Article:

Ampomah, Menford Owusu, Atkin, Karl Michael orcid.org/0000-0003-1070-8670, Ohene, Lillian Akorfa et al. (3 more authors) (2024) Financial Strain and Resilience::A Qualitative Exploration of Parental Perspectives on Caring for Children with Sickle Cell Disease in Ghana. BMC Health Services Research. 1380. ISSN 1472-6963

https://doi.org/10.1186/s12913-024-11773-8

Ampomah *et al. BMC Health Services Research* (2024) 24:1380
https://doi.org/10.1186/s12913-024-11773-8

BMC Health Services Research

RESEARCH Open Access

Financial strain and resilience: a qualitative exploration of parental perspectives on caring for children with sickle cell disease in Ghana

Menford Owusu Ampomah[1], Karl Atkin[2], Lillian Akorfa Ohene[3*], Gloria Achempim-Ansong[1], Kwadwo Ameyaw Korsah[1] and Luke Laari[3]

Abstract

Background In Ghana, nearly one in four (25%) of the population are sickle cell disease carriers. Furthermore, 2% of all babies born (20 for every 1000 live births) has sickle cell disease. However, little is known about how parents negotiate the financial challenges facing parents of a child with sickle cell disease. This study explores the financial difficulties of parents and children living with sickle cell disease.

Methods The study adopted a qualitative approach. Twenty-seven parents were purposively selected from a sickle cell clinic in Accra, Ghana. Data collection was through an in-depth, face-to-face interview, using an interview guide based on the research objectives, and analyzed using thematic analysis.

Result The findings showed that parents faced multiple financial difficulties (both direct and indirect) as they met the direct cost of medications, routine laboratory investigations, and hospital admissions. The National Health Insurance scheme does not wholly cover these costs. Families also describe more indirect costs, such as those associated with maintaining their child's well-being alongside those connected to their caring responsibilities, including the impact of giving up work and reducing working hours. Findings highlight the most pressing challenge, including the lack of access to financial support and a more general lack of understanding of the difficulties they faced on the part of policymakers.

Conclusion Supporting sickle cell parents' financial needs would improve their emotional and social well-being, enabling them to be more effective family carers.

Keywords Child/children, Financial costs, Ghana, Parenting, Family care, Sickle cell disorders/Disease

---

*Correspondence:
Lillian Akorfa Ohene
lohene@ug.edu.gh
[1] Adult Health Nursing Department, University of Ghana, Accra, Ghana
[2] Department of Sociology, law and Sociology Building, Heslington East Campus, University of York, Heslington, York, United Kingdom
[3] Department of Public Health Nursing, University of Ghana, Accra, Ghana

Background

Sickle cell disease (SCD) affects about 120 million people globally [1]. More than 66% of these individuals live in Africa, including Ghana [2]. About 1000 children with SCD are born daily in Africa, making it the region's most widespread genetically acquired condition [3]. Approximately 50–80% of these children will die from infection or severe anemia before age five [4]. The condition can result in serious health consequences, including recurring acute and chronic pain, anemia, infections, and stroke [5]. The most common SCD in Ghana is AS, thus including carriers, however, the most common SCA is SS. In Ghana, around 2% of newborns, out of 882,490 babies born yearly, have SCD [6].

The financial consequences facing parents of children with chronic illness, including SCD, have been documented in the international literature. These studies show the long-term financial implications of the condition on parents' lives, including inhibiting job performance and employability, with the resulting impact on socioeconomic status [7, 8]. These studies also demonstrate a significant economic impact associated with medical expenses, routine medical reviews, and frequent hospital admissions [9–11]. This impact is especially felt in many African countries, including Ghana, where healthcare services are generally not free at entry [12]. In addition, parents may also have to take unpaid time away from work to care for their children [13]. The costs associated with caring responsibilities create economic hardships, particularly for those who are self-employed, on low incomes, or are single parents [14]. Where families are larger or have additional caring commitments, the financial impact of time away from work can be greater [15, 16]. Nevertheless, any socioeconomic and environmental effects of SCD in sub-Saharan Africa give a different dimension, especially in comparison to high-income countries. These can alter outcomes, particularly since poverty impacts morbidity and mortality [17].

Health and social service provision for families with children with hemoglobinopathies in Ghana may show a multiplicity of underperformance, placing an additional financial burden on parents [18]. This is because direct guiding principles on funding routine investigations and interventions are given less consideration when dealing with chronic conditions [19]. In Ghana, SCD management has not had its fair share of attention and resources compared to other health priorities, such as malaria, HIV/AIDS, Tuberculosis, and poliomyelitis [20, 21]. Alongside the limited access to treatment facilities, healthcare budgets for chronic conditions such as SCD remain limited, creating further disadvantages for parents of a child with SCD, with the most significant impact on the poorest [10].

In Ghana, for example, out-of-pocket payments even with people with health insurance accounted for about 66% of total healthcare financing [22]. Without effective healthcare cost exemption mechanisms, poorer households, including those with a child with SCD, may be particularly affected [23]. Universal healthcare coverage requires that the health system provides all citizens with adequate healthcare at an affordable cost. Achieving such coverage calls for healthcare to be accessible according to need rather than the ability to pay. This remains a challenge for healthcare systems such as Ghana, where many competing priorities exist.

