KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY, KUMASI,

GHANA.

COLLEGE OF HEALTH SCIENCES

SCHOOL OF PUBLIC HEALTH

DEPARTMENT OF HEALTH POLICY, MANAGEMENT AND ECONOMICS

FACTORS CONTRIBUTING TO CLINIC DEFAULT AMONG SICKLE CELL CHILDREN

AT KOMFO ANOKYE TEACHING HOSPITAL (KATH), KUMASI, GHANA

BY

ENYONAM AMA KWAWUKUME

JUNE, 2019

FACTORS CONTRIBUTING TO DEFAULT AMONG SICKLE CELL PATIENTS KOMFO ANOKYE TEACHING HOSPITAL (KATH), KUMASI, GHANA

BY

ENYONAM AMA KWAWUKUME

A thesis submitted to the Department of Health Policy, Management and Economics, School of Public Health, College of Health Science, Kwame Nkrumah University of Science and Technology, in partial fulfilment of the requirement for the degree of Master of Public Health in Health Policy, Management and Economics.

JUNE, 2019

DECLARATION

I declare that, with the exception of references to other people's work which have been duly acknowledged, this paper is mine and it has not been submitted for the any award of any degree in this or any institution.

Signature: ……

Date: ……

ENYONAM KWAWUKUME

(PG:)

Signature: ……

Date: ……

PROF ELLIS OWUSU-DABO

(Academic Supervisor)

Signature: ……

Date: ……

DR. AGYEI BAFFOUR

(Head of department)

ACKNOWLEDGEMENT

I am grateful to God almighty for giving me the strength, knowledge and protection to endure and successfully complete my master's program on the KNUST campus.

I wish to thank my supervisor Prof. Ellis Owusu Dabo whose invaluable ideas, time, support and guidance have greatly contributes to the successful completion of my work. Many thanks to all the lectures of the school of public health for the knowledge they impacted me during the course.

I am grateful, to the Child Health Department (KATH), the Head of the Sickle Cell Unit (KATH), Dr Osei Akoto and all the staff of the Komfo Anokye Sickle Cell Unit for their enormous support given me during the data collection.

I would also like to appreciate my parent and siblings for persistently encouraging me to finish my project. My final appreciation goes to my colleagues for the support they offered me.

DEFINITION OF TERMS

Sickle Cell Disease – Inherited blood disorders that affects haemoglobin and shortens its life expectancy

Sex – Biological differentiation between female and male

Age- the length of time a person has lived or a thing has existed

Haemoglobin genotype- Types of haemoglobin

Default – Failure to attend scheduled review visits over a period of 12 months

Episodes of illness- illnesses that occurred

Access factors – The opportunity to Approach of enter the place.

Health staff related factors- The contribution of health staff

Vaso-occlusive crisis – A sickle cell disease complication which is characterised by pain.

Anaemia – Deficiency in the quality and amount of haemoglobin in the blood

Acute chest syndrome- The occurrence of a vaso-occlusive crisis in the pulmonary vasculature.

Hand-foot syndrome – A condition in which the hands and feet swell in children and infants

Septicaemia – presence of bacteria and toxins in blood

ABRREVIATIONS AND ACRONYMS

SCD Sickle Cell Disease

Hb SS	Haemoglobin Genotype SC
Hb SS	Haemoglobin Genotype SS
KNUST	Kwame Nkrumah University of Science and Technology
KATH	Komfo Anokye Teaching Hospital
MCHH	Maternal and Child Health Hospital
CDC	Centre for Disease Control and Prevention
WHO	World Health Organization
VOC	Vaso-occlusive crisis
ACS	Acute Chest Syndrome

ABSTRACT

Sickle Cell Disease (SCD) is one of the commonest haemoglobin hereditary disorders in the world. In sub-Saharan Africa, about 200,000 children are born with this disease annually contributing significantly to the global burden of disease. The disease is most common in the Mediterranean regions where there appears to be significant hemoglobinopathies including those of SCD. Studies done in Ghana show a carrier rate of between 10% to 30%. Children living with sickle cell disease experience a myriad of complications. The complications can be acute or chronic resulting in morbidity, increased hospitalisations and mortality. Children with SCD are supposed to be enrolled in a clinic and reviewed regularly to prevent these complications. Unfortunately children living with sickle cell are unable to attend these scheduled visits religiously. In the meantime, reliable data on why they are not able to meet these obligations are lacking. This research was therefore

carried out to access the factors that contribute to default for reviews among paediatric SCD patients.

