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Burden experienced by informal caregivers of children with sickle cell disease (SCD): a qualitative exploratory study at Tamale Teaching Hospital, Ghana

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ABSTRACT

Objective This study sought to explore the burden experienced by informal caregivers in caring for their children with sickle cell disease (SCD).

Design A qualitative exploratory design was employed in the study using in-depth interviews.

Setting The study was conducted at the sickle cell clinic of the Tamale Teaching Hospital, Ghana.

Participants Data were gathered from 15 purposely selected informal caregivers, whose children with SCD received care at the sickle cell clinic of the Tamale Teaching Hospital, using a semi-structured in-depth interview guide in May-June 2021. Their responses were audio-taped, transcribed and analysed using the reflexive thematic analysis approach.

Results Five major themes emerged from data analysis. These were: the burden of children’s ill-health; financial burden; employment challenges; psychosocial burden and determinants of caregivers’ burden. These burdens destabilised the personal lives, financial standing, social relationships, and employment of caregivers in general and that of other immediate family members, thus, impacting family processes and health.

Conclusions Health professionals must devise strategies for counselling, early diagnosis and effective management of children with SCD across Ghana. The Ministry of Health must subsidise medications and laboratory services for children with SCD to help minimise the financial burden on caregivers. Further, counselling and psychological support services must be established in hospitals to assist caregivers to cope effectively.

INTRODUCTION

Caring for a child with sickle cell disease (SCD) has been described by several studies across the world as burdensome most especially for parents or caregivers of these children.1 2 Caring for a child with SCD places extra demands on parents, both physically and psychologically, which may harm their quality of life.3 Parents have to face the reality of the illness after their children are diagnosed with SCD and to manage everyday life while caring for their children with SCD. Families of children with SCD most especially experience financial difficulties, and are unable to make quality time for their other children resulting in deteriorated social lives.2

Healthcare professionals must devise strategies for counselling, early diagnosis and effective management of children with SCD across Ghana. The Ministry of Health must subsidise medications and laboratory services for children with SCD to help minimise the financial burden on caregivers. Further, counselling and psychological support services must be established in hospitals to assist caregivers to cope effectively.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Being a qualitative study, the study ensured the unearthing of the caregivers’ experiences of burden as generated from their perspectives.

⇒ Despite efforts to achieve heterogeneity in the participation, the sample and results are shaped by caregivers who were willing to participate, which may limit the transferability of the findings.

⇒ Due to the small sample size, the results cannot be generalised. Transferability of the findings may also be limited to the setting.

⇒ The authors’ experiences as nurses may have influenced their interpretation of the participants’ experiences.

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setting, as it presents with varied psychological, physical, social and emotional distress on informal caregivers of affected children, hence requiring informal caregivers to adjust in various aspects of their lives, making life unbearable. The exhaustion resulting from caring for children with SCD, such as frequent follow-up visits to the hospital, care during vaso-occlusive painful episodes and the stress of combining these activities with employment, subjects these caregivers to extreme burnout and subsequently development of some chronic illnesses like hypertension and its medical complications.

SCD is a global burden accounting for 305,000 births in 2010, and affecting millions of people. Over 200,000 babies are born yearly with SCD in Africa and in Ghana, about 15,000 newborn babies have SCD, with 55% of them having the homozygous form. Despite the presence of newer modalities of management such as hydroxyurea in Ghana, it is observed that it is not being widely used. As a result of some of these issues, caregivers of children with SCD in some jurisdictions have reported negative emotional and personal life impacts of the disease, and others showing difficulty in maintaining family relationships and meeting the needs of other family members.

A retrospective review of admissions of children from the admissions register of the paediatric ward of the Tamale Teaching Hospital, from January 2018 to October 2020, revealed 242 admissions, of which the majority attended the SCD clinic. Despite the high prevalence of SCD in Ghana, the nature of the burden experienced by parents and other informal caregivers of these children remains largely unexplored in the country. This study, therefore, sought to explore the burden experienced by informal caregivers of children with SCD at the Tamale Teaching Hospital of Ghana.

