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EXPERIENCES OF PARENTS OF CHILDREN WITH SICKLE CELL DISEASE:

A STUDY AT 37 MILITARY HOSPITAL

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DECLARATION

I, Sylvia Anaman, certify that this thesis is the result of research undertaken towards the award of the Master of Philosophy in Nursing Degree in the School of Nursing and Midwifery, University of Ghana, Legon. This research has been undertaken with the guidance and supervision of Dr Patience Aniteye, School of Nursing and Midwifery, University of Ghana, Legon and Rev. Dr Thomas Akuetteh Ndanu, School of Medicine and Dentistry, University of Ghana, Korle-Bu. The undersigned supervisors certify that they have read the thesis and have recommended it to the School of Nursing and Midwifery for acceptance.

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ABSTRACT

Sickle Cell Disease is the most common life-threatening hematologic disorder found in Ghanaian children. The present system of care of these children relies mostly on their parents. Studies have shown that caring for a child with SCD is associated with numerous hardships. However, there is a dearth of literature on the experiences of parents of children with SCD in Ghana. Therefore, this study explored the experiences of parents of children with SCD at the 37 Military Hospital, Ghana using the ABCX family stress model as the guiding theoretical framework. The qualitative research approach that is descriptive and exploratory was used. Using the purposive sampling technique, twelve (12) parents of children receiving care at 37 Military Hospital were engaged in a face-to-face interview. The interviews were audiotaped, transcribed verbatim and analysed using thematic content analysis. Five (5) major themes with their corresponding sub-themes were derived from the data gathered. These themes were; caring for a child with SCD, resources used by parents, perceptions about SCD, the outcome of caregiving (crises) and determinants of the burden of caregiving. The study revealed that parents caring for their children with SCD experience a heavy burden related to the health of the child, physical, financial, occupational/work-related challenges and burden related to health services. The parents expressed a lack of support, especially financial support. The caregiving role altered the physical and psychosocial health of parents who were primary caregivers. In conclusion, the physical and psychosocial health of parents who are primary caregivers should be considered paramount in the plan of care of children with SCD. In addition, there should be adequate financial support for parents caring for children with SCD.

DEDICATION

I dedicate this work to my family without whom I could not have come this far; most especially to my husband, Francis for his unflinching support. To my children Eliza, Sean and Francis Jnr for being a source of strength to me in my trying moments when I was undertaking this study. Finally, I also dedicate this work to my parents and my mother-in-law who took care of my children throughout the entire period.

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LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
BECE	Basic Education Certificate Examination
GHS	Ghana Health Service
HBA	Adult Haemoglobin
HBF	Foetal Haemoglobin
HBS	Sickle Haemoglobin
HBSβ0-THALASSEMIA	Haemoglobin Sβ0-thalassemia
HBSβ+ -THALASSEMIA	Haemoglobin Sβ+-thalassemia
HBSC	Haemoglobin SC
HBSS	Haemoglobin SS
HIV	Human immunodeficiency virus
IRB	Institutional Review Board
KATH	Komfo Anokye Teaching Hospital
MOH	Ministry of Health
NCDs	Non- Communicable Diseases
NGO	Non- Governmental Organisation
NHIS	National Health Insurance Scheme
NMIMR	Noguchi Memorial Institute for Medical Research
OPD	Outpatient Department
SCA	Sickle Cell Anaemia
SCD	Sickle Cell Disease
UN	United Nations
WHO	World Health Organisation

CHAPTER ONE

This chapter presents the background of the study, problem statement, purpose and objectives of the study, significance of the study and operational definition of key terms.

1.1 Background

Marriage is a blissful union which by natural phenomenon usually leads to conception and delivery of children. It is the expectation of all parents to have a normal pregnancy, safe delivery, and healthy children. However, over seven million babies born to parents each year have deformities which may be caused by inheritance of a defective gene with the most prevalent type being Sickle Cell Disease (SCD) (Makani, Ofori-Acquah, Nnodu, Wonkam & Ohene-Frempong, 2013; Piel, Hay, Gupta, Weatherall & Williams 2013; Yawson et al., 2016).

Sickle Cell Disease is one of the most predominant lone-gene disorders, which is life-threatening and debilitating (Yanni, Grosse, Yang, & Olney, 2009). It is a group of genetic hematologic disorders which occur when production of normal adult haemoglobin (HbA), which carries oxygen throughout the body, is structurally varied through genetic mutation of the β- globin leading to an abnormal form called haemoglobin S (Hb S) (Chakravorty & Williams, 2015; Kenny, 2010). The sickle haemoglobin is the major haemoglobin found in people with Sickle Cell. The disease occurs at the β-globin chain when the amino acid occupying the sixth position is changed from valine to glutamic acid in addition to the replacement of thymine for adenine in the 17th nucleotide (Farrell et al., 2010; Frenette & Atweh, 2007; Rees, Williams, & Gladwin, 2010; Yawn et al., 2014). Deoxygenation causes this defective haemoglobin to polymerise easily changing the distinctive biconcave shape of normal erythrocyte cell into a sickle-shape. The cell becomes highly viscous, inflexible and impedes the flow of blood to organs. The disease leads to

symptoms such as severe pain, musculoskeletal problems, damage to organs, reduced blood level, pulmonary hypertension and risk of bacterial infection (Farrell et al., 2010; Kenny, 2010; Mulumba & Wilson, 2015).

The common types of SCD include homozygous haemoglobin SS (HbSS) and the compound heterozygous conditions such as haemoglobin Sβ0-thalassemia (HbSβ0-thalassemia), haemoglobin Sβ+-thalassemia (HbSβ+ -thalassemia), and haemoglobin SC disease (HbSC) with the homozygous type being the commonest(Frenette & Atweh, 2007; National Heart, Lung and Blood Institute [NHLBI], 2014; Rees et al., 2010). All these types can be found in the Ghanaian population especially HbSC and HbSS (Makani et al., 2013). Haemoglobin SS and HbSβ0-thalassemia are clinically called Sickle Cell anaemia (SCA) due to their clinical resemblance and the manifestation of severe symptoms (Frenette & Atweh, 2007; Yawn et al., 2014).

It is globally acknowledged that SCD was first discovered by a cardiologist in United State (US) when he first saw the sickle-shaped red blood cell but on the contrary, the disease has been popularly known in some parts of Africa even before the 20th century (Makani et al., 2013; Rees et al., 2010). Using the hand-foot syndrome, "cold- season rheumatism" and without the use of microscopes for any electrophoresis, Ghanaians had knowledge of this disease centuries before its discovery in Chicago, US (Konotey- Ahulu, 2014). In fact, each tribe in the country has a name for the disease. For instance in "Fanti," SCD is called "*Nnwiiwii"* and in "Twi" it is known as "*Ahotutuo",* the local way of describing the pain as chewing and plucking respectively. These names were given to clearly depict the painful nature of SCD.

Sickle Cell Disease was originally predominant in the tropics such as sub-Saharan Africa and central India due to the provision of resistance against malaria by the

heterozygous type of the disease (Chakravorty & Williams, 2015). However, due to migration, the disease is now found in other countries such as the United States with 10% of the population having Sickle Cell Disease (Piel, Hay, Gupta, Weatherall & Williams, 2013; Aygun & Odame, 2012). The disease also affects other people with different ethnic horizon such as Mediterranean, Caribbean, South and Central American, Arabian and East Indians (Gustafson, Bonner, Hardy, & Thompson, 2006; NHLBI, 2014; Yawn et al., 2014).

According to the World Health Organisation [WHO] (2011), approximately 5% of the world's population carry the Sickle Cell trait. However, the majority of the population carrying the Sickle Cell trait can be found in Africa mostly in countries located between the latitudes of 15° North and 20° South with prevalence ranging between 10% -40% of the total population (Agasa et al., 2010; Mulumba & Wilson, 2015). Globally, it is estimated that about 20-25 million people have SCD, out of which, 12- 15 million live in sub- Saharan Africa (Aliyu et al., 2008). The burden associated with SCD is predominant in sub- Saharan Africa especially in Nigeria (West Africa) where about 6 million of the country's population have Sickle Cell Disease (Aliyu et al., 2008). The prevalence rate of SCD in Africa may be more alarming than what is reported since most childbirths in Africa occur outside the hospital facility and death of these children go undiagnosed (Grosse et al., 2011). Hence, in determining the prevalence in Africa, equations such as Hardy-Weinberg's equation are used in the calculation of the expected birth rate of the disease (Makani et al., 2013; Piel et al., 2013; Williams, 2016).

Sickle Cell Disease is a serious public health issue in the world, especially in sub-Saharan Africa where mortality rate is 50-90% before the 5th birthday of a child and its global burden has been realised and acknowledged by the United Nations (UN) as the

"world's foremost genetic disease" which poses physical and psychosocial threat to the patients and their families (United Nations General Assembly, 2008).

In 2010, of all the babies born with Sickle Cell Anemia in the world, 79% occurred in babies born to parents in sub-Saharan Africa and it is estimated to increase to 88% in 2050 (Kocarnik, 2015; Piel et al., 2013). In Ghana, 2% of the total live births, that is 1 in 50 births are affected by this inherited genetic disease (Dennis-Antwi, Dyson, & Ohene-Frempong, 2008). Extremely common among the Ghanaian population is Sickle Cell carriers. In Ghana, 33.3% of the populace, carry the Sickle Cell trait and possess the ability to transfer it to their offspring (Konotey- Ahulu, 2014). It has been found that one in every 3 Ghanaian is a Sickle Cell carrier. Therefore 1 in 9 marriages in Ghana (male and female carrier) will lead to a child being born with SCD (Konotey- Ahulu, 2014). Out of the total number of children born every year in Ghana, 15,000 of these children are born with this chronic disease and this is expected to escalate in four years' time to 60,000 (Ohene-Frempong & Nkrumah, 2014).

The emergence of symptoms of the disease occur in the early childhood stages usually after a few months of age when the major haemoglobin at the foetal stage (Hb F) is gradually substituted by sickle haemoglobin (Hb S) (Antwi-Boasiako et al., 2015; Arab, 2010; Frenette & Atweh, 2007; Makani et al., 2013; Rees et al., 2010). Children with SCD suffer a lot of complications related to the disease and this initiates severe trauma in parents of the ill-children (Afolayan & Jolayemi, 2011). Sickle Cell Disease deforms the physical appearance of children by presenting with symptoms such as thin limbs, distended abdomen and craniofacial deformities such as frontal bossing, protruded midface and gnathopathy; a condition where there is protrusion of the upper teeth (Afolayan & Jolayemi, 2011; Kabiti, 2008).

Physiologically, patients are prone to complications such as severe pain resulting from vaso-occlusive crisis, acute chest syndrome, musculoskeletal problems, pulmonary hypertension and bacterial infection due to dysfunction of the spleen (Aliyu et al., 2008; Balogun et al., 2010; Battersby, Knox-Macaulay, & Carrol, 2010; Chakravorty & Williams, 2015; Makani et al., 2013; Mulumba & Wilson, 2015; Stankovic et al., 2012). Indeed, anaemia in SCD patients is the primary cause of high mortality and morbidity rate as it leads to the death of many patients prior to blood transfusion (Mulumba & Wilson, 2015).

Sickle Cell Disease patients are vulnerable to neurocognitive complications. Stroke, which causes a neurological alteration in the brain is one of the complications of SCD and according to Kolapo and Vento (2011), it is a problem in sub- Saharan Africa. The neurocognitive dimension is recognised in the low attention span of SCD children at school and coupled with a high level of school absenteeism, negatively affects their academic attainment (Mcclellan, Schatz, Sanchez, & Roberts, 2008). Psychologically, SCD patients are prone to feelings of anxiety, hopelessness, depression and low self-esteem as a result of continuous hospitalization, pain, loss of job, absenteeism from school, difficulty in getting pregnant, high risk of abortion and even difficulty in finding a spouse (Afolayan & Jolayemi, 2011; Kabiti, 2008; Mcclellan et al., 2008).

There are five main treatment modalities usually employed in the clinical management of SCD depending on the clinical phenotype of the patient. They are supportive, symptomatic, preventive, curative and abortive (Ballas et al., 2012). The supportive treatment strategy is the commonest and is intended to ensure the preservation of an essential requirement for good health such as balanced meal, adequate hydration, sleep and folic acid supplementation (Ballas et al., 2012; Pule & Wonkam, 2014). Symptomatic treatment is focused on the alleviation of specific symptoms of SCD as they occur, and it

includes blood transfusion for symptomatic anaemia, analgesia for pain and antibiotics for infections (Ballas et al., 2012; Makani et al., 2013). The preventive approach is to avert the occurrence of disease complications such as pneumonia and influenza vaccination, hydroxyurea which is an oral cytotoxic, and neoplastic drug for the induction of foetal haemoglobin (Adewoyin, 2015; Pule & Wonkam, 2014). It also involves blood transfusion to prevent primary and secondary stroke (Ware et al., 2011). The main aim of the abortive approach is to abort painful crisis by preventing them from worsening or precipitating other complications and nitric oxide is the only drug choice reported to completely stop chronic pain in patients with SCD (Pule & Wonkam, 2014). The fifth approach, the curative approach is the ultimate goal for all inherited genetic disorders and haematopoietic stem cell transplantation is the only approved curative treatment for patients with SCD (Ballas et al., 2012).

. Treatment modalities usually employed may be curative, preventive or symptomatic. Bone marrow transplant, which is curative is not usually opted by patients with SCD due to donor issues and complexities of conditions associated with the regimen postoperatively (Bolaños-meade & Brodsky, 2014). Therefore, most parents opt for symptomatic or preventive therapy which involve use of medications such as penicillin V and hydroxyurea which is an anti-neoplastic drug that activate the production of HbF (Frenette & Atweh, 2007; Gustafson et al., 2006; Odame, Kulkarni & Ohene-Frempong, 2011; Rees et al., 2010; Yawn et al., 2014).

The present system of care of chronically-ill children relies mostly on parents who adopt the unexpected role of “informal caregiver career” throughout the life of the ill child and due to medical and technological advancement, children with chronic illness are living longer increasing the caregiving responsibility of these parents (Hatzmann, Heymans,

Ferrer-i-Carbonell, van Praag & Grootenhuis, 2008). The role of parents in the management of their children with SCD cannot be overemphasized especially mothers who experience the major role change and are the main caregivers. Parents play an effective role in giving medications to children, keeping diaries for pain, managing pain, educating children on coping strategies and even supporting them spiritually (Moore, 2011).

It is only a well and healthy parent who can render effective care to a sick child, however, studies have shown that lifelong rendering of informal caregiving to chronically ill relatives alters the quality of life of the caregiver (Schulz & Sherwood, 2008; Wiener et al., 2013; Wonkam et al., 2013). The diagnosis of a child with chronic disease such as SCD has adverse effects not only on the ill-child but on their parents as well (Cousino & Hazen, 2013; Yawson et al., 2016). The severity of the effect of caregiving on parents varies according to the presence of complications, signs and symptoms and even the mode of therapy. Indeed, patients and their families encounter numerous difficulties depending on the severity of the disease, access to medical care and family modalities (Gold, Treadwell, Weissman, & Vichinsky, 2008).

Recognizing the social, economic and psychological impact of the disease on the patient, families and countries as a whole, UN encouraged its member states to strengthen efforts in the development of programmes to facilitate research in the sector (United Nations General Assembly, 2008). However, in sub-Saharan Africa, where the disease prevalence is high with a mortality rate of 50-90% before the fifth year of a child, recognition of the disease as a public health problem has been very sluggish (Dennis-Antwi et al., 2008, Odame et al., 2011). This situation is common in Ghana as the health status of SCD patients are repressed into the general data of common childhood illnesses such as respiratory tract infections and malaria (Dennis-Antwi et al., 2008). The notable attention given to SCD was

in 2010 when the country started a national programme on newborn screening with the support of the Government of Brazil and the National Health Insurance Scheme (Dennis-Antwi, Culley, Hiles, & Dyson, 2011). This was started in Kumasi in the Ashanti Region of Ghana and Greater Accra Region, the nation's capital. However, its expansion into other regions in the country has still not been achieved. Therefore most children in Ghana are only diagnosed after frequent visits to the hospital with complications of SCD (Osei-Yeboah & Rodrigues, 2011).

Owing to the minute attention given to Sickle Cell Disease and its patients in the country, it is not unusual that there is a dearth of information on the parents of these patients who are the main primary caregivers. Thus this study was carried out to explore this gap in knowledge.

1.2 Problem Statement

Sickle Cell Disease is the most common life-threatening hematologic disorder found in children in Ghana (Yawson et al., 2016). It is a chronic disease that requires constant care and attention. Sickle Cell Disease presents a vast array of physiological, psychological and neurological comorbidities in children with the disease. (Bhatt-poulose, James, Reid, Harrison & Asnani, 2016; Mcclellan et al., 2008; Mulumba & Wilson, 2015; Muoghalu, 2016). Children with SCD require frequent visits to the hospital for routine medical care and for management of complications. Treatment modalities available to manage SCD are usually symptomatic and preventive rather than curative (Ali & Razeq, 2017; Bolaños-meade & Brodsky, 2014). Therefore, the diagnosis of a child with the disease call on informal caregivers who are mostly their parents, to embrace the reality of providing care throughout the life of the affected child (Katooa, Shahwan-Akl, Reece, & Jones, 2015; Marsh, Kamuya, & Molyneux, 2011).

Caring for a child with SCD presents with myriads of emotional, social, physical and psychological encumbrances on parents of these children (Cousino & Hazen, 2013). It calls for major adjustments in various aspects of the parent's life and a study has shown that this is both stressful and demanding on parents (Ali & Razeq, 2017). The physical burnout emerging from frequent visits to hospitals, prevention of vaso-occlusive episodes and even the activities of daily living lead to tiredness, sleeplessness and sometimes the development of chronic conditions such as hypertension (Da Silva et al., 2012; Van Den Tweel et al., 2008).

In the Ghanaian context, children are expected to be born as a blessing after every marriage or union (Nukunya, 2003). Thus when a woman is seen to be pregnant after marriage, both families become happy. When the child is born, it is expected to be healthy and normal for the purpose of family continuation and when this happens it leads to joyous celebrations (Gyekye, 1996). However, if no children are born to the married couple or a disabled or ill child is born, the family becomes stigmatized and saddened both by external and internal social pressures (Fledderjohann, 2012).

Having a child suffering from SCD in a family is both worrying and stigmatizing (Niekerk, 2015). Families may warn their children not to marry into such a family for fear of having children with SCD (Ali & Razeq, 2017). Hence parents and caregivers suffer both physically and psychologically from their caregiving experiences and pressure from society.

Unfortunately, Ghana like most sub-Saharan African countries has no national policy, national guidelines for management, or national statistics on SCD (Dennis-Antwi et al., 2008). SCD and experiences of parents providing care to almost 60,000 children with SCD in Ghana have not been given the needed recognition in Ghana (Ohene-Frempong &

Nkrumah, 2014). This is evidenced by the paucity of published information on the experiences parents of these children go through in caring for their children with SCD.

Fully understanding the burden of the caregiving on the parents and their quality of life, as well as the impact on the SCD child and the rest of the family, will better help to offer appropriate support for them. Therefore there was the need to explore the experiences of parents caring for children with SCD at the 37 Military Hospital in the Accra Metropolis.

In order to fully describe the experiences of these parents, the study sought to explore the burden of parents caring for children with SCD, their perceptions about the disease, needed resources and the outcome of the caregiving role on their health and wellbeing. The ABCX model of family stress was used as the conceptual framework to guide the study since its major constructs well explained the experiences of the parents caring for children with the disease.

1.3 Purpose of the Study

This study sought to explore the experiences of parents of children with Sickle Cell Disease at the 37 Military Hospital in the Accra Metropolis.

1.4 Specific Objectives:

The specific objectives of this study were to;

1. Describe the burden of parents caring for children with SCD.
2. Identify the resources used by parents caring for children with SCD.
3. Find out the perceptions of parents and community members about SCD.
4. Identify the outcome of caregiving on the health and wellbeing of parents of children with SCD.
5. Ascertain the determinants of the burden of caregiving.

1.5 Research Questions

1. What is the burden of parents caring for children with SCD?
2. What are the resources used by parents caring for children with SCD?
3. What are the perceptions of parents and community members about SCD?
4. What is the outcome of caregiving on the health and well-being of parents of children with SCD?
5. What are the determinants of the burden of caregiving?

1.6 Significance of the Study

Parents are the main caregivers of patients with Sickle Cell. Therefore, it is imperative to explore their caregiving experiences and how these affect their health and wellbeing as well as the effects on the rest of the family. The findings from the research may help healthcare professional to understand the subjective experiences of these parents, their misconceptions, coping strategies and their health beliefs. It may also emphasize the need to provide psychological assessment and appropriate crisis intervention counselling on a regular basis to these parents as well as the rest of the family including the ill-child. The study findings may inform NGOs and benevolent societies about the burden of SCD caregivers and the need to donate to assist them. It may inform the Ministry of Health about the need to initiate and pursue neonatal screening and intensify genetic counselling among the populace. The public may also be informed about the need to support parents of children with SCD and how their perceptions about SCD affect the lives of parents and children. Finally, the study findings would add to the existing knowledge on experiences of parents of children with SCD and provide the basis for further studies.

1.7 Operational Definitions

A child with Sickle Cell Disease: A child who does not have the normal adult haemoglobin AA but has a combination of abnormal ones and manifest signs and symptoms of the disease such as pain in the joints.

Parent: A father or mother of such a child, an adult who adopted or playing a parenting role and is directly providing care to a child with SCD.

Experiences: the hardships and personal encounter about the daily routine and practical events that parents of children with SCD go through in caring for their children.

Burden: the toll caring for children with SCD exacts on their parents.

Health and well-being: the health status of the caregiver since the beginning of the caregiving responsibility.

CHAPTER TWO

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

This chapter focuses on the theoretical framework guiding the study and related literature reviewed. The ABCX model of Family Stress was the theoretical framework underpinning the study. The chapter also describes current empirical studies that focus on the research problem. The literature was structured according to the objectives of the study. The chapter finally concludes with a summary of the reviewed literature and the gaps identified which are addressed in this study.

2.1 Theoretical Framework (The ABCX Model of Family Stress)

In exploring the experiences of parents of children with Sickle Cell Disease, the ABCX model of Family Stress by Reuben Hill was used to guide the research. The ABCX model of family stress was developed in 1949 after studying how families reacted with the absence of fathers during the Second World War. The model was developed to explain "the crisis-proneness and freedom from crisis among families" (Hill, 1958 p. 143). Guided by the social systems theory and family sociological research, the model was propounded to explain variations in the family's response to stress (Rosino, 2016). It is one of the earliest theoretical models which has gone through a series of modifications and has guided the development of several models. However, the ABCX model has withstood critical assessment and is still the guiding framework for analysing and studying family stress and coping (Boss, 2006; Pat-Horenczyk, Brom, & Vogel, 2014).

The model is made up of three exogenous variables A, B, C which interact to produce an endogenous product, X. The variable A in the model represents stressor events which interact with B (resources) and C (perception) to bring out the product X (crises). 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 (Pat-Horenczyk et al., 2014; Rosino, 2016). Thus an important aspect of the model is that the crisis produced is not fixed in the stressful event but conceptually, it is the result of the affected family's response to the event (Boss, 2006; Price, Price, & McKenry, 2010).

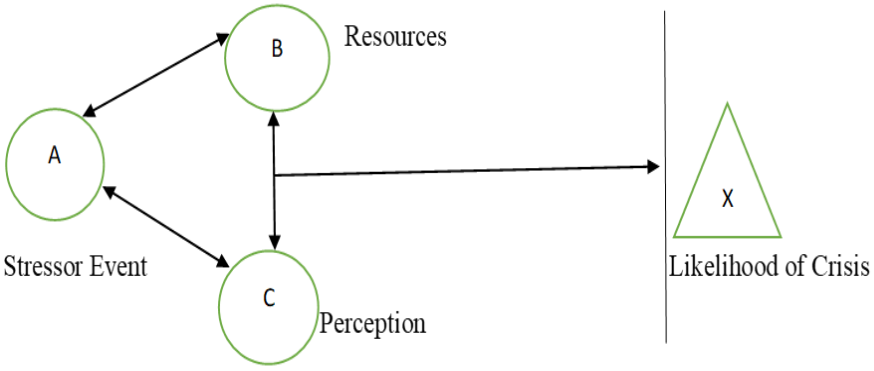

Figure 2.1: The ABCX Model of Family Stress

Source: Adopted from Hill (1949)

A- Stressor Events/ Situation

Hill (1958) defined stressor as "a situation for which the family has had little or no prior preparation and must, therefore, be viewed as problematic" (p.139). A stressor is an occurrence either positive or negative that has the ability to alter or can alter the family dynamics (Rosino, 2016). It was contended in the model that stressor events are experienced differently by each family based on the hardships or challenges associated with the event and these hardships or challenges are considered part of the stressor. According to Hill (1958), hardships are complications of stressor events that call on the resources of the families and they must be accorded with similar importance as the stressor itself. Some of these stressors include caring for an ill- child or spouse, reproductive decision and loss of a

job. The duration of the stressful event and associated hardships directly affect the level of crises/ stress experienced by the family or the individual thus a chronic situation will lead to a higher level of stress as this will precipitate additional hardships as compared to acute situations (Boss, 2006).

B- Resources of the Family

These are assets available to the individual or family that help to buffer or escape crisis after being faced with the stressor (Rosino, 2016; Weber, 2011). Thus, without these resources, the family has an increased likelihood of experiencing a higher level of crises when encountering a stressor. Thus the presence of resources in the family regulates "crises-proofness" or crises-proneness" of the family (Hill, 1958). Other important forms of resources are coping behaviours and social support that is obtained externally from religious institutions, government institutions and the community (Boss, 2006; Price et al., 2010).

C- Perception/ Definitions of the Stressor

The meaning attached to a stressor and the associated hardships influence the occurrence of crises. Families that negatively define stressful events have a higher likelihood of experiencing crisis than those that positively define the situation. This type of coping strategy is best used in situations where the event cannot be changed by the individual or the family but can be modified by reframing and having an optimistic attitude (Rosino, 2016).

X- The likelihood of Crisis

This factor represents the degree of crises experienced when a stressor interacts with coping resources and perception about the situation. Usually, crises occur when there are inadequate resources and inappropriate appraisal when the individual or the family is

confronted with a stressor (Rosino, 2016). These crises vary in type and can manifest in several ways to disrupt the health and wellbeing of the individual and the family.

Relevance and Justification of the Model to the Study

It must be acknowledged that the model was designed and used to understand the interwoven factors influencing family stress and coping. However, it has been applied to studies involving individual stress patterns in caregivers of children and adults with chronic diseases (Branscum, 2010; Ellingsen, Baker, Blacher, & Crnic, 2014; Norizan & Shamsuddin, 2010). 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 and to understand some of the predictors of stress in mothers of children with Down's syndrome.

