challenges of caregivers**

192

#### 193 **Background/context factors**

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

#### 198 ***Sociocultural Challenges:***

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

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

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

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

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

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

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

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

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

### 232 ***Economic status***

233 The caregivers in this study demonstrated in their submission that their sources of income were  
234 interrupted, and they had financial limitations in meeting the child's care needs. Having a child  
235 with CP means having an expenditure line inconsistent with routine household expenses, thus  
236 raising the cost of a family's budget. Most caregivers employed and unemployed, described  
237 their experience of having increased expenditures due to buying medications, assistive devices,

238 transportation costs, laboratory investigations, and food buying. The latter placed an extra  
 239 financial burden on caregivers who may not also receive financial support as there is no clear,  
 240 steady formal support for the vulnerable in Ghana. See the submission of some participants:

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

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

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

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

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

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

263

### 264 **Caregiver Strain Factors:**

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

#### 268 ***Physical care burden***

269 Caregivers recounted the challenges with providing activities of daily living such as bathing,  
 270 dressing, and moving their child whilst maintaining their routine responsibilities to themselves  
 271 and other family members. They lamented about the exhausting nature of caring for a child with  
 272 CP. Due to the physical and neurological incapacities of the child, they depend exclusively on

1  
2  
3 273 their caregivers to meet all their needs. Most participants of this study experienced struggles in  
4  
5 274 meeting the demands of children's daily care. Caregivers' reports indicate that lifting and  
6  
7 275 moving their children were particularly challenging as it affected their wellbeing, as stated in  
8  
9 276 their narratives below:

10  
11 277 *I usually feel tired due to carrying him always. It is a problem lifting him. I sometimes*  
12  
13 278 *get some body pain due to carrying him because he will not sit, so I do all the time I am*  
14  
15 279 *carrying him. I pray he can walk someday. If not, he will be a burden while growing up*  
16  
17 280 *because I cannot carry him (p3, caregiver of a 4year, 9months boy).*

18  
19 281 *I feel so tired of caring for him because he has a younger sibling I have to cater. At his*  
20  
21 282 *age (7 years), he should have been able to bathe and move about, but I still have to do*  
22  
23 283 *it (p5, caregiver of a 7year boy).*

24  
25 284 Caregivers also expressed experiencing body pains and having to depend on pain medications  
26  
27 285 to relieve themselves due to strenuous nature of the care they provide for their child with CP.  
28  
29 286 Caregivers also commented that the care became more challenging as their child grew older.  
30  
31 287 As seen in the verbatim quotations below, the complains of body pains is associated with  
32  
33 288 having to lift and move the children, as they grow physically and increase in size and weight.

34  
35 289 *...she doesn't want anyone to carry her, only me...so every day I have to be taking pain*  
36  
37 290 *medications, now she has reduced in weight... at first, she was heavy so when you carry*  
38  
39 291 *her hmmm my waist. Sometimes when I am in the room I cry because of the pains (P11*  
40  
41 292 *caregiver of a 2years old girl).*

### 42 293 ***Inadequate health information:***

43  
44 294 The data show that caregivers felt that healthcare professionals did not give them enough  
45  
46 295 information to enable them to understand, cope and care for their children. The lack of health  
47  
48 296 information made some caregivers believe in the community's claims of such children being  
49  
50 297 spirits or animals. For instance, some participants suggested that even though health workers  
51  
52 298 took the history of their child's condition, the health workers failed to give them information  
53  
54 299 about the condition. Caregivers with English literacy who could surf the internet resorted to  
55  
56 300 finding information about their child's condition, as demonstrated below.

57  
58 301 *They asked me questions some time ago about the child's condition, which they wrote down,*  
59  
60 302 *but I have not been given any information regarding his condition since then... they only said*  
303  
304 *we should come to this place (referring to the physio unit) and do the exercise (p5, caregiver*  
of a 7year boy).

305  
306 305 Even though participants report show that the internet has helped them to understand their  
307  
308 306 child's condition better, finding information from the internet that is not censored could be  
309  
310 307 misleading as there are sources that may not be credible. Thus, a lack of adequate information  
311  
312 308 from health workers could compel caregivers to sources of information that are not helpful.



1  
2  
3 309 *At first, I did not know what was wrong with him because the doctors would not give*  
4 310 *me more information about this condition...Now I am beginning to understand because*  
5 311 *I browse the internet and read about it. . . (p6, caregiver of a 2year boy).*

### 312 **Coping/Supportive Factors**

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

#### 318 ***Inadequate support from social networks***

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

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

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

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

#### 333 ***Inadequate access to formal education***

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

1  
2  
3 341 *They said I should take her to school, but in our place, they will not admit her. They said she*  
4 342 *could not sit, and she could not walk... When you send her to these regular schools, they will*  
5 343 *not take her. Moreover, no school in our area trains such children (p11, caregiver of a 3year*  
6 344 *old girl).*  
7  
8