METHODS
Design
The study employed an explorative qualitative research design, owing to the fact that there is paucity in literature about the phenomenon of the burden experienced by caregivers of children with SCD in Ghana. The researchers believed that exploring the phenomenon qualitatively will bring to the fore the various issues of burden experienced by informal caregiver or parents for the appropriate interventions to be recommended to help lessen their burden.

Setting and participants
The study was carried out at the Tamale Teaching Hospital, a tertiary healthcare facility in the Tamale Metropolis of the Northern Region of Ghana. The Tamale Teaching Hospital provides tertiary healthcare services, mainly to the general public within the northern part of Ghana. The hospital has a bed capacity of 800. The hospital is also a centre for undergraduate and postgraduate training of medical, nursing and other health professionals. The paediatric SCD clinic at the hospital was used as a setting for the recruitment of study participants. The study participants were informal caregivers or parents of children with SCD who sought healthcare at the Tamale Teaching Hospital.

Sampling and data collection
Eligible participants were approached, and the objectives for the study explained to them. They were subsequently given information sheets and consent forms to sign when they agreed to participate in the study. Face-to-face interviews were used to collect data while observing the COVID-19 preventive protocols. A semistructured interview guide based on the study objectives was used (see online supplemental file 1). The interview guide was translated into ‘Dagbani’ and ‘Dagaare’, native languages spoken by most people within the municipality where necessary. Flexibility of language allowed the researchers to ask participants open-ended questions and to probe issues of interest in participants’ own language. The interviews were audio-recorded, with each interview lasting 40–50 min over a period of 6 weeks (May–June 2021) until data saturation was reached. Data saturation was observed on the 15th interview when the interviews no longer produced new information.

Trustworthiness and rigour
To ensure credibility, the researchers explained to participants the purpose of the study to their understanding and were allowed to ask for clarifications. The researchers repeated some responses of participants to confirm the true reflections of their experiences, and made use of interviews, observations and field notes. Interviews continued until saturation when participants’ responses did not yield new responses to ensure dependability. Confirmability of data was ensured by ensuring that coded data were categorised into major and subthemes. Pilot studies were done for validity and reliability. Transferability was ensured by giving a detailed account of the research design, research setting and the use of purposive sampling method to select participants who met the inclusion criteria. This paper has been presented following the Standard for Reporting Qualitative Research by O’Brien et al.

Data analysis
Data gathered from participants were transcribed verbatim and analysed using thematic analysis. Thematic analysis is a method for systematically identifying, organising and offering insight into patterns of meaning (themes) across a data set. Focusing on the meaning across a data set, it allows the researcher to see and make sense of the collective or shared meaning and experiences. The use of field notes by the researchers also aided to better understand the phenomenon as espoused by Tenzek.

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

Demographic characteristics

Table 1 presents the demographic data of the 15 caregivers and their children with SCD who participated in the study. As shown in the table, majority of caregivers were male (9), aged between 35 and 60 years (mean age 44.5 years, SD±6.4), married (11) and educated to the tertiary level (11). In terms of employment, most were traders (5) and teachers (4), with monthly incomes of between Ghc (Ghanaian cedis) 300 and Ghc3000 (mean income Ghc1343, SD±827.8). Most of the children with SCD had ages ranging from 3 to 15 years (mean age of children with SCD 9.6 years, SD±2.8). The rest of the demographic characteristics are displayed in table 1.