The ABCX model of Family Stress was found suitable for this study because parents caring for children with Sickle Cell Disease who adopt the unexpected role of informal caregivers are predisposed to crisis. Having a child with Sickle Cell Disease and the numerous hardships or challenges associated with it are the stressors. These stressors interact with the parent's resources and perception about the disease and may precipitate a crisis in the parent. Additionally, the model was used in this study since its major constructs and their components were relevant to parents caring for children with Sickle Cell Disease and aided in achieving the research objectives.

The model was considered along with other models such as the caregiving process and caregiver burden model. However, this model was adopted for this study because it is simple but a comprehensive theoretical framework that encapsulates and organizes the numerous factors of parenting stress and coping into four basic domains for easy

comprehension and application. Additionally, it is not loaded with semantics and it guides the study of caregiving as a dynamic process.

In this present study, the "A" factor refers to burdens associated with caring for a child with SCD. The "B" factor refers to the resources used by parents. Factor "C" refers to perceptions of parents and community members about SCD. Finally, factor "X" refers to the physical and psychosocial health of the parent.

2.2 Review of Related Studies

Literature was reviewed using various sources such as books, published journals and the internet. Different electronic databases such as 'Sage', 'Science Direct', 'PUBMED', 'JSTOR', 'CINAHL', 'Google Scholar' and 'Wiley Online Library' were used. Data search was limited from 2008 to 2018. Keywords used singly or combined included words such as 'experience', 'caregivers', 'parents', 'children with sickle cell', 'chronic illness', 'illness perspective', 'physical health', 'psychosocial health' and 'coping strategies'. The reviewed studies are presented according to the objectives of the study.

2.2.1 The burden associated with caring for children with SCD.

Most research done across the globe have described the experiences of caring for a child with SCD as challenging and burdensome especially for parents of these children who are the primary caregivers (Adegoke & Kuteyi, 2012; Habeeb, Hassan, & Ahmed, 2015; Leite et al., 2013). Generally, parents of chronically ill children in the performance of their role experience relatively higher level of disease-related burden comparable to parents of healthy children (Cousino & Hazen, 2013; Feizi, Najmi, Salesi, Chorami, & Hoveidafar, 2014). Studies in West Africa have shown that most of the caregiving responsibilities are carried out by their mothers (Afolayan & Jolayemi, 2011; Wonkam et al., 2013; Yawson et al., 2016).

A plethora of studies carried out by researchers in different parts of the world on parents of children with SCD using different research designs prove that the health of the child is a contributory factor and a major source of burden to their caregivers (Ali & Razeq, 2017; Wonkam et al., 2013). It has been reported in different countries that parents are burdened by the frequent occurrence of painful vaso-occlusive crisis (Ali & Razeq, 2017; Brown et al., 2010a; Wonkam et al., 2013). According to the findings of these studies, the presence of frequent crises leads to frequent hospitalization, frequent absenteeism from school and even premature discontinuation of school. In addition to these, the studies further revealed that inadequate management of pain in children in crises leads to stress, anxiety and emotional distress in their parents. Findings of other studies carried out in central and eastern parts of Africa revealed that frequent hospitalization of children with SCD constitute a huge financial burden to their parents as they have to spend more money in these circumstances (Wasomwe & Ngoma, 2011; Wonkam et al., 2013). Frequent hospitalization brings a sense of insufficiency as parents feel they have neglected their responsibility to other members of the family (Ali & Razeq, 2017). Studies carried out among primary caregivers of children with SCD showed that disease severity, presence of complications such as stroke, poor growth and development, recurrent splenic sequestration, continuous hospitalization and frequent blood transfusion aggravate the level of stress experienced by the parents as it calls for more financial drain on the family (Barakat et al., 2007; Karlson et al., 2012). In addition, a study carried out in Nigeria showed that the presence of disease complications causes severe distress in parents as it leads to difficulty in transportation and alters the daily routine of parents (Afolayan & Jolayemi, 2011).

The chronic nature of SCD and the unpredictability of crisis occurrence requires constant care which places a physical burden on parents providing care to children with the

disease (Brown et al., 2010; Moskowitz et al., 2007). A study by Moskowitz et al. (2007) indicated that mothers provide two basic care to their sick children; technical and non-technical care. Technical care involves providing daily medications, taking them to routine hospital visits and care in terms of crisis. Non -technical care involves feeding, grooming, bathing and supporting the child through education on prevention of crisis and psychological support to help the child accept the disease condition. It was also revealed that a child in crisis may require maximum hours of care of about 13hours per day which may last for about a week, putting a lot of strain on the caregiver (Moskowitz et al., 2007). In addition to the strain on parents, there is an extra burden of supporting the medical needs of their children such as adherence to preventive measures against crisis occurrence, routine hospital visits and management of pain (Brown et al., 2010).

Parents of children with chronic diseases such as SCD are faced with a higher level of financial constraints from the cost of medical care which is exacerbated by continuous hospitalization (Gesteira, Bousso, Misko, Ichikawa, & Peres de Oliveira, 2016; Karlson et al., 2012). Findings of studies carried out in Nigeria revealed that parents of children with SCD in the low-income countries, where there is high level of poverty and inequitable distribution of resources, suffer additional economic hardships from the medical care of their children (Brown et al., 2010; Muoghalu, 2016; Olatunya et al., 2015). Indeed, the high cost of care increases the mortality rate of children with SCD as parents cannot afford quality medical care for their sick children (Ngolet et al., 2016).

A study by Tagoe (2012) to investigate the burden of non-communicable diseases (NCDs) on Ghanaian households collected data from 4,121 households. Findings indicated that the mean expenditure on medical cost is 49% higher than households with healthier individuals. These findings were confirmed by other studies carried out in three regions of

Ghana on 100 caregivers of chronically ill children. The studies showed that 41% of these respondents had financial difficulties especially during hospitalization and lacked financial support from significant others. Although the majority of the respondents in the study were insured, they did not escape the financial drain as most of them paid more than GH¢50 as an extra cost per hospitalization. (Dennis-Antwi et al., 2011). In a recent study carried out in certain parts of the country, it was revealed that, most parents in the study pleaded with the government to implement a policy where care of children with non- communicable diseases, of which SCD is the commonest, will have full benefit of the national health insurance scheme (Yawson et al., 2016).

Brown et al. (2010) revealed in their study that most parents are not able to cope with the caregiving stress as a result of a financial drain on the family. About 13.3% of Sickle Cell caregivers in their study acknowledged acquiring loans to support them carry out their responsibilities and that some of the loans were too huge to repay posing extra stresses on them. In fact, the financial constraints on the parents are so significant that in Ghana, children with Sickle Cell Disease are called “money will finish” as parents view children with this chronic diseases to be a financial drain on the family for as long as they live (Dennis-Antwi et al., 2011). In addition to this financial drain on the family, findings of studies have shown that parents mostly dedicate their entire life to providing quality informal care which makes them not employable in highly- paid business organisations leading to reduced economic strength of the parents (Brown et al., 2010; Karlson et al., 2012; Nur Saadah, Siti Hajar, & Rezaul Islam, 2014).

The constant demand for care of children with SCD causes conflict between caregiving responsibility and job responsibility of parents (Brown et al., 2010; Wonkam et al., 2013). A study was carried out by Wonkam et al. (2013) in Cameroon with 130 parents

of SCD children. The parents revealed in the study that caring for their chronically ill children affected their loyalty to their jobs and prevented them from working hard in their various jobs. Likewise, almost all parents in the study, 98% (n= 96) admitted missing at least one working day in a month and this definitely affected their retention in their various jobs. This also affected the economic sustainability of the family and put extra financial stress on the family.

Due to the nature of SCD, healthcare facilities become the second home to both the patient and the caregiver; they go to the facilities for a routine medical visit, or as a result of the crisis. However, how parents perceive healthcare professionals differ from the core mandate of providing quality care to their children which tends to arouse a feeling of distress in them. (Burnes et al., 2008; Javalkar et al., 2017; Welkom, 2012; Wesley et al., 2016). Wesley et al. (2016) reported in their study that, parents complained that healthcare professional tag their children as “drug seekers” and fail to acknowledge the extent of pain the children go through. This finding is further explained in an earlier retrospective medical chart review carried out by Zempsky et al. (2010). Comparing pain management in SCD children with vaso-occlusive pain and children with long bone fractures, it was discovered that indeed, SCD patients with vaso-occlusive pain were attended to earlier and given relatively higher dose of opiates, however, subsequently, these children received inadequate administration of analgesics as the healthcare providers are perturbed about “drug-seeking behaviour” and “opiate addiction”.

In an in-depth study, parents viewed many nurses and medical doctors in the mainstream who are not specialist as incompetent, having insufficient knowledge and lacking expertise when it comes to the management of children with SCD (Burnes et al., 2008; Wesley et al., 2016). Furthermore, caregivers involved in the research voiced out their

displeasure about the inadequate medical research concerning the disease irrespective of its high incidence among children and leaving their children to suffer. This, according to the parents sparks feelings of frustration, powerlessness and hopelessness. Other studies showed that parents are burdened by the bad attitudes of healthcare professionals especially nurses, long waiting time and untidy hospital environment (Ali & Razeq, 2017; Ofosu-Kwarteng, 2012).

2.2.2 Resources used by parents caring for children with SCD

In a study to assess the coping strategies adopted by caregivers of children with chronic illnesses, Leite et al. (2013) identified four major strategies adopted by parents of children with SCD. These were a problem-focused strategy, emotion-focused strategy, religion and social support. Plethoras of studies have shown that a problem-focused approach is a positive approach to coping with stressful situations (Desai, Rivera, & Backes, 2015; Lai & Oei, 2014; Leite et al., 2013; Leite, Collet, Gomes, & Kumamoto, 2010). This strategy involves seeking for knowledge and understanding about the disease, the responsibilities required from the caregiver to care for the sick child as well as the prognosis of the condition. It also calls for planning and modification of the caregiver's life and expectations as well as compromising in order to deal with the situation. A study by Desai et al. (2015) showed that caregivers who use this strategy have continuous communication with health professionals and even other parents of children with similar illnesses in order to solicit information on how to effectively adapt to the situation.

A qualitative study by Nur Saadah et al. (2014) revealed that most mothers opt for emotion-focused strategy than trying to gain in-depth knowledge about the disease condition of their children and how they can help. These mothers, according to the study findings appraise the situation positively and tend to accept their responsibilities. Other studies show

that mothers employing this strategy of coping are usually silent, do not talk about their situation and exhibit a high level of self-control whereas fathers who use this tend to distance themselves from their family and the sick child to the extent that they sometimes neglect them (Barak-Levy & Atzaba-Poria, 2013; Katooa et al., 2015; Leite et al., 2013; Nur Saadah et al., 2014; Popp, Robinson, Britner, & Blank, 2014). In the midst of internal and external crisis, mothers adopting this strategy tend to put up a brave appearance and a "selfless fortitude" (Ali, Mahmood, Moel, Hudson & Leathers, 2008; Baghdadi, 2011; Katooa et al., 2015). Parents using the emotion-focused approach also have disturbed family function, pessimistic view about child's condition and are usually seen to be nervous (Cappe, Wolff, Bobet, & Adrien, 2011; Lyons, Leon, Phelps, & Dunleavy, 2010).

Religion or spirituality is another coping strategy that parents adapt to manage stress from the caregiving role (Anarfi et al., 2016; Desai et al., 2015; Leite et al., 2013; Sira, Desai, Sullivan, & Hannon, 2014). It has been classified as a positive strategy especially when parents do not allow religious dogmas to contradict medical care to the child (Leite et al., 2013). Research has shown that faith in one's religion brings calmness and hope to these parents that technology and science can never and also helps them to adopt positive appraisal of the situation even when prognosis is bad (Lai & Oei, 2014; Leite et al., 2013; Nur Saadah et al., 2014). The findings of the study by Malhotra and Thapa (2015) indicated that most caregivers after diagnosis of their patients seek for spiritual affirmation of diagnosis.

Parents who were spiritual in coping had "optimistic outlook" and exhibited a positive appraisal of the situation by having the faith that the child will be better irrespective of the prognosis. In other related research, the findings disclosed that, these religious groups such as the church organisation that the caregiver is affiliated to become part of the

caregiver's environment that provide support spiritually, financially and emotionally to them (Leite et al., 2013; Nur Saadah et al., 2014).

Studies involving the coping strategies adopted by these caregivers have revealed that the most needed coping strategy that parents of children with chronic disease yearn for is social support because this support from friends, family and the society helps to reduce stress drastically by offering psychological and financial support (Lai & Oei, 2014; Nur Saadah et al., 2014). However, this type of coping strategy is the one most caregiver's lack. Studies have shown that most parents of these children are shunned by the family and the society due to misconceptions about the disease (Burnes et al., 2008; Wesley et al., 2016). Other parents tend to cover up their feelings and emotions as well as keep the child's diagnosis a secret for fear of stigmatisation thus rarely utilize this form of positive coping (Brown et al., 2010; Burnes et al., 2008; Lai & Oei, 2014; Nur Saadah et al., 2014; Wesley et al., 2016).

As a form of obtaining support from social groups, studies have shown that most parents of these children appreciate support groups consisting of mothers with children having similar chronic illnesses. Such groups are much appreciated by these caregivers for the reason of obtaining encouragement and support from people who think like them and understand them with no form of stigmatisation (Abu Bakar, Weatherley, Omar, Abdullah, & Mohamad Aun, 2013; Sira et al., 2014).

2.2.3 Perceptions of parents and community members about Sickle Cell Disease

Generally, the illness perception of an individual which is influenced by one's cultural beliefs and norms affect their health-seeking behaviour, self-esteem, mastery over the illness and their general health and well-being (Gyasi et al., 2016). This assertion is the same for caregivers of children with SCD in Ghana and in other African countries (Dennis-

Antwi et al., 2011; Marsh et al., 2011). A qualitative study carried out in the Ashanti Region of Ghana by Dennis-Antwi et al. (2011) revealed that most parents of children with Sickle Cell have various notions about the cause of the disease which tend to influence the experiences these caregivers go through as well as their health-seeking behaviour for their children. Ghanaian parents who were studied perceived the disease as a "bought disease"- "Nto-yare" whereby one's enemy buys it to inflict financial drain on the family. Others viewed these children as not surviving to adulthood and they are just in the family to squander all the family finances thus they called them "sika be sa"- "money will finish".

In assessing the beliefs of Ghanaian parents on chronic diseases of children, Yawson et al. (2016) found that most parents believe that it is not normal for children to suffer chronic illnesses. Therefore, these parents blamed themselves for the belief that the sickness developed as a result of their sins or sins of their forefathers and punishment from the supernatural ruler. Therefore most of the respondents confirmed calling on herbalists and ritualists to aid in the cure of their children.

In a related study carried out in Kenya by Marsh et al. (2011), findings revealed that although these parents believed in the hereditary nature of the disease, they are however certain it is a generational curse from the devil. The belief in the supernatural origin of the disease, its physical manifestations of the symptoms as well as lack of cure caused dilemmas and emotional stress in the parents of children with SCD as to whether to focus on traditional healers or on orthodox medicine. Most parents in the study confirmed adhering to both the medications from the medical professionals and those of the herbalists. The findings of the study by Wonkam et al. (2013) showed that parents form perceptions about SCD based on personal encounters such as the death of a child at a very early age. However, findings from other studies showed that most of the perceptions of parents about SCD originated from

perceptions of the community, schools and family (Dennis-Antwi et al., 2011; Orish, Onyeabor, Sanyaolu, & Iriemenam, 2014; Tusuubira et al., 2018).

Another major problem of parents of children with Sickle Cell is the stigma associated with the disease. Stigma is " an attribute that is deeply discrediting" (Goffman 2009 p.3). Studies have revealed that, due to the community's perceptions about SCD, most parents and their children with SCD are highly stigmatized, especially mothers of the children (Burnes et al., 2008; Dennis-Antwi et al., 2011; Marsh, Kamuya & Molyneux, 2011). Qualitative research carried out in a paternal family setting by Marsh et al. (2011) indicated that mothers are solely held responsible for any alteration in a child's health and that stigmatisation and accusation do not only come from their spouses but the entire extended family especially, their sisters-in-law. The fidelity of the mother in such a society is usually questioned especially when there is no obvious SCD case from the paternal side. Furthermore, the chronicity of the disease coupled with frequent hospitalization and reduced weight cause caregivers of SCD children to suffer stigmatisation similar to that of HIV/AIDs caregivers as SCD is mistaken by the society and some health professionals as HIV/AIDs.

In similar studies, Burnes et al. (2008) revealed in their findings that mothers are said to possess "bad spirits" and it is those spirits which come to attack the children. Also, others view and blame parents of these children for deliberately giving birth to a sick child when they knew their health status. Others complain of being stigmatized because of the lay notion of SCD as being contagious thus affecting their chances of securing a job. Hence, the children, as well as their mothers, are neglected by both their husbands and fathers as well as the community. Some family members distance themselves from the caregivers as well as their children to escape stigmatisation. A study by Chudleigh et al. (2016) revealed that for fear of stigmatisation, most parents keep the diagnosis of the disease condition from their

family, neighbours and friends. Parents in the study expressed worry that knowledge of people about their children's condition will affect their ability to marry or secure a job in future due to the stigmatisation of people with the disease. Apart from the stigmatisation that these parents experience from their immediate families, stigmatisation also comes from other sources including schools, healthcare professionals and the society at large (Burnes et al., 2008; Wesley et al., 2016).

2.2.4 The Outcome of Caregiving

Parents caring for children with chronic conditions such as Sickle Cell Disease are generally predisposed to many physical and psychosocial disorders which affect their health and wellbeing. (Brown et al., 2010; Heath, Farre & Shaw, 2016; Katooa et al., 2015; Popp et al., 2014; Sulkers et al., 2015). A study to explore the physical and psychological effects of family caregiving established that the detrimental physical effects on the parents cannot be compared with the psychological trauma these individuals need to contend with in order to care for their sick children (Richard Schulz & Sherwood, 2008).

Parents tend to neglect their own health and adopt unhealthy practices such as poor quality sleep, not eating properly and medical non- compliance. These behaviours predispose them to medical conditions such as frequent complaints of pain, especially neck pain and cardiovascular disorders especially in older caregivers (Brown et al., 2010; Schulz & Sherwood, 2008). Hatzmann et al. (2008) carried out a study and reported that most parents complained of symptoms such as pain, sleep disorders, low vitality, reduced positive and high negative emotions as well as low social and emotional functioning ability. It was found that most of the factors influencing the health and well-being of the SCD caregiver were related to the socioeconomic status of the caregiver along with other related variables of the caregiving process.

Parents of children with SCD usually encounter fear that alters their psychological health. Parents of these children go through the fear of having another child with SCD, fear of crisis occurring at inappropriate times, fear of death of their children, fear of hospital bills, fear of disability and fear of sickness and infection complicating the situation (Wonkam et al., 2013). Parents also contend with disbelief and denial upon diagnosis of their children with SCD (Chudleigh et al., 2016). Findings of studies carried out in parts of Africa revealed that parents tend to blame themselves for causing the illness and they regret marrying their spouses, especially when they knew their status before marriage (Adegoke & Kuteyi, 2012; Wasomwe & Ngoma, 2011).

Children with SCD go through many physical and psychosocial crisis and this causes severe distress for their parents (Brown et al., 2010; Grove, Grove, & Michie, 2013; Wonkam et al., 2013). In a study by Javalkar et al. (2017), it was showed that an increased number of medicines and injection intake and frequent visits to the emergency department causes severe distress to parents. Caring for children with SCD also has a negative impact on the rest of the family and alters the stability of the family (Wasomwe & Ngoma, 2011). Caring for a child with SCD alters the life of the other children in the family as they do not receive the needed attention and their needs are not fulfilled because most of the time of the parent is devoted to the care of the ill-child (Ali & Razeq, 2017; Brown et al., 2010; Gesteira et al., 2016; Wonkam et al., 2013). Additionally, as a result of lack of time for their spouses and burdens associated with SCD especially financial burden on the family, parents of children with SCD usually suffer marital disharmony in the form of frequent quarrels, disagreements and an atmosphere of tension and hostility (Adegoke & Kuteyi, 2012; Wonkam et al., 2013).

2.2.5 Determinants of the burden of caregiving

Studies in Ghana and other parts of the world have shown that the female gender specifically mothers are the sole primary caregivers of children with chronic diseases such as SCD and that being female is associated with a higher level of stress (Abuosi et al., 2015; Brown et al., 2010; Burnes et the al., 2008; DePasquale et al., 2015; Karlson et al., 2012; Wiener et al., 2013; Wonkam et al., 2014; Yawson et al., 2016). DePasquale et al. (2015) further explained that this difference is accounted for by the fact that, it is mostly women who sacrifice their jobs, their dreams and aspirations to provide care to their sick children. Furthermore, the gender difference in the experience of stress is accounted for by the lack of spousal support most women experience in giving care to their chronically ill children. Lack of control over the mother's own life such as planning for their future, socializing as a result of the unpredictability of occurrence of crisis related to SCD is another major factor resulting in the higher level experience of distress in mothers (Burnes et al., 2008).

Irrespective of the fact that mothers experience relatively higher level caregiving stress, fathers of these children go through emotional battles originating from different sources. In studying the experiences of stressors and burden in immigrant fathers of chronically –ill children, Khanlou, Mustafa, Vazquez, Haque and Yoshida (2015) found that fathers go through two main types of stress; informational stressors and practical stressors. Informational stressors emerge from the inability of fathers to acquire and be given adequate information about the health status of their children. In fact, Huang, Chen and Tsai (2012) posit that health care professionals view fathers from a negative perspective as intrusive, too assertive, not directly involved in childcare thus neglect them when providing information compared to their wives. Fathers may want to get involved in the healthcare of children,

however seeking time off from their employees to do so is much difficult compared to women (Khanlou et al., 2015).

The marital status of parents has a great impact on the experience of stress as well as the health of the caregiver. Studies have shown that demographically, single parents and parents either single or married perceiving themselves as lone when it comes to caregiving, specifically "mother-child families" mostly have significantly high levels of stress (Sulkers et al., 2015; Wiener et al., 2013; Wonkam et al., 2013). Wiener et al. (2013) disclosed that when dealing with caregivers of chronically- ill children, marital status of these parents must be considered in two ways; demographically single or perceived lone parenthood when caring for their sick children.

Several studies have identified the impact of education on the experience of caregiving stress although most parents/ caregivers of these children had some level of education (Brown et al., 2010; Feizi et al., 2014; Karlson et al., 2012). A study by Brown et al. (2010), assessing the burden of health-care of caregivers of children suffering from Sickle Cell Disease in Nigeria extracted information from 67 parents/ caregivers. The study findings showed that out of the 67 carers studied, 66 had some level of education. The study also revealed that although the relationship between caregivers' burden and educational level attainment was not statistically significant, parents with higher educational level employed better-coping modalities, understood the illness better and had better child health outcomes. Also, these parents were less influenced by misconceptions about the disease and had better family and marital relationships.

Children with SCD are prone to respiratory infections caused by pneumococcal bacteria with the highest risk occurring in children under 3years (Hirst & Owusu-Ofori, 2014). This infection occurs as a result of the damaged spleen or bone infections and is a

major cause of death in children with SCD under 5years of age (Makani et al., 2013; Battersby, Knox-Macaulay, & Carrol, 2010). In most high-income countries, the introduction of newborn screening has helped to curb this problem in children with SCD. Early screening of children for SCD leads to the timely introduction of penicillin prophylaxis, antimalarial prophylaxis and folic acid supplements which decreases the risk of infection. Studies carried out in parts of Sub-Saharan Africa have shown that neonatal screening is cost-effective, decreases the occurrence of complications and it allows for early start of penicillin prophylaxis which prevents morbidity associated with pneumococcal infections reduces the burden on parents of these children as the children usually have better quality of life (Dennis-antwi, Dyson, & Ohene-Frempong, 2008; Hirst & Owusu-Ofori, 2014; Kuznik, Habib, Munube, & Lamorde, 2016; Mcgann et al., 2015; Salman & Hassan, 2015).

Use of hydroxyurea drug treatment for patients with SCD has been shown to decrease the burdens of caregivers of patients with SCD (Da Silva et al., 2012). The hydroxyurea drug which works by increasing foetal haemoglobin improves haemoglobin level and prevents complications. It is the only drug that has been found to be effective to reduce pain from the vaso-occlusive crisis (Chakravorty & Williams, 2015; Santos et al., 2016). A study carried out by Da Silva et al. (2012) revealed that, caregivers of patients on hydroxyurea experience less caregiver burden in relation to the physical burden. In another study by Candrilli et al. (2011), the findings showed that treatment and adherence to hydroxyurea drug treatment result in reduced SCD-related hospitalization, decreased visits to emergency departments and reduction in the cost of care thus improving the economic outcome of the caregiver.

2.2.6 Summary of the Review

In summary, the reviewed studies have shown negative outcomes of caregiving on the physical and psychosocial health of parents caring for children with SCD. The literature on burdens associated with caregiving was limited in scope with major emphasis on the financial and emotional burden. Also, studies carried out in Sub-Saharan Africa had little emphasis on health service-related factors. Most of the reviewed studies were conducted in other African countries and high-income countries. Only one of the cited studies was carried out in Ghana which explored the lay perspectives of parents concerning SCD (Dennis-Antwi et al., 2011). Additionally, most of the studies employed the quantitative approach to assess the burden of parents caring for children with SCD. These reflect the paucity of knowledge about the experiences of parents of children with SCD in the Ghanaian setting. Therefore, guided by the ABCX model of Family Stress, the study employed a qualitative approach to explore the experiences of parents of children with Sickle Cell Disease receiving care at 37 Military Hospital.

CHAPTER THREE

METHODOLOGY

This chapter outlines the methodological framework that was used in this study and it incorporates the research design, the setting, target population, sampling method and sample size as well as the inclusion and exclusion criteria. Pretesting of instruments, data collection tool and procedure for collection of data are outlined as well. The chapter also describes the analysis of data, management of data, maintenance of research rigour and ethical considerations.

3.1 Research design

The research design is a "logical strategy", a plan or an analytical process with well-coordinated components developed to obtain information relevant to the set-out objectives and hypotheses (Maxwell, 2013). Qualitative research deals with the exploration and comprehension of the meaning participants ascribe to the particular phenomenon under study in order to provide a rich descriptive report from the participants' perspective (Colorafi & Evans, 2016; Patton & Cochran, 2002). Exploratory research is an important purpose of research that seeks to investigate the complete feature of phenomena, the manner in which it occurs and other related factors influenced by the phenomena (Polit & Beck, 2004). This form of research usually starts with a phenomenon of interest. Qualitatively, researchers employ descriptive study to aid in delineating, observing and providing an in-depth description of a phenomenon (Polit & Beck, 2004).