9 345

## 11 346 Discussion

12  
13  
14 347 Our findings show that caregivers in this context encounter sociocultural, physical, and  
15 348 economic challenges in caring for their children with CP. The study's findings resonate with  
16 349 existing evidence and signpost critical contextual and global issues that need consideration to  
17 350 develop support systems and relevant interventions. To support policy makers, practitioners,  
18 351 and researchers in the design of interventions, key findings of this study are discussed in three  
19 352 domains: (i) individual level issues (ii) community level and (iii) formal health care system  
20 353 (See figure 2). The study findings in these areas according to existing literature impact on  
21 354 caregivers' physical health, psychological health and general wellbeing (25,34–36).  
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26  
27

### 28 355 **Figure 2: Contextual Framing of Caregivers experiences and challenges**

29 356

#### 30 357 **Individual level Issues**

31  
32  
33  
34 358 Our finding indicates that caregivers of children with CP faced physical care burdens and  
35 359 economic pressures. Due to muscle spasticity, weakness and uncoordinated motor control,  
36 360 children with CP rely mainly on their caregivers for physical care, irrespective of age (37).  
37 361 Although there are assistive devices for aiding in the care of sick individuals with  
38 362 neuromuscular inadequacies and self-care deficit (38), the caregivers in this study had to lift  
39 363 and move their children manually, without such devices, resulting in caregivers' altered  
40 364 wellbeing such as aches and pains sometimes requiring medical attention. Meanwhile, the  
41 365 wellbeing of caregivers is critical, considering that most children with CP depend solely on  
42 366 them for their care (39,40). Therefore, though it might be useful to solicit the support of social  
43 367 networks to assist primary caregivers, it might even be more beneficial for health professionals  
44 368 to assist caregivers in learning manual handling and body mechanics to empower them to safely  
45 369 lift and move children (41,42).  
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56 370 Also at the individual level was the income cuts and increased expenditures of caregivers and  
57 371 their families. The loss of jobs, businesses and increased health care expenditures consequence  
58 372 of caring for a child with CP necessitate the need for employers and policy makers to create a  
59  
60

373 more flexible work culture that allows caregivers to engage in income-generating activities to  
374 lessen their financial burden (43–45). Even though the economic challenges for caregivers in  
375 this study are unavoidable, considering that the setting is generally a deprived area, the absence  
376 or limited financial support could limit caregivers' ability to access health care such as  
377 rehabilitation services for the care of their child as reported in other studies (43). Specific to  
378 this study's setting and similar populations, it might be beneficial if the current cost-sharing  
379 system of the National Health Insurance Scheme (46) is re-evaluated to meet the health  
380 financing needs of this marginalise populations with CP.

### 381 **Community level**

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

398 Furthermore, existing evidence suggest that children with CP without cognitive impairment  
399 could benefit from formal education (49). Nevertheless, caregivers reported that one of their  
400 challenges was finding school placement for their children with CP. Although Ghana has an  
401 all-inclusive education policy (50), it thus appear most schools in this setting do not have the  
402 capacity in terms of human resources and space to admit children with CP. This situation  
403 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.

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**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**

1  
2  
3 434 Patients or the public were not involved in the design, or conduct, or reporting, or dissemination  
4  
5 435 plans of our research.  
6

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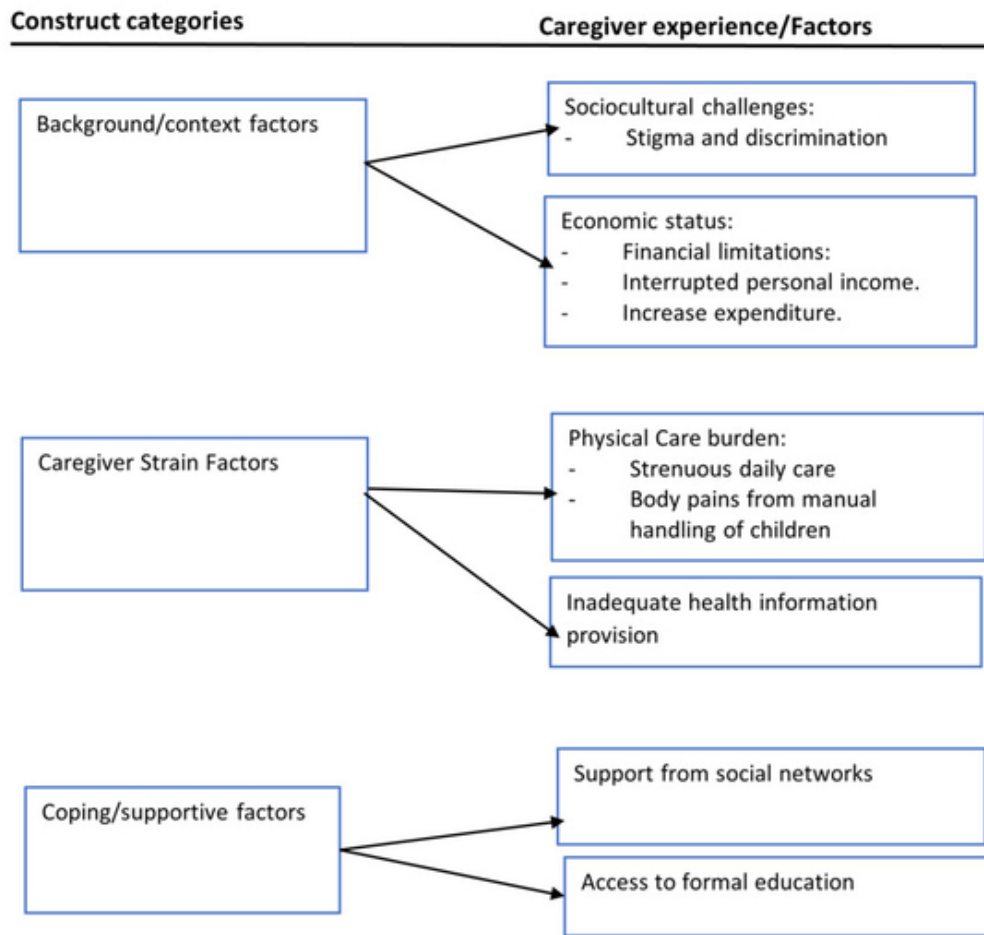


