

RESEARCH ARTICLE

Physical and socioeconomic burden of caregiving on family caregivers of children with cancer at a tertiary Hospital in Ghana

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Abstract

Background: Childhood cancer is proportionately higher in Africa and these result in increased demands on caregivers. The inability of affected children to take care of themselves; coupled with prescribed medical interventions presents physical and social burdens on family caregivers.

Aims and methods: This study used a qualitative exploratory design to explore the physical and socioeconomic challenges for family caregivers of children diagnosed with cancer and receiving care at one of the biggest tertiary hospitals in Ghana. A total of thirteen family caregivers of children with cancer were interviewed.

Findings: Two major themes were identified: *Burden of care on Physical Health and Socioeconomic burdens of caregiving on the family caregiver*. It was reported that family caregivers encounter physical challenges such as *Aches and Pains when performing caregiving activities, Loss of Appetite, Fatigue, Compromised Functional State and Sleep Disruption*. The second theme, *Socioeconomic burdens of caregiving on family caregivers* account for the consequences of caregiving on social lives, family relationships, finance and employment.

Conclusions and recommendations: The study recommends that measures that provided relief for the caregivers such as teaching them to adopt local measures of pain relief such as massage should be encouraged. Policies should adopt measures that encourage caregivers to have some days of rest whiles providing care to their children with cancer. Also, health insurance packages that provide relief for the cost of accessing healthcare, should be extended to children with cancers to support their caregivers.

KEYWORDS

burden, cancer, caregiver, children, family, hospital

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1 | INTRODUCTION

Childhood cancer caregiving is an enormous task for family caregivers globally. The rising incidence of childhood cancers in sub-Saharan Africa presents an increasing physical and social burden to affected families (Dambi et al., 2015; Young et al., 2021). Mostly in the sub-Saharan African context, affected children navigate two phases of treatment: active and continuation phases, warranting regular commuting to and from treatment centres. Consequently, the demand for care necessitates active family involvement. Contextually, the Ghanaian family performs a wide range of varying informal caregiver roles for the sick child in hospital (Ohene et al., 2019). Culturally, the presence of the biological mother to accompany the sick child to the hospital is first and most preferred (Ohene et al., 2020). In the absence of the mother, the help of any other female member of the family will be considered. However, in recent times, few fathers may be seen in playing active sick childcare roles. Typically, the family care roles include but not limited to administering medication, providing nutritional care, supervising treatment, paying bills and communicating with healthcare professionals to keep informed on treatment and child's progress (Petricone-Westwood & Lebel, 2016). As a result of these and other roles that families play in caregiving, family caregivers are challenged in their physical and social lives (Glajchen, 2012; Leonidou & Giannousi, 2018).

The trajectory of childhood cancer care is physically demanding; involving long duration, spanning from hours to weeks, months and years, which strains the caregivers' overall health (Souza et al., 2017). In the African context, parents are mostly the primary caregivers in a child's caregiving situation (Ortiz et al., 2015). Challenges with access to therapy for the sick child contribute to physical issues for parents. Koch and Jones (2018) reported that the pain and physical distress of parents is closely tied to the sufferings and discomforts of the sick child. Examples of physical health challenges include bodily pains, sleep disturbances, appetite problems and fatigue (Barrera et al., 2021; Ochoa et al., 2020). In a systematic review, Conway Keller et al. (2020) observed that most mothers who had traumatic experiences with their child's cancer diagnosis were at a higher risk of post-traumatic stress syndrome throughout the treatment trajectory.

It is noted that the burden of caregiving increases when there is disequilibrium between care demands and caregiver's time, social responsibilities and resource availability (Leonidou & Giannousi, 2018). The adjustment of roles to incorporate care demands can affect the relationships within the family unit (Long & Marsland, 2011). For instance, frequent hospital stays with the sick child contribute to couples becoming disconnected, and this strains marital relationships (Silva-Rodrigues et al., 2016; Wiener et al., 2017). In addition, family caregivers disconnect from other social tides and societal activities. These and other unresolved burdens negatively affect the caregivers' other social roles, relationships and general family cohesion (Bally et al., 2018).

