

The Experiences of Parents of Children with Sickle Cell Disease in the Tamale Metropolis, Ghana

Francis Borsongdeme Bayuo^{1*}, Winifred Pogsaa Wondong¹, Felix Apiribu², Edward Appiah Boateng², Philomena Ajanaba Asakeboba³

¹Department of Midwifery, Garden City University, Kumasi, Ghana; ²Department of Nursing, Kwame Nkrumah University, Kumasi, Ghana; ³Department of Nursing and Midwifery, University for Development Studies, Tamale, Ghana

ABSTRACT

Background: Sickle cell disease imposes complex demands on the lives of affected children and their families. Stress levels experienced by parents of children with sickle cell disease have been attributed to financial demands, physical burdens, maladaptive behaviors in children, feelings of social isolation and concerns about the child's lifelong care. In recent years, several studies have appraised the burden of care on parents of children with SCD in different parts of the world. This study explored the experiences of parents of children with SCD in the Tamale Metropolis, Ghana using the ABCX family stress model as the guiding theoretical framework.

Methodology: The exploratory qualitative research approach was used. Thirteen (13) parents were purposively selected and engaged in individual, face-to-face interviews. The interviews were audio-recorded, transcribed verbatim and analyzed using thematic content analysis.

Results: Three (3) major themes with their corresponding sub-themes were derived from the data gathered. The major themes were the perception of SCD by participants, the burden of care and the resources used by parents. Participants had negative perceptions of SCD and mostly avoided disclosing their child's sickling status due to fear of the stigmatization that seems rampant in their communities. Participants were reluctant to give birth again due to the challenges of caring for a child with sickle cell disease.

The study also found that having a child with SCD in a polygamous marriage is an emotional issue for the affected women as it leads to inferiority and inability to speak up. Resources used by participants were social support and coping strategies. Participants received significant social support from family members, friends, health providers, parent-to-parent support groups and the online community. Religion was used as a coping strategy to derive comfort from observing faith-based practices.

Conclusion: Participants mostly had negative perceptions of sickle cell disease and the implications of caring for children with SCD seem to add to the negative perceptions. Faith-based practices as well as a good support system aid parents in coping with the stresses of caring for their children with SCD. Genetic counselling before marriage should be highlighted in the awareness creation of SCD. Professional counseling services should be intensified to assist parents of children with SCD to promote their emotional health. Increased efforts should be directed at addressing stigmatization associated with having a child with SCD within communities in the Tamale Metropolis.

Key words: SCD parents experience; Burden of care; ABCX model of family stress; Genetic counselling

Correspondence to: Francis Borsongdeme Bayuo, Department of Midwifery, Garden City University, Kumasi, Ghana; E-mail: bayuofrancis9@gmail.com

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INTRODUCTION

The constant demand for care of children with chronic conditions, including Sickle Cell Disease (SCD) causes conflict between caregiving responsibility and the job responsibility of parents. A study by Wonkam et al. in Cameroon with 130 parents of children with SCD revealed that caring for their chronically ill children affected parents' commitment to their work. 98% of the participants admitted to missing at least one working day in a month and this affected their retention in their various jobs. This also affects the economic sustainability of the family and puts extra financial stress on the family. A study conducted in Brazil showed that the time spent caring for their children also compromised the physical and mental well-being of mothers as they lost control of their own lives. In a study by Anaman the physical burden of caregiving affected the physical health of the parents, with most of them, sleeplessness and fatigue while others complained of acquiring nosocomial infections such as the common cold due to frequent hospital stays [1].

In Ghana, most of the studies conducted on sickle cell disease have mainly focused on other areas of SCD other than the experiences of parents of children with SCD. The few studies conducted on the experiences of parents of children with SCD are in the Greater Accra and Ashanti regions of Ghana. Experiences of parents providing care to almost 60,000 children with SCD in Ghana have not been given the needed recognition. There is no published study on the experiences of parents of children with SCD in the northern part of the country. Tamale is a Muslim-dominated metropolis where polygamous marriages are common. Caring for a child with SCD in a polygamous marriage could have different implications for family dynamics. Fully understanding the experiences of parents of children with SCD in such settings will help to offer appropriate support for them.