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Participants’ sociodemographic characteristics</th>
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</thead>
<tbody>
<tr>
<td>Gender of caregivers</td>
<td>Frequency (n=15)</td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
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<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>Others</td>
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<tr>
<td>Age (years) of caregivers</td>
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<tr>
<td>35–39</td>
<td>1</td>
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<tr>
<td>40–44</td>
<td>8</td>
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<td>45–49</td>
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<td>50–54</td>
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<td>55–59</td>
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<tr>
<td>60–64</td>
<td>1</td>
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<tr>
<td>Educational level of caregivers</td>
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</tr>
<tr>
<td>No formal education</td>
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<tr>
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<tr>
<td>Secondary education</td>
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<tr>
<td>Tertiary</td>
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<tr>
<td>Caregivers’ employment status</td>
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<tr>
<td>Employed</td>
<td>9</td>
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<tr>
<td>Unemployed</td>
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<tr>
<td>Self-employed</td>
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<tr>
<td>Monthly income level of caregivers (Ghc)</td>
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<td>0–500</td>
<td>4</td>
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<tr>
<td>501–1000</td>
<td>2</td>
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<tr>
<td>1001–1500</td>
<td>4</td>
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<td>1501–2000</td>
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<td>2001–2500</td>
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<tr>
<td>2501–3000</td>
<td>1</td>
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<tr>
<td>Age (years) of children with SCD</td>
<td>Frequency (n=17)</td>
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<td>1</td>
</tr>
<tr>
<td>6–10</td>
<td>10</td>
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<tr>
<td>11–15</td>
<td>6</td>
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</table>

Mean age of caregivers=44.5 (SD±6.4) years, mean caregiver income=1343 (SD±827.8), mean age of children with SCD 9.6 (SD±2.8) years.
*Some participants had up to two children with SCD.
Ghc, Ghanaian cedis (currency of Ghana); SCD, sickle cell disease.

Themes

The caregivers, in their narratives, described life after the diagnosis of their children with SCD as being ‘difficult’, ‘unbearable’, ‘hard’, ‘a burden’, ‘sacrifice’ and ‘hell’. Analysis of the transcribed data generated five major themes, which included: burden of children’s ill-health; financial burden; employment challenges; psychosocial burden; and determinants of the burden. These themes are further illustrated in the ensuing sections.

Burden of children’s ill-health

Caregivers knew about the existence of SCD in their community, and even knew other people who lived with the condition. They, however, did not foresee the ordeal one had to pass through to provide care to their children with SCD. Some participants had more than one child with the condition. The major burden encountered by caregivers was attributed to the child’s ill-health. This mostly occurred during the vaso-occlusive painful episodes (crisis). According to the caregivers, the burden is worse when they see their child go through the pain. They indicated that this makes them (the caregivers) experience the condition as well (although indirectly). Sometimes, they wished they never brought the child to this world, and some caregivers who had more than one affected child even decided not to have any more children. The frequent and long hospital stays as a result of vaso-occlusive crises predispose some of the caregivers and other family members to nosocomial infections. This was typically expressed by one of the participants below:

… My son goes into crisis twice in a week, and anytime we are going to the hospital, we pack even cooking utensils because we always stay at the hospital for not less than a week… And throughout this period, my husband and our other 2 children are brought along. There is no one to care for them at home and usually 3 days after each discharge, we return to the hospital because either my husband or I or one of the siblings will also fall sick, sometimes even put on admission. (FC4, 40 years)

As a result of anaemia as a complication of SCD, most participants indicated that their wards have had to receive blood transfusion several times. Some explained that their relatives who donate blood for the transfusions have become fed up, and give excuses each time the wards required transfusion. Caregivers are therefore left with no choice but to pay strangers to donate for them. They expressed their fear of giving a stranger’s blood to their child and the risks involved as shown by the quote below:

… The major cause of my son’s hospitalization is anaemia. I have been told my blood is not good for
The caregivers expressed concern about the delay in growth and development of their children as compared with other children of the same age. They added that they spend a lot of money on food to ensure their children got all the nutrients they were educated to provide for them. However, they do not see the impact on their growth, which makes people judge them for not providing proper nutrition to their children. A mother shares her experience below:

One day, after church I was approached by an elderly church member about my daughter’s appearance. She asked me what I have been feeding her with and started lecturing me on food and how to combine them to make her grow well like her children. She even added that the frequency of her hospitalizations is because I don’t feed her well. I wept, knowing all the efforts I put into her diet. (FC5, 45 years)