Ghana introduced the National Health Insurance Scheme (NHIS) in 2005 to improve financial accessibility to healthcare [24]. This was presented as a pro-poor financing strategy to remove financial barriers to healthcare and protect all citizens from health expenditures. However, the scheme does not adequately cover the service and management costs associated with SCD [25]. Therefore, an individual may be required to pay for some services, such as laboratory blood investigations, scans, and medications. As noted, more indirect costs associated with caring responsibilities can be as important as their direct medical management [25, 26]. Little is known about how parents negotiate and experience these costs.

Methods

Study aims and design

This study aimed to explore the financial difficulties of parents and children living with sickle cell disease. It is a qualitative study which employed an interpretative constructivist approach [27] to investigate the financial consequences of parenting a child with SCD in Ghana. Parents of children with SCD were interviewed because of their experiences with caring for children with SCD (i.e., financial) and, consequently, informed by lived experiences, with emphasis on obtaining an inclusive account from them.

Research setting

A children's sickle cell clinic (SCC) in a teaching hospital in Ghana offered an ideal location to sample parents. It was one of the most significant SCCs in Ghana, serving a diverse population regarding the social and economic status of the parents. This hospital provided the study with sufficient parents to meet our target sample.

Participants and recruitment

A purposive sampling method was used [28], with the help of two healthcare professionals (registered nurses), who facilitated the recruitment of parents from a sickle cell clinic at a hospital in Accra, the capital of Ghana. Inclusion criteria considered parents who have a child with SCD over one (1) year. Parents, on their child's clinic appointment days, were contacted by the two healthcare professionals and given an information sheet about the study. The information, including the purpose of the research and expectations of parents' involvement, was verbally communicated to parents who could not read in English by the healthcare professionals. With the parent's permission, the researchers got the contact details of the parents for follow-up mobile phone calls. The researchers reiterated voluntary participation in the study during the phone calls. The interviews were conducted only with parents' consent. A total of 27 participants were involved in the study.

Research instrument and data collection

Data was collected through a semi-structured, face-to-face, in-depth interview with participants. The interviews were informed by an interview guide developed (see supplementary file) and agreed upon by the researchers to assist with 'guided conversations' [29]. The parents were interviewed once using a semi-structured interview guide (see supplementary file), which lasted 45 to 60 min. and considered questions including (1) "Can you outline the monetary cost of medical services for your child's condition?" (2), "Apart from the medical expenses, are there any other financial commitments in your child's care?" (3). "Tell me how this affects your family's finances?" and (4) "Tell me the financial support you get from any source in the care of your child." All the parents were interviewed by the first author (MOA) in the English language with few in Twi ($n=9$) at a preferred venue of the participants and audio recorded. Interviews that were conducted in Twi were translated into English before transcription.

Data analysis

The interviews and field notes were transcribed and analyzed manually using the thematic analysis strategy [30]. Some prior codes were established from the interview guide by two independent coders who are experts in qualitative analysis. The initial empirical analysis focused on generating themes and showing how often a characteristic pattern emerged from the parents' views [31], where themes and subthemes were developed and labeled. The organization and improvement in themes and subthemes for each transcript continued until saturation. This process generated key concepts that informed the basis of the study findings, making sense of the context in which parents face the financial burden of caring for a child with SCD.

Ethical considerations

The study gained ethics approval from a Departmental Ethics and Governance Committee at the University of York and the Institutional Review Board of the Teaching Hospital where the study took place in Accra, Ghana (Ref: 37MH – IRB IPN 007/2014). All participant gave informed consent before participation in the interviews. The interviews began by ensuring that parents understood the study, what would be involved should they agree to participate, why they were being asked to participate, and were informed that they could withdraw from the study at any time, with no consequences on their child's care. Parents also knew how their information would be managed and that the researchers would always respect their anonymity and confidentiality.

Results

Demographic characteristics

Overall, 23 mothers and four fathers (including two couples) were contacted for inclusion in the study. Their age range was 26–45 and 42–56 years for mothers and fathers, respectively. Twenty-five parents were interviewed at the sickle cell clinic and two in their homes. Pseudonyms (P1-P27) have been used for all participants in this study to ensure anonymity for a detailed sociodemographic description of the parents (see Table 1).

Themes and subthemes

This study focuses on the economic impact, experienced by parents when caring for a child with SCD in Ghana. The analysis of this study presents four themes, underpinned by eleven comparable explanatory subthemes (Table 2). The main themes forming the basis for this analysis are the direct cost of routine medical management of SCD; the costs associated with managing an SCD crisis; the indirect economic costs associated with caring responsibilities and maintaining well-being; and social-economic support from third parties.