The ABCX model of family stress by HILL guided the research. The model was developed in 1949 to explain "the crisis-proneness and freedom from crisis among families. The model is made up of three exogenous variables A, B, C which interact to produce an endogenous product, X. A specific stressful situation may not necessarily precipitate a crisis in the family or the individual if there is an adequate and efficient use of resources. It must be acknowledged that the model has been applied to studies involving individual stress patterns in caregivers of children, the stress of re-marriages and adults with chronic diseases. In these studies, the model was adapted to guide the study of the protective factors that control resilience in parents of children with developmental delays [2].

In this present study, the "A" factor/stressor refers to the burden associated with caring for a child with SCD. This matched the second specific objective of the study which explored the burden of SCD on the quality of life of parents. The "B" factor refers to the resources available to the parents. This also corresponds to the third objective which discussed the resources used by parents of children with sickle cell disease. Factor "C" refers to perceptions of parents on SCD. Hence, the first specific objective addressed the perception of parents of children with sickle cell disease. Finally, factor "X" refers to the psychosocial, financial, economic and physical health of the parent which matched the fourth objective of this study that discussed the outcome of caregiving by parents.

MATERIALS AND METHODS

Study design

A qualitative research design using an exploratory approach was used to achieve an understanding of the everyday experiences of parents who care for children with sickle cell disease [3].

Setting and sampling

Parents with children aged 6 months to 17 years who had a confirmed diagnosis of SCD met the inclusion criteria. Also, parents who had attended the sickle cell clinic for at least 6 months and were resident in the Tamale Metropolis were recruited for the study. These parents were purposely recruited from the Tamale Teaching Hospital (TTH), Tamale West Hospital (TWH) and Tamale Central Hospital (TCH) in Ghana. The tamale teaching hospital is a regional hospital in tamale in the northern region and serves as a referral hospital for the three northern regions of Ghana. It cooperates with the university for development studies in northern Ghana to offer undergraduate and graduate programs in medicine, nursing and nutrition. The hospital offers specialist services such as cardiothoracic surgery, cardiovascular diseases, ophthalmology, dermatology, general surgery, consultative and diagnostic medicine, maternity and gynaecological, public and nursing services. The Tamale Central and West hospitals are both municipal hospitals in the tamale metropolis. Both hospitals provide general medical and nursing care services. Cases from these hospitals that need specialist care are then referred to the tamale teaching hospital.

Parents were recruited for the study between January and July 2021. The sample size was informed by data saturation. No new patterns of information were emerging after interviewing 13 parents of children with SCD. All parents showed interest in the study and participated voluntarily, with no form of coercion or inducement. No participants withdrew their consent following the interviews [4].

Data collection

Semi-structured face-to-face interviews were used for data collection. The researcher sought the services of the paediatric nurse specialist who offered counselling to all parents before the interview process at the first hospital. However, counselling was done by registered mental health nurses at the other two hospitals. The counselling session was to prevent parents from emotional breakdown during the interview process due to the sensitive nature of the study. The longest interview took 42 minutes and the shortest interview took 27 minutes. Parents were told to express their feelings freely.

Data processing and analysis

Data for the study were only accessible to the research team and this was used for academic purposes exclusively. Participants' names were not used. Audio recorders, transcribed data and consent forms were kept under lock and key. Data were collected and analyzed concurrently using the ABCX model. All the

interviews were conducted in the English language and were transcribed verbatim by the researcher. To ensure validity, the interview guide was developed in accordance with the research objectives and the ABCX family stress model. Thematic Content Analysis (TCA) as proposed by Braun and Clarke was used for data analysis. According to Braun Thematic Analysis (TA) is a method for identifying, analyzing and interpreting patterns of meaning ('themes') within qualitative data. The phases of thematic analysis are described below; in the first phase of TA, researcher became familiarized with the data during and after data collection and generated transcripts. The second phase was generating codes for easy analysis where similarities and patterns across the data were noticed. Codes were then used to construct themes in the third phase. Revisions were made to the themes in the fourth phase. Further was the defining and naming subthemes for entire analysis. Finally, a report was produced [5].