Some of the participants also revealed that their children with SCD, due to delay in development, took a longer period to walk as compared with their siblings or other children of the same age who were not affected. This attracts gossip and ridicule from the community, church and caregivers’ workplaces. From their narrations, most of these children walked after 2 years as compared with other siblings who walked before or at 1 year old. A caregiver had this to say as an illustration:

My first child is the one with SCD. He started experiencing the joint pains and swelling as early as 7 months, and I think that delayed him from walking early. He started walking at 3 years, but his other 2 siblings all walked at 11 and 12 months. I believe it’s the condition that delayed the firstborn. (FC6, 40 years)

Financial burden
Caring for a child with chronic illness is financially draining as expressed by all the participants. Caregivers attributed their financial burden to the cost of medications and routine laboratory investigations. The caregivers narrated that the routine medications of their children such as folic acid, penicillin V and analgesics are not often available. As such, they have to buy them outside the hospital, which are often very expensive. The costs of laboratory investigations and new medications are often expensive as well, and unavailable at the health facilities. Getting these services from private laboratories and pharmacies drains them financially even further. These lead to delay in seeking medical services during the onset of illness because healthcare providers demand laboratory investigations to guide the care of the children. Therefore, caregivers resort to managing their wards’ conditions at home to a point where the child is no more responding to home management before seeking care at the hospital, by which time they might have managed to gather some little funds for care. Two caregivers illustrated this experience below:

I have to always prepare myself financially because he can fall sick at any time. Any time we visit the hospital we spend so much, especially on the laboratory investigations. So, I have to make sure I’m fully prepared for the expenses. If not, then I have to manage him at home until I get money, else our going there [hospital] will be useless. (MC9, 55 years)

There are occasions when we need to go for review, and I refuse. Sometimes, my daughter will think I have forgotten and she comes to remind me. But, I just have to lie to her that the date is rescheduled, not because I’m busy ooo, but because I don’t have money to do those laboratory investigations, there is no way you will visit the hospital without those labs done, it’s not easy. (FC2, 35 years)

The wards of caregivers being active registrants of the National Health Insurance Scheme (NHIS) did not relieve caregivers of the financial burden. All the children with SCD had active NHIS at the time of this study. Yet, all participants complained of financial hardships brought on by their children’s condition. Some caregivers intimated that it would have been better if their children were not registered for NHIS because almost every service they access has to be paid for in cash, especially laboratory services. A typical experience was shared by a caregiver below:

I renew his health insurance anytime it expires. But, I don’t even see the impact because I pay for every service. Most of the time we are requested to do the laboratory investigations at Lancet [laboratory] because that is the most trusted laboratory. However, their services are very expensive as compared to other private laboratories. The last test I have done there is Ghc60. Medications are not included. We are suffering. I wish some of those laboratories would accept the health insurance, it would have been very helpful. (MC7, 40 years)

In caring for a child with SCD, caregivers have always been counselled on giving highly nutritious meals to their children. The caregivers reported giving at least one fruit a day to their wards, and adding more vegetables to help boost their immunity and haemoglobin levels. However, those fruits and vegetables, according to some participants, are quite expensive, especially in the northern part of the country where such fruits are not native. Most caregivers, therefore, admitted they are unable to follow the nutritional recommendations given them. This is illustrated below by a caregiver:
When we were living in Techiman [a town in the south], we could get a variety of vegetables and fruits at very affordable cost. So, at that time, the cost was not a problem. But, when we came to Tamale [a city in the north], prices are high. So, it has been a challenge to meet her nutritional requirement, but we are trying. Once in a while, if we can afford, we get them [fruits and vegetables] for her. (FC1, 60 years)

It was also disclosed by some caregivers that the financial drain from the care of their children with SCD affects the care for other members of the family. The health of the sick children is always prioritised in spending their earnings as compared with the caregivers themselves and other family members. A male caregiver with three children with SCD shared his experience:

Last year, we had to change their [the children with SCD] siblings school to a low cost school because the financial demand had gone up. We can’t save any money because we spend almost everything on their healthcare. Just so we can also be at peace when the crisis is delayed. It was a hard decision for us to take. The siblings didn’t want to change school and wept bitterly but we had to console them. That was the only option else they have to be out of school. We couldn’t afford the fees any longer. (MC1, 50 years)

The financial burden experienced by caregivers affects the health services received by their children with SCD. Similarly, other members of the families are not spared. This sometimes makes it very difficult for them to fully access some basic needs of the family. Because caregivers are unable to help other family members in need, hardly do they also receive any financial help from those family members, making life extremely difficult for the caregivers.

Psychosocial burden

Facing the reality of their children’s diagnosis was very devastating to caregivers. The distress was worse for caregivers whose wards with SCD experienced several admissions and transfusions over the years. Some caregivers lived with anxiety and uncertainties for years, not knowing what their children were going through and its outcome. For those caregivers who knew their sickling status, it was much easier as the news of their children’s condition was not much of a surprise. Therefore, their experience of psychological distress was much shorter than the participants who did not know their sickling status before their children were diagnosed. Some had depression, while others are still living with the psychological stress of caring for a child with SCD, as expressed by a participant below:

I knew some friends at school and some church members who had SCD. …the painful experiences they had. Some had to leave school because of the with SCD. I was overburdened. There is no day I report to work early. Just 2 days ago, I received a query letter. I’m sure the next one will be a sack letter, to avoid loosing my job, my wife had to rather quit her job to support the children, because my salary is better than hers. (MC1, 50 years)

My child go into crisis about twice each month, and some times, we have to stay on admission for 3 to 4 days. All these hours are calculated and deducted from my pay at the end of each month. At the end of the day, the money I get is not able to care for our needs, but I can’t complain. I know my work output is reduced. I either have to manage with that or quit the job. It so frustrating. (FC4, 40 years)

I have worked as a nurse for 10 years now. But, I have never been promoted. My head will not recommend me because she complains that I’m lazy, even though I send her reports [medical] about my child’s condition. I sometimes feel like quitting, but where will I get money for all our expenses? (FC5, 45 years)

For those participants who run their own businesses, they complained bitterly of not being able to open their shops and business premises during days when their children were on admission. As such, they lose most of their customers and their goods get expired, making it difficult to pay their suppliers. One caregiver illustrated this:

... last month, we were on admission for one month because his condition was not improving. And all this while, my shop was locked. We spent more than two-thousand Ghana cedis. Since I returned, my daily sales have dropped. I could sell about 1000 cedis a day, but I hardly make up to 300 hundred cedis now. All my customers are gone. The shop is becoming empty. I can’t even settle my suppliers to refill it. (MC2, 44 years)
painless experiences. So, when I was told about the diagnosis, I reflected on all that I witnessed in the past and broke [down] into tears. In fact, for a month, I couldn’t eat well and wasn’t interested in anything. It took my husband’s consolation and reassurance to get better. I even had an accident [on a motorbike] a week after [the diagnosis] because I was always absent-minded. (FC5, 45 years)

Having a child with SCD means caregivers have to adjust in all areas of their life to cope with the care demands of the child. Most caregivers had to quit their jobs, others got sacked, while some exempted themselves from all social functions and relationships. According to the caregivers’ narrations, they have lost good friends and relationships because they were not present at social functions of such friends. Some friends of the caregivers reportedly felt that these caregivers were intentionally refusing to attend their social events, leading to the end of such friendships. This led to some caregivers feeling abandoned. Those friends and relations who were helpful to them no longer help them. The inability of some participants to make financial contributions during family and community contributions got them branded as being stingy. All these stress the caregivers psychologically and get them isolated socially. This has been illustrated by two caregivers below:

Just last month, my brother lost her wife and the funeral was at Kumasi. I couldn’t accompany him because my child was in crisis and on admission. I had no one to take care of him. That same month, my very close friend was doing her wedding and I was made the bridesmaid, but I had to disappoint her because of my child’s situation. I feel so ashamed for missing such important occasions, but I can’t do otherwise. Others try to understand [me], some too never does. I have to just let it be. (FC6, 40 years)

… I belong to a very big association in my church and contributed a lot to its growth. However, since my child was diagnosed, my services to the association has reduced. I have not been able to attend any of their meetings since last year. When my mother died, I invited them but they refused to come because I’m no more contributing much as I used to. I was really surprised at their action because they are aware of my child’s situation. I was very sad that day. (FC3, 42 years)

**Determinants of caregivers’ burden**

The age at which the children with SCD were diagnosed and the type of treatment received were the major factors that affected caregivers’ experience of burden of their children’s condition. This theme was determined from the participant’s narrations that these two factors either decreased or increased their experience of burden.

**Time of child diagnosis**

None of the 15 caregivers had their child diagnosed at birth. Only one participant had all his two affected children diagnosed at 3 months of age because the parents knew of their sickling status, and anticipated having children with SCD. As such, they sought early assessment and diagnosis. One participant also had his child diagnosed at 6 months because the child started showing symptoms at that age. Two others had their children diagnosed at age 1 year. So, they initiated treatment early. These caregivers added that early diagnoses and treatment initiation helped to cut down the hospitalisation and haemotransfusion rate of their children. These themes are illustrated in figure 1 and the ensuing quotes from some participants.

… because my wife and I knew we were carriers and have [the] chances of having children with SCD, though our children did not show any symptoms, at 3 months we sent them to be assessed. And so, both of them were diagnosed as early as 3 months and put on the treatment. I think the early diagnosis and initiation of the treatment was helpful because they hardly get any crisis. None have ever been on admission and their Hb have always been good, no transfusions. (MC3, 41 years)

The rest of the participants had their children diagnosed between the ages of 2 and 7 years. It was realised from the narratives that these caregivers, whose children were diagnosed late, did not know their sickling status until the diagnosis of their children. As such, it took several episodes of illnesses, admissions and blood transfusions before they were finally diagnosed. Sometimes, the diagnosis came at the point where complications have already set in. A participant underscored this in the narrative below:

My son was well until 4 years old when he started falling sick. We visited the hospital on several occasions, where they managed different conditions until a year later, he fell sick and was sent to the hospital. Even then, he was being managed as meningitis for a week before the sickling [test] was done to reveal his diagnosis. At that time, he had severe chest pains, appeared very thin, and though he is on treatment, I don’t see the difference because we still visit the hospital frequently, and he receives transfusion each time he goes on admission. Now, they said he has bone infection as well. (MC2, 44 years)

**Type of treatment given**

All the caregivers disclosed that their children were put on routine medications, which were identified as folic acid, multivitamin and penicillin V (for those under 5 years). They reported abiding by all the counselling received and administered the medications to their children as per directives. However, some reported not seeing any significant changes in the health of their children and increased crises
episodes. These themes are captured in figure 2, with an illustrative quote from a participant below.

… since diagnosis till now, upon all the medications and the routine medical reviews, I still see that my children are not improving. They look worse than before. Sometimes, I doubt if the medications are effective. Now, he [the male child] has even stopped schooling because he stays home frequently, and he is not performing [well] in his academic work. (MC7, 40 years)

Further, other caregivers made mention of the drug hydroxyurea as a new drug for their children’s condition. Though an additional cost to caregivers (since it was not covered by NHIS), some caregivers attested to its effectiveness as they went the extra mile to secure funds to buy the medication to improve their children’s health. A caregiver attested this in the following quote:

My daughter has been on hydroxyurea for 2 years now. Before the initiation of this medicine, she was frequently on admission and receiving blood most
at times, with frequent of the crises. So, the doctor counselled us about the medication and we agreed because we just wanted to see her fine and happy like her other siblings. So, we opted for it. We have never regretted accepting the hydroxyurea because it has massively improved my daughter’s health. She has never had any crisis since she started taking it. Her frequent blood transfusions have ceased because her Hb has now gone up to 11 as compared to the initial, which used to be as low as 5.4 to 7.5. She does’t miss school anymore and she has also improved academically. Despite the extra cost, at least it gives us peace.