In this study, the researcher, therefore, used the qualitative research approach that is descriptive and exploratory to explore and describe the experiences of parents of children with SCD in Ghana. This study design was employed to help the researcher gain an in-depth understanding of the experiences of parents caring for children with SCD.

3.2 Research setting

The study was carried out at the 37 Military hospital located in the Ayawaso East sub-locality in the Accra metropolis. Accra metropolis, the capital city of Ghana is an urban district and one of the five main districts in the Greater Accra region. It has a population of 1,779,165 with a population growth rate of 3.1%, the land capacity of 185km² and consists of 46.1% of the total population in the whole region making it densely populated (Ghana Statistical Service, 2010). It is made up of eleven sub-localities; Ablekuma Central; Ablekuma North; Ablekuma South; Ashiedu Keteke; Ayawaso Central; Ayawaso East, Ayawaso West-Wuogon; La, Okaikoi North, Okaikoi South and Osu Klottey.

The main ethnic groups in the district are Akans, Ga- Dangmes and Ewes with the indigenes involved in fishing and trading as the main occupation. Housing in this district is considered as; upper-class areas, middle-class areas and lower-class areas with the number of households occupying single or two rooms being 78.4%. There is an average room density of 2.8 which is higher than the national average of 2.3 with 81.8% of families being homeless (Government of Ghana, 2017). The metropolis has a lot of schools including tertiary institutions with the premier university, University of Ghana being situated in the district. In relation to health care facilities, there are a lot of clinics, health posts, registered traditional health centres and hospitals which are either private, public or quasi-government institutions.

The 37 Military Hospital, a major military- based hospital located in Ayawaso East sub-locality in the Accra metropolis, is a specialist hospital in the entire region after Korle-Bu Teaching Hospital. It is located on the main road between the University of Ghana, Legon and Accra Central near Jubilee house, the seat of government. It was established in 1941 by the British Military Officer, General George Griffard to provide medical services to troops

from the 2nd world war. However in 1956, the facility was opened to the general public and since then it has been providing specialized care to the military, the general public, United Nations and other foreigners in the sub-locality (Addae, 1997).

The hospital has a nursing training school that trains both civilians and military in post- basic nurse anaesthesia, health assistants, general nursing and midwifery. The hospital also provides postgraduate residency programmes for physicians. The hospital's healthcare personnel are either civilian or military with a bed capacity of 400 (Duncan-Wesley, 2015). The majority of the healthcare services are provided to the general public (Addo, 2016). The hospital has set up a Sickle Cell clinic that runs every Thursday at the paediatric outpatient department to provide exclusive care to the patients. Children with SCD are either admitted from the emergency unit or the Sickle Cell clinic into the paediatric ward of the facility.

3.3 Target population

The target population is a collective element or people under discussion from which information yearned for is secured (Greenland, 2005). The target population for this study were parents of children with Sickle Cell Disease who were receiving care at the Sickle Cell unit and the Paediatric ward at the 37 Military Hospital.

3.4 Inclusion criteria

This included adults between the ages of 18years and 60years caring for a child with Sickle Cell Disease, had cared for the child for more than 2years and who were willing to participate in the study.

3.5 Exclusion criteria

This included parents of children with SCD who had been diagnosed as having mental health problems. Parents of children diagnosed with Sickle Cell Disease in less than

two years and had not been given care for over two years were excluded since the impact of chronicity of the disease for newly diagnosed children is less defined.

3.6 Sampling method and sample size

Sampling is the technique or procedure a researcher adopts to select the required number of participants sharing similar attributes of the target population (Kumar, 2011). The purposive sampling method, which is a type of non-probability sampling technique enables a researcher to deliberately select participants who have the required properties stipulated in a study and have the ability to provide information useful to the study. Therefore, the researcher purposively recruited parents of children with SCD at the 37 military hospital who willingly obliged to share their experiences of caregiving.

The sample size is the total number of consented participants involved in a study that has the ability to increase knowledge of the phenomenon under study (Burmeister & Aitken, 2012). The basic aim of qualitative studies is not to generalize but to elucidate and comprehend the issue under study, thus a small number of participants is needed to gain an in-depth understanding. In qualitative studies, the sample size is guided by data saturation which occurs "when gathering fresh data no longer sparks new insights or reveals new properties" (Creswell, 2014 p. 239). The researcher, therefore, collected in-depth information from the participants until continuation did not yield new information. The researcher thus interviewed 12 parents of children with SCD at the 37 Military hospital.

3.7 Pre-testing of instrument

Pre-testing is the process of testing the instrument for the study in conditions that are analogous to the research setting as much as possible, not for publication, but to unearth the "glitches" in the statements used and to ensure clarity of the questions (Synodinos, 2003). The researcher conducted the pretest at Korle-Bu Teaching hospital with parents of similar

characteristics to those to be used at the 37 Military hospital. The researcher obtained permission from the hospital through a formal letter from the School of Nursing and Midwifery, University of Ghana.

Two participants who met the inclusion criteria were interviewed. The researcher sought their consent and carried out the interview in a convenient place at the Sickle cell clinic in the Korle-Bu Teaching Hospital. After each interview, data gathered were transcribed in order to allow the researcher to refine the interview guide. Data from the pre-testing were not included in the final study.

3.8 Data collection tool and procedure

An interview guide was developed using the conceptual model, reviewed literature and objectives of the study. The interview guide consisted of the demographic data and open-ended questions which aided in probing and gave an in-depth understanding of the issue under study. Demographic data gathered information on participants' age, marital status, and number of children cared for, total number of children with Sickle Cell Disease cared for, the age of the child, level of education, occupation, and place of residence. The other section of the guide gathered data on the caregiving experiences of the participants (See Appendix E).

Data collection is the process of systematically collecting desired information about a phenomenon from the object of study and the setting in which they occur (Chaleunvong, 2009). A copy of the proposal for the study was sent to the Institutional Review Board of the Noguchi Memorial Institute for Medical Research (NMIMR) for review and was approved (See Appendix A). Another copy of the proposal was sent to the Institutional Review Board of the 37 Military Hospital for review and it was approved (See Appendix B). With the help of the nurses in- charge and guided by the inclusion and exclusion criteria,

the researcher recruited participants for the study. Eligible participants were approached, and the objectives for the study were explained to them and subsequently given information sheets and consent forms to sign to undergo the study (See Appendices C and D).

Using the interview technique, the researcher involved participants in a face-to-face interaction creating an informal ambiance to unearth any feelings, emotions and ensure the proper exploration of personal and social factors that helped to enrich the data. Using an interview guide with open-ended questions, the researcher explored the experiences of these parents caring for children with SCD. The flexible nature of the interview guide allowed questions to be asked not in an ordered fashion but as and when a relevant topic of interest arose between the researcher and the participants (Patton & Cochran, 2002). This type of questioning allowed the researcher to fully explore the emotions and thoughts of the participants.

The interviews were conducted at the Sickle Cell clinic and the paediatric ward in a convenient place that ensured privacy and confidentiality. The interview was conducted in English, “Fante” and “Twi” (local dialects) after consent forms had been signed. Probing and follow-up questions were used to allow participants to provide quality and comprehensive information that enabled the researcher to gain an in-depth understanding of the information provided. Iterative questioning was also employed to avoid the ambiguity of answers provided. Background data were collected first in order to help establish rapport and make participants feel comfortable. The interviews lasted between 45-60 minutes and they were audiotaped with permission from participants. Field notes were used to capture all the non-verbal cues that participants exhibited during the session. A reflexive journal was used to assist in bracketing all feelings, biases, emotions, ideas and any other factors that could have influenced the interpretation of the response during analysis. The researcher

thanked the participants for undergoing the study. Participants were refreshed with fruit juice, cream crackers and a bottle of water. Data was gathered over a period of 12 weeks.

3.9 Management of data

Data management involves storage of research data in a way to be made available for future use which will decrease research risk and will benefit both the researcher and the institution by reducing the possibility of a loss of research findings (Pathan, 2015).

Data gathered were transcribed verbatim and those gathered in the local dialects were translated and transcribed into English by the researcher and a translator to avoid data distortion. Back translation was also ensured for purposes of quality control of the data. Field notes taken during the interview were incorporated during transcription of the data. Pseudonyms were given to the participants based on their sex and numerical entry into the study such as FP1 whereby 'F' stood for female, 'P' for parent and '1' for the first parent interviewed. Similarly, MP2 implied the second parent interviewed who was a male participant. Soft copies of the transcribed data were kept on a computer protected by a password known to the researcher alone. Other documents such as the consent forms that had identifiable information about participants were kept separately from the transcribed data. Hard copies of the transcribed data and other documents such as the consent forms and field diaries have been kept safely and separately from other documents in a locked cabinet accessible to only the researcher and her supervisors. Data will be stored for five years and destroyed after five complete years.

3.10 Analysis of Data

Raw data gathered from the field were analyzed immediately, following the interview. Data gathered from participants were transcribed verbatim and analysed using thematic content analysis. Content analysis is an objective and systematized mode of

analyzing data through the process of coding and categorizing gathered data to obtain the pattern, frequency, relationship, and structures embedded in the communicated information (Gbrich, 2007; Neuendorf, 2016; Vaismoradi, Turunen, & Bondas, 2013). On the other hand, thematic analysis deals with the identification, analysis, and communication of themes or patterns submerged in the data in order to produce a well-organized and rich description of data collected (Braun & Clarke, 2006; Daly, Kellehear, & Gliksman, 1997; Vaismoradi et al., 2013).

The researcher immersed herself in the collected data through repeated active reading. This aided in complete familiarization and identification of patterns and meanings embedded in the data, noting down initial ideas. Fundamental segments that were interesting in the data were outlined systematically and used to develop initial codes, collating specific aspects of the data that was related to it. Using tables, all the relevant codes were collated and merged into broader overarching themes. Individual themes were reviewed in relation to their coded extracts and the entire data set. This collapsed some of the themes into one and generated new themes with various subthemes. The themes were defined and clarified to achieve coherence and to identify the story in the raw data that the theme conveyed. This brought to light the essence of the theme in relation to the raw data. The story within and across the themes was used to produce a scholarly report by analysing the selected extract, which was clear and compelling, in relation to the research questions and the theoretical framework (See Appendix F).

3.11 Methodological rigour

The worth of any study is the maintenance of trustworthiness which is achieved through credibility, transferability, dependability, and confirmability of the studies (Lincoln & Guba, 1985).

Credibility is the confidence about the truth of the research findings establishing whether or not the research findings represent reliable information gathered from the participants' original view or is an appropriate interpretation (Anney, 2014; Graneheim & Lundman, 2004; Lincoln & Guba, 1985). For this purpose, the researcher ensured that all participants recruited for the study met the inclusion criteria, with the exclusion criteria strictly applied. Additionally, credibility was ensured by developing and asking the right questions that elicited the right responses from the participants. Also, probing skills were utilised and rephrasing of questions used to bring clarity in the questions asked and to ensure quality data was collected. Participants were assured of confidentiality being maintained throughout the whole process to encourage them to freely provide information without any fear. The researcher also employed reflexivity which is the process whereby researchers recognize and examine how their "social background, location, and assumptions affect their research practice"(Hesse-Biber, 2007 p. 17). Therefore the researcher was conscious of her own perceptions about children with SCD and their parents that could influence the study. These included the fact that the researcher is a nurse who has cared for children with SCD for seven years and had witnessed some of the challenges parents go through. Through the process of reflexivity, the researcher made explicit these perceptions and they did not influence the research process. To avoid researcher biases, member checks were employed whereby interpreted responses were discussed with participants to avoid misreporting of information. Some of the transcribed data were coded independently by the researcher and the principal supervisor in order to identify any inconsistencies and were discussed to reach an agreement.

Transferability, which is comparable to external validity in quantitative research is the degree to which the findings from the study can be applied in other contexts (Lincoln &

Guba, 1985) and according to Bitsch (2005 p.85), "researcher facilitated the transferability judgment by a potential user through 'thick description' and purposeful sampling". In ensuring this, the researcher has provided a thorough description of the participants, the context and research settings. In addition, all the research processes employed from the selection of participants, data collection, settings, and the final report have been vividly reported. The researcher used a purposive sampling method to select participants who were knowledgeable of the issue under study. All these efforts will facilitate replication of the findings.

Dependability is the consistency of the research findings over the course of time (Lincoln & Guba, 1985) and according to Bitsch (2005 p.86), dependability is the "the stability of findings over time". To achieve this, the researcher ensured that all the data were gathered using the same interview guide for all participants. The interview guide was developed based on the conceptual framework and was pretested to ensure effective data collection procedure and interpretation of findings (Colorafi & Evans, 2016; Hurst et al., 2015). The researcher also employed a code-recoding strategy whereby the same information gathered was coded twice with two weeks interval and the results compared to identify differences and similarities (Anney, 2014; Chilisa & Preece, 2005). Stepwise replication, whereby two different researchers analyse gathered data separately and compare results was done with my principal supervisor to unearth any inconsistency in the analysis of data (Chilisa & Preece, 2005).

Confirmability deals with "establishing that data and interpretations of the findings are not figments of the inquirer's imagination but are clearly derived from the data" (Tobin & Begley, 2004 p.392). To achieve this, the researcher ensured that audiotaped information was transcribed verbatim. The researcher created an audit trail whereby the specific steps

and decisions taken throughout the process of the study were explicitly outlined. The researcher also kept a reflexive journal which bracketed all her perceptions, experiences and opinions about the topic under study.

3.12 Ethical considerations

Ethical approval was obtained from the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR) and the Institutional Review Board of the 37 Military Hospital to seek formal permission to carry out the study. Before the commencement of each interview, the objectives and purpose of the study were explained to the participants and information sheets were also given to them for their perusal. Participants were informed about their right to opt out from the study anytime they so wished and they were told they could refuse to answer a question they felt uncomfortable to answer.

Participants were informed that the study had no physical harm to them. The researcher was careful when she asked questions that could arouse emotions, thus, participants did not exhibit any signs of stress, worry or tears during the interview. None of the participants was therefore referred to the clinical psychologist who was engaged by the researcher. Consent forms were given to participants to sign only after participants had given their approval to undertake the study. Demographic data were collected before the start of the interviews and participants were informed about the need to record the conversation which was to be used solely for the study. Privacy and confidentiality were ensured by assigning pseudonyms instead of using their names. Data gathered were kept in a closed cabinet which is accessible only to the researcher and her supervisors. Data would be stored for five years and destroyed after five complete years.

CHAPTER FOUR

FINDINGS OF THE STUDY

This chapter presents the findings of the study. These were organised into five major themes based on the thematic analysis of the data and the constructs of the ABCX model of family stress. The findings were presented under these major themes: Caring for a child with SCD, resources used by parents, perceptions about SCD, the outcome of caregiving (crisis) and the determinants of the burden of caregiving. The chapter first focuses on the demographic characteristics of the participants followed by the description of the themes with supporting quotes from the participants.

4.1 Demographic Characteristics of the Participants

A total of twelve (12) parents, who were the biological parents of the SCD children, participated in the study. The participants comprised of eleven (11) mothers and one (1) father who were Ghanaians and live in the Accra Metropolis. The ages of the parents ranged from 31 to 46years with eight (8) of them below 40 years and four (4) above 40years. Eleven (11) of the parents were married and living with their spouses and one (1) was single. All the participants were Christians of various denominations.

Concerning the parent's educational level, they had a varied educational background; six (6) of the parents had tertiary education, one (1) had vocational training and five (5) were basic school leavers. Furthermore, three (3) of the parents interviewed were traders, three (3) teachers, one (1) physician assistant, one (1) programme's producer, one (1) hairdresser, one (1) secretary and two (2) housewives. With respect to their monthly income, five (5) of the participants earned below GH₵500, three (3) earned between GH₵1000-GH₵1500 and two (2) earned between GH₵1600- GH₵2000. The rest being housewives did not have any monthly income.

In terms of parenting, the participants had between 1-6 children with one (1) having six children, two (2) having four children, two (2) of the participants had three children, four (4) participants had two children and three (3) had one child. Three (3) of the mothers had two children suffering from SCD with the rest of the parents providing care to one child with the disease. Most (10) of the children being cared for were firstling of their parents with the rest (5) being the second-born children of their parents.

Seven (7) of the SCD children were males and eight (8) were females with their ages ranging from 3-14years as at the time of the interview. The majority (13) of the children were below 10years and only two (2) were above 10years. The genotype of the SCD children was as follows: One (1) child had haemoglobin Sβ0-thalassemia (HbSβ0-thalassemia) and the rest (14) of the children were diagnosed as homozygous haemoglobin SS (HbSS). All the participants as well as their spouses were Sickle Cell carriers and did not have SCD (See Appendix G).

4.2 Organisation of themes

In all, five (5) major themes emerged from the subjective recount of parents' experiences. Four of the themes: Caring for a child with SCD, resources used by parents, perceptions about SCD and outcome of Caregiving (Crisis) were in line with the theoretical model. The other theme "determinants of the burden of caregiving" emerged contextually from the data gathered but was in line with the objectives of the study. Each of these themes had separate subthemes. In all fifteen (15) sub-themes were identified. All the themes and subthemes are described in the ensuing sections supported with specific quotes from the participants. Details of the themes and subthemes are presented in Table 4.1

Table 4.1: Themes and Sub-themes from Transcribed Data

THEMES	SUB-THEMES
Caring for a child with SCD	a) Burden related to health of the child b) Physical burden c) Financial burden d) Work-related/ Occupational Challenges e) Burden related to Health Services
Resources used by parents	a) Religion b) Social support
Perceptions about SCD	a) Parents' perception about SCD b) Community's perception about SCD c) Stigmatisation
The outcome of Caregiving (Crises)	a) Burden of caregiving on the physical health of the parent b) Burden of caregiving on the psychosocial health of the parent c) Overall burden of having a child with SCD on the family.
Determinants of the burden of caregiving	a) Time of diagnosis b) Type of treatment used

4.3 Caring for a Child with SCD

Following the diagnosis of SCD, parents of children with this disease were confronted with the reality of providing care for their ill children as well as managing other aspects of their lives. “Burden”, “hardship”, “difficulty” and “problem” was how these parents described their lives following the diagnosis of their children with SCD. It was noted from the interview that the burden of caring for a child with SCD emerged from five main areas; burden related to health of the child, physical burden, financial burden, work-related or occupational challenges and burden related to Health Services.

4.3.1 Burden related to health of the child

It was found that the health of the child being c9/ared for was the primary source of burden for the parents. The participants indicated that the major burden on them in relation to their children’s health, is when their children go into crises. All the parents expressed their desire of having a crises-free life for their children. They disclosed that seeing their children in such pain regularly made them feel they were also experiencing similar pain. This experience influenced the reproductive decisions of the mothers as most of them decided not to give birth again to avoid witnessing the pain and distress their children go through.

Anaemia, severe pain from the vaso-occlusive crisis and musculoskeletal problems such as joint pains and swelling of the limbs were some of the complications that sent children with SCD to the emergency room. Severe malaria and chest infections were the major causes of frequent hospitalization and a long stay at the hospital. The frequency of admission due to child’s illness made some of the parents consider the hospital as their second home. One mother expressed her burden in this manner:

> *…when we are discharged I won't spend even two weeks in the house and we will be admitted again. If you can't find me at home search for me at the hospital because that has become our second home. The moment we are discharged, it will not be long for us to be admitted again, it is serious oo. And when we come, it is not for a day or two, we spend weeks here so even the nurses here always pity me".*
>
> ***FP1, age: 39years***

The unpredictable nature of crisis occurrence prevented parents from carrying out already planned activities and fulfilling other obligations expected of them. Frequent stay at the hospital prevented the parents from attending funerals, weddings and other public functions of close relatives or friends.

> *"… because we are always at the hospital I cannot do anything apart from taking care of her. …even when my uncle died I couldn't go because we were then on admission. I was very close to my uncle and he took care of me, so everybody expected me to be there but I couldn't go. When my friends get married, I am not able to go because we are always at the hospital"*
>
> ***FP4, age: 37 years***

The parents were burdened by the poor growth and development of their children. They reported that irrespective of proper feeding practices their children still had stunted growth and were not growing like their other children. Musculoskeletal complications experienced by the children with SCD prevented them from walking early as expected. Some parents recalled when they had to carry their children as old as 5years at their back since the children could not walk. This was a big challenge for them because, in addition to the physical strain, society also frowns on carrying a child at that age. One mother shared these experiences:

> *…she is five years now and she is still not walking. She is always falling sick and at five years I have to carry her at my back wherever I go. Apart from getting tired, people will also be watching you, which is what even disturbs me…*
>
> ***FP12, age: 46years***

Blood transfusion was one of the major treatment for patients with SCD and most (9) of the parents said their children had been transfused before due to low haemoglobin levels. The problem associated with the transfusion was getting donors whose blood groups

matched those of their children to donate blood. The parents disclosed that they had to call in relatives to test before they could get blood for their children. Some also revealed that they had to pay many "blood contractors" to donate for their children and that even getting a match was a problem.

> *"Our last admission was horrible, we had to pay the blood contractors to donate because my brother who has been donating was not well. You pay this one, he goes and test and it does not match, you pay another person and it does not match. We really suffered before getting one. Later, some of our church members had to come in to help because we needed 3units. In fact, because of his blood group if I come and they (doctors) say they will transfuse him then I wish the earth will just swallow me up".* ***FP9, age: 44years***

Thus, the major source of burden for the parents caring for their children with SCD was maintaining the health of the child, especially during the period of crises. In the ensuing section, the physical experiences of parents are presented.

4.3.2 Physical burden

The physical burden associated with providing care to the child with SCD was presented in different ways. The basic care demand placed on these parents was ensuring that their children accomplish the activities of daily living such as bathing, grooming, and feeding. Some of the parents considered these responsibilities to be normal routine and part of parenthood. However, most of them revealed that caring for children with SCD cannot be compared to caring for "normal" children because it was more challenging and energy enacting. According to the parents, the responsibilities of preventing complications and caring for their children when they are in crisis were a huge workload on them. A mother with two children suffering from SCD said this:

> *I have had that experience before where both of them had a crisis. So I will clean this one up then move to the other one and clean him up, feed this one then move to feed the other. Moving up and down from one cot to another bed. It wasn't easy. People were even calling me the mother of twins "ataa maame" though they are not twins. In fact, having children with Sickle Cell is a very difficult situation especially when they are not well. If you don't have a child with this illness you will not appreciate it.* ***FP9, age: 44years***

The participants intimated that they had to be extra vigilant in the care of their children with SCD by ensuring proper feeding, appropriate clothing especially during cold weather and maintaining personal hygiene of their children. They also had to ensure proper hydration of their children and close monitoring of these children to avoid any injury, infections and other complications of the disease. Giving medications under prescribed conditions, such as the right time and at the right temperature, was very stressful for some of the participants because of their work schedule and frequent electric power outages in their vicinities. One mother said this:

> *"Looking at the nature of my job I close very late and I have to run home before she sleeps so that I can give her the medicine…"* ***FP4, age: 37years***

Another mother who had difficulty storing the hydroxyurea suspension said this:

> *… It wasn't easy preserving the suspension during the days of dumsor (load shedding of electricity). I had to buy ice blocks and put the medicine in it or sometimes put it in my sister's fridge when she has light. So I will take her(child) to my sister's house to give her the medicine and I will bring her back. In fact, it was so stressful".* ***FP11, age 45years***

Some parents also reported that their major challenge was feeding their children. According to the parents, their children with SCD did not like food. This was stressful for the parents because of their low appetite for food worsened their haemoglobin level. Thus parents reported that they had to go to every extent to ensure they were fed. A mother who had difficulty in feeding her child expressed her hardship in these words:

> *"…and it was not easy feeding her. At age 8 I really had to continue feeding her, I had to sing and dance before she could eat just a little. Meanwhile, her Hb too was low and she didn't want to eat. It was a burden for me".* ***FP4, age: 37years***

4.3.3 Financial burden

Providing care to children with SCD placed an enormous financial burden on parents and all the participants expressed experiencing financial hardship as a result of caring for their children with SCD. One major financial burden on parents was the cost of care. Describing their experiences, the parents mentioned that the major factor that burdens them was the cost of medicine and laboratory services. In the narration, parents disclosed that the cost of medications especially, antibiotics used to treat their children's illnesses was highly expensive and this drained them financially. The cost of laboratory investigations was another issue participants complained about. Many laboratory tests were usually requested prior to the start of new medications or anytime new complaints were made, this put a financial burden on the parents. Some of the parents disclosed that due to the high cost of care, they do not seek medical care immediately their children fall sick because of inadequate funds. According to them, they usually manage the illness with over-the-counter drugs until they get adequate funds to send the children to the hospital.

> *"Sometimes when she is sick and I don't have money I have to postpone it. Is like any time we have to come here (hospital) and there is no money, you have to find the money before you come because definitely you'll go to the lab and it is expensive, very expensive!"* ***FP3, age: 38years***

Although all the parents had registered their children under the national health insurance scheme (NHIS), views about the scheme were varied among the parents. Some of the parents appreciated the minimal financial relief they gain from the scheme, however, all the parents acknowledged that the insurance did not completely cover the medical costs. Thus they were burdened severely by the medical cost of their children. The parents displayed their displeasure about the incomplete financial support from the scheme. They disclosed that they went through the "cash and carry" system in the health facilities anytime

the particular medical services needed were not covered by the scheme. One caregiver recounted her experience this way:

> *"…the national health insurance does not cover the lab expenses and if you don't have money they won't do anything for you. It is cash and carry. I remember one time my son was having blood in stool and I was told to take the stool to the lab but they did not do it because of money. I really begged them until one guy that I know did one of the tests for me. Unfortunately, I didn't get money for the rest …*
>
> ***FP7, age: 37years***

All the participants pleaded with the government to offer SCD patients some form of subsidy as enjoyed by people with conditions such as HIV/AIDs who also receive free medication. One mother said:

> *"I always say the government should help us because, for AIDs patients who got the disease because of reckless lifestyle they even receive drugs free and Sickle Cell children who had the disease through no fault of theirs, they have neglected them. The government should really help us, those of us with children having the illness because it is difficult, we are suffering, they can even make the labs free".*
>
> ***FP1, age: 39years***

It was evident from the study that the unpredictability of crisis occurrence, as well as the constant attention required by the children with SCD, prevented parents from pursuing their economic activities. Due to the care demands on them, these mothers had to close their shops for longer periods of time in order to care for their ill children. This led to a loss of income and placed a financial burden on caregivers. One mother recounted:

> *"Eii! with this how can I work for somebody. I work for myself but my saloon is always closed and you lose your customers. It is when you are able to resume work that you need to be chasing and calling your customers that you are back. …the moment I touch someone's hair he (child) will fall sick right now. It is serious! The moment I touch someone's hair, he will start crying and if I don't mind him, he will get a fever and I have to rush him here (hospital). So I closed the saloon!*
>
> ***FP9, age: 44years***

Additionally, economic pressures were experienced when care demands on parents prevented them from seeking highly paid jobs. Some participants expressed their inability to seek their dream- jobs due to fear of not being able to care for their ill children. One mother said this:

> *"Working? Hmm, I've not even been able to look for work. I have completed a health assistant training school for more than four years now and I have not been able to look for a job. I am scared that if I start work I wouldn't be able to take care of her because these children need much time…, so now am just a housewife because of her. Meanwhile, if I was working I would have been able to support my husband financially."* ***FP8, age: 39years***

The effect of caregiving on their employability brought more economic hardship on the parents. Some participants mentioned that they had to go for loans in order to provide for the basic needs of their family since they "wasted" all their money on their children. One mother with two children having SCD shared this experience;

> *"What makes it sad is that you can't even save money. When you get the money it is as if it is being swept away… you suffer to get money and it all goes waste spending all of them (money) on them (children)… I have surrounded myself with loans all because of them".* ***FP5, age: 31years***

Another major issue that aggravated their financial burden was maintaining an optimal nutritional status of their children. The parents in their narration said that in order to improve upon the haemoglobin level of their children, their meal had to be enriched with an iron-rich meal. Some of the parents disclosed that the high financial burden caused by their children's illnesses has prevented them from saving for future eventualities. Some parents pointed out that this burden on them has prevented them from fulfilling their financial responsibilities in their extended families. They are therefore seen as "useless" and "stingy in their families of orientation. It was observed that the financial burden was felt by all participants. Parents who had extra sources of income and those who lived only on what they were able to acquire for the day complained of an extra financial burden on them.