Economically, childhood cancer care is expensive and involves maximum financial commitment (Liu et al., 2020). Affected families

in low-middle-income countries are burdened with the cost of care of children with cancer (Bona et al., 2014). In the context of Ghana, health policies like the national health insurance scheme do not cover the treatment of childhood cancers (for the full benefits package see <http://www.nhis.gov.gh/benefits.aspx>). Families depend on their savings and donor agencies (nationally and internationally). In the absence of effective healthcare cost exemption mechanisms, poorer households may be affected the most. The family's expenditure increases with frequent hospital visits and distance covered to access treatment, creating discord within the family (dos Santos Benedetti et al., 2014; Fluchel et al., 2014; Shepherd & Woodgate, 2011; Woodgate et al., 2016). Furthermore, the caring role decreases the employability and productivity of family caregivers (Hovén et al., 2017). Family caregivers leave their jobs to care for sick children with associated loss of income (Wakefield et al., 2014).

The assessment of family cohesion, social networks and support systems, employment and financial resources enable healthcare professionals to adopt strategies that improve family caregivers' caregiving role, promote their social well-being and consequently improve care outcomes. Fortunately, some social and cultural factors such as local community support influence the quality of life of family caregivers and affect them positively by providing acceptance, stability and recognition of self-worth (Abu-Raiya et al., 2015). Furthermore, the extended family system and polygamous marriage in Ghana (Gyimah, 2005) and other sub-Saharan contexts have expanded networks that presumably promote the social well-being of family caregivers.

Healthcare professionals have substantial roles to play to improve the lives of family caregivers to enable them to embrace the caregiving roles with minimal challenges (Liu et al., 2020). Professional interventions for families become easier to implement whether healthcare systems are aware of context-specific needs of informal caregivers. In low- to middle-income countries such as Ghana, there seem to be few empirical studies on family caregivers' experiences and needs of children with severe or chronic conditions. This study, therefore, aims to explore the physical and socioeconomic experiences of caregiving on family caregivers caring for children with cancer. The objectives were to describe the physical and socioeconomic challenges of caregiving on family caregivers of children with cancer in the largest tertiary facility in Ghana.

2 | METHOD

2.1 | Study design

A qualitative exploratory descriptive design was employed in this study because it provided the opportunity for the researchers to gain an in-depth understanding of the phenomenon under study (i.e. the physical and socioeconomic challenges faced by family caregivers). Qualitative exploratory descriptive studies look at an in-depth, plain sailing descriptions, of a phenomenon in its natural setting

(Bradshaw et al., 2017). This approach was relevant to this study as the researchers sought to unearth the vulnerability of family caregivers caring for their sick children.

2.2 | Study setting, population and sampling

The study was conducted at the Paediatric Oncology Day Care Unit in a tertiary hospital in Accra, Ghana. The facility is the largest tertiary hospital in Ghana and one of the two centres that manage childhood cancer cases within the country and its neighbouring countries. The targeted population was family caregivers who gave primary care to children diagnosed with cancer and receiving therapy at the unit. A purposive sampling approach was used to recruit participants who met the inclusion criteria. The inclusion criteria included a caregiver with a child below 12 years, diagnosed with cancer for more than 3 months and child receiving treatment at the research setting; a caregiver must be 18 years and above and could communicate well; and a caregiver who was emotionally stable and consented to participate in the research. Recruitment was done at the facility whereas the interviews were conducted at participants' location of choice. A total of fifteen family caregivers participated in the study, and this number was determined by data saturation. Data saturation, occurred by the thirteenth participant, thus, the point of data collection where no new information was forthcoming from the interviews. Additional two participants were interviewed to confirm data saturation.