(FC4, 40 years)

Other caregivers, however, rejected hydroxyurea therapy due the cost of medication, and their fear of its perceived future negative effect of infertility on their children. Below is typical expression by some caregivers:

... two years after diagnosis, I was told there is an alternative medication known as hydroxyurea which could improve my child’s health and reduce blood transfusions and admissions. I was, however, scared about its future effects as mentioned by family friends, who had children with SCD who never considered it an option because of as infertility. Others said it is very expensive. (MC4, 41 years)

DISCUSSION
Caring for a child with SCD is highly demanding and predisposes caregivers to various hardships and other challenges. In this study, the burden faced by informal caregivers in caring for their children with SCD generated five major themes, which included the burden of children’s ill-health, financial burden, employment challenges and psychosocial burden. Further, analysis revealed that the time of a child’s diagnosis and the type of treatment were the two main determinants of the caregivers’ burden. These findings are in line with the findings of a study by Muoghalu,5 which showed that caregivers of children with SCD encounter serious hardships and challenges in caring for their affected children when the diagnosis was delayed until later in life. This thus has implications for the burden experienced by caregivers. The development of SCD management policy, which includes newborn screening at all levels, is essential for early detection and prevention of complications, thereby reducing caregivers’ burden.

The major burden experienced by caregivers of children with SCD was related to the painful episodes of their children, which was the main cause of admissions, the fear and guilt of putting other children at risk. Witnessing the pain their children went through forced some participants in the study to put an end to childbirth. Similar findings were made in other studies6 19 and found that caregivers reduced the number of children they planned on having for fear of passing on the SCD genes to subsequent children.

The causes of admissions, according to caregivers in this current study, were severe anaemia, severe chest pains and abdominal pains experienced during crisis. These, the caregivers indicated, result in their frequent absence from home and neglect of parental responsibility to other family members, resulting in dysfunctional family processes. The burden of severe anaemia resulted in increased cost of getting suitable blood donors for transfusion and laboratory investigations, coupled with the fear of exposing their children to infections. These findings agree with findings of studies by Ali and Razeq6 and Unal et al.12 These two studies also revealed that caregivers of children with SCD reported feeling that they have neglected other family members as a result of the constant hospitalisation of the child with SCD.

This current study also revealed that caregivers were concerned with developmental delays in their children as a result of SCD. These findings conform with findings of studies by Anaman20 and Afolayan and Jolayemi,21 which indicated that delay in walking by children with SCD due to musculoskeletal complications results in transportation challenges and alteration in their daily routines.

Caregivers, irrespective of their income levels, experienced financial drain as a result of the various laboratory investigations and cost of medications. Most of the medications were unavailable at the hospital, though all participants had active health insurance. This brought serious financial hardships on caregivers. Caregivers expressed the need for SCD to be recognised as a disease of public health concern, and for the routine medications and laboratory investigations to be subsidised by the government. Comparable findings have been made by other studies.4 5 22 In studies by Yawson et al4 and Muoghalu,5 caregivers of children with SCD in poor countries are faced with extra economic hardships in taking care of their children’s medical care cost.22 Similarly, the cost of medical care led to delays in seeking healthcare by some caregivers resulting in serious complications for their children, thereby reducing the lifespan and increasing mortality among children with SCD.

Despite the financial hardship experienced by caregivers of children with SCD, findings of this current study revealed that most families had only one partner working and earning income. The other partner had either been sacked or had to quit their job due to inability to meet work demands. Those who were self-employed could not cope with the care demands and that of their businesses. As such, customers are usually lost as a result of the regular shutting of their shops. This increases the financial loss and burden to the caregivers and their family as shown by similar studies.23–25 Finding from these studies showed that caregivers of children with SCD are unable to seek high-paying jobs because they are not able to work effectively, leading to layoffs, salary reductions and dismissals.