ages of the parents ranged from 24 years to 45 years and all participants were married and living with their spouses. Ten of the parents were Muslims and three were Christians. Participants had varied educational levels; seven had tertiary education, one had secondary education and five had basic education. In addition, the participants had varied occupations as reflected in the summary of demographic characteristics (Table 1). Regarding their monthly income, three parents earned below Ghc 500.00 (US \$5,350 @ US \$1=GHC10.70 as at 29/05/23), four earned between Ghc 500.00-999.00, five earned between Ghc 1000-2000 while one was a housewife with no regular monthly income (Table 1).

RESULTS

Description of sample

A total of thirteen (13) participants, comprising eight mothers and five fathers of children with SCD were interviewed. The

Table 1: Sample characteristics.

Participants	FP01	MP01	FP02	FP03	MP02	FP04	FP05	MP03	MP04	FP06	FP07	FP08	MP05
Gender	F	M	F	F	M	F	F	M	M	F	F	F	M
Age (in years)	30-34	40-46	35-39	35-39	40-45	40-45	24-29	40-46	35-39	30-34	24-29	30-34	34-39
Level of education	Basic	Tertiary	Tertiary	Tertiary	Basic level	Tertiary	Tertiary	Senior high	Tertiary	Tertiary	Basic level	Basic level	Basic level
Occupation	Trader	Town planning officer	Teacher	Teacher	Farmer	Public servant	Student nurse	Trader	Teacher	Health information officer	Housewife	Northern kente weaver	Farmer/ Security
Religion	Muslim	Muslim	Pentecost	Muslim	Catholic	Muslim	Muslim	Muslim	Catholic	Muslim	Muslim	Muslim	Muslim
Ethnicity	Dagomba	Dagomba	Dagao	Dagao	Dagao	Dagomba	Dagao	Dagomba	Dagao	Dagomba	Dagomba	Dagao	Dagomba
Monthly income (in GHC)	500-600	2000	1000-1500	1500-2000	500	1600	None	900	1500-2000	200-250	None	200-400	400
No. of children	4	3	2	2	6	2	1	1	3	2	1	4	4
Children with SCD	1	3	1	1	1	2	1	1	1	2	1	1	2

Sex of children with SCD	Male	Females	Female	Female	Male	Female, male	Male	Female	Female	Females	Female	Male	Male, female
Genotype of children with SCD	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS
Age of children with SCD (in years)	2	6, 8, 14	8	5	7	7, 9	3	17	5	1, 3	5	10	8

The number of children by the participants ranged from one to six. One parent had all three children diagnosed with SCD, three parents each had two children diagnosed with SCD and nine parents each had a child diagnosed with SCD. In all, the participants had a total of eighteen children diagnosed with SCD, comprising twelve females and six males. The ages of the children diagnosed with SCD ranged from two years to seventeen years; four children were under 5 years, ten children aged 5-9 years and three children aged 10-17 years. All the children were diagnosed with homozygous Haemoglobin SS (HbSS). Also, all the participants (both father and mother) were carriers of the sickle cell gene, neither of them had sickle cell disease.

Themes generated

Three (3) major themes with their corresponding sub-themes were derived from the data gathered. The themes of the data presented below is the same as the main constructs of the ABCX model of family stress as our theoretical framework. The major themes were the perception of SCD by participants (Factor C, perception of stressor in ABCX model), the burden of care (Factor A, stressor event) and resources used by participants (Factor B, resources of the family). Perceptions on SCD described the caregivers' beliefs and understanding about the causes, prevention and management of SCD. It also involved how participants perceived the community's beliefs and understanding about the causes, prevention and management of SCD and the associated discrimination and labeling of caregivers because of the illness of their children [6].