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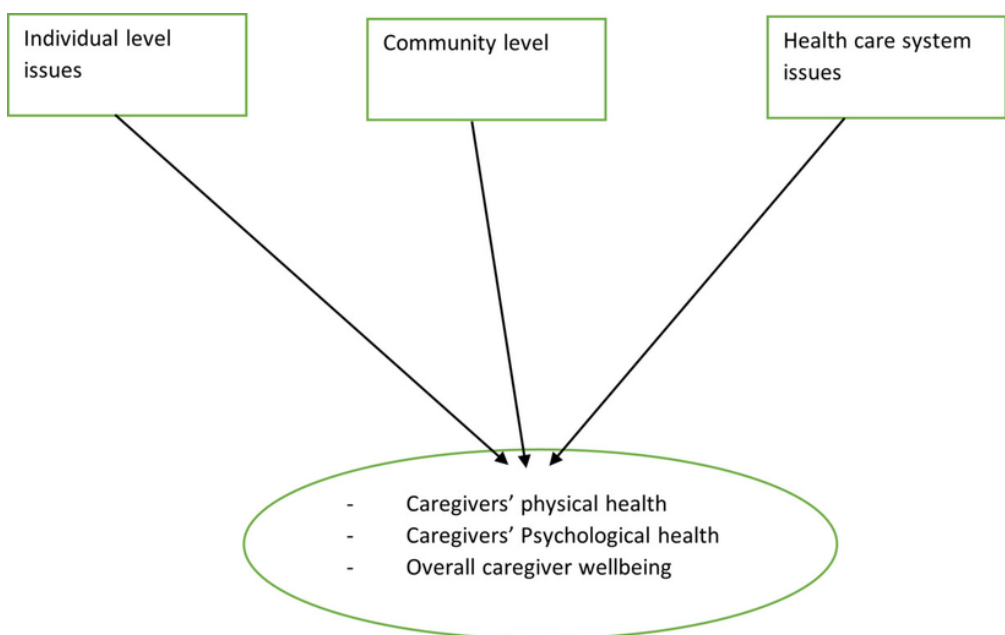
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Multidimensional experiences and challenges of caregivers

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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
	<ul style="list-style-type: none"> <li>• Relationship of caregiver to child</li> <li>• Age of caregiver</li> <li>• Educational level of caregiver</li> <li>• Occupation of Caregiver</li> <li>• Marital status of Caregiver</li> <li>• Age of child</li> <li>• Type of cerebral palsy</li> </ul>	
	Interview guide	
	<p>1. Tell me about your experience of caring for a child with cerebral palsy?</p> <p>Probes: Ask probing questions base on response of each participant.</p> <p>2. Tell me about any challenges that you experience in your role as a caregiver.</p> <p>Probes: Ask probing question to explore details of challenges mentioned by caregivers.</p>	

# 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

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Keywords:	Qualitative research, Rehabilitation

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16 12 **Credentials and occupation of Researchers**

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18 14 Lecturer

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3 **17 Abstract**  
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6 **18 Introduction**  
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8 19 Caring for a child with cerebral palsy may be more emotionally and physically exhausting than  
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10 20 caring for a typical growing child. The family caregivers' perspective of this phenomenon needs  
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12 21 exploring to facilitate the development of services. Our study explored the challenges family  
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14 22 caregivers face with children with cerebral palsy in a resource-limited context in northern  
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16 23 Ghana.

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18 **24 Methods**  
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20 25 We conducted a qualitative study underpinned by phenomenological principles where it is  
21  
22 26 believed that the reality of a phenomenon is tied to caregivers' perspectives of their own  
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24 27 experiences. In this study, we unearthed caregivers' experiences/challenges from their own  
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26 28 perspectives. The method of data analysis used was to allow the issues to emerge from the data  
27  
28 29 (Inductive process) using the content analysis approach. We recruited 13 caregivers of children  
29  
30 30 with cerebral palsy from the physiotherapy unit at Tamale teaching hospital, and conducted  
31  
32 31 individual in-depth interviews supported by an open-ended topic guide. Interviews were audio  
33  
34 32 recorded, transcribed, and translated and coded inductively before conducting a content  
35  
36 33 analysis of the data when grouped into themes.