Cost of routine medical management of SCD

Mothers and fathers said that the economic consequences of SCD on their families are caused initially by the impact of the costs of medication and laboratory tests, which form part of routine management. The medical cost for these patients varies depending on one's circumstances and the healthcare facility being used (Note: £1 was equivalent to GH¢ 5.6 (Ghanaian Cedis), and the average income among participants was GH¢ 500–1200 per month at the time of interview). A child with SCD, for example, must take folic acid and vitamins supplement for life and penicillin-V up to the age of five years. For many parents, this is cost. In Ghana, apart from newborn testing for SCD, which is free in some government healthcare facilities, the care and management of the disease are not always free. Parents with the national health insurance scheme (NHIS) have some exemptions from basic routine blood tests and less expensive medications. Even with the NHIS subscriptions, most parents still

Table 1 The study sample: Socio-demographic description of parent participants/ number of children and their SCD status

Participants (Pseudonyms)	Age (yrs)	Marital Status	Level of Education	Occupation	Nº of children	Age (yrs)/ SCD status
P1	37	Married	JHS	Seamstress	1	6/SS
P2	26	Married	HND	Caterer	1	4/SS
P3	24	Single	SHS	Student	1	2/SF
P4	37	Married	JHS	Trader	2	9/SS; 3/AS
P5	39	Married	Form 4	Trader	2	15/AS; 10/SS
P6	36	Married	Tertiary	Secretary	3	7/AS; 3/SC; 1/SC
P7	26	Single	SHS	Seamstress	1	6/SS
P8	46	Married	Form 4	Trader	1	17/SS
P9	33	Separated	SHS	Trader	2	7/SS; 5/SS
P10	32	Married	Tertiary	Insurance	1	3/SC
P11	43	Married	JHS	Trader	1	16/SS
P12	35	Married	Tertiary	Journalist	3	5/SS; 2/AS; 2/SS
P13/P14 *	36	Married	SHS	Trader	1	6/SS
P15	45	Widow	None	Trader	1	15/SS. Two SS deceased
P16/P17*	41	Married	Tertiary	Adm Assist.	#2	11/AS; 4/SS
P18	43	Married	Form 4	Unemployed	2	11/AS; 8/SS
P19	38	Married	SHS	Security Officer	2	14/SS; 12/SC
P20	42	Married	Tertiary	Seamstress	1	11/SS
P21	44	Widow	Tertiary	Teacher	2	15, F, AS; 10/SS
P22	44	Married	Form 4	Trader	4	21/AS; 17/AS; 11/SS; 5/ AS
P23	42	Married	Diploma	Counter Assistant.	3	19/AS; 14/SS; 2/SS
P24	26	Married	Primary	Trader	1	5/SS;
P25	37	Married	SHS	Trader	2	5/SC; 3/SC
P26	56	Married	O' level	Ret. Naval Officer	5	20/AS; 9/AS; 4/SS
P27	42	Married	A' levels	Trader	1	7/SS

*# partners; *JHS* Junior High School, *SHS* Senior High School HND Higher National Diploma, GCE O'& A' General Certificate of Education, Ordinary, and Advance Levels

Table 2 Thematic findings

Themes	Context Findings
Cost of routine medical management of SCD	*Cost of medication* *Cost of lab investigation*
Managing the SCD crisis phase	*Extra monetary cost during crisis* *Hospital admission* *Medication* *Transportation to a medical facility*
Associated Financial Costs	*Balanced nutritious diet* *Good housing* *Parental jobs* *General household*
Socio-economic support	*Employer support* *Family/relation support* *Other source of support* *Government support*

struggled with medical related costs. Despite the challenges, parents prioritized their children.

P20 explained:

> *"Economically, yes! We will be buying medicine and all those things, so at times you do not have money, you have to make sure that all the time he has his medicine, and it is a problem if he does not". P15 agreed:*

> *"Concerning this sickness, it is all about money matters. Sometimes when he is sick, I must bring him to the hospital, but there may be no money. You must bring him to the hospital even if you do not have the money".*

Those in low-paid jobs or unemployed or single parents especially struggle to pay for medical care for their children. This encouraged some to seek cheaper and less effective traditional/herbal care. Sometimes, parents needed to borrow money from family members, friends, or church leaders before they could access medical care for their children.

P21, a teacher, and single parent, recounted the financial difficulties of having to come for a medical review every fortnight because her child was part of a trial for Hydroxyurea:

> *"I do lab every two weeks for GH¢ 25. I did the card GH¢ 10 and the medication, is it GH¢ 40–45; and where I live is far from the hospital".*

Other parents ($n=10$) said their children were on a Hydroxyurea trial. Like P21, their children required laboratory tests every two weeks. The medicine was also needed, even though it was administered as part of a trial. Many of these parents initially assumed the medication would be free. For some, this meant they had to withdraw from the trial. This saddened them, as they believed being part of the trial would improve their child's well-being.

P13 explained:

> *"The work I am doing now brings meager income, so to support my husband in buying medicine, we also have other dependants. So, money is tight, and now they say Hydroxyurea, but the cost involved, meaning every month we will have to do a test, and it is almost GH¢ 20, so her father said if we are to do the test and the treatment, it will be difficult for him. He is not ready for her to start the medication. Because sometimes we buy her medications and there is no money at home".*

P13's husband is a technician with the military and has free medical care at the hospital, but he needed to pay for the cost of Hydroxyurea before their child could receive that treatment. P27 said his daughter could not have access to the Hydroxyurea treatment because he could not afford it:

> *"(…) about the drugs, like the Hydroxyurea which they are talking about; many of the parents, if they get, want, but this is the case whereby the financial means come in. For instance, I came for the first meeting when they met with parents about the drug, but until now, because of financial issues, my daughter is not on it".*

He went on:

> *"But I keep praying to God, that oh God, this is a medicine that can let my daughter feel good, but this is the case that I don't have the money (tears start to flow), but I believe that God, Allah, you are the makers of heaven and earth, so help me and make my daughter take the Folic Acid and vitamins but turn it to be the Hydroxyurea. That is my belief because I do not have the money they are discussing. Because what I learned is that if you buy it and stop it, it is not good. Yeah, so I have to be careful".*

P27 was desperate to ensure his daughter got the best possible treatment. His only hope was his belief in God, to whom we prayed for a miracle.