The second theme was burden of care which referred to the burden and challenges associated with caring for a child with SCD. This included financial challenges associated with the caregiving responsibility, the emotional burden and the dual role of caregiving and their work. Finally, the resources used by participants was discovered. These resources were the assets available to parents that they used to buffer or cope with the hardships associated with caregiving. In this work, resources referred to the support systems. These resources were from family and friends, religious observations, health staff and online community.

Theme 1: Perceptions of SCD by parents

Participants of this study had different perceptions of the cause, transmission and management of SCD. Their beliefs and views were influenced by the different social and cultural dynamics among them. Parents in this study mentioned that the local name in Dagbani for SCD is "Darimihi" which means a "sickler". This is because these children constantly fall sick and are termed "sicklers".

Participants also added that they got to know of the disease for the first time when their children were admitted. However, some believed that the cause of SCD was ancestral, with the assumption that SCD results when ancestors do not support a marriage. Participants indicated that some community members held the belief that these children have a short life span on this earth. According to the participants, some community members believed SCD was caused by evil spirits. Hence, community members admonished participants to seek local treatment involving spiritual incantations as the cure. The fear of stigma was also explored. Issues from this subtheme focused on parents' willingness to disclose their child's condition the majority of the parents (nine) revealed they were not ready to disclose their children's condition even to their immediate family members. This is what a parent had to say [7].

Theme 2: Burden of care

Participants complained that the cost of care causes a huge financial burden to them. They mentioned the high cost of medication, especially antibiotics. Laboratory tests are usually requested before the start of new medications or anytime new complaints are made and this adds to the financial burden on participants. Others also stated that the cost of transportation to the health facility during crisis and review days takes a toll on their finances. Participants also mentioned that the time dedicated to caring for their children with SCD greatly affects them at their various places of work. Participants appraised the work-related burden differently due to their varied occupations. The burden of care for parents who are public-sector workers relates to seeking permission at their workplaces. Some participants described how difficult this process is for them.

Hours spent by participants while their children are on admission or on review days also affect their work life significantly. They have to work extra hours to compensate for the lost ones. Some parents also stated that they have difficulty concentrating at the workplace. This is because they have to contact their child's school during working hours to monitor their child's health.

Participants who are self-employed, however, explained that they intermittently lock up their shops to attend to their children when the need arises. This reduces their daily sales as their customers may meet their absence. One participant who is a shop owner shared that he is unable to monitor his shop attendants whenever he attends to his child during emergencies.

Emotionally, some of the participants said the burden of care experienced during their child's crisis had affected their reproductive decisions to give birth again. They did not know about genetic counselling before marriage and regretted their decision for marrying. Some explained that some nurses attempted to share their emotional pain but ended up giving unacceptable advice by advocating for family disharmony. Some participants described feeling ashamed as the only woman in a polygamous marriage having a child with SCD and how this is giving her emotional torture. She always feels guilty and uncomfortable around their rivals. This makes them feel inferior in the marriage because they are always reminded of the child's condition whenever they want to speak up.

Theme 3: Resources used by participants

The resources used in this study were social support and coping behaviors as resources to buffer crisis-proneness. Participants stated that they received social support from family members, friends, health providers, parent-to-parent support groups and the online community. The support came in the form of financial, psychological and physical support. All the parents in this study admitted they received financial support from family members, friends and health providers at one point in time. They alluded to the fact that support from the above sources helped them pay for the cost of laboratory investigations, drugs, transportation and the nutritional needs of their children.

Participants also mentioned the use of parent-parent support groups as a powerful resource. According to them, this psychological support was from parent-parent support groups initiated by hospital management. Additionally, participants mentioned they received physical support from family members, the health provider and friends who helped with their physical presence during hospitalization. Participants sought comfort from observing religious practices based on their faith. Some Christians said they used holy water and prayed the rosary to buffer crisis while some interviewed Muslims said they prayed to Allah for his strength to cope with the situation [8].