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38 **34 Results**  
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40 35 We have identified barriers to managing a child with cerebral palsy, including; socio-cultural  
41  
42 36 barriers (values, attitudes and belief systems within society), economic challenges and  
43  
44 37 immediate physical care burdens. Specific barriers included; discrimination and isolation, lack  
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46 38 of family and societal support, with poor access to health information and formal education.  
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48 39 Others were lack of information on the cause and course of CP, caregivers' loss of jobs,  
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50 40 increased healthcare expenditure and struggles in lifting and moving children, which resonates  
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52 41 with evidence-based multidimensional model of caregiving process and caregiver burden.

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54 **51 Conclusion**  
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56 43 Caregivers have the arduous task of caring for a child with cerebral palsy. Social support  
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58 44 interventions and policy initiatives that seek to ameliorate caregivers' finances and make formal  
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60 45 education accessible to this marginalised child population may be beneficial in this context.

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**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.

## 74 Introduction

75 Cerebral palsy (CP) is a lifetime physical disability due to non-progressive injuries to the  
76 immature or developing brain (1–3) The risk factors associated with developing CP occur  
77 before, during or after pregnancy and include but not limited to intrauterine hypoxia, premature  
78 rupture of membranes, placenta abnormalities, preterm or post-term birth, asphyxia, prolonged  
79 labour, infections, hypoglycaemia, intracranial haemorrhage and respiratory distress syndrome  
80 (4,5). CP is estimated to occur in approximately 2.11 per 1000 live births globally (6), affecting  
81 males more than females (7), with more living in resource-limited settings (5,8,9).

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

## 100 Methods

### 101 Design

102 Phenomenological research methods have been employed in underpinning this study as it aims  
103 to describe the lived experience of individuals caring for children with CP. The qualitative  
104 research design literature shows that phenomenological principles acknowledge people's ties  
105 with their physical, social, and emotional world (19–24), suggesting that truth about the reality  
106 of a phenomenon is embodied in people's lived experiences (20,24). Thus, whilst a descriptive

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3 107 qualitative approach could equally be used to unearth the data required in this study to explain  
4 108 the experiences of carers of children with cerebral palsy, the phenomenological approach fitted  
5 109 in better (19,22). Caregivers vary in how they adapt to caregiving demands, and the process is  
6 110 unique with a special meaning for the individual involved (25). The study design adapted  
7 111 enabled us to account for the variability in caregivers' interpretations of their experience of  
8 112 care (26).

### 113 **Participants and Setting**

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

### 127 **Sampling and recruitment**

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

### 140 **Data collection**

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

### 160 **Data analysis**

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

## 171 Ethical considerations

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

## 180 Findings

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

185 *Table 1: Demographic Characteristics of Participants*

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



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

186

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

### 195 **Figure 1: Multidimensional experiences and challenges of caregivers**

196

#### 197 **Background/context factors**

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

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3 203 ***Sociocultural Challenges:***  
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5 204 The sociocultural issues pertain to society's cultural and intuitive beliefs about CP and its  
6  
7 205 impact on caregivers. Caregivers reported how they perceived that individuals within society  
8  
9 206 were often hostile to them, challenging their ability to live with their children with CP. In  
10  
11 207 particular, caregivers mentioned how other members within their community often stigmatised  
12  
13 208 them and had misconceptions about CP, including how it might have been caused. For example,  
14  
15 209 one caregiver of a 2-year-old child with CP explained how attending social gatherings was a  
16  
17 210 challenge due to the negative language used to describe her child as not human but animal:

18 211 *Whenever there is an 'occasion' (marriage, naming ceremonies and funerals), I do not*  
19 212 *go because of how they treat the child; I do not like it. People will just be calling her*  
20 213 *all sorts of names, saying she is not human, so I should not waste my time on her (p11,*  
21 214 *caregiver of a 2year old girl).*

23 215 One mother enunciated how she felt the subject of ridicule - describing how she believed that  
24 216 some members of the community intentionally questioned her on things they knew her child  
25 217 could not do.” Furthermore, this same mother recounted how she and her child were even seen  
26 218 as having something that might be “caught” or infectious with others purposely not sitting near  
27 219 her on public transport:

30 220 *We are now laughing stock to most people, some people know what the child is going*  
31 221 *through, and they will see you and intentionally ask you, so your child is still not*  
32 222 *walking 'Penh'? Sometimes in a car like this, they do not even want you to sit closer to*  
33 223 *them, or the child should touch them... (P6 caregiver of a 2year boy).*

36 224 Similarly, some caregivers mentioned how they felt discriminated against even by their  
37 225 relatives who would not allow their own children to interact with a child with a disability in  
38 226 case it might be infectious. Thus, the child and caregiver could not freely relate with others due  
39 227 to emotional trauma and stigmatisation from others. Such constraints encountered by  
40 228 caregivers observed in their sample narrations are as follows:

45 229 *As for discrimination, it exists. Some relatives do not allow their children closer to my*  
46 230 *child because they feel he is not normal (p5 caregiver of a 7year boy).*

48 231 It was shocking to hear that one caregiver even described how much community members  
49 232 stigmatised children with CP – believing that CP results as a punishment from “the Gods” and  
50 233 furthermore, that children with CP are “spirits and not human. This emerged in caregiver’s  
51 234 verbatim as emotionally very painful, leading some caregivers to seek cures through traditional  
52 235 healers to better understand whether their children were “spirits” or “possessed”.