Some parents struggled to pay for routine drugs outside a trial setting.

P8 explained:

> *"Sometimes they say the drugs are not expensive, but they may deceive us. It is costly. The last time we bought drugs to the tune of GH¢100, just one drug. Therefore, where will you turn to if you don't have the money? So at least if you have a good job and can save some money for the future, I think it helps".*

Managing the SCD crisis phase

The painful crisis caused financial difficulties. Its management can be expensive, involving additional medications and hospital fees. A child's admission could also impact employment and reduce family income. Having more than one child, the SCD, added to the challenges. P16 said:

> *"In a month, if we do not have an SCD crisis, we spend about GH¢ 30, but if we have a crisis, it might go higher than that because you go in for admission, and then they would put some infusion, and the bed or ward charges. They add up, and you will pay almost GH¢ 80–90".*

P17, P16's husband, agreed:

> *"Yeah, I will say the worst situation that has ever happened; one time we had a continuous crisis, and it's a lot of spending continuously, and it came to the point that money got short, that is where I need to make sure that I provide any medical care that we need".*

P16 and P17's experience was typical among other parents. P16, a mother with two children with SCD, remarked:

> *"(Laughs) Yeah, when they fall sick continuously, we spend a lot of money. Especially if they both fall sick within the same month, we normally get short of cash, but when my husband gets his salary, we can put things in place and manage our little".*

P12, who also had two children with SCD, made similar observations:

> *"Ehmm, it is to do with the labs, some of the lab tests and drugs. The drugs are expensive as well. When they are in a severe crisis, the drugs can cost like GHS 150 or 180, which they have once or twice a day".*

She added:

> *"Even though the government is helping with some lab tests, the drugs should also be included to relieve some financial burdens on us."*

The help from the Government to which P12 is referring occurs when one is registered with the NHIS.

P16 pointed out that traveling to the hospital could create additional costs.

Traveling by public transport to the hospital is not easier. Parents regarded it as slow and unreliable. P16 explained:

> *"You know it involves money. Anytime you go to the hospital, you must get 'dropping' (Taxi). If in crisis, you need a taxi to the hospital as soon as possible, so whether you have money or not, you must get it by any means".*

Like other parents, P12 mentioned financial support for some laboratory tests through the NHIS. This scheme, however, did not cover the cost of the drugs required to manage a crisis. P12 said:

> *"All I can say is that we are managing with our little. When they don't have a crisis, we only buy folic Acid and some vitamins for the boy; and for the girl, we add Penicillin-V. So, it is not that bad, but when there is an SCD crisis, and they go on admission, we are made to buy other expensive drugs and IV infusions".*

Parents believe there should be more Government support by making such medications available at government healthcare facilities. Many parents said they must buy many medications from private pharmacy shops, which are more expensive.

Associated Financial costs

We have already mentioned the additional costs of travel when a child is having a crisis. Travel could also be costly if parents lived some distance from specialist care centers where routine care was provided. Less obvious costs were associated with maintaining the child's general well-being. A balanced and nutritional diet was seen as especially important by parents. They also said this was more costly. This created a dilemma about what to prioritize when spending financial resources, particularly when these decisions impact other family members. P11 explained:

> *"Some people do not have the money; they don't have the food for their children. These children (with SCD) eat 'posh,' like rich people. You need to always buy them rich food (a nutritious diet) so they would not short blood (anemic), so you don't have to give them anything. So, if some parents cannot provide, and you give them 'banks' and pepper daily, they will fall sick and weak".*

In addition to diet, parents discussed the general costs associated with maintaining their child's well-being. This included creating a healthy environment for his child. P17 emphasized the importance of good quality housing. He said that the family could have gone for a lesser and cheaper accommodation that could help, but because their child had SCD, they needed to go the 'extra mile:

> *"We put in a bigger budget to meet the standard to make him comfortable and safe. Anything we do, he's brought into the picture, and he is considered first, increasing our budget".*

Other parents mentioned the importance of having decent accommodation to help protect their child from malaria infection. Malaria is common in Ghana and more so in poor and disadvantaged communities. To avoid exposing their child to infections or diseases due to poor environmental conditions, some parents spend more on rent, living in moderate to expensive communities. Four parents lived in their own built houses. A common narrative among parents concerned how their child's SCD impacted their employment, further influencing family income.