4.3.4 Work-related/ occupational challenges

The effects of caregiving on their job responsibilities was mentioned by all the participants in the study. The parents revealed that the constant care needed by children with SCD at home and frequent hospitalization caused them to regularly ask for permission from

work to take their children for a routine medical checkup and sometimes during hospitalization which is very frequent. They mentioned that because their employers do not know of the disease condition of their children, they tend to complain of their frequent excuses. It was revealed that this has led to some of the parents being denied promotion at work. This was what one mother said:

> *…it has not been easy. I have to be asking permission, taking admission sheet from the doctors to send it to work, hmm a whole lot. Both my employers and co-employees complain that my child is sick always. At times they don't even believe it. Sometimes they ask, how come your child is always sick? Because of that, they are refusing to promote me, am just managing it".* ***FP6, age: 42years***

Some of the parents complained that their work output has been reduced because of the caregiving responsibility they have to fulfill. One father who is a teacher expressed his frustration in this manner:

> *"now that am talking I have a lot of scripts to mark almost about 700 scripts lying there… fill my reports, I mean I have a lot of work to do. But look at me for three days now I have not slept, not to talk about marking my scripts.*
>
> ***MP2, age: 36years***

Most of the caregivers complained that they could not concentrate at work as they were constantly worried about their children's conditions. When at work, they had to call their children's school regularly to check up on their children, while neglecting their job responsibilities. It was noted that the high level of absenteeism and low productivity led to the loss of job of a parent as indicated in the quote:

> *"I had just gotten the job, I was on probation when she was diagnosed. When I started asking for permission I saw that my boss wasn't happy. I couldn't go to work early because there was too much to do in the morning. So one day they called me and I knew my time had come. I was fired just like that".*
>
> ***FP12, age: 46years***

4.3.5 Burden related to Health Services

Sickle Cell Disease, being a chronic and debilitating illness warranted frequent visits to the hospital for admission, follow up or medical consultation at the OPD. Thus parents and their children with SCD were in and out of the hospital. The service-related factors the parents in this study were confronted with were quality of care and its components. These factors are discussed in the sections that follow.

Parents expressed varied views concerning the quality of care received in the healthcare facility and how it influenced their caregiving. The parents understanding of the quality of care covered competence of the healthcare professionals, staff attitudes, waiting time and cleanliness of the hospital environment. A few of the parents showed satisfaction with the competence level of healthcare professionals (nurses, doctors). Most of them, however, exhibited some level of dissatisfaction. Parents did not doubt doctors' competency as general practitioners but concerning the care of SCD which is a "special area", they doubted their knowledge level specifically during the management of the crisis. This doubt was seen to have originated from the difficulty with which their children were diagnosed at various healthcare facilities. Almost all participants stated that they had to go through a series of laboratory tests and isolations at the ward until their children were finally diagnosed.

Some parents also mentioned in their narration that care was being provided by different doctors at the same healthcare facility and each one contradicting the treatment prescribed by the other. In light of this, a lot of money was wasted in the purchase of different medicines with most of them being abandoned due to changes by different doctors. According to the parents, most of the doctors did not have adequate knowledge about SCD management and always had to call on their "bosses" to help. Therefore, care was provided

by different doctors at each hospital visit which affected the continuity of care. In describing his view on the competency of medical professionals, a father made this comment:

> *"…what frustrated me was that they were aware of it (sickling status) but you know, different, different doctors trying to figure out the problem. They knew he was SS but as to what exactly was happening was what they didn't understand. This doctor will come and write a drug for us to buy, another doctor will come, look at the history prescribe a drug and you go and buy. So virtually it was not only one person taking care of him. I was expecting a seasoned doctor who has specialized in Sickle Cell and knows virtually all the symptoms to manage these children. I knew they were doctors and am sure they were general practitioners, at least they had little knowledge about the illness".* ***MP2, age: 36years***

All the participants were content with the attitudes of the various healthcare professionals during emergency visits with their SCD children. They described their emergency response system as impeccable with a good triage system. However, most caregivers questioned the attitudes and professionalism of the staff on the wards. A few of the parents were content with the attitudes of the staff specifically doctors, nurses at the outpatient department and pharmacists. Most of the parents complained about the professionalism and attitude of nurses on the ward and laboratory technicians. One mother stated:

> *"Display of professionalism is a problem, the nurses will frustrate you especially when on the ward and that will compound your problem. Sometimes if you are lucky some of the nurses will measure the medicine for you and make sure you give it to the child but some of them will just ask you if you have the medicine and will instruct you the amount to give. They will then leave you, they don't care whether you understood them or whether you really gave the medicine to the child, that is not their problem at all, they don't care. So I will say the system here cannot be compared to a private hospital. When you complain then they tag you. So all the nurses start behaving strange towards you and they see you as a nuisance. But it is my right, I had to suffer to pay the bill".* ***FP11, age: 45years***

The parents also complained of long waiting time during routine care at the outpatient department (OPD). Another major problem that was observed from the narratives was long queues and congestion at the laboratory. According to the parents, a laboratory test was requested on each visit to the OPD and they often have to wait for hours in a queue.

This was a burden for them because they believed it could have been used to attend to equally important issues. One mother who was pregnant expressed her challenge this way;

> *"We came here early oo! we came here around 6 am but we are still here. I thought we will finish early so I will go back but I am still here because of the queue. Most of the time they (nurses) will tell you to come around 6 am but the doctors will come around 9 am. Today, for instance, there is only one doctor. Most of the time there are two doctors but today there is only one and the queue is not moving. Meanwhile, I have to go to antenatal and they are wasting my time like this."*
>
> ***FP8, age: 39years***

The cleanliness of the hospital environment, specifically the ward, was also a challenge for the participants. They described the ward environment as dirty, an environment which does not stimulate recovery. One mother said this;

> *"This hospital is not comfortable for me, especially the children's where there are a lot of mosquitoes. They don't give us a mosquito net for our children. When you sleep there, the mosquitoes really feast on you. You know the children have Sickle Cell but you bring us here for the mosquitoes to bite us. There were cobwebs all over. I reported two times to one of the big people here, he called the orderlies but they never came. It is very bad!"* ***FP10, age: 34years***

4.4 Resources used by parents

These are the resources of the caregiver according to the ABCX family model and the presence of these factors protect the caregiver from the crisis. The findings revealed that the parents depended on two main coping mechanisms; religion and support to deal with the stresses originating from the caregiving role. The factors are discussed in turns.

4.4.1 Religion

The belief and practice of religion influenced parents' evaluation of the burden associated with having a child with SCD. All the parents in their narratives made it clear that they were taking comfort in their religion and that was what has enabled them to go through all their challenges. The majority of parents sought for 'confirmation' of the diagnoses and the cause of the illness from their spiritual leaders. When the parents were told of the

diagnosis some believed that there was spiritual attack and did not fully comply with medical advice and treatment. It was observed that the parents believed the verdict of the religious leaders more than the medical diagnoses. Therefore, when the medical cause of SCD was affirmed by their spiritual heads they abandoned the initial perception of spiritual causes and fully co-operated with medical advice. One mother said this;

> *"Initially, I never believed that it was that particular sickness (SCD) that was worrying my son. But now, I cannot say someone bought that sickness for my son because throughout the prayer meetings and camps I have attended, none of my pastors said that someone is causing that sickness. My Pastor said as humans, we fall sick and it is possible that the illness my child is suffering from is from the blood. So now, I listen to the nurses, all the advice that they give, I follow them".*
>
> ***FP7, age: 37years***

It was observed from the narrations that most of the parents appraised their situation based on their religious beliefs and this reduced the psychological distress of self-blame. They interpreted the disease as a way of a supernatural being (God) testing their faith in him and that if one is able to overcome all the challenges, there are blessings that await the individual. It was noted that caregivers with such beliefs expressed some form of calmness and hope that their "toil will not be in vain". The commonest form of religious coping observed was prayer. All the parents pointed out in the interview that they have prayed one time or the other especially when their children were in crisis and they doubt their children will survive. Parents used this mode of coping to offload all their "problems" onto a supreme being (God). It gave them hope that someone was taking care of their problems spiritually. It was also noted that prayer made the parents optimistic about their children's condition that irrespective of their children's ill-health they will not die but rather one day be cured by God. One mother shared her experience this way;

> *"But as time went on, as the splenomegaly was becoming serious, we had to pray. We had to consult our spiritual father. I always say drugs are prescribed and given by doctors but that is not what heals them, healing is from God".* ***FP4, age: 37years***

In some cases, some of the parents, due to their strong faith in supernatural healing failed to abide by medical advice given and this almost led to the death of the ill child. One mother recounted this experience:

> *"My spiritual father told me the enemy was finding a way to kill my girl. I lost all hope in the medicine they gave me because she was always falling sick though I was giving her the medicine. So I stopped giving her the medicine and started fasting. We stayed at the prayer camp for more than two weeks until one afternoon I saw that my girl's body was very hot…very very hot that I got scared and rushed her here (hospital)… I didn't even give her any paracetamol. The nurses told me to look at her, the girl is really sick. She was becoming very stiff. I thought I had lost her".*
>
> ***FP3, age: 38years***

4.4.2 Support

Parents reported receiving support from their nuclear and extended families, a few church members and also from healthcare professionals. However, they hardly received support from people except those very close to them that is the siblings of the parent and a few church members. Three main types of supports were received by the parents of children with SCD which helped them to cope with the challenges associated with caring for their children. These were informational support, emotional support, and instrumental support.

With regards to instrumental support, the parents reported that their spouses were their main source of financial support. They also reported in the interview that other children in the family, especially those who were relatively older, helped them to care for the ill-children and also to manage other household responsibilities such as cooking, cleaning the house and bathing their other siblings. The parents also disclosed receiving some form of financial support from their siblings and their church members. A father had this to say:

> *"Financially, it is my sister in the UK who has been supporting us. She is very generous even though she knows I am working but she still supports us. She knows how difficult the economy of Ghana is. Anytime I call her, she may have other plans but she still supports me".* ***MP2, age: 36years***

Another mother who was supported by her church expressed:

> *"My church also has been of immense help. I remember the last time they had an offering for me and my family, and surprisingly that time things were bad so that the money really helped us. The other time too, the women's movement at church also gave me 50.00".* ***FP12, age: 46years***

Some parents disclosed that their siblings offer support by buying clothes for their children and supporting them with foodstuffs which help to take off some hardship. Healthcare professionals also provided major support to the parents. Some of the parents recounted receiving financial support from doctors to buy medicine and pay their bills. Emotional support was the main source of support the parents reported receiving from their family and church members. According to them these people usually call to offer them words of encouragement and pray with them especially when on admission with their children. In terms of informational support, it was noted that the parents got most of the information about SCD from healthcare professionals. The emotional burden created when their children were diagnosed was lessened through the education the healthcare professionals gave them that SCD is genetic and with proper care, their children will not die. The healthcare professionals also supported the parents by showing them SCD patients who have survived the disease and were doing well. This demystified the disease and gave the caregivers hope. Other informational support came from the siblings of parents who were healthcare professionals

> *"My sister is a nurse so when my son was diagnosed she got me a file on dieting habits and she was counseling me. We spoke and I got a bit of relief from there".*
>
> ***MP2, age: 36years***

It was observed from the narratives that the parents placed more value on financial support compared to other forms of support due to the economic hardship placed on them. Additionally, the parents reported that the kind of support they expect at a particular point in time is not what they receive. Parents on admission usually expected more of financial support compared to other kinds of support but they complained that most of the people who

come to visit just offer words of encouragement with no financial support. One mother said this:

> *"…both my family members and that of my husband have never given us a penny to support us before. All that we get from them is prayers, encouragement and advise, that is all. Even on admission that things are hard, they know things are hard but they will just come and pray with you and go. I'm not saying prayer is not important but on admission what we need is money to pay for all the expenses".*
>
> ***FP1, age: 39years***

4.5 Perceptions about SCD

In exploring the perceptions about SCD, three main subthemes emerged; parents' perception about SCD, community's perception about SCD and stigmatisation from the community based on their beliefs.

4.5.1 Parents' perception about SCD

Sickle Cell Disease was perceived and appraised differently by parents of SCD children in this study. In the parents' bid to comprehend this chronic disease, the study found that these parents have generated their own meaning within the context of their social and cultural background. "Sasabro" and "Nwiwii" were the local names the participants ascribed to the disease. Due to its characteristic association with pain and inflammation at the joints, some parents called SCD "rheumatism". The parents expressed their beliefs about the cause of the disease, lifespan of children with SCD and management of the crisis in these children.

Only a few parents of children with SCD in the study attributed the cause of SCD to genetics or heredity. They understood that children inherit the disease from their parents. However, the vast majority of the parents interviewed did not believe the disease is inherited from one's parents. A misconception the latter group of parents had was that SCD traits should exhibit the same characteristics or symptoms as SCD patients. Thus, they argued that since they or their spouses do not have any of such symptoms, they cannot

be traits and should not bear children with SCD. Based on these perceptions, most of the parents did not accept heredity as the cause of SCD in their children.

The parents held the belief that SCD was not hereditary but there were some supernatural influences. Some of them believed that these children are normally born healthy but when the witches see their bright future, they switch their health with the disease, to stall their progress in life. Others saw it to be a punishment from wrongdoing or defaulting payment after borrowing money from someone who is a sorcerer.

> *"Sometimes I just keep reminding myself what did I go wrong, what did I do to someone, you see that kind of superstition come to mind, did I, wrong somebody, did I steal somebody's money, did I borrow money from a sorcerer that I didn't pay, could it be a punishment in disguise on something. I just reflect this shouldn't happen to me, in the family nobody has it."* ***MP2, age: 36years***

Other major beliefs held by a majority of the parents were that the disease was inflicted upon the children by their enemies to put a financial burden on the parents and prevent them from prospering. One mother expressed her beliefs this way;

> *"…In the western world, you can easily say this illness is genetic but we are Africans, if you follow that assumption you will be sorry. Me, I believe there is a spiritual backing to all these illnesses. Sometimes, that is how your enemies in the family get to you. They will buy this disease for one of your children so that you don't prosper. How can you prosper when these children take all your time, squander all your money and even prevent you from working, hmm, it is a curse on you not to prosper and you can't unless you take them away from your life. But I'm asking you, how can you kill your own child? You can't, so the enemy wins. So this illness my child is suffering from, I see it as an attack just to punch me and my household and to make my life very difficult. I know it can be from any source so for me I don't believe in this hereditary thing they are saying."* ***FP12, age: 46years.***

Concerning the characteristics of the disease, parents held various views about the symptoms of the disease. Children with SCD were described to be usually weak, thin, have "yellow eyes" sickly and have big heads. All the parents held the belief that children with SCD have a brief life span and usually die in their early twenties. However, they believed

that it is not SCD that kills the children but supernatural forces that hide behind the illness to shorten the lifespan of the children. One of the parents expressed:

> *"Sickle Cell Disease does not kill. When the witch sees that they are sicklers then they will join the illness and worry them, they will kill the child for you and you will blame it on the illness."* ***FP6, age: 42years***

It was noted that most of the recounted views of the parents were myths and what they have been made to believe other than personal encounter. Crises are characteristic features of SCD and in terms of their management, the participants had varied views. Some of the parents believed that it is advisable to rush them quickly to the hospital since any form of treatment at home will not work. However, some expressed the belief that not all illnesses must be sent to the hospital and that some must be managed at home. Some of the parents held the view that frequent visits to the hospital increase the occurrence of the crisis.

4.5.2 Community's perception about SCD

From the parents' narratives, it was found that their lives, experiences and their perceptions about SCD were influenced by the community's beliefs about SCD patients. The sources of these beliefs included their close relatives the entire community. The community had different views concerning the cause of the disease and life span of SCD children. Some participants reported in the interview that children with SCD were seen to have a short life span and are "passing through life briefly" thus these children were not seen to be part of the extended family and were considered "useless". Some of the people in the community reportedly consider these children to be children of some spirits. One mother narrated the belief of her community about SCD in this manner:

> *"…in my community whenever a child falls sick regularly they say the child has Nwiwii and they are children of some spirits who don't like where they find themselves that is why they are constantly falling sick."* ***FP10, age: 34years***

Some parents reported that they were blamed by the community for being reckless and intentionally marrying a cursed spouse or marrying into a family which has been cursed. SCD was perceived as contagious in some communities such that when a pregnant woman exposes herself to a child with the disease, she gives birth to one. One parent had this to say:

> *"For my husband's people they believe that when you are pregnant and you go close to a child who has the illness (SCD), you will surely have a child with the disease (SCD). So my mother-in-law blames me that I wasn't careful enough and that my child is a sickler because I was exposing myself to such children when I was pregnant. She forgets that I'm a teacher and I wll not know the child who has it (SCD)."* ***FP11, age: 45years***

It was found during the interview that the occurrence of a crisis in patients with SCD was prevented in some communities with by taking concoctions.

> *"I went to church that day. When I returned and I took my baby I smelt the alcohol all over him. My son was just 3 years and I had to rush him to the hospital. He (brother-in-law) knew the child was a sickler and he went ahead to give it (concoction) to him because according to him, that concoction containing bark of a tree and "akpeteshie" (locally distilled alcohol) helps to prevent sicklers from falling sick. The child was drunk when I picked him up…."* ***FP8, age: 39years***

The perception of the community about Sickle Cell Disease translated into labeling and discrimination of parents caring for children with the disease.

4.5.3 Stigmatisation

One major social burden encountered by the parents of SCD children was stigmatisation and the fear of it. A few (4) of the parents expressed receiving sympathy from friends and family who learned of their children's illness. However, it was evident in the narrations that the main socio-cultural factor associated with SCD was fear of stigmatisation of the parent as well as the ill child. Most parents feared labeling and discrimination from their neighbours as well as from their distant relatives thus they had to keep the disease a secret from them. Some of them denied when they were openly confronted about their children's to avoid stigmatisation which might even be carried to the future. It was observed that the fear of stigma was largely influenced by the community's perception and myths

surrounding the disease. Some even feared the ability of their children to get married in the future will be affected thus parents withheld information concerning their children's health status from their friends and distant relatives. One mother with two girls having SCD expressed her fears this way:

> *"...no one can ask me and even if they do I will not tell them or they will be pointing fingers at me. I don't want people to know because you know both of my children are girls and a time will come when they will grow up. People will tag them that they are sicklers and when they grow, even marriage will be a problem. Few parents will allow their children to marry a girl who is a sickler so I don't want them to know or they will suffer when they grow up. So I don't say it and I will never say it even if someone is bold enough to ask me. Someone was bold to ask me why my children's eyes are yellow and I told her I also had the same eyes when I was a child just to take her mind off* ***FP5, age: 31years***

Some mothers were stigmatised by their neighbours because they saw a SCD child as equally as contagious as an AIDS patient and would not want to go near them for fear of contracting the disease.

> *"...so I decided to sell bread just in front of our house still the people in my area did not buy it. I didn't understand why until one day I overheard someone saying that my girl has AIDs because she is always falling sick and she is very tiny."*
> ***FP3, age: 38years***

Another mother reported her experience this way;

> *"Sometimes if you even want to go to the toilet you won't get anyone to hold him. I don't know if it is because he is not growing fat or because of eyes or swollen hands that scares them. I don't know but nobody wants to hold him so wherever I'm going I have to go with him even to the public toilet."* ***FP9, age: 44years***

It was observed from the narratives that the experience of stigmatisation was not present in the parents' immediate environs only. It was extended to their churches and other organisations they belonged to. Thus, these parents preferred excluding themselves from a social gathering to avoid the discrimination.

4.6 Outcome of Caregiving (Crises)

Describing their experiences of caring for their ill-children, it was observed that caregiving directly affected the health and wellbeing of the parents. Indirectly, parents

experienced psychosocial trauma from the burden of the caregiving on the rest of the family which includes burden on the ill-child, other siblings and spouses of caregivers.

4.6.1 Burden of caregiving on the physical health of the parent

It was observed that the physical burden of caregiving affected the physical health of the parents. Most of them complained of tiredness and fatigue emerging from a frequent routine visit to the hospital, especially during admission. These parents complained of sleepless because they are always worried and spend most of the night thinking about the hardships they will be going through. Some of the parents complained of acquiring nosocomial infections such as common cold due to a frequent hospital stay. One father described his experience as follows:

> *"I get fatigued all the time you know, hospital up and down, I get cough easily because anytime I visit the hospital, people are coughing and I have to go and treat myself again. Anytime I come around (ward), there is some needle somewhere and before I say jack I get pricked especially when they (doctors) are trying to get a vein, he (child) struggles and I have to hold him".* ***MP2, age: 36years***

Due to the burden from the caregiving responsibility, some of the parents reportedly developed chronic conditions such as hypertension and even seeking medical attention was problematic due to lack of time. Thus some parents in the narration made it known that even if they fall sick they have to ensure their children are fine and doing well before they can attend to themselves. A parent expressed:

> *"…as am speaking to you I'm sick, am tired but I cannot even take care of myself. I have to make sure he is fully fit before I can have little time for myself. It is really stressful and a burden I have to carry forever".* ***FP7, age: 37years.***

Some also had problems with substance abuse such as alcoholism due to their inability to withstand the pressure associated with the responsibility of caring for children with SCD. One father shared this experience;

> *…when I saw him in pain I just couldn't take it. I went out with my friends that evening, went to a bar to drink my head off. My friends were wondering why I was drinking so much. The next day, as usual, I went drinking again, this time the number of bottles increased. Now I was going to the bar every evening, it was becoming too much for me and I realised that I was getting into it (drinking alcohol)…*
>
> ***MP2, age: 36years***

4.6.2 Burden of caregiving on the psychosocial health of the parent

Getting to know a child's diagnosis was distressful for parents. Participants expressed that they had to go through fear and anxiety due to the presence of pre-diagnostic symptoms and complications such as fever, weight loss, swollen limbs, and jaundice. The children of the majority of the participants were not diagnosed early. Therefore, they had to go through uncertainty and anxiety for more than a year when their children were exhibiting pre-diagnostic symptoms of the disease. The parents reported going through intense psychological distress when their children were diagnosed with SCD. The diagnoses of their children led to emotional expressions such as uncontrollable weeping, shock, disbelief, hurt and sadness:

> *"I was sad, very sad, I cried because I'm a health worker and I see people with Sickle Cell and know what they go through, the labs and everything… it was really a shock because I never expected it to happen to me. I cried the whole day and my family came to console me. I asked myself, what have I brought upon myself? From that moment I knew my life will never be the same again".* ***FP4, age: 37years***

The parents regretted and blamed themselves for not taking the result of their genotype test seriously. They blamed themselves for marrying a Sickle Cell carrier while knowing their sickling status. Seeing their children go through the pain and other complications of the disease brought about feelings of frustration, regret, anxiety, and sadness. Majority of the parents regretted marrying their spouses and they blamed themselves for causing their children to suffer and to go through intense pain. One father said this in the interview:

> *"...when he gets crisis it becomes a bit tough, I blame myself for bringing this upon my son. I just reflect, this shouldn't have happened to me. In the family nobody has it and a learned person like me I know what this sickness is about so why should I go into it and later on have to regret. Why did I even marry this girl? So that's when psychologically it becomes tough and emm (bows down the head)".*
>
> ***MP2, age: 36years.***

It was also noted that fear was one of the most predominant psychological problems on the parents. They exhibited fear of death of their children, fear of their children being disabled due to disease complications, feared that crisis will occur at times when they are not financially prepared and also fear of giving birth again to a child with SCD. However, none of the parents reported being admitted for the diagnosis of anxiety and depression.

4.6.3 Overall burden of having a child with SCD on the family.

The parents in their narration stated that in addition to the challenges originating directly from the caregiving responsibility, they also had to deal with the burden of the disease on the ill child. They mentioned that their children go through a lot of suffering because of the disease condition.

The children have to undergo pain from the vaso-occlusive crisis and other complications associated with the disease. In addition, children with this chronic disease are put on medication immediately they are diagnosed and have to stay on these medications for their lifetime. This causes the children to complain and especially when they realize their siblings, who do not have SCD, do not take any medication. One parent, in describing this burden said this:

> *"...she will also be complaining why am I the only one taking drugs but my brother is not? There is always medicine in her mouth but she still falls sick".*
>
> ***FP3, age: 38years***

From the interviews, it was found that frequent admissions and continuous hospital stay put a major burden on these children. SCD children had to undergo frequent needle pricks as well as separation from their family and friends. A father said this;

> *"His last admission, for instance, the whole veins were pricked, there was no way they could get a vein, now they had to prick the neck then the head, small boy barely four years, I mean how come?. Then the lab people will also do their pricking. God have mercy, I really pitied him!"* ***MP2, age: 36years***

It was also observed that long hospital stay affected their children's schooling and their intellectual abilities. One mother narrated how her son had to write a Basic Education Certificate Examination (BECE) whilst on admission:

> *"…they gave him a lot of injections and the doctor said the medicine they've given him will be too much and he will sleep when writing the exams. He then started crying and he said he will complete school no matter what happens and will not let this illness stop him from completing JHS again. We were admitted but he will go and write the exams and I'll bring him back to sleep in the hospital after each paper".* ***FP9, age: 44years***

Children with SCD were described as "Active", "energetic", "very playful". The children repeatedly yearned to play and involve in activities such as playing of football, joining cadet corp in their schools, running around like their peers. However, they were prevented by their parents and teachers which according to their parents makes them sad. In addition to these, it was observed that the parents were psychologically burdened by the numerous instructions their children with SCD had to take such as drinking a lot of water, not bathing during cold weather and wearing of warm clothing.