57 236 *Others make insulting remarks like this your child is not a human being. We have even*  
58 237 *visited a shrine on several occasions because of that... They will give herbal*  
59 238 *preparation to bathing the child; if he is not human, he will die after bathing those*

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

### 241 ***Economic status***

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

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

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

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

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

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

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

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3 274 **Caregiver Strain Factors:**  
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5 275 The second domain of factors, caregiver strain, denotes caregiving demands and perception  
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7 276 of family centeredness of formal healthcare services. Some participants narratives generally  
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9 277 reflected the sheer physical care burden and inadequate formal health information, as detailed  
10  
11 278 below.

12  
13 279 ***Physical care burden***

14 280 Caregivers recounted the challenges with providing activities of daily living such as bathing,  
15  
16 281 dressing, and moving their child whilst maintaining their routine responsibilities to themselves  
17  
18 282 and other family members. They lamented about the exhausting nature of caring for a child with  
19  
20 283 CP. Due to the physical and neurological incapacities of the child, they depend exclusively on  
21  
22 284 their caregivers to meet all their needs. Most participants of this study experienced struggles in  
23  
24 285 meeting the demands of children's daily care. Caregivers' reports indicate that lifting and  
25  
26 286 moving their children were particularly challenging as it affected their wellbeing, as stated in  
27  
28 287 their narratives below:

29 288 *I usually feel tired due to carrying him always. It is a problem lifting him. I sometimes*  
30  
31 289 *get some body pain due to carrying him because he will not sit, so I do all the time I am*  
32  
33 290 *carrying him. I pray he can walk someday. If not, he will be a burden while growing up*  
34  
35 291 *because I cannot carry him (p3, caregiver of a 4year, 9months boy).*

36  
37 292 *I feel so tired of caring for him because he has a younger sibling I have to cater. At his*  
38  
39 293 *age (7 years), he should have been able to bathe and move about, but I still have to do*  
40  
41 294 *it (p5, caregiver of a 7year boy).*

42 295 Caregivers expressed how they often experienced body pains - depending on medications to  
43  
44 296 relieve the pain from the strenuous nature of the care they provide for their child with CP.  
45  
46 297 Caregivers also commented that care became more challenging as their children grew older  
47  
48 298 and particularly mentioned how body pains were related to having to lift and move the children  
49  
50 299 manually.

51 300 *...she doesn't want anyone to carry her, only me...so every day I have to be taking pain*  
52  
53 301 *medications, now she has reduced in weight... at first, she was heavy so when you carry her*  
54  
55 302 *hmmm my waist. Sometimes when I am in the room I cry because of the pains (P11 caregiver*  
56  
57 303 *of a 2years old girl).*

58 304 ***Inadequate health information:***

59 305 The data show that caregivers felt that healthcare professionals did not give them enough  
60  
61 306 information to enable them to understand, cope and care for their children. The lack of health

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3 307 information made some caregivers believe in the community's claims of such children being  
4  
5 308 spirits or animals. For instance, some participants suggested that even though health workers  
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7 309 took the history of their child's condition, they failed to give them information about the  
8  
9 310 condition. Caregivers with English literacy who could surf the internet resorted to finding  
10  
11 311 information about their child's condition, as demonstrated below.

12  
13 312 *They asked me questions some time ago about the child's condition, which they wrote down,*  
14 313 *but I have not been given any information regarding his condition since then... they only said*  
15 314 *we should come to this place (referring to the physio unit) and do the exercise (p5, caregiver*  
16 315 *of a 7year boy).*

17  
18 316 Even though participants reported that the internet helped them to understand their child's  
19  
20 317 condition, finding information from the internet that is not censored could be misleading as  
21  
22 318 there are sources that may not be credible. Thus, a lack of adequate information from health  
23  
24 319 workers could compel caregivers to sources of information that are not helpful.

25  
26 320 *At first, I did not know what was wrong with him because the doctors would not give*  
27 321 *me more information about this condition...Now I am beginning to understand because*  
28 322 *I browse the internet and read about it. . . . (p6, caregiver of a 2year boy).*

### 30 323 **Coping/Supportive Factors**

31  
32 324 The factors included in this third and final construct consist of social support, family function  
33  
34 325 and accessibility to formal education. Social support comprises of the informal support from  
35  
36 326 immediate family members, friends, neighbours, and the community, while function  
37  
38 327 describes the extent to which the family function as a unit in supporting caregivers. The  
39  
40 328 findings related to these are described further below.