2.3 | Data collection

In-depth individual face-to-face interviews were conducted, and audio recorded using a semi-structured interview guide. The interview guide comprised open-ended questions related to the physical and socioeconomic domains of the well-being of family caregivers. Some key questions asked included; *"share your experiences of caring for your sick child with me; what have been the challenges for you as the caregiver? How has caring for this child affected your physical health and functioning? Tell me about your social lifestyle since the diagnosis of the child until now. How do you manage with work and the caring role?"* The interviews were conducted mostly in English, with few participants (four) mixing English with a common locally spoken language, Twi. The interviews lasted between 30 and 80 min. The first author conducted all the interviews, translated those in Twi and produced the transcripts for analysis. Member-checking was done to increase data credibility and reliability.

2.4 | Data analysis

The interviews were transcribed verbatim. The transcriptions were carefully reviewed for accuracy and completeness. Data analysis was done using thematic analysis procedures. The transcript was

read several times to achieve familiarization with the data. Initial codes were assigned to words and phrases which relate and reflect the objectives of the study. As data analysis progressed, trends and patterns were identified across the transcripts. Major themes and subthemes were generated ensuring linkages. The research team reviewed and refined themes and subthemes for the final research report.

2.5 | Trustworthiness

The trustworthiness of the research was ensured using the criteria by Polit & Beck (2014) as cited by Connelly (2016). Credibility was ensured through conscious recruitment of participants who met the inclusion criteria; prolonged engagement with participants during data collection; and member checks with participants during data collection and analysis. Transferability was ensured by an appropriate description of the design, sample size and sampling technique, data collection procedure and inclusion and exclusion criteria. Dependability was also ensured by documentation of the research process and an audit trail which involved scrutiny of data (transcripts and recordings). Confirmability was ensured through the exact presentation of views of the participants.

2.6 | Ethical considerations

Ethical clearance was obtained from the hospital's Institutional Review Board (REDACTED) before the start of the study. Participants were given an explanation of the study and assured of anonymity and confidentiality. Benefits, risks and discomfort associated with the study were explained to study participants. Participation was voluntary and participants were informed that they could withdraw from the study without any consequences. Participants gave verbal and written consent. Data were managed appropriately and kept safely (hard copies were kept in a safe under lock, whilst soft copies were kept in a secured folder in google drive, double password-protected and accessible only to researchers). Identification codes were assigned to each participant to ensure anonymity.

3 | FINDINGS

3.1 | Demographic characteristics of participants

Fifteen participants between the ages of 30 and 70 years were interviewed. They came from different regions in Ghana to seek care for their children in Accra, the capital city of Ghana. Most participants (7) were within the ages of 30–39, five, were within ages 40–49, two were within ages 50–59 and one was within the age of 60–69. Twelve of the participants were females, and three were males. The majority (11) of participants had some level of formal education, thus from elementary to tertiary, except for four, who had no formal education. Most

of the participants (12) were employed (either self-employed or with government agencies). Three of them were unemployed. Most of the participants (12) were married, one was single, and two were widows.

3.2 | Themes and subthemes

Two major themes originated from the objectives of the study. The first theme; *Burden of care on Physical Health* of family caregivers describes the physical health challenges that family caregivers encounter in the course of caregiving. The subthemes include *Aches and Pains due to Performance of Caregiving Activities*, *Loss of Appetite*, *Fatigue*, *Compromised Functional State and Sleep Disruption* (See Table 1). The second theme, *Socioeconomic burdens of caregiving on family caregivers* describes the consequence of caregiving on social lives, family relationships, finance and employment. The subthemes include *Social Isolation*, *Role Adjustment and sibling neglect*, *Financial Burden and Loss of Employment* (See Table 1).

3.3 | Theme I: Care burden on physical health

Family caregivers experience challenges with their physical health as a consequence of caregiving. The subthemes that emerged included aches and pains, loss of appetite, fatigue, compromised functional state and sleep disruption.

3.4 | Aches and pains

Most of the participants reported physical body pains and discomfort due to involvement in caregiving activities. One caregiver

intimated that her pains were associated with consistently carrying her weighty child.