P12, a 35-year-old mother, married with three children, of whom two have SCD, explained how she needed to give up her job as a journalist because of her caring responsibilities. The pressures of the job, she said, meant she was not there for her child:

> *"It was like I was going to lose him. He started losing weight and became malnourished, so I just decided to quit for his sake. I resigned (…) for me to be able to take good care of him. I did not want to lose him. So social life, hmmm! I don't go out much (laughs)".*

P12 resigned from her job to take "good care" of her two children with SCD. The family decided that her husband would work to support the family. This, however, was not going to be easy:

> *"Yea, and sometimes it depresses me because now I am not financially sound. Because when I was working, you knew you would receive a monthly salary. But people must buy before they get money, and my husband supports the family as a teacher. He is alone, and it is not easy. Consequently, it has affected us, yes!"*

P7, who was self-employed, recounted how her son's condition affected her business. She was learning a trade as a seamstress. With about a year and a half left before training was complete, her child started having frequent SCD crises. She had to give up her training and her "dreams" of starting her own business:

> *"I end up spending all my money on his medications and admissions. That has indeed affected my progress in life".*

Juggling caring responsibilities for other family members with looking after a child with SCD created further financial struggles, especially in larger families. P8 described her frustration:

> *"We have other children and many 'mouths to feed,' which is difficult for us. The father didn't have a well-paid job by then, so buying drugs became very difficult and made me very depressed. I was even telling people who need not tell them about my situation. They don't even help you, which is like selling yourself to them".*

26 agreed:

> *"So, if you take care of the child well, and if you are spending money on the child, which we do, they (extended family members) say you are useless to the family. However, they know we struggle to support the family because of our child's condition".*

Socio-economic support

Working for employers who paid medical bills as part of employment benefits was a great advantage for some parents. P22 said:

> *" It is not a big issue, though. It is not difficult as we have insurance, and the father has a well-paid job that even refunds hospital bills. But if he has no money during a time of crisis, it makes it very difficult. Anytime they refund the money, he collects it".*

P10 agreed:

> *"It's my husband's company that pays for the bills when we come. There is an insurance card we have, which we use".*

P10 said they would have been lost without such support: *"Yes, I should say so because it takes care of everything when we visit the hospital."*

Such support, however, was not available to all parents, and even parents who had access to such support felt vulnerable and worried about losing their job. This may make them reluctant to seek opportunities elsewhere. Most parents described receiving financial support from their extended family.

P16 explained:

> *"Yes, my parents and my husband's family also know. They help, yea; they help a lot. Sometimes when we have a crisis, they come to our aid and help us carry the burden. When we are on admission, they help us both financially and moral support".*

P3 spoke of the support received from her mother:

> *"My mum helps in terms of money and those things. If he falls sick and the dad is not around, sometimes she helps financially."*

Other parents said they received financial support from their church. P8 said:

> *"My church does help me. A man (name withheld) and his wife in my church sometimes help me. The church also helps. When they hear of my situation and want to help, some people do help financially".*

She went on to say:

> *"Oh, sometimes I get money from them. Sometimes when we come from admission, money for food is even a problem, so when people hear of it, they can bring us money for the family's upkeep. Some may not even give me money but may offer intercession prayers, which I greatly appreciate".*

These informal sources of support further demonstrate the lack of access to formal financial help from the Government. Ghana had no special healthcare package for patients with SCD and their families. P27 said: *"For the government; I get no support from the government."* P4 agreed: "*We (parents) have been taking care of her; no source of support from anywhere."* P18 remarked: *"No, we do not get help from anywhere or anyone. We take care of our child"*. P1 explained how this reinforced the importance of more informal sources of financial support:

> *"Well, sometimes my Pastor gives us money for his school fees and other things, but no help from the government or NGOs."*

Parents felt neglected and identified areas where Government support could help them. Adowa said:

> *"Yes, I think the Government should supply their medication, for instance, Folic Acid and Penicillin-V. They are not too much expensive. Thus, if the Government can support parents to get them. Because I know in some cases, the parents don't have money to buy the Folic Acid, so they may stop giving it to the child for some time, and whenever they get money to buy, they continue, which I think is not the best, and the NHIS, if that can cover the sickle cell cases, review, and the drugs. I think it will help parents".*

P1 agreed and believed care for those with chronic conditions should be free. In a statement, she said, *"We need a lot more help. I thought the government said doctors should see us for free, but that is not the case. But it should be free".* P17 made a similar observation; *"Free medical care for these children; quality, and free quality medical care. That is what they need most; that one alone is enough".*

P5 supported this:

> *"Yes, just as when HIV/AIDS came, they gave them free medicines, so they can also give us free medicine or buy them at a lower cost. We don't know when they will tell us to stop, so as they do with those with AIDS, if they do the same with us, it will help".*

P12 also made a comparison with the provision for HIV/AIDS by saying, *"If everything is free for us like AIDS patients, yes! Just the labs and drugs are all we need".* P8, however, spoke of the importance of more indirect support, which would provide financial security and, therefore, remove the need for direct Government payments:

> *"You know I cannot always go to them for help, and there is no work. So, the kind of help that I will need from the Government is that I would like the Government to give me a job that can earn me some money and happiness. This is better than always going to the Government for help. If I get a job from the Government, I will be happy because when you sell things, people don't buy, and the little money you get, you just spend it all before the profit, yeah!"*

Other parents were sensitive to the Ghanian Government's difficulties as it tried to juggle different healthcare priorities. Parents, however, wanted to care for children with SCD to be part of these considerations. They were not convinced they were.