#### 41 329 ***Inadequate support from social networks***

42  
43  
44 330 Some caregivers indicated that they received minimal or no support from family members and  
45  
46 331 others in providing care for their children. Most caregivers expressed concerns that their  
47  
48 332 children may be abandoned in the event of their absence:

49  
50 333 *It is not easy to get someone to care for him, especially when I am not feeling well. I*  
51 334 *still have to manage and care for him because, the way he is, who will have time to take*  
52 335 *care of him? (p3, caregiver of a 4year, 9months boy).*

53  
54 336 As shown in the demographics, most caregivers were females and mothers to the children.  
55  
56 337 Although caregiving roles in Ghana are traditionally female, considering the additional care  
57  
58 338 needs of a child with CP, many mothers might benefit from support from spouses. It was clear,  
59  
60 339 however in the statements of most of the caregivers that we interviewed that spouses were

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3 340 unsupportive and unhelpful most of the time – almost in rejecting the child with CP and their  
4  
5 341 caregiver.

6  
7 342 *With this one, my husband is not helping me care for him. Do you think I will try to give*  
8 343 *birth again? He does not mind us any longer. At least once in a while, he should also*  
9 344 *pick him, and I will also rest, but he doesn't. (p3, caregiver of a 4year, 9months boy)*

### 11 345 ***Inadequate access to formal education***

12 346 Another challenge caregivers encountered was that they could not find a suitable school that  
13  
14 347 would render quality education for their children. Some mothers felt their children would not  
15 348 be accepted into the mainstream schools due to their condition, and special schools were  
16  
17 349 unavailable. Thus, all schools within reach of caregivers were not resourced to admit children  
18  
19 350 with special needs like CP. Some community members who seem not to know the depth of the  
20  
21 351 child schooling problem kept recommending that the child be taken to school. See the following  
22  
23 352 expressions of participants.

24  
25  
26 353 *They said I should take her to school, but in our place, they will not admit her. They said she*  
27 354 *could not sit, and she could not walk... When you send her to these regular schools, they will*  
28 355 *not take her. Moreover, no school in our area trains such children (p11, caregiver of a 3year*  
29 356 *old girl).*

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32 357

## 34 358 **Discussion**

35 359 Our findings show that caregivers in this context encounter sociocultural, physical, and  
36  
37 360 economic challenges in caring for their children with CP. The study's findings resonate with  
38  
39 361 existing evidence and signpost critical contextual and global issues that need consideration to  
40  
41 362 develop support systems and relevant interventions. To support policymakers, practitioners,  
42  
43 363 and researchers in the design of interventions, key findings of this study are discussed in three  
44  
45 364 domains: (i) individual level issues, (ii) community level and (iii) National level (See figure 2).  
46  
47 365 The study findings in these domains, according to existing literature, impact caregivers'  
48  
49 366 physical health, psychological health and general wellbeing (25,34–36).

### 50 367 **Figure 2: Contextual Framing of Caregivers' Experiences and Challenges**

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### 371 **Individual level Issues**

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

384 Also, at the individual level were the income cuts and increased expenditures of caregivers and  
385 their families. The loss of jobs, businesses, and increased healthcare expenditures for a child  
386 with CP necessitate employers and policymakers to create a more flexible work culture that  
387 allows caregivers to engage in income-generating activities to lessen their financial burden  
388 (15,43,44). Even though the economic challenges for caregivers in this study are unavoidable,  
389 considering that the setting is generally a deprived area, the absence or limited financial support  
390 could limit caregivers' ability to access health care such as rehabilitation services for the care  
391 of their child as reported in other studies (15). Specific to this study's setting and similar  
392 populations, it might be beneficial if the current cost-sharing system of the National Health  
393 Insurance Scheme (45) is re-evaluated to meet the health financing needs of these marginalised  
394 populations with CP.

### 395 **Community level**

396 The relations of children with CP, the general public and caregivers misunderstand CP  
397 especially in settings with limited general literacy (46), leading to the attribution of the  
398 condition to supernatural causes, such as punishment from the gods and witchcraft, as reported  
399 in this study and others (46,47). In our study context, Children with CP were perceived as spirit  
400 children and punished by the gods. These perceptions were translated into the level of  
401 community engagement with the caregivers and the children. Existing evidence shows that  
402 beliefs in witchcraft and punishment by the gods lead to labelling, stigmatisation and

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3 403 discrimination against families and children with CP (47). Lack of support for caregivers  
4 404 resulting from stigma has been reported in the existing literature (11,17). This limited support  
5 405 could compound the inherent challenges of having a child with special needs. Thus, society's  
6 406 understanding of CP is critical in reducing stigmatisation and discrimination against families  
7 407 with children with CP and the associated cyclical effect on the child and caregiver. It is  
8 408 therefore critical that health information on CP is intensified to ensure that communities  
9 409 understand the causes and course of CP, promoting empathy and involvement of support  
10 410 systems in providing care for the child to improve their quality of life.