The disease burden on the siblings of the ill-child, spouses and on their marriage was reflected in the caregivers' narration and these were seen to be major bother for the parents. The parents in the study emphasized that their children with SCD received more attention, care, and special treatment compared to the other children in the family. Children with SCD were excluded from any form of household duties whilst the other siblings, irrespective of

their ages, perform these duties. During admissions of the ill child, the parents disclosed that the management of the household and care of other children were usually left in the hands of one of the children. This causes the child in question to stay out of school hospitalization period the duration in order to fulfill these responsibilities. One mother said this;

> *My husband also needs to go to work and from work, he has to come here (hospital). So now that we are not at home, my second child who is a girl, 9years is the one taking care of the rest of the children. She has been out of school I think three days now and she cannot go until we are discharged and I go home. It is a burden on all of us.* ***FP1, age: 39years***

The financial burden placed on the family also had a toll on other children in the family. Some parents explained that siblings of the ill-child sometimes had to stay away from school because all the money had been "wasted" on the ill-child and there was none to pay for school fees. Some also mentioned that other children in the family were made to engage in street hawking to provide financial support towards the upkeep of the house. During admission of ill-children, some of their siblings had to stay at the hospital with their parents. This, according to the parents causes the children to develop nosocomial infections which put additional problem on them. One mother said this;

> *"Even with the younger one, I had to sleep with him on the hospital floor. Because the elder one was at the hospital and there was nobody to take care of him. He too developed some cough for staying at the hospital with us. He also had some other infections that I had to send him back to the hospital".* ***FP11, age: 45years***

All the participants also made it known in the interview that the illness had placed a huge financial burden on their spouses. The manner in which they interacted, related among themselves and the harmony that was existing in their marriage were also said to be compromised as a result of the illness of the child. Some mothers of children suffering from SCD indicated that their spouses doubted the paternity of their children and blamed them for infidelity since SCD was not found in the family. Other parents expressed the desire to divorce their spouses in order to have "normal children" with other men because they

strongly believed their spouses have had normal children outside marriage. Due to the financial burden on their spouses, some parents experience strained marital relationships as they were blamed by their spouses for not taking proper care of their children and rushing them to the hospital with the least illness.; A mother having two children with SCD said this;

> *"For me since the diagnosis of my first son I have never been in happy in marriage. We don't even sit down to talk. Even when he returns from work and you welcome him he will not mind you. Now I'm not working so all the burden is on the man so that makes him very annoyed with me. He thinks I intentionally send the children hospital to drain his pocket. If marriage were to be like slippers where you can easily remove when you are tired, I would have removed mine a long time. I know time will tell. He doesn't take me out, he doesn't mind me but it wasn't like that initially".* ***FP10, age: 34years***

4.7 Determinants of the burden of caregiving

This theme emerged directly from the data collected. These were factors that were observed to predispose parents of children with SCD to the burden of caregiving. These were the time of diagnosis of SCD in their children and the type of treatment used.

4.7.1 Time of diagnosis

The findings of this study revealed that out of the twelve parents interviewed, three parents had their children diagnosed a few weeks after birth because they knew their status. According to them, their children were immediately started on medicines after diagnosis. The parents pointed out in the interview that since the time of diagnosis the only illness they remember their children having was common cold and cough and that their children have neither been admitted or been transfused. One mother said this;

> *"...since I came, they gave us penicillin V, folic acid and multivitamin and she has been on it since she was 2 months when they diagnosed him. She was diagnosed early unlike my first child. Though she was not falling sick I asked them to test her so that I will know her status and since that time, the only illness she has suffered from is cold and cough which I know is normal with all kids".*
>
> ***FP5, age: 31years***

Another mother whose child was diagnosed three weeks after birth describes her experience;

> *…he was diagnosed when he was just 3 weeks old at Komfo Anokye Teaching Hospital and since that time I have been monitoring him a lot and paid a lot of attention to his health. I must say to the glory of God that he has never had a crisis, never. We have never slept in this hospital before for 9years now.*
>
> ***FP6, age: 42years***.

However, it was observed that parents whose children were diagnosed after exhibiting pre-diagnostic symptoms like anaemia, splenomegaly and musculoskeletal problem were frequently visiting the hospitals, had frequent admissions and were transfused more often.

> *"She wasn't eating so we took him to a clinic and they gave us some blood tonic to improve her eating but it was not working and her Hb was still low. We were admitted and had to stay at the hospital for two weeks. They transfused her twice … since that time we have been moving in and out of the hospital. Last year, for instance, he got crisis three times".* ***FP3, age: 38years***

4.7.2 Type of treatment used

The study revealed that the type of treatment given to the children also influenced the experience of hardships associated with caring for a child with SCD. All the participants disclosed that their children were managed on penicillin, folic acid, and multivitamin, however, irrespective of how their effort to prevent the crisis in their children proved futile. It was observed from the parent's narration that upon the advice of the doctors those who could a afford to place their children on hydroxyurea and according to them it reduced the occurrence of a crisis. A mother described her experience this way;

> "*She wasn't gaining weight and the Hb has always been constant 7-9 no matter what you do because the folic acid and all medications I make sure she does take it. The first year she had admission here and the following year she had two admissions with blood transfusion so since that time we had to put her on the hydroxyurea because it was affecting her education because sometimes she has to be on admission and I have to go to work and those things so we decided to put her on the hydroxyurea and she has been on it for I think a year and there has been some improvement because the Hb is about 11.9 and she has not missed school and no joint pains and performance at school has also improved".*
>
> ***FP4, age: 37years***

Another mother with two children having SCD but only one was on hydroxyurea, revealed that the one on hydroxyurea was having a better quality of life than the other child.

> *"I take care of them equally, give them the same food and everything but the older one still falls sick regularly. Whenever we are on admission then it is because of him so I think it is due the absence of hydroxyurea because before we started his sister on the medicine she was also falling sick regularly like him, admission here and there but now it is only him"* ***FP10, age: 34years.***

In summary, the findings from this study revealed the varied experiences of caregivers of children diagnosed with SCD at 37 Military hospital. The demographic characteristics of caregivers revealed that all of them were biological parents of the children. All the parents had one child suffering from SCD except three parents who had two children each with SCD. All the parents had some level of education and all except one of them were married. Most of the children being cared for were diagnosed with HbSS and one had HbSβ0-thalassemia. All the participants, as well as their spouses, were Sickle Cell carriers.

The experiences of these caregivers were explored guided by the ABCX family stress model and well as the objectives of this study. Some of the themes and subthemes emerged from the data. Five major themes emerged from the narrations of the parents: Caring for a child with SCD, resources used by parents, perceptions about SCD, the outcome of caregiving (crisis) and determinants of the burden of caregiving. The parents disclosed distinct experiences in relation to these five main areas.

The findings revealed that the burden associated with caring for a child with SCD was related to the health status of the child, was physical, financial, work-related or occupational and health service-related factors. Parents used religion and social support as the main resources to buffer the stress of caregiving. Parents and their communities had varied perceptions about SCD and due to the community's perceptions SCD, children with SCD and their parents suffered stigmatisation. The outcome of caregiving affected the

physical and psychosocial health of the parents. Time of diagnosis of SCD and type of treatment used were the determinants of the burden of caregiving.

CHAPTER FIVE

DISCUSSIONS OF FINDINGS

The discussion of the findings of the study is presented in this chapter. The findings are discussed in relation to the existing literature based on the constructs of the theoretical framework guiding the study. It begins with the discussion of demographic characteristics of the parents followed by the major themes derived from the study.

5.1 Demographic Characteristics

All the participants in the study were the biological parents of the children. The majority were mothers of the children with SCD except for one primary caregiver who was a father to the ill child. The findings highlight the role of the Ghanaian woman in the family whereby in the typical Ghanaian setting women have a traditional role of providing care to members of the family especially when the individual is sick. Thus it explains why almost all the participants were mothers. This finding is consistent with findings of studies carried out in other parts of West Africa where it was found that women were the main informal caregivers of children with SCD since they placed high value on childbearing and caring for their children especially when they are ill (Afolayan & Jolayemi, 2011; B. J. Brown et al., 2010b; Wonkam et al., 2013; Yawson et al., 2016).

All except one of the participants in the study were married and were living with their spouses. One important observation made was that most of the mothers as caregivers reported that when it comes to the physical care of their ill-children, it was carried out by them alone with no support from their spouses. Thus, one can assert that although demographically these mothers were married they felt “single” when it comes to the physical care of their children. This corroborates the findings of a study carried out among parents of chronically ill children in the United State of America which assessed the relation of parents’

perception of “lone” parenting and other socioeconomic factors. The study showed that although parents of chronically-ill children might be married when it comes to the care of their ill children most parents consider themselves to be single parents and alone (Wiener et al., 2013).

All the parents in the study had some level of education with most of them up to the tertiary level. 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 (Katooa et al., 2015). It was further observed that all the parents who had attained tertiary education knew their sickling status before marriage. The rest of the parents got to know of their status either during antenatal or when their children were diagnosed with the SCD. However, to effectively prevent Sickle Cell births, there should be the introduction of SCD teaching and screening into the educational programmes and genetic counseling for teenagers before marriage (Diallo & Guindo, 2014).

It was also observed that parents who tested for their sickling status before marriage did so because it was part of the general health screening prior to their admission to tertiary educational or health institutions. In addition to this, none of these parents was able to recognize the symptoms of the disease before their children were diagnosed. Thus, it can be said that generally, knowledge about SCD was inadequate among the participants and that parents with a higher level of education did not exhibit adequate knowledge about SCD. This is in contrast with the findings of a study which revealed that caregivers with higher levels of education were seen to have in-depth knowledge of SCD (Wonkam et al., 2013).

5.2 The burden of parents caring for children with SCD

The findings of this study provided insight into some of the hardships that parents who were providing care to a child with SCD had to endure. Having and caring for a child with SCD was seen to be demanding and a burden for the parents who were the main caregivers of the children. In this study, the parents encountered numerous challenges in the course of caring for their children. The parents experienced challenges related to the health of the child, physical, financial and work-related or occupational challenges. Some of the hardships associated with the caregiving also originated from factors related to health services. This highlights the fact that providing care to a child with SCD is compounded by factors originating from numerous sources. The findings are congruent with the findings of studies among parents of children with SCD in Nigeria which showed that these parents go through untold hardship in the course of providing care to their ill- children (Adegoke & Kuteyi, 2012; Afolayan & Jolayemi, 2011; Muoghalu, 2016).

Following the diagnoses of their children with SCD, the lives of these parents were totally changed due to the hardships that accompanied the caregiving responsibility. Sickle Cell Disease by its nature is usually characterized a by a series of painful episodes from the vaso-occlusive crisis and this was discovered in the study to be the major burden experienced by parents in relation to the health of their children. Seeing their children in pain aroused the feelings of empathy and distress. This is consistent with the findings of a study which showed that the major burden emerging from the health of their children was pain from the vaso-occlusive crisis (Ali & Razeq, 2017). Due to the severe pain experienced by their children, most of the mothers in this study decided not to give birth again to avoid going through the same experience. This corroborates the findings of a study which showed that

parents based their reproductive decision on their previous experience of SCD complications especially vaso-occlusive crisis (Gallo et al., 2010).

The two major conditions that led to frequent hospitalization and a long stay at the hospital were chest infections and severe malaria. Parents were tasked heavily by the hardship of frequent hospitalizations because it prevented them from fulfilling certain obligations to their friends and family. This finding is consistent with findings of a study carried out in Jordan; Asia which showed that frequent hospitalization brings about a sense of insufficiency in parents of children with SCD as they feel they have neglected their responsibilities to another member of the family (Ali & Razeq, 2017).

Delayed growth and development of children with SCD despite adequate feeding was another burden for the parents in this study. In addition to stunted growth of their children, parents were stressed when their children delayed in walking due to musculoskeletal complications. This finding is consistent with the findings of a study by carried out in Nigeria which showed that presence of disease complications causes severe distress in parents as it leads to difficulty in transportation and alters the daily routine of parents (Afolayan & Jolayemi, 2011). This underscores the importance of continuous monitoring of growth and nutritional status of these children, in order to implement appropriate nutritional intervention and the use of physiotherapy (Al-Saqladi, Cipolotti, Fijnvandraat, & Brabin, 2008).

There was the expression of a heavy burden in relation to the frequent blood transfusion of children with SCD. The major problem of the parents was getting compatible donors. They often had to plead with relatives and pay many “blood contractors” to donate for their children. This finding is congruent with findings of studies which showed that due

to red cell antigens discrepancy among Africans, SCD patients have difficulty getting blood as a result of compatibility issues (Diallo & Guindo, 2014; Sarode & Altuntas, 2006).

The responsibility of achieving activities of daily living for their children with SCD was considered as normal parental responsibility, yet, compared to the care of other children who do not have the disease, this was unduly demanding. It was highlighted in the study that, caring for a child with SCD was physically demanding for the parents especially when the child is in crisis and when one had to care for more than one child with SCD. Parents were burdened physically when they had to ensure adequate feeding, appropriate clothing, especially during cold weather, maintaining personal hygiene of their children and giving medications under prescribed conditions. This finding is consistent with the findings of previous studies which indicated that parents of children with SCD are burdened with two types of cares; technical care which involve providing daily medications, taking them for routine hospital visits as well as non -technical care which involve feeding, grooming, bathing and supporting the child to accept the disease condition (Brown et al., 2010; Moskowitz et al., 2007) .

All the parents experienced financial hardships irrespective of their economic status. In this study, the greatest financial burden was the cost of care specifically the cost of medicine and laboratory investigations. The chronic nature of the disease coupled with complications meant a series of laboratory investigations and medications. All these were expensive and brought huge financial drain on the family. This is congruent with the findings of studies carried out in Nigeria which showed that parents of children with SCD in low income countries where there is a high level of poverty and inequitable distribution of resources suffer additional economic hardship from the medical care of their children (Brown et al., 2010; Muoghalu, 2016; Olatunya et al., 2015; Yawson et al., 2016).

Although all the parents had registered their children under the National Health Insurance Scheme, most of the laboratory investigations and medicines used by SCD patients are not captured under the policy. The parents expressed that there is marginalization of people with SCD by the government compared to people with diseases such as HIV/AIDS who in addition to insurance receive some form of subsidy for their medications. This corroborates with findings of studies carried out in part of the country by Dennis-antwi, Dyson and Ohene-Frempong (2008) which showed that, SCD has been hardly recognised as a disease of public health importance in Ghana such that there is no special subsidy for people with SCD and the extent of coverage for the disease complications in the country is not clear. The cost of care was found to be so expensive that some parents could not take their children to hospital when they fell sick until they got adequate funds to do so. This highlights the fact that most of these children will be suffering from complications of SCD which will increase the risk of mortality because of cost of care. This is consistent with the findings of a study carried out in D.R. Congo which showed that the cost of care increases the mortality rate of children with SCD as parents cannot afford quality medical care for their sick children (Ngolet et al., 2016).

Maintaining the nutritional status of their children further increased the financial burden of parents as the children were managed on high nutritious diets to maintain optimal haemoglobin levels and this came at a cost. This is consistent with findings of studies by Muoghalu (2016) which revealed that, parents suffer additional financial burden from nutritional costs. The financial burden on parents was so enormous that some of them had to borrow money from people in order to provide for the basic needs of the family. This finding is congruent with findings of studies carried out in certain parts of Africa; Nigeria and Zambia Africa which revealed that parent of children with SCD experience high

economic hardship causing them to assess loans which become too huge to repay and this poses extra burden on them (Brown et al., 2010; Wasomwe & Ngoma, 2011).

It was also found that, the already impoverished financial status of parents was worsened by the inability of mothers who were self-employed, mostly petty traders, to work leading to loss of income. Other parents because of the high caregiving demands on them were not able to seek for high-paid jobs irrespective of their level of education. This is congruent with the findings of a study carried out in Malaysia which indicated that due to caregiving demands on mothers of chronically-ill children, they suffer economic stress from their inability to work full-time and inability to seek high paid jobs (Nur Saadah et al., 2014).

Another burden experienced by parents in this study, who were employees, was a conflict between the caregiving role and their work. The parents reported that due to frequent hospitalization and routine medical check-up, they were always asking permission to stay out of work. This led to demotion, denied promotion at work and even loss of job as some were sacked due to low productivity. This finding is congruent with findings of a study by Wonkam et al. (2014) in Cameroon which revealed that parents providing care to their children with SCD compromised their loyalty to their jobs and prevented them from giving out their best in their various jobs.

The findings of the study showed that the hardships associated with caring for a child with SCD also came from the quality of care received and its component factors related to the health services. It was found in the study that all the parents did not doubt the knowledge and competency of doctors as general practitioners who have some knowledge about SCD. However, in relation to the effective management of SCD and associated complications, most of the parents were dissatisfied with the knowledge and competency level of healthcare professionals, especially doctors. This was evident in the difficulty in diagnosing the disease

in their children. This is congruent with the findings of studies that disclosed that, caregivers view many nurses and medical doctors in the mainstream who are not specialist as incompetent, having insufficient knowledge and lack expertise when it comes to management of Sickle Cell children as most of them do not undergo specialty training but provide care based on the basic knowledge about SCD acquired from school (Burnes et al., 2008; Dennis-Antwi, Dyson, & Ohene-Frempong, 2008; Wesley et al., 2016).

In addition to this, care was provided by different doctors in the same healthcare facility with each care regimen contradicting the treatment prescribed by the other. In light of this, a lot of money was wasted in the purchase of different medicines with most of them being abandoned due to changes by different doctors. Thus this affected continuity of care and extended their hospital stay sparking feelings of hopelessness in the parents. This shortfall in the healthcare system was acknowledged by Edwin, Edwin, and Etwire (2011) and they proposed that, in order to effectively optimise health care for people with SCD, a holistic approach with a multi-disciplinary team coordinated by a haematologic team is needed to provide paediatric and specialist care to these patients.

Furthermore, it was found in the study that the attitude of medical staffs during an emergency was very good, yet, participants in the study questioned the attitude and professionalism of nurses and laboratory technicians during admission. One of the parents recalled being neglected by nurses and her child's medication was not served as she was tagged by the nurse as a nuisance because she complained of their bad attitude towards them. In all, it was observed that the parents were pleased with the attitude of doctors and pharmacist compared to other medical staff. This is consistent with the findings of a study which showed that parents of children with SCD are burdened by the poor attitude of hospital staffs except for the attitude of doctors(Ali & Razeq, 2017).

Another factor related to the health service that was a burden for the parents was long waiting time during routine care as a result of long queues and congestion at the laboratory. The parents expressed distress because the time could have been used productively to earn income or undertake other equally useful activities. Cleanliness of the hospital environment was another burden that the parents in the study had to deal with. Although the general hospital environment was described as clean especially the outpatient department, the parents were however not pleased with the ward environment. They described the ward as not neat with mosquitoes and cobwebs which do not stimulate recovery. Yet, the hospital environment is as important as the medications given, according to the nurse theorist Florence Nightingale. This is especially so for SCD patients in sub-Saharan Africa where the major causes of mortality are infections, especially malaria (Makani et al., 2013). The findings of this study are consistent with the findings of a study carried out at Koforidua in the eastern part of Ghana which observed the poor attitude of healthcare professionals especially nurses, long waiting in the outpatient department with some parts of the hospital environment neglected and not tidied (Ofosu-Kwarteng, 2012).

5.3 The resources used by parents caring for children with SCD

Going through all these hardships associated with caring for a child with SCD, it became evident in this study that parents adopted two main support system which helped them cope. The main resources which influenced the ability of the parents to cope with these hardships were religion and social support. All the parents in their narratives made it clear that they were taking comfort in religion and that was what had seen them through all the struggles. Parents sought for confirmation of the diagnosis and the cause of the illness from their spiritual leaders. It was observed that it was only when their spiritual leaders affirmed that the disease condition of their children was solely medical with no spiritual attack that

the parents totally abided by the medical advice and treatment. This is consistent with findings of a study by Malhotra and Thapa (2015) which indicated that most caregivers after diagnosis of their patient seek for spiritual affirmation of diagnosis.

Parents also appraised the illness of their children as a test of their faith in a supernatural being and this helped to erase the psychological burden of self- blame. The commonest form of religious coping observed was prayer. Parents used this mode of coping a lot especially when their children were in crisis. It gave them hope that someone was taking care of their problems spiritually. It was also noted that prayer made the caregivers optimistic about their children condition. This is consistent with the findings of studies which revealed that faith in one's religion bring calmness and hope to these caregivers that technology and science can never do as well as helping these caregivers adopt positive appraisal of the situation even when prognosis is bad (Lai & Oei, 2014; Leite et al., 2013; Nur Saadah et al., 2014). However, it became clear from this study that not all forms of religious coping were beneficial to the health of the ill child. In some cases, some of the caregivers due to their faith in supernatural healing failed to abide by medical advice given and this almost led to the death of the ill child.

Parents reported receiving emotional, informational and instrumental support basically from their nuclear family and from their extended family, few church members and from healthcare professionals. The parents pointed out that their main source of support was their spouses who supported them financially. It was observed that most of the support received by the parents were from close relatives and a few members of the church. In the narration, none of the parents expressed receiving support from friends and their neighbours although they had many social ties. It was observed that the parents in the study received limited support from their numerous social support because, due to fear of stigmatisation,

the parents kept the illness of their children from people they were connected to. Therefore, they did not gain enough support from them. This corroborates with the findings of studies which indicated that parents tend to cover up their feelings and emotions as well as keep child's diagnosis secret for fear of stigmatisation thus rarely receive support from the society (Brown et al., 2010; Lai & Oei, 2014; Wesley et al., 2016).

It was observed from the narratives that, parents sought for knowledge and understanding about SCD from healthcare professionals, their family members, and their religious leaders. The findings of studies by Desai et al. (2015) indicated that this type of coping strategy is a problem-focused which is a positive approach to coping with stressful situations. Furthermore, it was observed that the parents placed more value on financial support compared to other forms of support due to the economic hardship placed on them. This is in contrast with the findings of a study carried out in Malaysia where parents of children with SCD placed much importance on emotional support (Nur Saadah et al., 2014). This difference in findings could be due to the higher per capita income and well-developed economy in Malaysia compared to Ghana. Thus parents of children with SCD in Malaysia may not have much financial burden compared to Ghanaian parents.

5.4 The perceptions of parents and community members about SCD

In the parents' efforts to comprehend SCD, the study found that the parents had generated their own meaning within the context of their social and cultural background. The parents were familiar with the SCD and had local names for the disease based on the signs and symptoms of the disease. Parents in the study doubted genetics as the sole cause of the disease and their disbelief originated from their perceptions about the Sickle Cell carrier. Some of the parents had the perception that carriers should exhibit the same signs and symptoms those with the disease show. Thus they did not understand why they do not show

any symptoms but their children have the disease. This finding corroborates the findings of a study in Uganda where there was the perception among the participants that, Sickle Cell carriers should be frequently ill as people with the SCD (Tusuubira et al., 2018).

The parents in this study had the belief that there were supernatural influences on SCD. They held the perception that the disease may be caused by witches, as a punishment from wrongdoing or defaulting payment. The parents also believed that the disease is inflicted by one's enemy to put a financial burden on them and prevent them from prospering. There was the belief that children with SCD have a short lifespan and usually die in their early twenties. This is congruent with the findings of a study in other parts of Ghana which revealed that because of the hardship associated with having a child with SCD, most parents attribute the cause of the disease to supernatural influences and they held the belief that these children have short life span (Dennis-Antwi et al., 2011).

This study revealed that the belief of some parents in relation to crisis management affected the health-seeking behaviour for their children. There was the belief that sending children to the hospital on the occurrence of crisis leads to frequent crises thus the hospital was not their first point of call. Parents often managed crisis first at home with over- the-counter drugs before sending their children to the hospital when their conditions became serious. This is congruent with findings of a study which revealed that the perception of parents about vaso-occlusive crisis influence the degree of threat associated with the disease and the urgency with which care is sought (Pantaleao, Diplacido, Guite, & Zempsky, 2018).

It was observed from the study that most of the views of parents were myths and what they had been made to believe from their communities. Through effective and continuous education on the SCD, these beliefs can be altered. It was also observed that the major source of knowledge about SCD was from the community which shows that the

perception of the community has a great influence on the perception of parents. The findings of other studies in Ghana and Uganda have indicated that the main source of knowledge about SCD was from the family and schools (Orish et al., 2014; Tusuubira et al., 2018).

Parents in this study revealed that the community had varied views concerning the cause of the disease, treatment, and lifespan of children with SCD. Children with SCD were considered to have a short lifespan and therefore they were not considered as functional members of the extended family. The children were also regarded to be children of spirits and a curse on families. This finding is congruent with the findings of a study which revealed that most communities in Africa ascribe supernatural explanations to the cause of SCD where it is believed to be a generational curse (Marsh et al., 2011).

It was discovered in the study that due to the perceptions of the community on SCD, parents of children with SCD feared stigmatisation. Therefore the parents kept the disease from their distant relatives and their neighbours and even denied it when asked. There was the fear that the ability of their children to get married in the future will be affected due to stigmatisation, therefore, the disease condition of their children was kept a secret in their communities. This finding corroborates the findings of studies carried out in Zambia and the United Kingdom which indicated that parents are reticent to share their children's diagnosis with the community due to fear of stigmatisation which might affect their children's ability to marry or secure a job in future (Chudleigh et al., 2016; Wasomwe & Ngoma, 2011).

Due to the perception of the short lifespan of children with SCD, the children were considered useless and their mothers were thought to be struggling in vain. The disease was considered to be contagious and due to poor growth and development, children were considered to be HIV/ AIDs patients. These findings are consistent with findings of studies

which showed that SCD is considered to be contagious and parents and children with SCD suffer similar stigmatisation as HIV/AIDs patients (Marsh et al., 2011; Wesley et al., 2016).

5.5 Outcome of caregiving

This study highlighted the fact that the burden of caring for a child with SCD together with the perception and resources of these parents led to the crisis by affecting the health of the caregiver and placing a burden on the rest of the family. Generally, the study showed that caregiving impacted more on their psychological health than physical health. This is congruent with the findings of a study which indicated that the physical effects on the caregiver cannot be compared with the psychological trauma these individuals go through to care for children (Schulz & Sherwood, 2008).