Discussion

The findings from this study highlight the profound financial burdens parents and families face managing the care of their children with SCD in Ghana. The findings reveal a complex interplay of medical costs, personal sacrifices and informal support systems that underpin the families' effort to secure care for their children. Although these findings support similar reports from different authors in Ghana [14] and from other sub-Saharan contexts [14, 32, 33], our study has some limitations regarding limited analysis of the family's economic activities and average income per household in Ghana.

The findings regarding medical care illustrate the costs associated with routine medical management of SCD, such as medications like hydroxyurea, folic acid, and other maintenance supplements. The cost implications of these medications are significant and can be overwhelming for many families. Evidence from the literature corroborates that families caring for individuals with chronic illnesses often face escalated medication costs compared to the general population without such responsibilities [34, 35]. Some parents in the context of this study indicated they resorted to borrowing money or seeking less effective traditional treatments, which echoes trends noted in the literature that indicate financial strain often leads families to alternative care routes, exacerbating health inequities [36–38].

The emphasis on maintaining a nutritious diet for children with SCD is noteworthy. Parents indicated that a nutritious diet is a priority, however, this responsibility often come as expensive and challenging to sustain. These findings align with the findings of other studies, which indicate that dietary needs in children with chronic illness can strain family finances [39–41]. Parents' concerns revealed an intersection between medical advice, dietary requirements, and financial resources, which suggest that healthcare providers must consider these socio-economic factors when designing treatment plans.

This study further reveals that caring for a child with SCD significantly impacts parents' employment opportunities. A few of the parents spoke about having to quit their jobs or reducing their work commitments, which led to decreased family income. The literature emphasizes the trade-offs that family caregivers often make, balancing work and care, which can lead to a cycle of financial insecurity [42, 43]. Additionally, the emotional toll of caregiving contributes to stress and depression, further affecting employment stability [39]. It is essential to acknowledge how family caregivers' health outcomes can be influenced by these financial pressures, as evidenced in the works by [44], which highlight the psychological effects of chronic caregiving [45].

Interestingly, participants discussed the critical roles of informal support systems, such as extended family and religious communities, in mitigating some of the financial burden associated with healthcare. The reliance on social networks for financial and emotional support has been well documented in the literature as a coping mechanism for families affected by chronic disease [46]. This illustrates how communal ties can buffer against hardship, although it also raises questions about the sustainability of relying on informal support in the long term, especially given the variability in such networks.

The participants consistently noted the insufficiency of governmental support and expressed a desire for more comprehensive healthcare provisions. This aligns with literature that critiques inadequate healthcare policies for chronic diseases in low-income countries, advocating for targeted interventions [46, 47]. Moreover, the comparison made by participants to the support provided for HIV/AIDS treatment is particularly salient. It signals a need for equitable healthcare strategies across various chronic health conditions, emphasizing the importance of inclusive policies that recognize the complexities of conditions like SCD.

Strengths and limitations

This study complements our understanding and awareness of parenting a child with SCD. Given the small number of studies in this area, further research would be helpful when developing our insights. Although the study participants and their narratives may not be directly generalizable to other parents with a child with SCD giving the fact that the study was confined a the greater Accra, the capital city of Ghana, analysis permits the identification of a thematic understanding likely to be relevant to parents looking after a child with a chronic condition and living in a low/middle-income country.

Conclusion

This study explores parents' financial challenges when caring for a child with SCD. The finding shows that parents with a child with SCD in Ghana face many additional costs associated with their caring responsibilities. These include the direct costs of care and treatment, and the more direct costs associated with maintaining their child's health and well-being. Caring also impacted parents' employment, and this created further financial difficulties. Parents reported little or no support from the Government of Ghana or NGOs. The only State support was through the NHIS, which may cover some medical bills. Parents struggle to care for their children with little financial support from the Government.

Abbreviations

SCC	Sickle Cell Clinic
SCD	Sickle Cell Disease
NGO	Non-Government Organization
HIV/AIDS	Human immunodeficiency virus /Acquired immunodeficiency syndrome

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-024-11773-8.

Supplementary Material 1.

Acknowledgements

We want to show appreciation to all parents who committed their time to share valuable experience with us. We say thank you to them all.

Authors' contributions

MOA and KA conceptualized the study. MOA conducted the interviews with the research participants. MOA, KA, LAO, GAA KAK and LL participated in the data analysis. MOA produced the initial draft.All the authors (KA, LAO, GAA KAK and LL) took turns to review and finalized the manuscript.

Funding

This study had no external funding.

Data availability

The data generated during the study are available from the first author on reasonable request.

Declarations

Ethics approval and consent to participate

All methods were carried out in accordance with relevant guidelines and regulations.

Ethics approval was gained from the Departmental Ethics and Governance Committee at the University of York and the Institutional Review Board of the Teaching Hospital where the study took place in Accra, Ghana (Ref: 37MH – IRB IPN 007/2014).

To participate in the study, informed consent from all participants and their legal guardian for study participation was gained.

Consent for publication

Not applicable to this study.

Competing interests

The authors declare no competing interests.