### 17 411 **National level**

18 412 The study's findings suggest that primary caregivers received limited or no health information  
19 413 about their child's condition. Limited information on health issues and services is a global  
20 414 challenge (48–50). However, challenging settings such as Ghana, with limited economic  
21 415 independence, are worst in this regard(43,51–55). Anecdotal evidence from the study setting  
22 416 suggests that health professionals provide ad hoc health education to caregivers of children  
23 417 with CP and other disabilities, using medical terms that caregivers and their support systems  
24 418 may not understand. Yet, there is evidence that adequate caregiver knowledge may promote  
25 419 better care for children with CP (55,56). Indeed, the trend of breaching the gap in service users'  
26 420 understanding of health issues and contributing effectively to service provision is through  
27 421 deliberate efforts to ensure public participation (57). Therefore, to forestall the challenges  
28 422 communities encounter with their health management, conscious efforts must be made to utilise  
29 423 evidence such as that identified in this study and introduce appropriate interventions that ensure  
30 424 optimal public participation in health care at every health service level.

31 425 Furthermore, existing evidence suggest that children with CP without cognitive impairment  
32 426 could benefit from formal education (58). Nevertheless, caregivers reported that one of their  
33 427 challenges was finding school placement for their children with CP. Although Ghana has an  
34 428 all-inclusive education policy (59), it thus appear most schools in this setting do not have the  
35 429 capacity in terms of human resources and space to admit children with CP. This situation  
36 430 resonates with other study findings in India and Kenya reporting lack of formal education  
37 431 opportunities (43,60,61). This suggests the need to operationalise educational policies that  
38 432 makes formal education more accessible to all including children with CP.



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3 433 Conclusively, though the study findings might not be generalisable, it raises issues related to  
4 434 child physical care, cultural perceptions, health information, and educational needs that must  
5 435 be translated into appropriate individual, community and national level response.  
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14

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16 440 literature review. MMM and JNS undertook the data collection, transcription, and analysis.  
17 441 YNA reviewed transcript compared with audios, JNS and MWK drafted the manuscript. MWK  
18 442 and MMM reviewed manuscript for intellectual content. All authors read and approved the  
19 443 final manuscript for publication.  
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24 444 **Data Availability:** All data relevant to the study are included in the article and its  
25 445 supplementary.  
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#### 29 446 **Patient and Public Involvement**