...she is heavy and everywhere I go she wants to be carried at my back. If she is crying that she would not sit down, she must be at my back while I do house chores. All those things affected my back. My back aches a lot...

(FC3)

In most instances, the bodily pain progressed to chronic pains that affected the daily activities of the caregivers.

...I feel aches a lot. It became a chronic waist pain when lying down my body, my waist, and my legs ache. All the fibers in my body ache and I'm unable to do my usual daily activities...

(FC8)

Carrying the child at the back is one of the comforting techniques of Ghanaian mothers. In this study, all the participants reported that they carry their children on their back, irrespective of age, size or occasion. However, few participants, especially the younger parents did not report body pains and ache.

3.5 | Loss of appetite

The finding from this study revealed that parents experienced similar symptoms as their sick children. According to the participants, they experienced loss of appetite same time when their children lost interest in eating.

TABLE 1 Themes, subthemes and sample codes

Themes	Subthemes	Sample codes
Burden of care on Physical Health	Aches and Pains	Back ache, knee pains, headaches, severe headaches sharp pains in the heart
	Loss of appetite	Altered eating pattern, coerced to eat, lost appetite, ate once daily, lost weight, feed child first, eat child's leftover, days without food
	Fatigue	Doing everything by self, does everything for child, tired, fed up, exhausting
	Compromised functional state	Diagnosed with hypertension, self-care neglect, chronic pains affecting mobility, hospitalized, fainted
	Sleep disruption in response to care demand	Disrupted sleep, keeps wake, sleepless nights, sleep deprivation
Socioeconomic burdens of caregiving	Social isolation	No social gathering, restricted by caregiving, no social events, absent from church-whole year, shuttling home and hospital
	Role adjustment and sibling neglect	Siblings care for themselves, no family support, husband does chores, husband caring for kids, Keeping up with follow-up, siblings home alone, no supervision of kids, lateness to school, absenteeism
	Financial burden	Treatment expensive, financial constraints, investigations costly, cannot pay, do not have money, cost of transportation, withdrew all investments
	Loss of employment	Difficulty managing work and child, used all available leave, leave without pay, husband-lost job

Note: Source: Field, 2019.

...my child is not able to eat, sometimes a whole week, so me, as the mother too I cannot eat, I cannot feel comfortable to eat while my child is not eating the whole week...

(FC3)

Some participants noted that they will often get interrupted whilst eating. These needed interruptions were efforts to attend to the needs of the child. Mostly, it was impossible to continue eating afterward due to loss of appetite.

My eating pattern has changed completely. When I am eating and he needs something, I stop to attend to him. When I am eating and I remember him, then I lose appetite, I will not eat again. At times, I can stay for hours without feeling hungry...

(FC1)

Some participants were unable to find their regular meals due to changes in the environment. They were unable to prepare their food especially, during hospitalization.

It is hard to find what to eat when we come on admission. We do not cook here, we buy food, and mostly it is difficult to find the food of your choice. We only do with what is available, sometimes, what is served the child in the hospital is what we eat.

(FC8)

From the analysis, parents' inability to feed properly was due to physiological changes related to the caregiving, the state of the sick child and change in environment during hospitalization.

3.6 | Fatigue

Most participants indicated that they experienced tiredness and general exhaustion. Morning fatigue was reported among some of them.

...it got to a time I was so tired...I felt tired mostly in the morning when I wake up. It was not easy for me, I felt very tired.

(FC2)

Some alluded the tiredness to demanding care activities without respite, whilst others attributed it to travelling to and from the hospital, considering the distance covered on each journey.

...walking up and down always was tiring...going here and there to make sure the child gets the best of care. Aside from that, traveling from a long distance for follow-up every time is exhausting.