A descriptive cross sectional study was used in this research and it involved the administration of questionnaires to caregivers of children aged 0-14 years (150 in total) suffering from SCD at the Komfo Anokye Teaching Hospital from April 2018 to June 2018. The questions focused on the demographic factors and barriers to health care experienced prior to receiving healthcare. Associations between demographic factors and reasons for not attending clinics on scheduled dates were tested with Stata software version 13.

Educational and marital status of caregivers were significant contributing factors to defaulting clinical reviews with p values of (0.045 and 0.022) respectively, while 50% of study participants had ever defaulted reviews. There was a significant influence of family size to default to reviews. The larger the family size the more likely they were to default reviews (OR 1.40 p-value 0.039). There is a less likelyhood for patients who have been admitted more than once to default (OR=0.281 with p-value= 0.122>0.050). High cost of healthcare contributed to default for reviews, (Chi-square= 28.959, p-value 0.000). The causes of admission were anaemic crisis followed by pain crisis. Health staff related issues such as rude staff, impatient providers and intimidating staff did not affect default for reviews.

Children living with sickle cell disease need scheduled visits. Therefore caretakers must be educated continuously to ensure compliance. Sickle cell clinics should be set up in many hospitals across the country.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1

1.0 Introduction

1.1. Background

Sickle cell disease (SCD) is known to be the commonest haemoglobin hereditary disorders in Africa. About 200 000 babies are delivered with this condition annually (Ansong *et al.*, 2013). Researches have recorded higher rates of childhood mortality in sickle cell patients, with a 50 to 90% specific to SS homozygous (Serjeant, 2013). SCD prevalence is high in the Middle East, Africa, India and the Mediterranean regions (Piel, Steinberg and Rees, 2017). Prevalence ranges from 10 to 40% across equatorial Africa. Nigeria and Ghana have prevalence of 15% to 30% (World Health Assemby, 2006).

Sickle cell disease is a genetic disorder with its pathology originating from the inheritance of a sickle cell gene which is homozygote or double heterozygote with another relating gene (Serjeant, 2013). In this disorder, the 6^{th} codon of the beta-globin chain becomes mutated on the on chromosome elevens short arm. This causes a defection in the globin chain. Sickle cell Disease patients tend to have abnormal haemoglobin molecules which is called haemoglobin S. this causes distortions of the red blood cells making them crescent or sickle in shape. There Sickle cell disease comes in many forms but Haemoglobin Genotype SC (HbSC) and Haemoglobin Genotype Ss (HbSS) are more dominant. Their haemoglobin tend to breakdown faster and earlier than people who do not have the disease. These Red Blood Cells (RBCs) are the carriers of oxygen in the human body, thus increased rate of breakdown causes low oxygen tension. When there is low oxygen tension the chains polymerize and RBCs become curved stiff and sticky making them look like sickles. The name given to this disease is from the shape the RBCs assumes after

polymerization. These changes lead to the various episodes of illness SCD patients present with. These deformed blood cells block smaller blood vessels as they pass through them and causes complications.

In Ghana, children born with this disease are victims of these complications. Some of these complications are acute, which occurs suddenly and others are chronic. These events have a negative effect on the financial status of the care givers as their children have to be admitted and managed well. In Ghana common causes of hospital admissions of these children are Vaso Occlusive Crisis (VOC), stroke and Acute Chest Syndrome (ACS). Of these vaso-occlusive crisis is commonest, characterized by excruciating pain in the affected body parts (Frimpong, 2016). The disease begins to manifest in early childhood with dactylitis (swollen painful hands and feet) being the first manifestation. New-borns with this inherited disease is on the rise in Ghana and globally. (Frimpong, 2016)

These complications are usually triggered by some factors. Precipitating factors for the complications experienced by children born with SCD may be varied but infections is the leading factor with major contribution to sickness and mortality. The risk of infections especially to bacteria is increased in these children because they have sickle cell genes. Other precipitating factors are dehydration, very low or high temperatures, low humidity and high wind speed. Poor hygiene and poor socioeconomic conditions also contributes to the development of crisis.

Inappropriate health-seeking behaviour is a basic to all societies. Healthcare and services utilization is a multiple behavioural phenomenon. Sickle cell patients do not stick to their

scheduled appointments. Poor health seeking behaviour has direct consequences on morbidity of sickle cell patients (Begashaw and Tesfaye, 2016).

In Ghana not many studies have been done to find out the morbid conditions that cause the hospitalization of children who have sickle cell disease and why these children are not brought for regular check-up. By carrying out this study there is going to be available data on this issue which will help in the planning of preventive measures and the identification of educational programs for families of these children and also the identification of areas to commit more resources to. This would yield a reduction in hospital admissions and an increase in attendance to scheduled reviews. In light of the above, a study to describe why patients with sickle cell disease default scheduled visits.