Received: 27 September 2023 / Accepted: 16 October 2024

References

1. Aygun B, Odame I. A global perspective on sickle cell disease. Pediatr Blood Cancer. 2012;59(2):386–90.
2. Diallo D, Tchernia G. Sickle cell disease in Africa. Curr Opin Hematol. 2002;9(2):111–6.
3. John TD, Namazzi R, Chirande L, Tubman VN. Global perspectives on cellular therapy for children with sickle cell disease. Curr Opin Hematol. 2022;29(6):275–80.
4. Piel FB, Patil AP, Howes RE, Nyangiri OA, Gething PW, Dewi M, et al. Global epidemiology of sickle haemoglobin in neonates: a contemporary geostatistical model-based map and population estimates. Lancet. 2013;381(9861):142–51.
5. Labie D, Elion J. [The problem of sickle cell disease in Africa]. Med Trop (Mars). 2010;70(5–6):449–53.
6. Ohene-Frempong K, Oduro J, Tetteh H, Nkrumah F. Screening newborns for sickle cell disease in Ghana. Pediatrics. 2008;121(Supplement2):S120–1.
7. Tsui EK. Say trouble's gone: chronic illness and employability in job training programmes. Sociol Health Illn. 2013;35(1):82–96.
8. Fauser D, Zimmer JM, Golla A, Schmitt N, Mau W, Bethge M. Self-reported prognosis of employability as an Indicator of need for Rehabilitation: a Cohort Study in people with Back Pain. Rehabilitation (Stuttg). 2022;61(2):88–96.
9. Oron AP, Chao DL, Ezeanolue EE, Ezenwa LN, Piel FB, Ojogun OT, et al. Caring for Africa's sickle cell children: will we rise to the challenge? BMC Med. 2020;18(1):92.