(FC13)

3.7 | Compromised functional state

Most of the participants indicated a change in their health and functional ability. Some developed hypertension, others had chronic pain that limited their mobility. One participant indicated she was hospitalized shortly during caregiving:

...it got to a time I was sick ... I was going to fetch water for my son and collapsed. I woke up to find myself in bed and nurses attending to me...

(FC10)

Participants maintained that caring for their children was an obligation and they could not allow their ill-health to stop them. One participant who indicated was pregnant at some point, resumed caregiving for the sick child shortly after delivery:

... I remember there was a time I sat in a chair by the bedside throughout the night and my legs got swollen... it was not easy, but I passed through all that. When I gave birth on Thursday, the following Tuesday I had to bring my sick son to the hospital for review...I had to do it.

(FC9)

3.8 | Sleep disruption in response to care demand

Participants indicated having had sleep disturbances due to preoccupation of thoughts and anticipation of the child's needs. Some keep wake to give prompt response to child's demands:

I sat by him throughout the serious moments. I just doze off a little and then I'm awake again because he might need something.

(FC13)

Participants also reported that their children mostly experienced pain in the night and cried a lot and hence found it difficult to sleep.

When she is in pain at night, she will be screaming and disturbing the whole household. Our neighbors even complained. As long as she is not asleep you would not sleep as well...

(FC3)

3.9 | Theme II: Socioeconomic burdens of caregiving on family caregivers

Family caregivers have their social lives and financial sources of livelihood disrupted as a result of caring for a child with cancer. Their finances were affected greatly due to the cost of cancer therapy.

The subthemes included social isolation, role adjustment, and sibling neglect, financial burden and loss of employment.

3.10 | Social isolation

Participants reported changes in their social lives as a result of the care of the sick child. Mostly, isolation from social activities was reported. This had a wide impact. Participants prioritized the care of their children over social activities such as attending church services, funerals, weddings and other community engagements.

...I have stopped a lot of social activities. There are things I have to do but I have left them because now all my attention is on him...I don't mingle any more. Even church, I don't go...

(FC10)

Other participants were unable to engage in social activities because of the nature and presenting symptoms of their child's illness. For example, a child with leukaemia and experiencing neutropenia could not be exposed in public due to the high risk of contracting infections.

Social life was also hell for us. I did not go to church for about a whole year. We got to know her neutrophil count was low, and she was prone to infection, so I don't take her out. We have been home and hospital for a whole year. Because of neutropenia, when somebody is even having a cough, she can easily get infected. So, I was careful she doesn't get infected, so, that kept me home.

(FC2)

Some participants isolated themselves to avoid negative comments from people. Such participants perceived that visible side effects like alopecia and weight loss were significant changes about their children that may invite questions and comments from people.

...sometimes you take the child out and people pass comments or ask what's wrong with the child. I am not comfortable with having to explain my child's illness all the time, so every time we stay at home... From the hospital to the house.

(FC4)

3.11 | Role adjustment and sibling neglect

Participants noted role adjustments to integrate the care roles into their usual routines. House chores were mostly delegated to the male spouses whilst they focused on the sick child. Typically, in the Ghanaian socio-cultural context, males are not factored in roles distribution during household chores.

Sometimes you are supposed to cook but you are somewhere...my husband does the chores. Although he does not complain I am not so comfortable...

(FC3)

Most participants recalled strain in their family relationships especially during the critical stages of the disease. Typically, the long distances between hospitals and homes of families seeking medical care for their sick child were one factor that caused a strain in families. Other factors included psychological trauma related to acceptance of the news of cancer diagnosis, acute phase of treatment and child's adverse reactions to treatments. It was mostly at these phases of the treatment that parents stay long in the hospital far from the other siblings of the sick child. According to the participants, their absence from home due to hospitalization affected the academic performance of the other siblings of the sick child.

... emotionally it was difficult for the kids to understand and accept the situation. Mostly, they would come back from school and stay in the house all by themselves because we are admitted to the hospital. My absence from home means nobody to supervise them. They were not learning as they use to do, and this was affecting them academically.