1.2. Problem statement

About ten to forty percent of the Africans have the sickle cell trait contributing to a two percent estimated sickle cell disease prevalence (Society, 2016). The public health implications of this disease are significant as the sickle cell disease causes about 5% of deaths in the under-five population in Africa of which 9% of these mortalities occur in West Africa. (World Health Assemby, 2006).

A number of financial and non-financial factors work together to prevent or delay families from getting healthcare when their children fall sick. These factors which include; long travel time;

financial barriers; sociocultural factors and lack of knowledge and awareness are very common in poor countries.

Children living with the disease usually come with various types of complications. Even though Sickle Cell disease comes with a myriad of complications, the prospects of children living with this illness in developing countries must be improved. It is attainable by offering comprehensive care for patients, which includes giving antibiotics and folic acid, good nutrition, adequate pain management,and increased water intake. This can be achieved through regular scheduled hospital visits.

Delivery of comprehensive care is a challenge in developing countries like Ghana but also most of the patients do not turn out for reviews at their scheduled time. Some do not even show up until they are faced with major complications and majority of the complications they present with could have been avoided if patients followed a regular check-up time table. Delays in seeking health and inappropriate health seeking behaviour have a significant consequence on standard living, morbidity and mortality among SCD population. This study sought to throw light on the factors that influence default for reviews in children living with SCD.

1.3. Purpose of the study and objectives

For effective planning and better management of patients who have sickle cell disease it is crucial to know which medications and forms of management help them. This can be done when children come for regular scheduled visits. This would help the health care giver know the common conditions their wards present with in addition to knowing how they are faring on their current

treatment. Children living with SCD have various needs and often receive little care due to some perceived hindrances they face. These barriers lead to preventable complications, costly emergency room visits and hospitalization.(Jacob, Childress and Nathanson, 2016).

Data on factors contributing to default among children with sickle cell disease will give more understanding on how to manage these children and prevent unwanted morbidities and mortalities. The data would also help policy makers allocate resources to reduce the burden families' face when seeking care for their children and wards. Few studies have been conducted on factors that contribute to default among children with chronic diseases. They studies have focused on other diseases like asthma.

In Ghana studies have not been conducted on the factors that influence default for reviews among children who have sickle cell disease. Thus by conducting this study at the KATH sickle cell clinic, data are going to be made readily available and accessible on why children with this disease are not able to honour scheduled visits. This would help in the policy making in putting up measures that would help address this unhelpful habit. The outcome of this would be a reduction in sickle cell emergencies and admissions and eventually a reduction the cost burden associated with hospital admissions and emergency management. There is a need to identify the health care barriers so the standard of living of these children would be improved. (Jacob, Childress and Nathanson, 2016).