It was found from the interviews that the physical burden of caregiving affected the physical health of the parents. Most of them complained of tiredness, sleeplessness, and fatigue. Some of the parents complained of acquiring nosocomial infections such as common cold due to the frequent hospital stay. As a result of the burden associated with caregiving responsibility, some of the parents developed chronic conditions such as hypertension. These parents were not able to seek medical attention because of lack of time. The effects of having a child with SCD on their psychological health such as depression caused some parents to adopt unhealthy lifestyles as a way of 'protecting' themselves from the hardships. Some started abusing substances such as alcohol due to their inability to withstand the burden associated with the responsibility. This finding corroborates that of studies which indicated that caregivers of children with SCD who are usually their parents, tend to neglect their own health and adopt unhealthy practices such as poor quality sleep, not eating properly and medical non- compliance which predispose them to medical conditions especially neck pain and cardiovascular disorders (Brown et al., 2010; Schulz & Sherwood, 2008).

The initial problem of getting their children diagnosed coupled with pre-diagnostic symptoms led to anxiety, uncertainty, and fear in parents of children with SCD. Uncontrollable weeping, shock, disbelief, and denial were some of the emotional outbursts the parents described in this study. It was observed that these emotions expressed the disappointment regarding the health status of their children and their belief of how their lives and those of their family would be altered. This is consistent with the findings of studies carried out in Jordan and the United Kingdom which showed that, caregiving affect the psychological health of parents and that the emotional battle of disbelief and denial is a grieving for a parent for the "normal" child they thought they had (Ali & Razeq, 2017; Chudleigh et al., 2016).

The parents blamed themselves for genetically transferring a defect onto their children. Participants also blamed themselves for bringing such hardship and burden on themselves. There were regrets, particularly for marrying their spouses. This is consistent with findings of studies done in Nigeria and Zambia which showed that most parents go through self-blaming and regret for bringing illness on their children and for marrying their spouses (Afolayan & Jolayemi, 2011; Wasomwe & Ngoma, 2011).

It was found that the major psychological effect was fear which came from fear of death of their children, fear of children having a physical disability, fear of crisis occurring at a point in time when they are not financially prepared and fear of giving birth again to a child with the disease. These findings are congruent with the findings of a study which indicated that caregivers of SCD children usually encountered fear from so many sources thus altering their psychological health (Wonkam et al., 2013).

It was revealed in this study that SCD affected the physical and psychosocial health of the children having the illness and this constantly brought psychological distress to their

parents. The major psychological disturbance on the children was the frequent intake of medicines which made them feel different from their siblings and peers. The parents said in the interview that their children were always questioning them on why they were treated differently from their siblings. The children, in addition to pain from vaso-occlusive crisis also suffered additional pain from frequent needle pricks during laboratory investigations and intravenous fluid administration. The parents stressed that frequent admissions, psychosocially affected their children as it made them felt separated from their friends at school and the rest of the family. This is consistent with the findings of a study by Javalkar et al. (2017) which revealed that an increased amount of medicine and injection intake causes distress in parents of children with chronic illnesses.

Frequent hospital admissions caused emotional burden in the children because their education was affected. Parents expressed worry about frequent absenteeism of their children with SCD from school and that their children of school going age could not attend school because of frequent illness and hospitalization. According to the parents, children with SCD were depressed whenever they were excluded from school activities. In addition to these, the parents highlighted that their children were burdened by the numerous instructions associated with the disease such as drinking a lot of water, not bathing during cold weather and wearing of warm clothing. These findings are consistent with the findings of studies which shows that children with SCD go through a lot of physical and psychosocial crisis and these cause severe distress for their parents (Brown et al., 2010; Grove, Grove, & Michie, 2013; Wonkam et al., 2013).

This study also highlighted the fact that caring for a child with SCD disrupted the life of healthy siblings of the ill-child thus altered parent-child interaction. Due to the increased demand of care and frequent hospital utilization, the other children in the

household receive less attention and sometimes children as young as nine (9) years had to take up the responsibility of managing the household and taking care of their younger siblings. Some of the siblings of children with SCD had to stay away from school and some had to engage in street hawking due to the financial burden on the family. During admissions, some of the siblings of the ill-child had to stay at the hospital with their parents which affects their health. This is similar to the findings of studies which revealed that caring for a child with SCD alters the life of the other children in the family as they do not receive the needed attention and their needs are not fulfilled (Gesteira et al., 2016; Wonkam et al., 2013). It can be said that these problems could lead to psychopathological disorder in the healthy siblings of children with SCD thus there is the need for regular psychological assessment and assistance.

Family interaction and harmony in marriage were also observed to be compromised in the families studied as a result of the illness of their children. Some parents recounted that their spouses doubted the paternity of their children and blamed the caregiver (mothers) for infidelity since SCD was not found in the family. Some parents (mothers) expressed the desire to divorce their spouses in order to have “normal children” with other men. Due to the financial burden on their spouses, some parents experienced strained marital relationships as they were blamed by their spouses for not taking good care of their children thus rushing them to the hospital with minor illnesses. This is congruent with findings of studies which indicated that the presence of a child with SCD in the family causes frequent quarrels, marital disharmony and family (Habeeb et al., 2015; Wonkam et al., 2013).

5.6 Determinants of the burden of Caregiving

The parents in this study indicated that the hardships associated with caring for a child with SCD were influenced by time of diagnosis and the treatment option used. A few

parents had their children checked for SCD a few weeks after birth because they knew their statuses. These children who were diagnosed early were started on treatments such as penicillin prophylaxis immediately after diagnosis. It was observed that unlike children who were diagnosed after experiencing pre-diagnostic symptoms such as vaso-occlusive crisis and musculoskeletal complications, the children who were diagnosed early hardly fell sick and were occasionally hospitalized mainly as a result of severe malaria. This helped them to lead a relatively normal life such as attending school regularly. However, children who were diagnosed after experiencing complications of the disease were frequenting the hospitals and were mostly hospitalized for conditions such as chest infections, anaemia, and vaso-occlusive crisis. It can, therefore, be said that early screening and diagnoses help children to be started early on prophylaxis. Additionally, parents of the children who were diagnosed early were also educated earlier on caring for children with SCD as well as prevention of complications of the disease. This is congruent with findings of a study which showed that early diagnosis of SCD is cost-effective, decreases the occurrence of complications and it allows for an early start of penicillin prophylaxis which prevents morbidity associated with pneumococcal infections (Dennis-antwi, Dyson, & Ohene-Frempong, 2008; Hirst & Owusu-Ofori, 2014).

The study showed that the type of treatment given to the children also influenced the experiences associated with caring for a child with SCD. All the participants whose children were diagnosed after experiencing the disease complications disclosed that their children were managed on penicillin, folic acid, and a multivitamin. However, these children were mostly anaemic, regularly experienced vaso-occlusive crisis and were hospitalized frequently. The children were frequently missing school and prevented their parents from earning income. Some of the parents opted for the hydroxyurea drug therapy

based on the advice of their doctors and according to parents of these children, the occurrence of crisis reduced drastically with an improvement in their children's haemoglobin level. This reduced the frequent hospitalizations, complications and some of the burdens associated with caring for children with SCD. The only condition that caused hospitalization in children on hydroxyurea drug was severe malaria. This matches the findings of studies which showed that the use of hydroxyurea drug as a treatment option leads to reduced hospital stay, reduced occurrence of SCD-complications, especially vaso-occlusive crisis, decrease in the rate of hospitalization and results in a better economic outcome for their caregivers (Candrilli et al., 2011; Da Silva et al., 2012; Salman & Hassan, 2015). Beyond induction of HbF in patients, this cytotoxic non-teratogenic drug has been proven to preserve splenic function, prevent organ damage, enhances growth and development and use in the treatment of vaso-occlusive events in both children and adults (Agrawal, Patel, Shah, Nainiwal, & Trivedi, 2013). In Ghana, irrespective of the disease burden in patients and their caregivers, newer modalities of disease management such as the use of hydroxyurea are rarely used (Asare et al., 2018). But since asthma is not treated to prevent intubation, diabetes to prevent ketoacidosis, SCA should not be managed just to prevent complications of the disease but to help the patient and family enjoy better life (Agrawal et al., 2013).

In summary, the findings of the study were consistent with the constructs in the ABCX family stress model. In relation to "A" (stressor event and its hardship), it was found that parents caring for children with SCD go through many challenges which include; burden related to the health of their children, physical burden, financial burden, work-related or occupational challenges and burden related to health service. Parents were burdened by the physical health conditions of their children and caregiving demands on them especially when

their children are in crisis. Most parents were financially challenged by the cost of medical care and provision of the appropriate nutritional diets for their children with SCD. Combining the responsibility of caring for their ill-children with work was another major challenge of the parents as it led to demotion and loss of a job. Furthermore, the parents were burdened with issues concerning the quality of care they received at healthcare facilities.

The parents used social support and religion as resources (B) to deal with the hardships associated with caring for a child with SCD. Parents relied on religion which gave them comfort and hope about their children's condition. They adopted a problem-focused strategy to cope with the hardships of caregiving. Parents received emotional, informational and instrumental support from close family, few church members and healthcare professional.

In relation to perception about the event (C), parents created their own meanings within the context of their social and cultural background. The perceptions of the community about SCD led to fear of stigmatisation in the parents. Parents and their children with SCD suffered stigmatisation from their communities.

The outcome of caring for a child with SCD led to the crisis (X) in parents of children with SCD. Physically, parents experienced tiredness, sleeplessness, and fatigue. Psychologically, these parents experienced self-blame, regret, depression, anxiety, uncertainties, and fear. Caring for a child with SCD affected the life of healthy siblings of ill-children and led to marital disharmony.

Another finding emerged from the data and was not consistent with the constructs of the ABCX model of family stress, however, it was in line with the objectives of the study. These were the determinants of the burden of caregiving specifically, the time of diagnosis

and the type of treatment used. Early diagnosis and use of hydroxyurea drug led to a better quality of life of children with SCD.

CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS, CONCLUSIONS, AND RECOMMENDATIONS

This chapter presents a summary of the study, its implications, limitations, conclusions, and recommendations.

6.1 Summary of the Study

The study explored the experiences of parents of children with SCD using the ABCX model of family stress as the theoretical framework guiding the study. Ethical approval was sought from the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR) and the Institutional Review Board of the 37 Military Hospital. Data was gathered for a period of 12 weeks from the paediatric Outpatient Department and the Nkrumah ward at the 37 Military Hospital. Consent was given by participants by signing the consent form before the conduction of the interview. Each interview was recorded and transcribed verbatim. Data were analysed using thematic content analysis.

The key findings of this study revealed that parents caring for children with SCD experienced many hardships; a burden related to the health of their children, physical burden, financial burden, work-related or occupational challenges and another burden related to health services. Concerning the health of the children, it was seen that the major conditions that made parents frequent the hospital and caused long stay at the hospital were chest infections and severe malaria. Parents were burdened with frequent episodes of severe pain from the vaso-occlusive crisis, frequent hospitalization, delayed growth and development of their children and non-availability of blood for frequent blood transfusion. Physically, the parents expressed hardship in relation to the responsibility of preventing complications and caring for their children during a crisis. Parents were also financially

overburdened from the cost of care and cost of nourishing foods required to boost their haemoglobin levels and health status in general. The financial burden was due to loss of income and inability to work due to the caregiving demand on them. The parents felt that their children with SCD were marginalized by the government because people with SCD did not have any special subsidy compared to people with other chronic conditions such as HIV/AIDS. Caring for children with SCD also brought conflict between parents' caregiving responsibility and their work. Thus, they were denied promotion, got demoted and some parents lost their jobs. Health- service-related factors also burdened parents. Competency and knowledge levels of healthcare professionals, attitudes of medical staff, waiting time and cleanliness of the hospital were the issues relating to the quality of care that posed a problem to parents.

The time of diagnosis and the type of treatment given were the determinants of the burden of caregiving. Children who were diagnosed early were started early on prophylaxis and did not experience crisis and other complications of SCD. Additionally, children who were managed on hydroxyurea had increased levels of haemoglobin level and reduced frequency of admissions. Irrespective of the time of diagnosis and type of treatment used to manage the condition, it was found that the major indications for hospitalization in the children with SCD were severe malaria.

The parents used social support and religion as resources to deal with the hardships or burdens associated with caring for a child with SCD. Parents found comfort in religion and that was what helped them to cope with these hardships. Prayer was the main coping measure which eased the emotional burden of self-blame and led to optimism in the parents. Parents received support from close family, few church members and healthcare professional. None of the parents expressed receiving support from friends and neighbours,

although there were social ties. Parents attached much importance to instrumental support, especially financial support due to the level of the economic constraints experienced.

Parents created their own meanings of SCD within the context of their social and cultural background. Parents were familiar with the disease and had local names for it. They held the belief that there were supernatural explanations to the cause of the disease in addition to genetics or the hereditary factors. There was also the belief that children with SCD usually have a shorter lifespan and that crisis should sometimes be managed at home. It was observed that their beliefs were myths and highly influenced by their communities' beliefs about SCD. Parents disclosed that their communities had varied views concerning the cause of the disease, treatment, and lifespan. Lay perspectives of the community about SCD made parents fear stigmatisation, thus they kept the disease secret from their friends, neighbours and distant relatives which influenced the level of support they received socially. Some parents and their children were stigmatized for the belief that SCD was contagious and children with SCD have a brief life span; thus the children were not considered as functional members of their extended families.

The caring of children with SCD led to the crisis in the parents of these children. Physically, parents complained of tiredness, sleeplessness, and fatigue. There were frequent episodes of nosocomial infections due to staying in the hospital with their children and some had chronic conditions such as hypertension. Having a child with SCD in some instances, led to the adoption of unhealthy lifestyles such as alcoholism and skipping medical checkup. Psychologically, these parents experienced self-blame, regret, depression, anxiety, uncertainties, and fear. Caring for children with SCD also led to the disruption of life of healthy siblings of the children with SCD. The siblings of children with SCD had to stay out of school due to financial constraints experienced by the family. Other siblings also engaged

in street hawking to support their households. Family interactions and harmony in marriage were compromised and the paternity of some of the children with SCD was challenged. There were strained marital relationships because of the problems associated with the care of the child with SCD.

In conclusion, parents caring for children with SCD encountered numerous challenges associated with the caregiving role which disrupted the health and wellbeing of the primary caregiver and the entire family, especially siblings of the ill children. Given all these burdens, counseling of parents with children having SCD is imperative and there is the need to incorporate psychological support for the parents who are the primary caregivers.

6.2 Implications

The findings of the study have some implications in relation to nursing practice, nursing education, nursing research, and policy formulation.

6.2.1 Nursing Practice

The findings of this study showed that most of the parents got to know of their sickling status during antenatal visits or when their children were diagnosed with SCD. This implies that there is limited knowledge concerning the importance of genetic testing and counseling, therefore, there is the need to intensify education given to the public about the disease. It was found that most of the parents had misconceptions about the disease. There is a need to identify the knowledge level of parents about SCD before giving them an education in order to correct any misconceptions about the disease. Additionally, parents in the study were not content with the attitudes and level of professionalism of nurses on the wards compared to those at the outpatient department and this was a concern to them. Regular supervision of nurses on the wards by nurse managers is essential to ensure good professional conduct. Additionally, the health facility should organize ward conferences and

seminars to update staff, especially those at the paediatric unit on SCD complications and management highlighting pharmacological and non-pharmacological management of pain in vaso-occlusive crisis.

6.2.2 Nursing Education

The findings of the study revealed that some parents questioned the knowledge of nurses about SCD management, especially management of pain in vaso-occlusive crisis. There is the need to organize continuous professional development programmes on the management of SCD and its complications based on the latest research in SCD. Nurses with higher education in various educational institutions can develop a comprehensive care model which incorporates care of primary caregivers and other family members who provide care to children with SCD.

6.2.3 Nursing Research

This study has revealed that there is a need for further research on the experiences of parents of children with SCD in order to provide a deeper understanding of the phenomenon. Guided by the ABCX model of family stress, this study was done qualitatively but by using a quantitative method, the levels of influence of the variables in the study on the phenomenon under investigation, can be measured and their relationship can be determined. Accra Metropolis is urban with many amenities, health centres, and economic opportunities. Further studies can be carried out in a health facility in a rural community. Other areas that can be explored include the effects of caring for a child with SCD on other children in the household and the spouses of the caregivers. Communities' perceptions about SCD and their influence on their health-seeking behaviour can also be explored to provide an adequate understanding of the phenomenon.

6.2.4 Policy Formulation

The study showed that most of the children with SCD were diagnosed with the disease after suffering from complications of the disease. The study further revealed that children who were diagnosed with the disease early had better health outcomes and reduced the burden on parents caring for children with SCD. Therefore there is the need to extend neonatal screening for SCD to other healthcare facilities and incorporated into prenatal care. This will allow for early diagnosis of the disease and early management with prophylaxis in order to reduce mortality and co-morbidities associated with the disease. It was observed from the study that irrespective of the time of diagnosis and type of treatment used to manage SCD, the major indication for hospitalization in the children was severe malaria. Therefore in addition to neonatal screening, children confirmed positive should also be given antimalarial prophylaxis and parents should be advised to use treated mosquito nets. There should also be regular psychological support to the primary caregiver and the entire family, especially siblings of the ill-child to alleviate the emotional burden.

6.3 Limitations

The researcher acknowledges the limitations of the study. Based on the parents' request, some interviews were conducted in the presence of their children. This could have affected the narration of their experiences, especially the burden they experience and the effects on their health. Therefore, future studies should consider this and avoid it.

Translation of the interview data from the local dialects may pose a threat to trustworthiness as the specific meaning of some statements may be lost. However, intense efforts were made to use words which were closest to the translated words as much as possible.

6.4 Conclusion

Most of the findings of this study were consistent with the constructs of the ABCX model of family stress. These findings were; caring for a child with SCD and the burdens associated with it, resources, perceptions about SCD and outcome of caregiving (crisis). Other findings that were not consistent with the constructs were the time of diagnosis and type of treatment used. These were seen to affect parents caring for children with SCD as well as the children themselves. The key findings of this study revealed that parents caring for children with SCD experienced many hardships; a burden related to the health of the children, physical burden, financial burden, work-related/ occupational challenges and burdens related to health services. The parents utilised social support and religion as resources to deal with the hardships associated with caring for a child with SCD. There were varied perceptions about SCD among the parents which were influenced by the community's perceptions. Based on the community's perception about SCD, parents feared stigmatisation and some were stigmatized. Caring for a child with SCD affected the health and wellbeing of the parent as well as other members of the family. It was observed that knowledge about genetic counseling was limited and most of the children were not diagnosed early. Therefore, there is a need to intensify education on genetic counseling and testing for SCD. Neonatal screening in various healthcare facilities in Ghana would be beneficial. Additionally, there should be education on hydroxyurea as a treatment option and this should be placed on the Essential Medicine list by the government to make it affordable to all families with children who have SCD.

6.5 Recommendations

Based on the findings of the study, the following recommendations have been made to the following institutions:

Ministry of Health (MOH)

The Ministry of Health should:

- Develop clear guidelines for the management of vaso-occlusive crisis at the various healthcare facilities.
- Organize training of healthcare professionals including midwives, nurses, doctors and laboratory technicians on early diagnosis of SCD in children.
- Collaborate with the appropriate agencies and authorities and ensure the expansion of neonatal screening to other healthcare facilities to ensure early diagnosis of SCD in children.
- Set up a centre for genetic counseling and testing at various public health institutions.
- Intensify antenatal screening of Sickle Cell trait in pregnant women and their spouses should be checked as well if the mother has the trait.
- Provide nationwide education on SCD and the importance of genetic counseling and testing.
- Lobby the government so that in addition to the NHIS, people with SCD will have an additional subsidy for the management of Sickle Cell complications.
- Carry out research on hydroxyurea as a treatment option, educate the public about its importance and lobby the appropriate agency so that the drug can be subsidized for parents to be able to afford.
- Put children confirmed SCD positive on antimalarial prophylaxis and educate their parents on the need to use treated mosquito nets for their children.

- Ensure free delivery of treated mosquito nets
- Develop local leaflets and flyers of the main Ghanaian languages to improve parental literacy on SCD.
- Make available free treated mosquito nets to parents of children with SCD.
- Include Hydroxyurea in the Essential Medicine List and the National Health insurance Medicine list.

Ghana Health Service (GHS)

The GHS should:

- Organize more continuous professional development training in SCD and its management especially pain from vaso-occlusive crisis
- Organize training for nurses and doctors on customer care and human relations
- Equip various healthcare facilities, especially the laboratory with modern equipment so that Sickle Cell disorders and the specific type can be diagnosed promptly.
- Create awareness of genetic counseling and testing.
- Educate the public on SCD to dispel misconceptions and stigmatisation in the communities.

37 Military Hospital

The Hospital should:

- Organize seminars and conferences to sensitize hospital staff on customer care and human relations
- Increase supervision and monitoring of nursing staff to ensure professionalism
- Organize in-service training and refresher courses on proper management of crisis and complications in SCD.

- Monitor and supervise orderlies at the various units to ensure the cleanliness of the various wards.
- Provide continuous counseling and psychological support for the family of the child with SCD.
- Ensure a daily or routine engagement by the Nursing management to allow communication of complaints from parents of children with SCD.
- Create support groups at the community or facility level for parents of children living with SCD.

Nursing and Midwifery Council of Ghana

- Develop the professional attitude and curriculum modification on child chronicity and parental engagement.

The Christian Council of Ghana

The Council should:

- Stress the importance of genetic counseling before marriage
- Periodically invite specialists to educate and sensitize congregations on SCD
- Offer emotional and financial support to parents of children with SCD
- Educate their congregation on stigmatisation of SCD.

The general public

The general public should:

- Avoid stigmatisation and labeling of children with SCD and their families
- Provide support to parents of children with SCD.

Parents of children with SCD

The parents should;

- Seek early medical care whenever their children fall sick
- Provide care and support and should not neglect the other siblings of the ill-child.
- Seek routine medical care for themselves and not neglect their own health.

REFERENCES

Abu Bakar, S. H., Weatherley, R., Omar, N., Abdullah, F., & Mohamad Aun, N. S. (2013). Projecting social support needs of informal caregivers in Malaysia. *Health and Social Care in the Community*, *22*(2), 144–154. Retrieved 12/01/2018 from https://doi.org/10.1111/hsc.12070

Abuosi, A. A., Adzei, F. A., Anarfi, J., Badasu, D. M., Atobrah, D., & Yawson, A. (2015). Investigating parents/caregivers financial burden of care for children with non-communicable diseases in Ghana. *BMC Pediatrics*, *15*(1), 185. Retrieved 12/04/2018 from https://doi.org/10.1186/s12887-015-0504-7

Addae, S. K. (1997). *The Evolution of Modern Medicine in a Developing Country: Ghana 1880-1960*. Durham Academic Press. Retrieved 28/10/2017 from https://books.google.com.gh/books?id=R5oeAQAAIAAJ&redir_esc=y

Addo, C. (2016, August 4). No Title. *37 Military Hospital Launches 75th Anniversary Celebrations*. Retrieved from http://www.ghananewsagency.org/health/37-military-hospital-launches-75th-anniversary-celebrations-106428

Adegoke, S. A., & Kuteyi, E. A. (2012). Psychosocial burden of Sickle Cell Disease on the family, Nigeria. *Afr J Prm Health Care Fam Med.*, *4*(1), 380–386. Retrieved 6/01/2018 from https://doi.org/http://dx.doi.org/10.4102/ phcfm.v4i1.380

Adewoyin, A. S. (2015). Management of Sickle Cell Disease: A Review for Physician Education in Nigeria (Sub-Saharan Africa). *Anemia*, *2015*, 1–21. https://doi.org/10.1155/2015/791498

Afolayan, J. A., & Jolayemi, F. T. (2011). Parental Attitude to Children with Sickle Cell Disease in Selected Health Facilities in Irepodun Local Government , Kwara State, Nigeria. *Ethno Med*, *5*(1), 33–40.

Agasa, B., Bosunga, K., Opara, A., Tshilumba, K., Dupont, E., Vertongen, F., … Gulbis, B. (2010). Prevalence of Sickle Cell Disease in a northeastern region of the Democratic Republic of Congo: What impact on transfusion policy? *Transfusion Medicine*, *20*(1), 62–65. Retrieved 04/03/2018 from https://doi.org/10.1111/j.1365-3148.2009.00943.x

Agrawal, R. K., Patel, R. K., Shah, V., Nainiwal, L., & Trivedi, B. (2013). Hydroxyurea in sickle cell disease: Drug review. *Indian Journal of Hematology and Blood Transfusion*, *30*(2), 91–96. https://doi.org/10.1007/s12288-013-0261-4

Ali, R. M. A., & Razeq, N. M. A. (2017). The Lived Experience of Parents of Children with Sickle Cell Disease : A Qualitative Study. *Open Journal of Nursing*, *7*, 1348–1364. Retrieved 6/03/2018 from https://doi.org/10.4236/ojn.2017.711097

Ali, S. R., Mahmood, A., Moel, J., Hudson, C., & Leathers, L. (2008). A qualitative investigation of Muslim and Christian women's views of religion and feminism in their lives. *Cultural Diversity and Ethnic Minority Psychology*, *14*(1), 38.

Aliyu, Z. Y., Kato, G. J., Taylor IV, J., Babadoko, A., Mamman, A. l, Gordeuk, V. R. & Gladwin, M. T. (2008). Upper and lower respiratory tract infections by human enterovirus and rhinovirus in adult patients with hematological malignancies. *American Journal of Hematology*, *83*, 63–70. Retrieved 09/10/2017 from https://doi.org/10.1002/ajh

Al-Saqladi, A.-W. M., Cipolotti, R., Fijnvandraat, K. & Brabin, B. (2008). Growth and nutritional status of children with homozygous Sickle Cell Disease Growth and nutritional status of children with homozygous Sickle Cell Disease. *Annals of Tropical Paediatrics*, (28), 165–189. Retrieved 12/01/2018 from https://doi.org/10.1179/146532808X335624

Anarfi, J. K., Badasu, D. M., Yawson, A., Atobra, D., Abuosi, A. A. & Adzei, F. A. (2016).

Religious affiliation and health-seeking behavior related to non-communicable diseases among children in Ghana. *International Journal of Healthcare*, *2*(2), 57–66. Retrieved 10/01/2018 from https://doi.org/10.5430/ijh.v2n2p57

Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: looking at trustworthiness criteria. *Journal of Emerging Trends in Educational Research and Policy Studies*, 5(2), 272-281. Retrieved 12/03/2018 from 10.3109/08941939.2012.723954

Antwi-Boasiako, C., Frimpong, E., Ababio, G. K., Dzudzor, B., Ekem, I., Gyan, B., … Antwi, D. A. (2015). Sickle cell disease: reappraisal of the role of foetal haemoglobin levels in the frequency of vaso-occlusive crisis. *Ghana Medical Journal*, *49*(2), 102–106. Retrieved 14/05/2018 from https://doi.org/10.4314/gmj.v49i2.7

Arab, H. (2010). Sickle Cell Disease and Sickle Cell Anaemia, 1–8.