(FC2)

In some situations, siblings were mostly left to care for themselves since parents took more interest in the care of the sick child. One participant reiterated that they left their children who were below 12 years often without supervision to be at the hospital:

My husband shuttles between home and the hospital. Either he brings food to us in the hospital, or he is at home. He mostly stays late at the hospital leaving the children alone at home. They were 5 years and 9 years at the time...

(FC2)

Participants reported that sibling rivalry and empathy increased. Some siblings expressed empathy as they realized the suffering of their siblings. In other cases, they were jealous of being deprived of attention.

...it got to a time the younger ones started complaining that I have given all the attention to their brother. So the moment I tell them I am going to the hospital they will retort, 'do not sleep over'. Sometimes I had to convince them of their brother's critical state before leaving. He is the eldest so I understand their outrage since they are younger and needed attention too. It was very difficult...

(FC9)

3.12 | Financial burden

Inadequate family finances were another leading factor that caused strains in most families. Participants reported the demand on their savings due to the cost of treatment. Some spent huge sums of money during the intensive care period. Others said they could not quantify the total cost because they are still spending on the maintenance therapy.

...before we got here, we spent a lot. And over here too the errands here and there is an extra cost. All my life savings were exhausted. We were told the treatment will span 2 to 3 years; you can imagine all that will go into it...

(FC10)

Participants resorted to selling their properties to raise funds for the treatment of their children. Most of them were in debt because they had to borrow money from several sources.

...I have spent so much, and at a point, I decided to sell my house to keep my daughter alive. It's a hard decision but I had no other option. I sold some property which I don't want to mention now, and I borrowed a lot. As it stands, I have a lot of debts and my idea was that when I sell my house, I will use part of the proceeds to clear the debts and then we will depend on the rest.

(FC10)

Some participants were unable to afford regular meals due to financial difficulties. They were unable to buy food especially, during hospitalization. The situation led to some begging for food:

I sleep without eating. Sometimes I stay 3 or 4 days without food. I make sure the children at least get something to eat, so if I beg for money and it is not enough, I use it on the children...when people around cook, they give us some to eat. I make sure whatever I get, I give to the children, when they are satisfied and some are left, I also eat.

(FC5)

The above remark from participants shows how childhood cancers put enormous financial pressure on families in Ghana. It indicates that if parents have no financial resources, especially when the children need urgent medical care, they might need to look for financial assistance from family or friends. It may therefore be needful for health policy to address these difficulties for such parents, more importantly, those who may be struggling financially.

3.13 | Loss of employment

The participants noted that caring for their sick children affected their work. Some had to resign from their work temporarily to make time for their sick children.

...I like doing my own business. I deal in children's clothes, but I had to stop because when I buy the things, I am unable to go and sell them. I was not getting time, so I had to stop.

(FC9)

Another participant used her annual and casual leaves without pay from her formal employment to enable her to have adequate time to care for her child throughout hospitalization.

I was on my annual leave when this sickness started, and I took another leave to add to it, but it was not enough. I asked the doctors to help me, so they gave me three months of excuse duty. I was still on pay for the period, 4 months was added. After all these leaves, I still needed more time, so my employer gave me leave without pay.

(FC2)

4 | DISCUSSION

The trajectory of family caregiving is detrimental to the health of the caregiver. Family caregivers experience physical health-related symptoms, such as physical aches and pains, because of care roles. Studies indicate the intense physical discomfort associated with family caregiving (Barrera et al., 2021; Glajchen, 2012; Liu et al., 2020) stemming from physical manoeuvres associated with care that ensures the sick child's comfort, safety and reduced anxiety (Torimoto-Sasai et al., 2017). In most instances, caregivers prioritized the sick child's needs over their health needs and paid little attention to their own discomforts. Family involvement in caregiving is embedded in the African culture where physical or intimate closeness is perceived as mothering, when a child is indisposed. Achema and Ncama (2016), Ohene et al. (2019) and Østergaard et al. (2016) reported that physical closeness is key in providing psychological, emotional and social well-being to a sick child in the Ghanaian context. Family caregivers' obligation to satisfy the physical and emotional needs of the sick child overrides their self-care and consequently impacting negatively on their physical health.