DISCUSSION

This section contains the study findings guided by a comprehensive literature review and in line with the main constructs of the ABCX model of family stress which guides the

study. The section contains a discussion of the study objectives which were to describe perceptions of participants on SCD, to explore the burden of care and to identify the resources used by participants caring for children with SCD. The ensuing paragraphs detailed the discussions.

Demographic characteristics

All the participants in this study were the biological parents of the children who were all married and lived together. The findings also revealed the care of the child with SCD was done by both parents as fathers were deeply involved in the caregiving process. The study findings differed with previous studies that most caregivers of children with SCD were their biological mothers but agrees with findings by Bukini that fathers were involved in the care of their children with SCD. All the participants in the study had some level of education with most of them up to the tertiary level. The level of education can help parents of children of SCD have a positive definition of SCD. This is congruent with the findings of a study carried out among caregivers of chronically ill children which showed that all the caregivers had some level of education [9].

Considering the monthly income of the parents, it was observed that most of them had some form of income. This is a positive finding because financial resources according to the ABC-X model of family stress can determine crisis-proneness or proofness. This finding is congruent with previous studies that highlighted the financial burden in caring for children with sickle cell disease.

Perception of parents on SCD

To understand SCD in their local context, participants, called SCD, a "sickler" due to its signs and symptoms. Participants perceived that the disease make their children always look weak and constantly sick due to their regular visits to the hospital. The findings corroborate a previous study in Ghana by Dennis-Antwi et al. where parents developed local names for SCD due to its cause and manifestation [10].

Additionally, the way participants perceive the attitude of community members in caring for their children with SCD informed the coping mechanisms employed by these parents. Participants indicated that some community members held the belief that these children have a short life span on this earth. This finding agrees in the literature that children with SCD have a short lifespan.

Due to fear of stigmatization, the majority of the participants (nine) in this study were not ready to disclose their children's condition to their neighbors. This was due to the fact that most family members have inadequate knowledge on SCD and that closed family members have a negative perception of SCD and hence there is the need for rigorous public awareness of SCD. Therefore, according to the ABCX model of family stress as used in this study, participants had a negative perception/definition of the stressor (SCD) [11].

Burden of care

A key finding is that some participants are reluctant to give birth again due to the challenges of caring for a child with sickle cell disease. However, such decisions are met with resistance as people insult such women for starving their husbands of their reproductive rights. This is because children show a man's might and worth in the study area, so any attempt by a woman to stop child bearing is resisted. The participants expressed that they would have married the most compatible partner if they knew of pre-marital genetic counselling. Awareness of sickle cell disease is important because it helps people make informed reproductive choices. This is also true of a study where family members and significant others were cautious so that their relatives with SCD could make informed reproductive choices [12].

The study also found that having a child with SCD in a polygamous marriage is an emotional issue for the affected women as it leads to inferiority and inability to speak up. Indeed, in polygamous marriages, wives tend to compete for their husband's attention on a daily basis and this impacts responsibilities such as the provision of food, housekeeping money, children's education and sexual affection. Hence, a woman who has a child with SCD in such a marriage is disadvantaged and possibly marginalized by her husband and rivals [13].

Also, participants reported that due to frequent hospitalization and routine medical check-up, they are always asking permission to stay out of work. Though a majority of the parents mentioned their superiors are cooperative and permit them to attend to their children, a few of them had difficulty getting permission at their workplaces. This is congruent with a previous study by Wonkam et al. in Cameroon which revealed that parents providing care to their children with SCD compromise their loyalty to their jobs. Indeed, caring for children with chronic diseases affects parents' work behaviour, causing them to miss, at least, one working day in a month which, ultimately, affects their retention. The current study also revealed that those who are self-employed do not have issues with getting permission to be absent from work for child care as they are usually their own bosses. However, they still end up losing income as they usually have to close their shops which tend to send a signal of closure of business or non-seriousness to their clients/customers. This tends to affect the longevity of their enterprises [14].