Asare, E. V., Wilson, I., Kuma, A. A. B.-A., Dei-Adomakoh, Y., Sey, F., & Olayemi, E. (2018). Burden of Sickle Cell Disease in Ghana: The Korle-Bu Experience. *Advances in Hematology*, *2018*, 1–5. https://doi.org/10.1155/2018/6161270

Aygun, B., & Odame, I. (2012). Review: A Global Perspective on Sickle Cell Disease. *Pediatric Blood Cancer*, *59*, 386–390. Retrieved 12/10/2017 from https://doi.org/10.1002/pbc

Ballas, S. K., Kesen, M. R., Goldberg, M. F., Lutty, G. A., Dampier, C., Osunkwo, I., … Malik, P. (2012). Beyond the definitions of the phenotypic complications of sickle cell disease: An update on management. *The Scientific World Journal*, *2012*. https://doi.org/10.1100/2012/949535

Balogun, R. A., Obalum, D. C., Giwa, S. O., Adekoya-Cole, T. O., Ogo, C. N., & Enweluzo, G. O. (2010). Spectrum of musculo-skeletal disorders in Sickle Cell Disease in Lagos,

Nigeria. *Journal of Orthopaedic Surgery and Research*, *5*(2), 1–6. Retrieved 16/06/2018 from https://doi.org/10.1186/1749-799X-5-2

Barakat, L. P., Patterson, C. a., Weinberger, B. S., Simon, K., Gonzalez, E. R., & Dampier, C. (2007). A Prospective Study of the Role of Coping and Family Functioning in Health Outcomes for Adolescents With Sickle Cell Disease. *Journal of Pediatric Hematology/Oncology*, *29*(11), 752–760. Retrieved 12/01/2018 from https://doi.org/10.1097/MPH.0b013e318157fdac

Barak-Levy, Y., & Atzaba-Poria, N. A. (2013). Paternal versus maternal coping styles with child diagnosis of developmental delay. *Research in Developmental Disabilities*, *34*(6), 2040–2046.

Battersby, A. J., Knox-Macaulay, H. H. ., & Carrol, E. D. (2010). Susceptibility to Invasive Bacterial Infections in Children With Sickle Cell Disease. *Pediatric Blood Cancer*, *55*, 401–406. Retrieved 19/04/2018 from https://doi.org/10.1002/pbc

Bhatt-poulose, K., James, K., Reid, M., Harrison, A., & Asnani, M. (2016). Increased rates of body dissatisfaction , depressive symptoms , and suicide attempts in Jamaican teens with Sickle Cell Disease. *Pediatric Blood Cancer*, *63(1)*, 2159–2166. Retrieved 12/04/2018 from https://doi.org/10.1002/pbc.26091

Bitsch, V. (2005). Qualitative research: A grounded theory example and evaluation criteria. *Journal of Agribusiness,23(1), 75-91*.

Bolaños-meade, J., & Brodsky, R. A. (2014). Blood Reviews Blood and marrow transplantation for Sickle Cell Disease : Is less more ? *Blood Reveiws*, *28*(2014), 243–248. Retrieved 12/03/2018 from https://doi.org/10.1016/j.blre.2014.08.001

Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss.* New York: W. W. Norton and Company.

Branscum, A. Y. (2010). *Stress and coping model for family caregivers of older adults*. *Dissertation Abstracts International Section A: Humanities and Social Sciences*. Iowa State University. Retrieved 6/4/2018 from http://lib.dr.iastate.edu/etd/11363

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. Retrieved 21/06/2018 from http://dx.doi.org/10.1191/1478088706qp063oa

Brown, B. J., Okereke, J. O., Lagunju, I. A., Orimadegun, A. E., Ohaeri, J. U., & Akinyinka, O. O. (2010). Burden of health-care of carers of children with Sickle Cell Disease in Nigeria. *Health and Social Care in the Community*, *18*(3), 289–295. Retrieved 15/04/2018 from https://doi.org/10.1111/j.1365-2524.2009.00903.x

Burmeister, E., & Aitken, L. . (2012). Sample size : How many is enough ?. *Australian Critical Care, 25(4),* 271-274. Retrieved 30/01/2018 from https://doi.org/https://doi.org/10.1016/j.aucc.2012.07.002

Burnes, D. P. R., Antle, B. J., Williams, C. C., & Cook, L. (2008). Mothers raising children with Sickle Cell Disease at the intersection of race, gender, and illness stigma. *Health & Social Work*, *33*(3), 211–20. Retrieved 22/01/2018 from https://doi.org/10.1093/hsw/33.3.211

Candrilli, S. D., Brien, S. H. O., Ware, R. E., Nahata, M. C., Seiber, E. E., & Balkrishnan, R. (2011). Hydroxyurea adherence and associated outcomes among Medicaid enrollees with Sickle Cell Disease. *Am. J. Hematol.*, *86*, 273–277. Retrieved 12/01/2018 from https://doi.org/10.1002/ajh.21968

Cappe, E., Wolff, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: A key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes.

Quality of Life Research, *20*(8), 1279–1294. Retrieved 16/01/2018 from https://doi.org/10.1007/s11136-011-9861-3

Chakravorty, S., & Williams, T. N. (2015). Sickle Cell Disease: A neglected chronic disease of increasing global health importance. *Archives of Disease in Childhood*, *100*(1), 48–53. Retrieved 11/02/2018 from https://doi.org/10.1136/archdischild-2013-303773

Chaleunvong, K. (2009). *Data collection techniques.* Hamburg: UNESCO Institute of Education

Chudleigh, J., Buckingham, S., Dignan, J., Driscoll, S. O., Johnson, K., Rees, D., … Metcalfe, A. (2016). Parents ' Experiences of Receiving the Initial Positive Newborn Screening (NBS) Result for Cystic Fibrosis and Sickle Cell Disease. *J Genet Counsel*, *25*, 1215–1226. Retrieved 12/01/2018 from https://doi.org/10.1007/s10897-016-9959-4

Colorafi, K. J. & Evans, B. (2016). Qualitative Descriptive Methods in Health Science Research. *Health Environments Research and Design Journal, 9(4), 16-25.*

Cousino, M. K., & Hazen, R. a. (2013). Parenting stress among caregivers of children with chronic illness: A systematic review. *Journal of Pediatric Psychology*, *38*(8), 809–828. Retrieved 29/04/2018 from https://doi.org/10.1093/jpepsy/jsto49

Creswell, J.W. (2014). Research design: *Qualitative, Quantitative and Mixed Methods Approaches* (4th ed.). Thousand Oaks, California: Sage Publications.

Da Silva, L. B. L., Ivo, M. L., Souza, A. S. De, Pontes, E. R. J. C., Pinto, A. M. A. C., & Araujo, O. M. R. De. (2012). The burden and quality of life of caregivers of sickle cell anemia patients taking hydroxyurea versus those not taking hydroxyurea. *Revista Brasileira de Hematologia E Hemoterapia*, *34*(4), 270–274. Retrieved 12/01/2018 from https://doi.org/10.5581/1516-8484.20120070

Dennis-Antwi, J. A., Culley, L., Hiles, D. R., & Dyson, S. M. (2011). "I can die today, I can die tomorrow": lay perceptions of Sickle Cell Disease in Kumasi, Ghana at a point of transition. *Ethnicity & Health*, *16*(4–5), 465–81. Retrieved 12/01/2018 from https://doi.org/10.1080/13557858.2010.531249

Dennis-Antwi, J. A., Dyson, S. M., & Ohene-Frempong, K. (2008). Healthcare provision for Sickle Cell Disease in Ghana: challenges for the African context. *Diversity in Health and Social Care*, *5*(4), 241–54. Retrieved 28/03/2018 from http://www.ingentaconnect.com/content/rmp/dhsc/2008/00000005/00000004/art00004

DePasquale, N., Polenick, C. a., Davis, K. D., Moen, P., Hammer, L. B., & Almeida, D. M. (2015). The Psychosocial Implications of Managing Work and Family Caregiving Roles: Gender Differences Among Information Technology Professionals. *Journal of Family Issues*, 1–25. Retrieved 12/01/2018 from https://doi.org/10.1177/0192513X15584680

Desai, P. P., Rivera, A. T., & Backes, E. M. (2015). Latino Caregiver Coping With Children ' s Chronic Health Conditions : An Integrative Literature Review. *Journal of Pediatric Health Care*. Retrieved 12/01/2018 from https://doi.org/10.1016/j.pedhc.2015.06.001

Diallo, D. A., & Guindo, A. (2014). Sickle cell disease in sub-Saharan Africa: Stakes and strategies for control of the disease. *Current Opinion in Hematology*, *21*(3), 210–214. https://doi.org/10.1097/MOH.0000000000000038

Duncan-Wesley, S. (2015). Knowledge and Perception of Prostate Cancer among male patients at 37-Military hospital. Retrieved April 10, 2019, from Academia website: https://www.academia.edu/19052459/Knowledge_and_perception_of_prostate_cancer_among_men_attending_37_military_Hospital_Accra-Ghana

Edwin, A. K., Edwin, F., & Etwire, V. (2011). Controlling sickle cell disease in Ghana - Ethics and options. *Pan African Medical Journal*, *10*, 14. https://doi.org/10.4314/pamj.v10i0.72223

Ellingsen, R., Baker, B. L., Blacher, J., & Crnic, K. (2014). Resilient parenting of preschool children at developmental risk. *Journal of Intellectual Disability Research*, *58*(7), 664–678. Retrieved 4/3/2018 from https://doi.org/10.1111/jir.12063

Farrell, K., Dent, L., Nguyen, M. L., Buchowski, M., Bhatt, A., & Aguinaga, M. P. (2010). The relationship of oxygen transport and cardiac index for the prevention of sickle cell crises. *Journal of the National Medical Association*, *102*(11), 1000–1007. Retrieved 18/01/2018 from https://doi.org/10.1016/j.biotechadv.2011.08.021.Secreted

Feizi, A., Najmi, B., Salesi, A., Chorami, M., & Hoveidafar, R. (2014). Parenting stress among mothers of children with different physical, mental, and psychological problems. *Journal of Research in Medical Sciences : The Official Journal of Isfahan University of Medical Sciences*, *19*(2), 145–152. Retrieved 17/03/2018 from https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3999601/

Fledderjohann, J. J. (2012). 'Zero is not good for me': implications of infertility in Ghana. *Hum Reprod*, *27*, 1383–1390. Retrieved 4/10/2019 from https://doi.org/doi.org/10.1093/humrep/des035.

Frenette, P. S., & Atweh, G. F. (2007). Science in medicine Sickle Cell Disease : old discoveries , new concepts , and future promise. *The Journal of Clinical Investigation*, *117*(4), 850–858. Retrieved 14/03/2018 from https://doi.org/10.1172/JCI30920.850

Gallo, A. M., Wilkie, D., Suarez, M., Labotka, R., Molokie, R., Thompson, A., … Johnson, B. (2010). Reproductive decisions in people with Sickle Cell Disease or sickle cell trait. *West J Nurs Res.*, *32*(8), 1073–1090. Retrieved 12/01/2018 from

https://doi.org/10.1177/0193945910371482.

Gbrich, C. (2007). *Qualitative Data Analysis: An Introduction* (1st ed). London: Sage Publications.

Gesteira, E. C. R., Bousso, R. S., Misko, M. D., Ichikawa, C. R. de F., & Peres de Oliveira, P. (2016). Families of children with Sickle Cell Disease: an integrative review. *Objn*, *15*(2). Retrieved 7/11/2017 from http://www.objnursing.uff.br/index.php/nursing/article/view/5289/html

Ghana statistical Service. (2010). *2010 Population and housing census: Summary report of final results*. Accra. Retrieved 12/01/2018 from http://www.statsghana.gov.gh/docfiles/2010_District_Report/Greater%20Accra/AMA.pdf.

Goffman, E. (2009). *Stigma: notes on the management spoiled identity*. New York London: Simon & Schuster Inc.

Gold, J. I., Treadwell, M., Weissman, L., & Vichinsky, E. (2008). An expanded Transactional Stress and Coping Model for siblings of children with Sickle Cell Disease: Family functioning and sibling coping, self-efficacy and perceived social support. *Child: Care, Health and Development*, *34*(4), 491–502. Retrieved 12/01/2018 from https://doi.org/10.1111/j.1365-2214.2008.00810.x

Greenland, S. (2005). Target population. *Encyclopedia of Biostatistics*, *8*. Retrieved 12/01/2018 from 10.1002/0470011815.b2a03126

Grosse, S. D., Odame, I., Atrash, H. K., Amendah, D. D., Piel, F. B., & Williams, T. N. (2011). Sickle cell disease in Africa: A neglected cause of early childhood mortality. *American Journal of Preventive Medicine*, *41*(6 SUPPL.4), S398–S405. Retrieved 12/01/2018 from https://doi.org/10.1016/j.amepre.2011.09.013

Grove, J., Grove, O., & Michie, C. (2013). The Real Effects of Sickle Cell Disease on Children and Adolescents. *The West London Medical Journal*, *6*(1), 11–17.

Gustafson, K. E., Bonner, M. ., Hardy, K. ., & Thompson, R. . (2006). Biopsychosocial and Developmental Issues In Sickle Cell Disease. In R. . Brown (Ed.), *Comprehensive Handbook of Childhood Cancer and Sickle Cell Disease: A Biopsychosocial Approach* (pp. 431–448). New York: Oxford University Press.

Gyasi, R. M., Asante, F., Abass, K., Yeboah, J. Y., Adu-Gyamfi, S., & Amoah, P. A. (2016). Do health beliefs explain traditional medical therapies utilisation? Evidence from Ghana. *Cogent Social Sciences*, *2*(1), 1–14. Retrieved 12/03/2018 from https://doi.org/10.1080/23311886.2016.1209995

Gyekye, K. (1996). *African cultural values: An introduction.* Sankofa Publishing Company.

Habeeb, A. D., Hassan, M. K., & Ahmed, B. A. (2015). Psychosocial Impact of Sickle Cell Disease on Families in Basra , Southern Iraq ; An Experience of Caregivers. *International Journal of Medicine and Pharmaceutical Sciences (IJMPS) ISSN(P):*, *5*(4), 41–52.

Hatzmann, J., Heymans, H. S. A., Ferrer-i-Carbonell, A., van Praag, B. M. S., & Grootenhuis, M. A. (2008). Hidden Consequences of Success in Pediatrics: Parental Health-Related Quality of Life--Results From the Care Project. *Pediatrics*, *122*(5), e1030–e1038. Retrieved 12/01/2018 from https://doi.org/10.1542/peds.2008-0582

Heath, G., Farre, A., & Shaw, K. (2016). Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. *Patient Education and Counseling*. Retrieved 12/01/2018 from https://doi.org/10.1016/j.pec.2016.08.011

Herndon, P. (1991). Family Life Among the Ashanti of West Africa. Retrieved April 4,

2019, from Yale-New Haven Teachers Institute website: http://teachersinstitute.yale.edu/curriculum/units/1991/2/91.02.04.x.html

Hesse-Biber, S. N. (2007). *Handbook of feminist research: Theory and praxis.* Thousand Oaks, CA: SAGE Publications Inc.

Hill, R. (1958). Generic features of families under stress. *Social Casework*, *49*, 139–150.

Hirst, C., & Owusu-Ofori. (2014). Prophylactic antibiotics for preventing pneumococcal infection in children with sickle cell disease (Review). *Cochrane Database of Systematic Reviews*, *3*(11), 1–24. Retrieved 23/03/2018 from https://doi.org/10.1002/14651858.CD003427.pub3.www.cochranelibrary.com

Hurst, S., Arulogun, O. S., Owolabi, M. O., Akinyemi, R., Uvere, E., Warth, S., & Ovbiagele, B. (2015). Pretesting qualitative data collection procedures to facilitate methodological adherence and team building in Nigeria. *International journal of qualitative methods*, *14*(1), 53-64.

Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of Caregiver Burden among Mothers of Children with Chronic Conditions. *Children*, *4*(39), 1–10. Retrieved 12/02/2018 from https://doi.org/10.3390/children4050039

Kabiti, I. A. (2008). Anthropometric Profiles of Homozygous Sickle Cell Children in North–western Nigeria. *AJOL*, *11*(2).

Karlson, C. W., Leist-haynes, S., Smith, M., Faith, M. A., Elkin, T. D., & Megason, G. (2012). Examination of Risk and Resiliency in a Pediatric Sickle Cell Disease Population Using the Psychosocial Assessment Tool 2 . 0. *Journal of Pediatric Psychology*, *37*(9), 1031–1040. Retrieved 11/01/2018 from https://doi.org/10.1093/jpepsy/jss087

Katooa, N., Shahwan-Akl, L., Reece, J., & Jones, L. (2015). Characteristics of Mothers with Chronically Ill Children in Jeddah, Saudi Arabia. *International Journal of Nursing*, *2*(1), 59–73. Retrieved 14/03/2018 from https://doi.org/10.15640/ijn.v2n1a7

Kenny, T. (2010). Sickle Cell Disease and Sickle Cell Anaemia. Retrieved October 29, 2016, from patient.info/health/sickle-cell-disease-and-sickle-cell-anaemia-leaflet Sickle

Kocarnik, J. M. (2015). Sickle Cell Trait Associated With Increased Risk of Renal Disease. *Science Spotlight*, *5*(1), 19–21. Retrieved 17/04/2018 from https://doi.org/10.1001/jama.2014.15063.2

Kolapo, K. O., & Vento, S. (2011). Stroke: A realistic approach to a growing problem in sub-Saharan Africa is urgently needed. *Tropical Medicine and International Health*, *16*(6), 707–710. Retrieved 08/05/2018 from https://doi.org/10.1111/j.1365-3156.2011.02759.x

Konotey- Ahulu, F. I. D. (2014). *No TitleSickle Cell and Allied Haemoglobinopathy: The Genetics That Touches You and Me – University of Cape Coast, Ghana, GOLDEN JUBILEE MESSAGE*. Cape Coast. Retrieved 7/2/18 from http://bit.ly/1w3BuvM

Kumar, R. (2011). *Research Methodology: a step-by-step guide for beginners*(3rd ed). New Delhi: Sage Publications

Kuznik, A., Habib, A. G., Munube, D., & Lamorde, M. (2016). Newborn screening and prophylactic interventions for Sickle Cell Disease in 47 countries in sub-Saharan Africa : a cost- effectiveness analysis. *BMC Health Services Research*, *16*(304), 1–12. Retrieved 12/04/2018 from https://doi.org/10.1186/s12913-016-1572-6

Lai, W. W., & Oei, T. P. S. (2014). Coping in Parents and Caregivers of Children with Autism Spectrum Disorders (ASD): a Review. *Rev J Autism Dev Disord*, *1*, 207–224. Retrieved 12/06/2018 from https://doi.org/10.1007/s40489-014-0021-x

Leite, M. F., Collet, N., Gomes, I. P., & Kumamoto, L. H. M. C. da C. (2010). Coping with chronic condition in childhood by family caregivers: a qualitative research. *Online Brazilian Journal of Nursing*, *9*(3).

Leite, M. F., Gomes, I. P., Ribeiro, K. S. Q. S., Anjos, U. U. dos, Moraes, R. M. de, & Collet, N. (2013). Coping strategies for caregivers of children with a chronic disease: a methodological study. *Online Brazilian Journal of Nursing*, *12*(2). Retrieved 12/01/2018 from http://www.objnursing.uff.br/index.php/nursing/article/view/4056/html_1

Lincoln, Y. S. & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75). Newbury Park, CA: Sage Publications.

Lyons, A. M., Leon, S. C., Phelps, C. E. R., & Dunleavy, A. M. (2010). The impact of child symptom severity on stress among parents of children with asd: The moderating role of coping styles. *Journal of Child and Family Studies*, *19*(4), 516–524. Retrieved 12/03/2018 from https://doi.org/10.1007/s10826-009-9323-5

Makani, J., Ofori-Acquah, S. F., Nnodu, O., Wonkam, A., & Ohene-Frempong, K. (2013). Sickle Cell Disease: new opportunities and challenges in Africa. *TheScientificWorldJournal*, *2013*, 1–16. Retrieved 21/01/2018 from https://doi.org/10.1155/2013/193252

Malhotra, M., & Thapa, K. (2015). Religion and Coping with Caregiving Stress. *International Journal of Multidisciplinary and Current Research*, *3*(June 2015), 613–619. Retrieved 19/01/2018 from m http://ijmcr.com

Marsh, V. M., Kamuya, D. M., & Molyneux, S. S. (2011). "All her children are born that way": gendered experiences of stigma in families affected by sickle cell disorder in rural Kenya. *Ethnicity & Health*, *16*(4–5), 343–359. Retrieved 14/05/2018 from

https://doi.org/10.1080/13557858.2010.541903

Maxwell, J. (2013). *Qualitative research design: An interactive approach* (3rd ed). USA: Sage Publications.

Mcclellan, C. B., Schatz, J., Sanchez, C., & Roberts, C. W. (2008). Validity of the Pediatric Quality of Life Inventory for Youth with Sickle Cell Disease. *Journal of Pediatric Psychology*, *33*(10), 1153–1162. Retrieved 12/02/2018 from https://doi.org/10.1093/jpepsy/jsn036

Mcgann, P. T., Grosse, S. D., Santos, B., Bernardino, L., Kassebaum, N. J., Ware, R. E., … Centers, H. (2015). A Cost-Effectiveness Analysis of a Pilot Neonatal Screening Program for Sickle Cell Anemia in the Republic of Angola. *J Pediatr.*, *167*(6), 1314–1319. Retrieved 18/01/2018 from https://doi.org/10.1016/j.jpeds.2015.08.068.A

Moore, R. M. (2011). *A Family-Based Cognitive-Behavioural Intervention for Pediatric Patients with Sickle Cell Disease*. Faculty of Virginia Polytechnic Institute and State University.

Moskowitz, J. T., Butensky, E., Harmatz, P., Vichinsky, E., Heyman, M. B., Acree, M., … Folkman, S. (2007). Caregiving Time in Sickle Cell Disease: Psychological Effects in Maternal Caregivers. *Pediatric Blood Cancer*, *48*, 64–71. Retrieved on 10/05/2018 from https://doi.org/10.1002/pbc

Mulumba, L. L., & Wilson, L. (2015). Sickle Cell Disease among children in Africa: An integrative literature review and global recommendations. *International Journal of Africa Nursing Sciences*, *3*, 56–64. Retrieved 18/05/2018 from https://doi.org/10.1016/j.ijans.2015.08.002

Muoghalu, C. O. (2016). The Burden of Sickle Cell Disease to Parents of Sufferers in Nigeria. *SOJ Genet Sci*, *3*(1), 1–5.

National Heart, Lung and Blood Institute. (2014). *Evidence-Based Management of Sickle Cell Disease: Expert Panel Report*. Retrieved 12/03/2018 from http://www.nhlbi.nih.gov/guidrlines

Neuendorf, K. A. (2016). *The content analysis guidebook* (2nd ed). Thousand Oaks, California: Sage Publications

Ngolet, L. O., Engoba, M. M., Kocko, I., Dokekias, A. E., Mombouli, J., & Moyen, G. M. (2016). Sickle-Cell Disease Healthcare Cost in Africa : Experience of the Congo. *Anemia*, *2016*, 1–5. Retrieved 12/04/2018 from https://doi.org/doi.org/10.1155/2016/2046535

Niekerk, K. V. A. N. (2015). *Knowledge and experiences of parents with children affected by Sickle Cell Disease in Cape Town*. University of cape town.

Norizan, A., & Shamsuddin, K. (2010). Predictors of parenting stress among Malaysian mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, *54*(11), 992–1003. Retrieved 13/03/2018 from https://doi.org/10.1111/j.1365-2788.2010.01324.x

Nukunya, G. K. (2003). *Tradition and change in Ghana: An introduction to sociology.* Ghana Universities Press.

Nur Saadah, M. A., Siti Hajar, A. B., & Rezaul Islam, M. (2014). Coping Strategies Among Mothers of Chronically Ill Children: A Case Study in Malaysia. *Journal of Social Service Research*, *40*(2), 160–177. Retrieved 5/1/18 from https://doi.org/10.1080/01488376.2013.866613

Odame, I., Kulkarni, R., & Ohene-Frempong, K. (2011). Concerted global effort to combat Sickle Cell Disease: The first global congress on Sickle Cell Disease in Accra, Ghana. *American Journal of Preventive Medicine*, *41*(6 SUPPL.4), S417–S421. Retrieved

28/01/2018 from https://doi.org/10.1016/j.amepre.2011.09.019

Ofosu-Kwarteng, J. (2012). *Healthcare delivery and customer satisfaction in Ghana. A case study of the Koforidua Regional Hospital.* Kwame Nkrumah University of Science and Technology.

Ohene-Frempong, K., & Nkruman, F. K. (2014, June 11). Newborn screening for Sickle Cell disease can save lives in Ghana (Part Two). *Daily Graphic*, p. 34.

Olatunya, O. S., Ogundare, E. O., Fadare, J. O., Oluwayemi, I. O., Agaja, O. T., Adeyefa, B. S., & Aderiye, O. (2015). The financial burden of Sickle Cell Disease on households in Ekiti , Southwest Nigeria. *ClinicoEconomics and Outcomes Research*, *5*(7), 545–553. Retrieved 22/01/2018 from https://doi.org/https://doi.org/10.2147/CEOR.S86599

Orish, V. N., Onyeabor, O. S., Sanyaolu, A. O., & Iriemenam, N. C. (2014). Evaluating the knowledge of Sickle Cell Disease and hemoglobin electrophoretic pattern among people living in Sekondi-Takoradi Metropolis, Ghana. *J Med Trop, 16*, 56–60. Retrieved 12/01/2018 from https://doi.org/10.4103/2276-7096.139047

Osei-Yeboah, C. T., & Rodrigues, O. (2011). Renal Status of Children With Sickle Cell Disease in Accra, Ghana. *Ghana Medical Journal*, *45*(4), 155. Retrieved 22/04/2018 from http://www.ncbi.nlm.nih.gov/pubmed/22359421\nhttp://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC3283093\nhttps://www.ncbi.nlm.nih.gov/pmc/articles/PMC3283093/

Pantaleao, A., Diplacido, J., Guite, J. W., & Zempsky, W. T. (2018). Children ' s Health Care Caregiver factors related to emergency department utilization for youth with Sickle Cell Disease utilization for youth with Sickle Cell Disease. *Children's Health Care*. Retrieved 12/03/2018 from https://doi.org/10.1080/02739615.2018.1454838

Pat-Horenczyk, R., Brom, D., & Vogel, J. M. (Eds.). (2014). *Helping Children Cope with Trauma: Individual, Family and Community Perspectives*. New York: Routledge.

Pathan, B. R. (2015). Research Data Management with Context of Different Countries. *International Journal Of Advanced Research in Engineering & Management (IJAREM)*, *1*(7), 121–128.

Patton, M. & Cochran, M. (2002). *A Guide to Using Qualitative Research Methodology*. UK: Medicins Sans Frontieres.