Moreover, most family caregivers are unable to discuss their health challenges for medical attention. Perhaps limited family-centred care practice in the African context poses a challenge for families to discuss their own health needs with professionals (Uhl et al., 2013). This makes family caregivers often rely on self-medication practices that predispose them to high medical risks (Badiger et al., 2012). To mitigate these challenges, family caregivers could be educated to practice alternative measures of symptom relief rather than self-medication. In the context of Ghana, nurses and doctors could recommend periodic body massage as one of the non-pharmacological means of physical relief (Aziato et al., 2017). The healthcare system and practitioners must recognize the involvement

of the family in caring for the sick, and as such, integrate the concept of family-centred care in healthcare delivery for quality care (Ferrell & Wittenberg, 2017).

The caregiving process affects the eating patterns of family caregivers. The intensity and hours spent in caregiving have been noted to affect the eating patterns of family caregivers (Lee et al., 2021; Margolis et al., 2021). Conversely, family caregivers who received some level of support experience normal routines and relatively adequate self-care (Mosher et al., 2015). The influence of finance on the availability of food is an issue of concern in sub-Saharan Africa (Connolly-Boutin & Smit, 2016). Family caregivers were unable to have regular meals because of financial constraints and the hardship imposed by the child's illness (Santacroce et al., 2018). Ghana is classified as a middle-income country, yet the standard of living and poverty level among rural dwellers is alarming. Recently, the Ghana Poverty Profile (GPP) did indicate that about 2.4 million Ghanaians are living with extreme poverty (Ghana Statistical Service, 2019). This reflects in the findings of the study which infers that food security is still a challenge in most sub-Saharan African countries. It is imperative to note that changes identified in the pattern of eating are linked with the preoccupation with caregiving activities and unavailability of food associated with financial constraints.

Caring for a child with cancer poses other physical health challenges such as fatigue and general exhaustion. Caregiving involves physical energy and combining care roles with routine activities and care of other children which are exhausting (Salehitali et al., 2018). Support for caregivers promotes respite (Qualls, 2016), however, family caregivers in this study received limited support. Evidence shows that caring for individuals with chronic diseases unsupported can predispose caregivers to diseases such as hypertension, cardiovascular and musculoskeletal problems (Saria et al., 2017). Extreme exhaustion and burnout result in frequent hospitalization of family caregivers (Grant et al., 2013), which interferes with the caregiving process. Family caregivers noted meaningful disturbances and disruptions in their sleep patterns (Margolis et al., 2021). Their inability to sleep well alters daytime activities and their overall health (Barrera et al., 2021). Assessment of family caregivers before the assumption of care roles and in the course of caregiving is imperative to improve their well-being (Ferrell & Wittenberg, 2017). Currently, in the sub-Saharan African context, evidence suggests that family caregiving is a dominant informal practice in the health delivery system, yet given little recognition (Bekui et al., 2020; Nortey et al., 2017; Ohene et al., 2020).

Caregiving affects the social lives, finance, employment, roles and relationships of family caregivers. Social isolation, reported by caregivers in this study emanated from intentional withdrawal from social activities to have time for their sick child. The increasing responsibilities associated with care (Otis-Green & Juarez, 2012), limitations imposed by the presenting illness and side effects contribute to the disconnection from society. Social isolation, irrespective of the reason, has implications for psychological and emotional well-being which also resonates in physical health challenges (Bally et al., 2018).