30 447 Patients or the public were not involved in the design, or conduct, or reporting, or dissemination  
31 448 plans of our research.  
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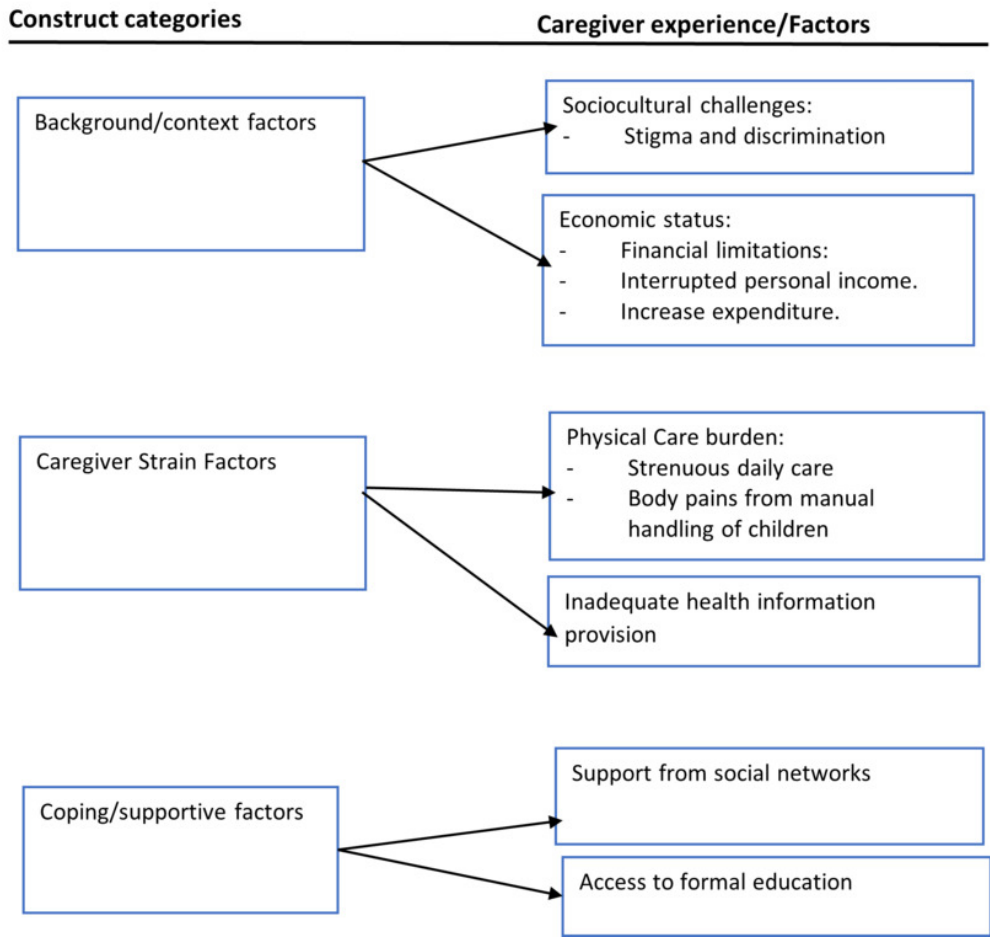
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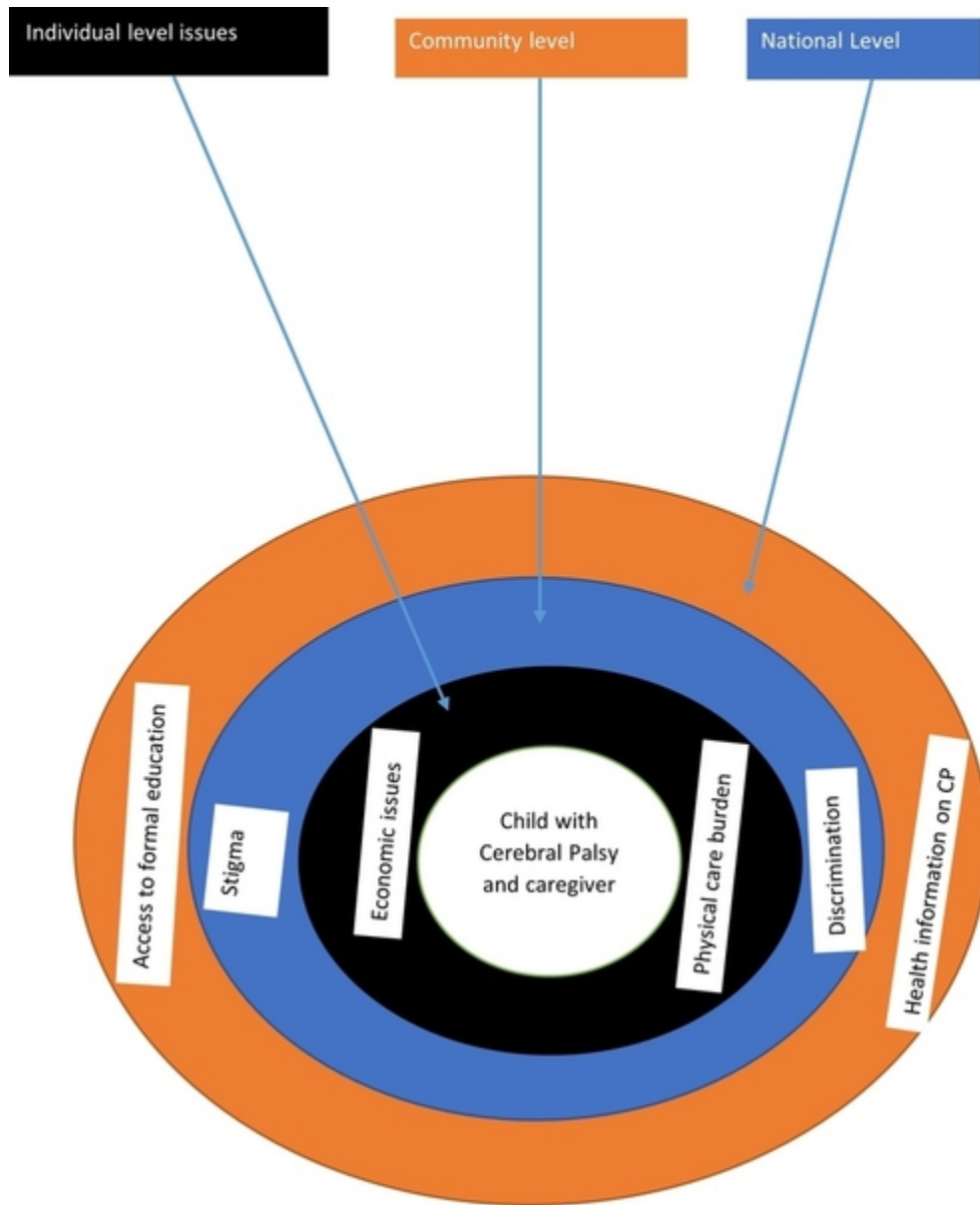
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Multidimensional experiences and challenges of caregivers

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
<ul style="list-style-type: none"> <li>• Relationship of caregiver to child</li> <li>• Age of caregiver</li> <li>• Educational level of caregiver</li> <li>• Occupation of Caregiver</li> <li>• Marital status of Caregiver</li> <li>• Age of child</li> <li>• Type of cerebral palsy</li> </ul>		
Interview guide		
<p>1. Tell me about your experience of caring for a child with cerebral palsy?</p> <p>Probes: Ask probing questions base on response of each participant.</p> <p>2. Tell me about any challenges that you experience in your role as a caregiver.</p> <p>Probes: Ask probing question to explore details of challenges mentioned by caregivers.</p>		