Piel, F. B., Hay, S. I., Gupta, S., Weatherall, D. J., & Williams, T. N. (2013). Global Burden of Sickle Cell Anaemia in Children under Five, 2010-2050: Modelling Based on Demographics, Excess Mortality, and Interventions. *PLoS Medicine*, *10*(7). Retrieved 12/04/2018 from https://doi.org/10.1371/journal.pmed.1001484

Piel, F. B., Patil, A. P., Howes, R. E., Nyangiri, O. A., Gething, P. W., Dewi, M., … Hay, S. I. (2013). Global epidemiology of Sickle haemoglobin in neonates: A contemporary geostatistical model-based map and population estimates. *The Lancet*, *381*(9861), 142–151. Retrieved 12/05/2018 from https://doi.org/10.1016/S0140-6736(12)61229-X

Polit, D. & Beck, C. (2004). *Nursing Research: Principles and methods* (7th ed). Philadelphia, PA: Lippincott Williams & Wilkins.

Popp, J. M., Robinson, J. L., Britner, P. A., & Blank, T. O. (2014). Parent adaptation and family functioning in relation to narratives of children with chronic illness. *Journal of Pediatric Nursing*, *29*(1), 58–64. Retrieved 12/04/2018 from https://doi.org/10.1016/j.pedn.2013.07.004

Price, S. J., Price, C. A., & McKenry, P. C. (2010). Families Coping With Change: A conceptual Overview. In S. J. Price, C. A. Price, & P. C. McKenry (Eds.), *Families and Change: Coping with Stressful events and Transitions* (4th editio). USA: SAGE

Publications Ltd.

Pule, G., & Wonkam, A. (2014). Treatment for sickle cell disease in Africa: should we invest in haematopoietic stem cell transplantation? *Pan African Medical Journal*, *18*, 1–5. https://doi.org/10.11604/pamj.2014.18.46.3923

Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. *The Lancet*, *376*(9757), 2018–2031. Retrieved 12/05/2018 from https://doi.org/10.1016/S0140-6736(10)61029-X

Rosino, M. (2016). ABC-X Model of Family Stress and Coping. Retrieved 17/01/2018 from https://doi.org/10.1002/9781119085621.wbefs313

Salman, Z. A., & Hassan, M. K. (2015). Hospitalization Events among Children and Adolescents with Sickle Cell Disease in Basra , Iraq. *Anemia*, *2015*. Retrieved 12/01/2018 from https://doi.org/10.1155/2015/195469

Santos, B., Tomlinson, G. A., Mcgann, P. T., Stuber, S., Latham, T., Aygun, B., … Investigators, R. (2016). Hydroxyurea Therapy for Children With Sickle Cell Anemia in Sub-Saharan Africa : Rationale and Design of the REACH Trial. *Pediatr Blood Cancer*, *63*, 98–104. Retrieved 12/03/2018 from https://doi.org/10.1002/pbc

Sarode, R., & Altuntas, F. (2006). Blood Bank Issues Associated With Red Cell Exchanges in Sickle Cell Disease. *Journal of Clinical Apheresis*, *21*, 271–273. Retrieved 15/01/2018 from https://doi.org/10.1002/jca.20112

Schulz, R., & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *The American Journal of Nursing*, *108*(9 Supplement), 23–27. Retrieved 19/01/2018 from https://doi.org/10.1097/01.NAJ.0000336406.45248.4c.Physical

Sira, N., Desai, P. P., Sullivan, K. J., & Hannon, D. W. (2014). Coping Strategies in Mothers of Children with Heart Defects : A Closer Look Into Spirituality and Internet Utilization

Coping Strategies in Mothers of Children with Heart Defects : A Closer Look Into Spirituality and Internet Utilization. *Journal of Social Service Research*, *40*(5), 606–622. Retrieved 12/05/2018 from https://doi.org/10.1080/01488376.2014.908808

Stankovic, S, K., Steichen, O., Lefevre, G., Bachmeyer, C., Avellino, V., Grateau, G., … Lionnet, F. (2012). High lactate dehydrogenase levels at admission for painful vaso-occlusive crisis is associated with severe outcome in adult SCD patients. *Clinical Biochemistry*, *45*, 1578–1582. Retrieved 12/04/2018 from https://doi.org/10.1016/j.clinbiochem.2012.07.114

Sulkers, E., Tissing, W. J. E., Brinksma, A., Roodbol, P. F., Kamps, W. A., Stewart, R. E., … Sanderman, R. (2015). Providing care to a child with cancer: A longitudinal study on parents' experiences with caregiving during the first year after diagnosis. *Psycho-Oncology*, *24*, 318–324. Retrieved 12/05/2018 from https://doi.org/10.1002/pon.3652

Tagoe, H. A. (2012). Household Burden of Chronic Diseases in Ghana. *Ghana Medical Journal*, *46*(2), 54–58.

Tobin, G. A., & Begley, C. M. (2004). Methodological rigour within a qualitative framework. *Journal of Advanced Nursing*, *48*(4). Retrieved 12/05/2018 from https://doi.org/10.1111/j.1365-2648.2004.03207.x

Tusuubira, S. K., Nakayinga, R., Mwambi, B., Odda, J., Kiconco, S., & Komuhangi, A. (2018). Knowledge , perception and practices towards Sickle Cell Disease : a community survey among adults in Lubaga division , Kampala Uganda. *BMC Public Health*, *18*(561), 1–5. Retrieved 12/03/2018 from https://doi.org/https://doi.org/10.1186/s12889-018-5496-4

United Nations General Assembly. (2008). *Recognition of Sickle-cell anaemia as a public problem. A/RES/63/237*. Retrieved from Retrieved 12/03/2018 from

http://www.worldlii.org/int/other/UNGARsn/2008/277.pdf

Van Den Tweel, X. W., Hatzmann, J., Ensink, E., Van der Lee, J. H., Peters, M., Fijnvandraat, K., & Grootenhuis, M. (2008). Quality of life of female caregivers of children with Sickle Cell Disease : a survey. *Haematologica*, *93*(4), 588–593. Retrieved 11/03/2018 from https://doi.org/10.3324/haematol.11610

Ware, R. E., Schultz, W. H., Yovetich, N., Mortier, N. A., Alvarez, O., Hilliard, L., … Helms, R. W. (2011). Stroke With Transfusions Changing to Hydroxyurea (SWiTCH): A Phase III Randomized Clinical Trial for Treatment of Children With Sickle Cell Anemia, Stroke, and Iron Overload. *Pediatric Blood and Cancer*, *57*, 1011–1017. https://doi.org/doi.org/10.1002/pbc.23145

Wasomwe, M. M., & Ngoma, C. (2011). A Study to Assess Problems Encountered by Immediate Family Members in Caring for Children Affected With Sickle Cell Disease at University Teaching Hospital , Lusaka , Zambia. *Medical Journal of Zambia*, *38*(1), 2–6.

Weber, J. G. (2011). *Individual and Family Stress and Crises.* California, USA: Sage Publications.

Welkom, J. S. (2012). *The Impact of Sickle Cell Disease on the Family : An Examination of the Illness Intrusiveness Framework*. Georgia State University. Retrieved from Retrieved 12/04/2018 from http://scholarworks.gsu.edu/psych_diss

Wesley, K. M., Zhao, M., Carroll, Y., & Porter, J. S. (2016). Caregiver Perspectives of Stigma Associated With Sickle Cell Disease in Adolescents. *Journal of Pediatric Nursing*, *31*(1), 55–63. Retrieved 12/01/2018 from https://doi.org/10.1016/j.pedn.2015.09.011

WHO. (2011). *Sickle-cell disease and other haemoglobin disorders*. Retrieved on 31/10/10

from http://www.who.int/mediacentre/factsheets/fs308/en/

Wiener, L., Pao, M., Battles, H., Zadeh, S., Patenaude, A. F., Madan-Swain, A., … Kupst, M. J. (2013). Socio-Environmental Factors Associated With Lone Parenting Chronically Ill Children. *Children's Health Care*, *42*(3), 264–280. Retrieved 12/01/2018 from https://doi.org/10.1080/02739615.2013.816612

Williams, T. N. (2016). Sickle Cell Disease in Sub-Saharan Africa. *Hematology/Oncology Clinics of North America*, *30*(2), 343–358. Retrieved 12/05/2018 from https://doi.org/10.1016/j.hoc.2015.11.005

Wonkam, A., Mba, C. Z., Mbanya, D., Ngogang, J., Ramesar, R., & Angwafo, F. F. (2013). Psychosocial burden of Sickle Cell Disease on parents with an affected child in cameroon. *Journal of Genetic Counseling*, *23*(2), 192–201. Retrieved 12/06/2018 from https://doi.org/10.1007/s10897-013-9630-2

Yanni, E., Grosse, S. D., Yang, Q., & Olney, R. S. (2009). Trends in Pediatric Sickle Cell Disease-Related Mortality in the United States, 1983-2002. *Journal of Pediatrics*, *154*(1), 541–545. Retrieved 23/01/2018 from https://doi.org/10.1016/j.jpeds.2008.09.052

Yawn, B. P., Buchanan, G. R., Afenyi-Annan, A. N., Ballas, S. K., Hassell, K. L., James, A. H., … John-Sowah, J. (2014). Management of Sickle Cell Disease. *Jama*, *312*(10), 1033–1048. Retrieved 12/05/2018 from https://doi.org/10.1001/jama.2014.10517

Yawson, A. E., Abuosi, A. A., Badasu, D. M., Atobra, D., Adzei, F. A., & Anarfi, J. K. (2016). Non-communicable diseases among children in Ghana: Health and social concerns of parent/caregivers. *African Health Sciences*, *16*(2), 378–388. Retrieved 12/04/2018 from https://doi.org/10.4314/ahs.v16i2.6

Zempsky, W. T., Loiselle, K. A., Mckay, K., Lee, B. H., Hagstrom, J. N., & Schechter, N.

L. (2010). Do Children with Sickle Cell Disease Receive Disparate Care for Pain in the Emergency Department ? *Journal of Emergency Medicine*, *39*(5), 691–695. Retrieved 25/05/2018 from https://doi.org/10.1016/j.jemermed.2009.06.003

APPENDICES

Appendix A: Ethical Clearance (Noguchi Memorial Institute for Medical Research-Institutional Review Board)

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana
INSTITUTIONAL REVIEW BOARD

Phone: +233-302-916438 (Direct)
+233-289-522574
Fax: +233-302-502182/513202
E-mail: nirb@noguchi.ug.edu.gh
Telex No: 2556 UGL GH

Post Office Box LG 581
Legon, Accra
Ghana

My Ref. No: DF.22
Your Ref. No:

13th November, 2017

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824 **IRB 00001276**

NMIMR-IRB CPN 038/17-18 **IORG 0000908**

On 13th November, 2017, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL : **Experiences of Parents of children with sickle cell Disease: A study at 37 Military Hospital**

PRINCIPAL INVESTIGATOR : **Anaman Sylvia M.Phil Cand.**

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 12th November, 2018. You are to submit annual reports for continuing review.

Signature of Chair: .....
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)

Appendix B: Ethical Clearance (37 Military Hospital Institutional Review Board)

Institutional Review Board
37 Military Hospital
Neghelli Barracks
ACCRA
Tel: 0302 769667
Email:irbmilhosp@gmail.com

19 December 2017

ETHICAL CLEARANCE

37MH-IRB IPN 155/2017

On 21st November 2017, the 37 Military Hospital (37MH) Institutional Review Board (IRB) at a Board Meeting reviewed and approved your protocol.

TITLE OF PROTOCOL: Experiences of Parents of children with sickle cell Disease: A study at 37 Military Hospital

PRINCIPAL INVESTIGATOR: Sylvia Anaman

Please note that a final review report must be submitted to the Board at the completion of the study.

Please report all serious adverse events related to this study to 37MH-IRB within seven (7) days verbally and fourteen (14) days in writing.

This certificate is valid until 20th November 2018.

DR EDWARD ASUMANU
(37MH-IRB, Vice Chairperson)

37 MILITARY HOSPITAL
INSTITUTIONAL REVIEW BOARD
DATE 19-12-17

Cc: Brig Gen MA Yeboah-Agyapong
Commander, 37 Military Hospital

Appendix C: Information Sheet

INFORMATION SHEET

Title of Research: Experiences of Parents of Children with Sickle Cell Disease: A study at 37 Military Hospital.

Purpose of the study: This study seeks to explore the experiences of parents of children with Sickle Cell Disease at 37 Military Hospital in the Accra Metropolis.

1.4 Specific Objectives:

The specific objectives of this study are to;

1. Describe the burden of parents caring for children with SCD.
2. Identify the resources used by parents caring for children with SCD.
3. Find out the perceptions of parents and community members about SCD.
4. Identify the outcome of caregiving on the health and well-being of parents of children with SCD and the rest of the family.
5. Ascertain the determinants of the burden of caregiving.

Participants of the Study

Inclusion criteria: This will include adults between the ages of 18years and 60years caring for a child with Sickle Cell Disease, have cared for the child for more than 2years and who are willing to participate in the study.

Exclusion criteria: This will include parents of children SCD who have been diagnosed as having mental health problems. Parents of children diagnosed with SCD in less than two years and have not been giving care for over two years will excluded since the impact of chronicity of the disease for newly diagnosed children is less defined.

Ethical Considerations

This study has received ethical approval from the Institutional Review Board (IRB) of the Noguchi Memorial Institute for Medical Research and the Institutional Review Board (IRB) of the 37 Military Hospital. Consent procedures, ensuring confidentiality, privacy, risk and benefit will be followed and researcher will explain the purpose, objectives and potential risk and benefits to respondents in their preferred language. Participants will be given adequate time to decide on their participation.

Possible Risk and Discomfort

No physical harm is anticipated to occur during the study. However, psychological disturbances like worry, distress and tears may occur when enacting your story. In such a case, you will be allowed to grieve and referred to the clinical psychologist unit in the hospital at no cost to restore emotional health (psychologist's contact details: Maj. Emmanuel Yobanya, Senior Clinical Psychologist; 0277746182).

Possible Benefits

For now, there will be no direct benefit from the study. However, the study will help the general public, policy makers and healthcare professionals to appreciate what you go through as a caregiver of these children which will facilitate programs to be designed to support you.

Confidentiality

The interview that will be carried out will be recorded and later put in words. The conversation we will have will be previewed to only me and my supervisors and will be used exclusively for academic purposes. Your name will not for any reason be included in the entire process rather special numbers will be assigned. Your demographic data will be collected before the start of the interview and will not be recorded. Data will be stored for five years and destroyed after five complete years.

Compensation

During the interview you will be given water. At the end of the interview, you will be given fruit juice and cream crackers.

Voluntary Participation and Right to Leave the Research

The decision to partake in this study is solely your decision. Therefore at any time if you decide to opt out of the study you are free to do so without fear of receiving any form of victimization from the hospital staffs.

Contacts for Additional Information

If there are any concerns or you need additional information, the following people can be contacted using these addresses;

Dr. Patience Aniteye (Department of Community Health)

School of Nursing and Midwifery, University of Ghana, P. O Box LG 43, Legon

Tele/Fax: +233(0)302513250

Mobile: +233(0)244681352

Email :paniteye@ug.edu.gh 3

Sylvia Anaman
Department of Community Health,
School of Nursing and Midwifery,
College of Health Sciences,
University of Ghana, Legon.
Tel. Number: 0246391783/ 0501564347
Email: sylan09@gmail.com / sanaman003@st.ug.edu.gh

Mr. Prince Ashitey

IRB Administrator, 37 Military Hospital

Tele: 0243004247

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

This research has been reviewed and approved by the Institutional Review Board of 37 Military Hospital. If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through telephone numbers; 0302775958, 0243004247 or email address: irb37milhosp@hotmail.com

Appendix D: Consent Form

CONSENT FORM

Title: Experiences of parents of children with sickle cell disease: A study at 37 Military Hospital

Principal Investigator: Sylvia Anaman

Address: Department of Community Health,

School of Nursing and Midwifery,

College of Health Sciences,

University of Ghana, Legon.

Tel. Number: 0246391783/ 0501564347 **Email:** sylan09@gmail.com

General Information about Research

The aim of this study is to explore the experiences of parents of children living with sickle cell disease and will like you to provide me with information on some of the factors that has influenced your caregiving to your child, some of the coping strategies you have employed and how the caregiving process has affected your health and wellbeing. You will be interviewed to solicit the information and this is expected to last between 45- 90 minutes. Our conversation will be audiotaped. You will be required to sign the consent form to show your willingness to participate in the interview. Interview will be conducted at a place and time convenient to you and a second interview may be conducted if it becomes necessary.

Possible Risks and Discomforts

No physical harm is anticipated to occur during the study. However, psychological disturbances like worry, distress and tears may occur when enacting your story. In such a case, you will be allowed to grieve and referred to the clinical psychologist unit in the hospital at no cost to restore emotional health (psychologist's contact details: Maj. Emmanuel Yobanya, Senior Clinical Psychologist; 0277746182).

Possible Benefits

For now, there will be no direct benefit from the study. However, the study will help the general public, policy makers and healthcare professionals to appreciate what you go through as a caregiver of these children which will facilitate programs to be designed to support you.

Confidentiality

The interview that will be carried out will be audiotaped and later put in words. The conversation we will have will be previewed to my supervisor, my research assistants and me and will be used exclusively for academic purposes. Your name will not for any reason be included in the entire process rather special numbers will be assigned. Your demographic data will be collected before the start of the interview and will not be audiotaped. Data will be stored for five years and destroyed after five complete years.

Compensation

During the interview you will be given water. At the end of the interview, you will be given fruit juice and cream crackers.

Voluntary Participation and Right to Leave the Research

The decision to partake in this study is solely your decision. Therefore at any time if you decide to opt out of the study you are free to do so without fear of receiving any form of victimization from the hospital staffs.

Contacts for Additional Information

If there are any concerns or you need additional information, my supervisor can be contacted using this address;

Dr. Patience Aniteye (Department of Community Health)

School of Nursing and Midwifery, University of Ghana, P. O Box LG 43, Legon

Tele/Fax: +233(0)302513250

Mobile: +233(0)244681352

Email :paniteye@ug.edu.gh

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title

"Experiences of parents of children with sickle cell disease: A study at 37 Military Hospital" has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date _____ Name and signature or mark of volunteer _____

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date _____ Name and signature of witness _____

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date _____ Name Signature of Person Who Obtained Consent _____

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Appendix E: Interview Guide

Section A: Demographic Information

Code

1. Gender……
2. Please how old are you?
3. What is your marital status?
4. What religious faith do you belong?
5. What is your level of education?
6. What work do you do?
7. What is your main source of income?
8. What is the range of your monthly income?

Below GH₵500 [ ], GH₵1000-GH₵1500 [ ], GH₵1600- GH₵2000 [ ], Above GH₵2000

9. What is your nationality?
10. How many children do you have?
11. How many of your children have SCD?
12. What is the position of the child/ children with SCD?
13. What is the age of the child/children with SCD?
14. Gender of child/ children?
15. Which type of SCD is your child having?
16. Please can you tell me your genotype?
17. Please can you tell me the genotype of your spouse?

Section B: Guiding Questions

A: Having a child with SCD and the burden associated with it.

1. How did you get to know about your child's diagnosis?
2. When did you get to know about your child's diagnosis?

   Probe

   - Immediately after birth?
   - Did he/she fall sick?

3. Can you please share with me exactly how you felt when you were told about your child's diagnosis?

   Probe

   - Sad?
   - Anxious?
   - Surprised?
   - Scared?
   - Disturbed?
   - Any other sentiment not mentioned? Please share with me.

4. Can you share with me how the child's health has been after diagnosis?

   Probe

   - Any Admissions (How many, which one will you never forget)?
   - Any blood transfusions?
   - Any complications?
   - What were the admissions (if any) for?
   - Length of hospital stay?

- Cost implications
- Quality of care by health professional
- Satisfaction with care

5. Which types of medications are your child on?
6. What goes into the day to day care of the child?

Probe

- Types of care demanded from you?
- Is child totally dependent?
- Is child independent?
- Share with me your overall perception of your child's state of health

7. Share with me about your child's crises (if any)

- Number of crises in 3 – 6 months
- What triggers the crises?
- What happens during the crises?
- Share with me what you do in such times

8. What goes into the care of your child during crises?

Probe

- What do you do?
- Where do you go and why (Clinic, church, drugstore, hospital)?

9. How has your work life been since child's diagnosis?
10. Can you please share with me how you feel about caring for the child?

Probe

- Burdened?
- Stressful?

- Resentment?
- Rewarding?
- Any other feeling?

11. Can you please share with me your experience with the healthcare system in the care of the child?

Probe

- Cost of care and use of national health insurance?
- Distance to travel to hospital?
- Care during emergencies?
- Admission procedures
- Hospital policies
- Waiting time?
- Availability of medications?
- Availability of supplies/consumables
- Hospital environment?

12. Can you please share with me your experience with healthcare workers in the care of your child?

Probe

- Attitude of healthcare workers (nurses, doctors, pharmacist and laboratory technicians)?
- Knowledge base of nurses and doctors in sickle cell management?
- Competence of staff to manage illness and crises

B: Resources used by parents of children with SCD

13. Share with me whether you get any support in your child's care.
14. Where do you get support for your child's care through these times?

Probe

- Family?
- Friends?
- Church?
- Social organisations?

15. What kind of support do you receive from people?

Probe

- Financial?
- Emotional?
- Could you please describe the support to me?

16. How do you cope with the situation?

Probe

- Religion/spirituality?
- Positive mental attitude?
- Indifferent?
- Gaining more information about the disease?
- Please tell me exactly how you cope with the situation

C: Perceptions of parents and community members about SCD

17. What thoughts came into your mind when you got to know your child's diagnosis?

Probe

- Doubtful?
- Cause of illness?

18. What first step did you take following disclosure

Probe

- Called husband?
- Visited pastor?
- Told friends, family, remaining children?

19. Why did you take that first action?
20. Can you please share with me what your thoughts are concerning your child's illness?

Probe

- Self- blame?
- Solely genetics?
- God/ injustice?
- Ancestral/ family curse?

21. How does the society react to you and your child/ children?

Probe

- Stigmatisation?
- Sympathy?
- Apathy?

X: Outcome

22. How has your personal life been like since child's diagnosis?

Probe

- Attending social gatherings?
- Marriage life?
- Decisions (on giving birth again)?

23. How has family life been like since child's diagnosis?

Probe

- Family finances?
- Care of other children?
- Spouse (job, social, marriage)?
- Extended family (relationship with in-laws)?
- Family dynamics
- Family cohesion
- Recreation

24. How has your physical health been like since the diagnosis of your child? Please share this with me.

Probe

- Chronic headaches?
- Back pains?
- Hypertension?
- Other chronic illnesses?
- Any other issues of concern?

25. How has your psychosocial health been like since the diagnosis of your child?

Probe

- Fear?

- Anxiety?
- Depression?
- Social life?

26. Is there any other thing you wish to share with me? **Thank you.**

Appendix F: Thematic Framework

Table 8.1: Description of Themes and Sub-themes

THEMES AND SUB-THEMES	MEANING/DESCRIPTION	CODES
CARING FOR A CHILD WITH SCD	The burden and challenges associated with caring for a child with SCD	**CCS**
Burden related to health of the child.	The state of health of the child at any point in time	HoC
Physical burden	The burden on caregivers in relation to the workload and demands on caring for a SCD child.	PhB
Financial Burden	Economic challenges associated with the caregiving responsibility	FiB
Work-related/ Occupational challenges	Challenges arising from the dual role of caregiving and their work	WrC
Burden related to Health Services	All issues and challenges related to healthcare delivery.	Bhs
RESOURCES USED BY PARENTS	These are assets available to parents that they use to buffer or cope with the hardships associated with caregiving.	**RUP**

Religion	All the spiritual help caregivers rely on or receive.	Rel
Social support	All forms of assistance caregivers get to provide care	Sup
PERCEPTIONS ABOUT SCD	The meaning parents and community members attached to SCD	**PAS**
Caregivers' perception about SCD.	The caregivers' beliefs and understanding about the causes, prevention and treatment of SCD.	CaP
Community's perception about SCD.	The community's beliefs and understanding about the causes, prevention and treatment of SCD.	CoP
Stigmatisation	Discrimination and labelling of caregivers because of the illness of the children.	Stg
OUTCOME OF CAREGIVING (CRISES)	The overall impact of caring for a child with SCD on the physical and psychosocial health of the caregiver and the rest of the family	**OUT**
Burden of caregiving on the physical health of the parent.	All issues/ challenges arising from the caregiving on the physical health of caregivers	PhP

Burden of caregiving on the psychosocial health of the parent.	All issues/ challenges arising from the caregiving on emotional and social health of caregivers.	PsP
Overall burden of having a child with SCD on the rest of the family	All issues/ challenges arising from the caregiving on other children and spouses of caregivers.	BoF
DETERMINANTS OF THE BURDEN OF CAREGIVING	Factors which influence the challenges associated with caring for a child with SCD	**DOB**
Time of diagnosis	The period at which the child was declared a SCD patient.	ToD
Type of Treatment used	All the drugs and treatments used by the child to manage SCD.	ToT

Appendix G: Summary of Demographic Characteristics of Participants

Table 8.2: Demographic Characteristics of Participants

Participants	FP1	MP2	FP3	FP4	FP5	FP6	FP7	FP8	FP9	FP10	FP11	FP12
Gender	Female	Male	Female	Female	Female	Female	Female	Female	Female	Female	Female	Female
Age (years)	39	36	38	37	31	42	37	39	44	34	45	46
Marital Status	Married	Married	Married	Married	Married	Single	Married	Married	Married	Married	Married	Married
Educational Level	Tertiary	Tertiary	Basic level	Tertiary	Basic level	Tertiary	Basic level	Tertiary	Basic level	Basic level	Tertiary	Vocational training
Occupation	Teacher	Teacher	Trader	Physician Assistant	Trader	Programmes' Producer	Trader	Unemployed	Hairdresser	Unemployed	Teacher	Secretary
Nationality	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian	Ghanaian
Religion	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian	Christian
Total number of children	6	1	2	2	3	1	4	1	2	3	2	4
No. of children with SCD	1	1	1	1	2	1	1	1	2	2	1	1
Sex of children with SCD	Male	Male	Female	Female	Females	Male	Male	Female	Males	Male, Female	Female	Female
Type of SCD	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	HbSS	Sβ0-thalasseia
Age of child with SCD(years)	12	3	5	8	8, 6	5	6	4	3, 14	3, 6	4	5
Position of child with SCD	1^{ST}	1^{ST}	1^{ST}	1^{ST}	1^{ST} , 2^{ND}	1^{ST}	2^{ND}	1^{ST}	1^{ST} , 2^{ND}	1^{ST}, 2^{ND}	1^{ST}	2^{ND}