Increased financial expenses related to cancer care drain the family's financial resources (Wakefield et al., 2014). Family caregivers sell properties, secure loans and solicit financial assistance from various sources to continue paying for treatments (Bona et al., 2014). Families struggle to sustain payment for treatment despite the cost-effectiveness of management of childhood cancer in Ghana (Renner et al., 2018; Santacroce et al., 2018). The treatment cost for childhood cancer care is among diseases not included in Ghana's National Health Insurance Scheme (NHIS), which makes every expenditure the responsibility of the family. Consequently, financial strains result in default or discontinuation of treatment, as typical in low-middle-income countries in the childhood cancer context (Bestvina et al., 2014). Increased demand for physical care and constant presence at the bedside of the sick child, made caregivers endure challenges in the area of employment. Some family caregivers resign from employments (Bona et al., 2014), whilst others use leaves of absence (Chung et al., 2013), to focus on the care of the sick child. Most self-employed caregivers in the study lamented about losing customers and products. Role adjustment was imperative to incorporate new roles. Other siblings were often caring for themselves. Sibling empathy and rivalry were evident. Older siblings of the sick child were empathetic and showed concern whilst the younger ones were often jealous that they were deprived of their parents' affection (Long & Marsland, 2011).

5 | LIMITATIONS

The study was limited to a tertiary hospital in Ghana and does not reflect the perspectives of family caregivers from other settings. The study also involved recall hence liable to participant bias. The authors were more concerned about unearthing the challenges of family caregivers in the childhood cancer caregiving process in the Ghanaian socio-cultural context for advocacy.

6 | CONCLUSION

The challenge of informal caregiving and its impact on the well-being of family caregivers cannot be underestimated. Family caregivers experience challenges in their physical health and social lives as a result of caregiving. These challenges affect their well-being. It would be appropriate for policymakers to develop measures that will address the physical and social needs of family caregivers of children with cancer. Empowering family caregivers with needed skills and knowledge on cancer caregiving and promoting support, would minimize the negative physical and social impact of caregiving. The Ministry of Health, Ghana, with other stakeholders should lobby for the inclusion of childhood cancer treatment in the nation's NHIS to ease the financial burden on the family. Family caregivers should be encouraged to communicate their health problems to professional healthcare providers for

appropriate attention and guided to plan care activities to allow respite. Professional health care providers can encourage the development of peer support groups within their communities. Clinicians should build a trusting relationship and employ effective communication skills in interacting with family caregivers to identify challenges and recommend appropriate measures of solution. They should also design tools to assess the physical and social well-being of caregivers as part of their protocols. Satellite diagnostic centres for childhood cancer should be opened in every region to minimize the distance covered to access treatment. The government and all stakeholders should lobby for funding for childhood cancer and inclusion in the NHIS.

AUTHOR CONTRIBUTIONS

All the authors conceived the study. BAA collected the data and developed the transcripts. All authors: BAA, LAO, CB, MOA and LA analysed the data at scheduled research meetings. BAA produced the first draft of the manuscript for LAO, LA, CB and MOA to review. All authors read and approved the final manuscript.

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (<http://www.icmje.org/recommendations/>)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

ACKNOWLEDGEMENTS

The authors extend their profound gratitude to the Head of Department of Child Health, of the Paediatric Oncology Unit for their invaluable support during the recruitment of participants. We also thank all the participants who availed themselves for this study.

CONFLICT OF INTEREST

The authors do hereby declare that there are no competing interests from any organization of affiliation. They neither have personal nor financial relationships that might have influenced the writing of this paper.

DATA AVAILABILITY STATEMENT

All data generated or analysed during this study are included in this manuscript and its supplementary information files.

ETHICS APPROVAL

Institutional Review Board (KBTH-IRB/000125/2018), Korle-Bu Teaching Hospital, Accra, Ghana.

DECLARATION

We declare that this manuscript is our original work, and all references were duly acknowledged.

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How to cite this article: Bekui, B. A. A., Ohene, L. A., Badzi, C., Ampomah, M. O., & Aziato, L. (2023). Physical and socioeconomic burden of caregiving on family caregivers of children with cancer at a tertiary Hospital in Ghana. *Nursing Open*, 10, 915–925. <https://doi.org/10.1002/nop2.1359>