Resources used by parents

According to the ABCX family model, the presence of resources in the family regulates "crisis proofness" or crisis-proneness". The findings revealed that the parents used social support and coping behaviors as resources to buffer crisis-proneness. Parents received financial, psychological and physical support from family members, friends, health providers, parent-to-parent support groups and the online community.

Parents admitted financial support from family members, friends and health providers helped them paid for the cost of laboratory investigations, drugs, transportation and the nutritional needs of their children. This is in line with a study by (Tenkorang-Twum) that families offered immense support in

diverse ways to ensure that the suffering of a member was alleviated or lessened.

Parents also stated psychological support was within the couple involved and from parent-to-parent support groups initiated by hospital management. However, parents mention the presence of COVID-19 halted their parent-to-parent support group meetings and they expressed worry about this development. They all mentioned they were expectant of the revival of the meeting soon. This supports previous studies by Ali and Razeq that networking in parents of children with SCD took two forms namely; family-family relationships and family-nurse partnerships. Networking through family-family relationships was a platform for gaining a better understanding of your child's condition [15].

The parents mentioned they received physical support from family members, the health provider, and friends who helped with their physical presence during hospitalization. In the Ghanaian culture, the family goes beyond the nuclear family to the extended family and hence a disturbance in the family becomes a responsibility for every other family. This accounted for the immense support received from the extended family in this study as alluded by the parents and is consistent in the literature that family members and friends often acted as reliable sources of care and encouragement to them in times of crisis. Findings from this study disagree with study findings from Nigeria that 97% of mothers complained of family neglect during the crisis of the child.

Participants used religion as a resource by observing religious practices based on their faith. Some Christians said they used holy water and prayed the rosary to buffer crisis while some interviewed Muslims said they prayed to Allah for his strength to cope with the situation. This agrees with a study that the faith of fathers served as an active coping strategy for the fathers affected and energized their belief in prayer and hope for God's grace.

CONCLUSION

In conclusion, participants in this study had a negative perception/definition of SCD which according to the ABCX model of family stress increased the development of stress (burden of care) as evidenced in this study. Due to the negative perception/definition of SCD, parents experienced the burden of care in the form of financial burden, physical and work-related burden. Also, the emotional burden experienced by some parents informs their reproductive decisions not to give birth again. The study revealed that having a child with SCD leads to emotional torture and an inability to speak up in a polygamous marriage. Parents received support from family members, friends, health workers, parent-parent support groups and the online community as resources to buffer the likelihood of development stress.

The NHIS has improved universal access to key health interventions in Ghana. Adding key healthcare services such as (free constant supply of hydroxyurea and free hemoglobin electrophoresis) to the list of conditions covered under the NHIS would reduce the financial burden on parents of children with SCD tremendously. More efforts should be directed at

increasing awareness of genetic counselling before marriage or childbirth among the populace. This would inform their choices and contribute to a significant reduction in the prevalence of children with SCD. Support services, including counselling services and other psychological interventions would promote the emotional and psychological well-being of parents of children with SCD. Promoting social activities (support groups) among parents of children with SCD in the various hospitals would not only promote their social life but also serve as a means to share experiences and support among parents.

LIMITATIONS

The researcher considers the sample size used was small and so the findings cannot be representative of the study population. This was due to low attendance at the sickle cell units resulting from the COVID-19 outbreak since data was collected in June and July, 2020.

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AVAILABILITY OF DATA AND MATERIALS

The datasets generated and/or analyzed during the current study are not publicly available due to restrictions by the relevant institutions to protect participants' privacy. However, datasets are available from the principal investigator upon reasonable request.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethics approval was obtained from the research and ethics committees of tamale teaching hospital (ref. no. TTH/R&D/SR/127) and Ghana health service (ref. no. GHS/RDD/ERC/Admin/App/21/235). Before the interviews, the interviewer explained the participants' rights to the parents, including the matters of confidentiality and the right to decline to answer any given question if the participant so wished. All participants consented in writing to participate in the study and use audio recordings before the interviews.

COMPETING INTERESTS

There is no conflict of interest to declare.

CONSENT FOR PUBLICATION

This was not applicable.

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