Early screening and diagnosis aid in early treatment, which prevent the development of complications and
lessen caregivers’ burden, which could be achieved through public awareness and policy. A study by Ohene-Frempong et al.\textsuperscript{13} to assess the knowledge and attitude of public servants towards SCD, indicated that only about a quarter of participants knew their sickling status or that of their spouses before marriage or first child. In this current study, most of the children were diagnosed late, at a time when they had already experienced several painful episodes, infections, admissions and developed several complications. These were experienced despite the children being on their routine medications of folic acid, penicillin V and multivitamins. These compounded the burden experienced by their caregivers. Delayed diagnosis resulted in delayed initiation of treatment and the development of complications that could have been prevented. In similar studies,\textsuperscript{26–27} caregivers indicated the need for early screening to help diagnose and commence early management of children with SCD to avoid the complications. Further, these perceived benefits of early diagnosis and treatment are consistent with findings from studies by Whitehead et al.\textsuperscript{27–28} and Hirst and Owusu-Ofori.\textsuperscript{27–28}

Some caregivers in this current study opted for hydroxyurea for their wards after diagnosis. These caregivers reported massive improvement in their children’s health, including increased haemoglobin level and reduced painful episodes. Similar findings were made by Habeeb et al.\textsuperscript{3} in an Iraqi study where the use of hydroxyurea for treatment of SCD was seen to have reduced vaso-occlusive painful episodes, complications and frequent admissions, thereby reducing the financial burden of caregivers. Irrespective of the reported benefits of hydroxyurea in improving the lives of children with SCD, most caregivers in this current study refused to opt for it due to cost and the perceived future adverse effects on their children such as infertility. Similar finding have been made by Asare et al.\textsuperscript{10}

STRENGTHS AND LIMITATIONS OF THE STUDY

This is possibly the first qualitative exploratory study of informal caregivers’ experiences of burden in caring for their children with SCD in the setting. This study therefore helps plug the knowledge gap on the subject. Being a qualitative study, it helped unearth the caregivers’ experiences as generated from their perspectives. It further helped in identifying areas of practice and policy for interventions that could assist in reducing the burden of these caregivers. Despite these strengths, the study is limited by a number of factors. The small sample size and the subjective nature of the result limit generalisability and transferability. Also, despite efforts to achieve heterogeneity in participation and results, these are shaped by caregivers who were willing to participate, which may further limit transferability of the findings to the study setting. More studies, using different methodologies and bigger sample sizes, may help. Further, given that the gender and power dynamics in Northern Ghana favour men in the family, this could have given the male respondents an unfair advantage of being available for selection and participation in the study, resulting in over half of the respondents being male. Finally, the authors’ experiences as nurses may have influenced their interpretation of the participants’ experiences.

Conclusion and implication for practice and policy

Caregivers of children with SCD experienced several challenges with regard to the ill-health of their children, such as financial challenges, psychosocial hardships and employment challenges. These hardships are related to the cost of medical services, nutrition, impaired family processes, social isolation, and a threat to their employment and income. These burdens destabilised the lives and health of caregivers in general, and that of other immediate family members. Despite these burdens, there are no targeted interventions to help caregivers of such children with SCD. The findings have implications for policy interventions. The SCD management policy of the Ministry of Health of Ghana should include and support a mandatory newborn screening for SCD at all levels of the health system for early detection and management to prevent complications, thereby reducing caregivers’ burden. Further, the Ministry of Health and the NHIS of Ghana need to support as well as subsidise the cost of medications and laboratory services for children with SCD to help minimise the financial burden on caregivers. Further, counselling and psychological support desks must be established in hospitals offering SCD treatment to assist caregivers cope effectively with the situation in which they find themselves.

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