10. Wayne AS, Schoenike SE, Pegelow CH. Financial analysis of chronic transfusion for stroke prevention in sickle cell disease. Blood. 2000;96(7):2369–72.
11. Armstrong EP, Skrepnek GH, Sasane M, Snodgrass SM, Ballas SK. Long-term persistency and costs associated with the use of iron chelation therapies in the treatment of Sickle cell disease within Medicaid programs. J Med Econ. 2013;16(1):10–8.
12. Bosu WK. A comprehensive review of the policy and programmatic response to chronic non-communicable disease in Ghana. Ghana Med J. 2012;46(2):69–78.
13. Panepinto JA, Pajewski NM, Foerster LM, Sabnis S, Hoffmann RG. Impact of family income and sickle cell disease on the health-related quality of life of children. Qual Life Res. 2009;18:5–13.
14. Mumuni ND, Osman W, Alhassan BA, Alhassan A. Burden experienced by informal caregivers of children with sickle cell disease (SCD): a qualitative exploratory study at Tamale Teaching Hospital, Ghana. BMJ Open. 2023;13(4):e066311.
15. Adegoke SA, Kuteyi EA. Psychosocial burden of sickle cell disease on the family, Nigeria. Afr J Prim Health Care Family Med. 2012;4(1):1–6.
16. Adegoke SA, Abioye-Kuteyi EA, Orji EO. The rate and cost of hospitalisation in children with sickle cell anaemia and its implications in a developing economy. Afr Health Sci. 2014;14(2):475–80.
17. Dyson S. Sickle cell and the social sciences: health, racism and disablement. Routledge; 2019.
18. Anie KA, Olayemi E, Paintsil V, Owusu-Dabo E, Adeyemo TA, Sani MU, et al. Sickle cell Disease Genomics of Africa (SickleGenAfrica) Network: ethical framework and initial qualitative findings from community engagement in Ghana, Nigeria and Tanzania. BMJ Open. 2021;11(7):e048208.
19. de-Graft Aikins A, Unwin N, Agyemang C, Allotey P, Campbell C, Arhinful D. Tackling Africa's chronic disease burden: from the local to the global. Globalization Health. 2010;6(1):1–7.
20. Odame I. Developing a global agenda for sickle cell disease: report of an international symposium and workshop in Cotonou, Republic of Benin. Am J Prev Med. 2010;38(4 Suppl):S571–5.
21. Amertil NP, Ayitey EK, Kpongboe DG, Attafuah PYA. Exploring self-management in adult sickle cell disease patients' at a Teaching Hospital in Ghana. Nurs Open. 2021;8(3):1336–44.
22. Amporfu E, Arthur E, Novignon J. Billing the Insured: an Assessment of Out-of-Pocket payment by Insured patients in Ghana. Health Serv Insights. 2023;16:117863292211493.
23. Akazili J, McIntyre D, Kanmiki EW, Gyapong J, Oduro A, Sankoh O, et al. Assessing the catastrophic effects of out-of-pocket healthcare payments prior to the uptake of a nationwide health insurance scheme in Ghana. Global Health Action. 2017;10(1):1289735.
24. Fiestas Navarrete L, Ghislandi S, Stuckler D, Tediosi F. Inequalities in the benefits of national health insurance on financial protection from out-of-pocket payments and access to health services: cross-sectional evidence from Ghana. Health Policy Plann. 2019;34(9):694–705.
25. Akazili J, Gyapong J, McIntyre D. Who pays for health care in Ghana? Int J Equity Health. 2011;10(1):1–13.
26. Ezenwa MO, Dennis-Antwi JA, Dallas CM, Amarachukwu C, Ezema CI, Yao Y, et al. The Crisis of Sickle Cell Disease in Africa from insights into primary Prevention in Ghana and Nigeria: notes from the field. J Immigr Minor Health. 2021;23(4):871–8.
27. Bogna F, Raineri A, Dell G. Critical realism and constructivism: merging research paradigms for a deeper qualitative study. Qualitative Res Organ Management: Int J. 2020;15(4):461–84.
28. Rai N, Thapa B. A study on purposive sampling method in research. Kathmandu: Kathmandu School of Law; 2015. p. 5.
29. Warren CA. Qualitative interviewing. Handbook Interv Res. 2002;839101:103–16.
30. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qualitative Res Sport Exerc Health. 2019;11(4):589–97.
31. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Res Psychol. 2006;3(2):77–101.
32. Olatunya O, Ogundare EO, Fadare J, Oluwayemi IO, Agaja O, Adeyefa B, et al. The financial burden of sickle cell disease on households in Ekiti, Southwest Nigeria. Clinicoecon Outcomes Res. 2015;7:545–53. https://doi.org/10.2147/CEOR.S86599.
33. Ekwochi U, Osuorah DC, Ndu IK, Ezenwosu OU, Amadi OF, Nwokoye IC, et al. Out-of-pocket cost of managing sick newborns in Enugu, Southeast Nigeria. Clinicoecon Outcomes Res. 2014;6:29–35. https://doi.org/10.2147/CEOR.S54674.
34. Allshouse C, Comeau M, Rodgers R, Wells N. Families of children with medical complexity: a view from the front lines. Pediatrics. 2018;141(Supplement3):S195–201.
35. Martire LM, Helgeson VS. Close relationships and the management of chronic illness: associations and interventions. Am Psychol. 2017;72(6):601.
36. Saunders M, McHale P, Hamelmann C. Key policies for addressing the social determinants of health and health inequities. 2017 [cited 2024 Sep 15]; https://books.google.com/books?hl=en&lr=&id=FnSyDwAAQBAJ&oi=fnd&pg=PR4&dq=financial+strain+often+leads+families+to+alternative+care+routes,+exacerbating+health+inequities&ots=n1lBIgAAWT&sig=GBU1-nHSEzgvZeeVxTT_PkC1kLY.
37. Cooper M, Pugh AJ. Families across the income spectrum: a decade in review. J Marriage Family. 2020;82(1):272–99.
38. Camacho S, Henderson SC. The social determinants of adverse childhood experiences: an intersectional analysis of place, access to resources, and compounding effects. Int J Environ Res Public Health. 2022;19(17):10670.
39. Bekui BAA, Ohene LA, Badzi C, Ampomah MO, Aziato L. Physical and socioeconomic burden of caregiving on family caregivers of children with cancer at a tertiary hospital in Ghana. Nurs Open. 2023;10(2):915–25.
40. Abaah D, Ohene LA, Adjei CA. Physical and social wellbeing of family caregivers of persons with hepatitis B associated chronic liver disease in Ghana: a qualitative study. BMC Prim Care. 2023;24(1):82.
41. Donkor CM, Lee J, Lelijveld N, Adams M, Baltussen MM, Nyante GG, et al. Improving nutritional status of children with cerebral palsy: a qualitative study of caregiver experiences and community-based training in Ghana. Food Sci Nutr. 2019;7(1):35–43.
42. Howard AF, Lynch K, Thorne S, Porcino A, Lambert L, De Vera MA, et al. Occupational and financial setbacks in caregivers of people with colorectal cancer: considerations for caregiver-reported outcomes. Curr Oncol. 2022;29(11):8180–96.
43. Chy S. Family Caregivers: Profiles, Economic Challenges, and Access to Social Insurance [Internet] [PhD Thesis]. The University of Wisconsin-Madison; 2024 [cited 2024 Sep 15]. https://search.proquest.com/openview/4a715999888e5fce465136b9684c0e3e/1?pq-origsite=gscholar&cbl=18750&diss=y.
44. Bentum LS, Ohene LA, Agyare VA, Laari L, Ampomah MO. Fathers' experiences of caring for children living with cerebral palsy: a qualitative study in a low resourced socioeconomic context, Ghana. J Pediatr Nurs. 2023;73:e100–6.
45. Bekui BA, Aziato L, Ohene LA, Richter MS. Psychological and spiritual wellbeing of family caregivers of children with cancer at a teaching hospital in Ghana. Int J Afr Nurs Sci. 2020;13:100231.
46. Powell RE, Lovett PB, Crawford A, McAna J, Axelrod D, Ward L, et al. A Multidisciplinary Approach to Impact Acute Care utilization in Sickle Cell Disease. Am J Med Qual. 2018;33(2):127–31.
47. King A, Herron S, McKinstry R, Bacak S, Armstrong M, White D, et al. A multidisciplinary health care team's efforts to improve educational attainment in children with sickle-cell anemia and cerebral infarcts. J Sch Health. 2006;76(1):33–7.

Publisher's note