1.4. Conceptual Framework

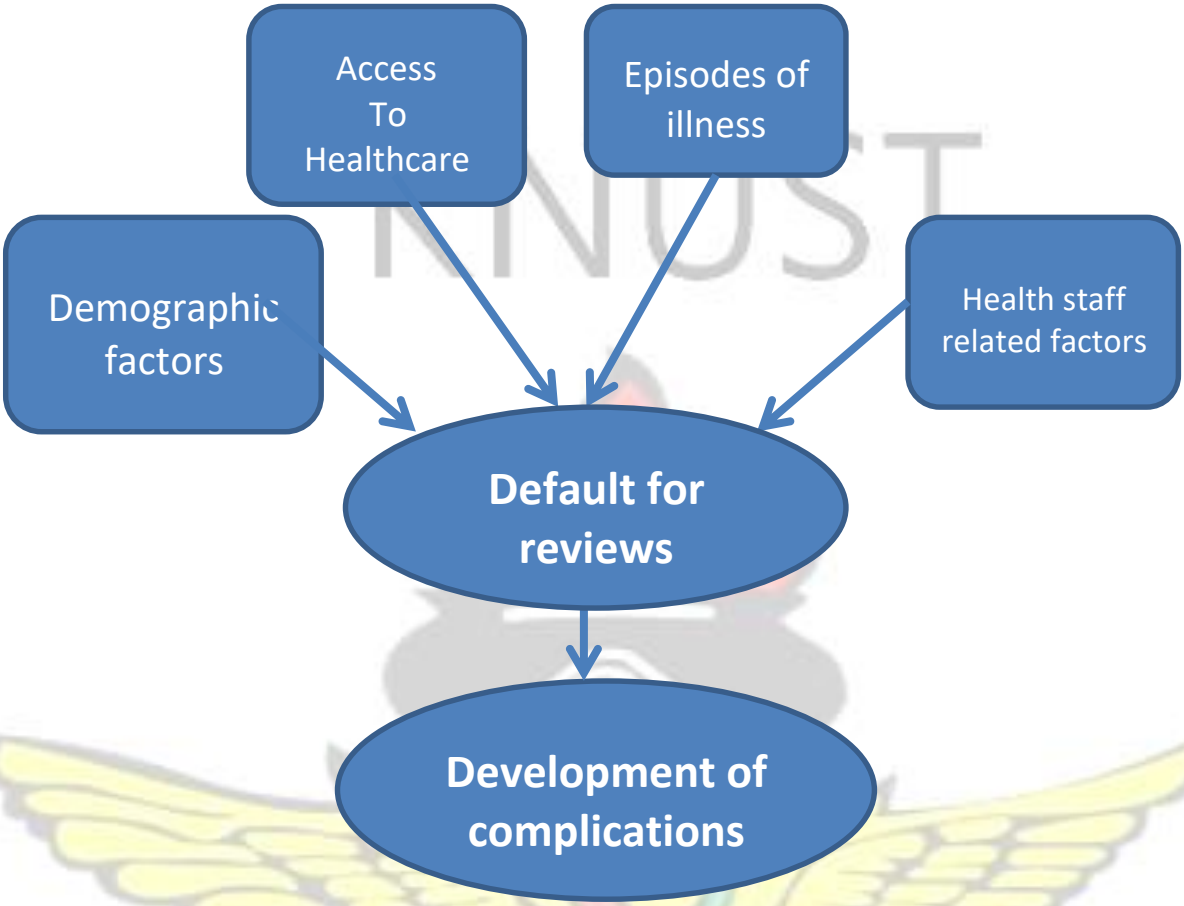

Figure 1: Conceptual framework for factors that influence default in reviews among SCD patients.

Sickle cell disease is a familiar inherited blood disorder in Africa (Williams and Weatherall, 2012). People with sickle cell diseases experience various complications which can be mild moderate or severe. These complications are influenced by the environment they live in. It is necessary for a child with this illness to see his or her care giver on regular basis. This is however not the fact on the ground as the children face some hindrances. Factors that contribute to default among children with sickle cell are influenced by access barriers. Geographical, financial, socioeconomic and lack of knowledge barriers deters the parents or guardians seeking care regularly. The attitude of health workers also prevents some parents from bringing their ward to the hospital. Episodes of illness

and phenotypic factors also prevent and delay health care among sickle cell disease patients. Demographic factors and how often people get sick can influence the default behaviour. When children with SCD default reviews they end up with complications which lead to hospital admissions.

1.5. Research Questions

The research questions are:

1. What are the demographic factors contributing to default among children with sickle cell disease at KATH?
2. What is the relative contribution of episodes of illness to defaults for reviews?
3. How does barriers factors such as access to health care contribute to default to reviews among sickle cell patients at KATH?
4. How does health staff related factors contribute to defaults to reviews in children with sickle cell disease who attend KATH?

Specific Objectives

1. To describe the demographic factors contributing to defaults for reviews among children with sickle cell disease at KATH.
2. To determine the relative contribution of episodes of illness to default defaults for reviews.
3. To assess barrier factors such as access to healthcare as a contributing factor to default for reviews.
4. To identify health staff related factors contributing to defaults for reviews among sickle cell disease children at KATH.

1.6. Research hypothesis

There is no relationship between demographic factors of caregivers of children with SCD and default among SCD patients.

Poor Hospital access to healthcare contributes to default for reviews

Health staff not relating well to patients is a cause of default for reviews

1.7. Scope of the study

This research reviewed data collected from guardians whose wards have sickle cell disease and were enrolled onto the sickle cell clinic at Komfo Anokye Teaching Hospital in 2018. Data on the phenotypic factors, access barriers, health care related barriers and episodes of illness among these children were collected and analysed to determine the common factors that contribute to default in reviews. A well-structured questionnaire containing all the necccesary variables was used to gathert data from guardians of children living with SCD.

1.8. Organization of Report

The project is structured into six main chapters. The first chapter is the introduction and comprises the background of the study, problem statement, purpose of the study, conceptual framework, research question, general objective and specific objective, hypothesis, organization of the report and the assumption of the study. The second chapter contains relevant literature on the study. The third contains the method used for the research. The fourth chapter shows the

results. The fifth chapter is the discussion and the sixth chapter concludes and gives recommendations of the thesis.

1.9. Assumption of the Study

Source of data reflect the actual situation over the period of reseach.

CHAPTER TWO

2.0 LITERATURE REVIEW

Introduction

Disorders of haemoglobin used to be seen in only African, Indian and countries in the middle east but these disorders are now found in countries all over the world due to migrations and intercontinental marriages (Ballardini *et al.*, 2013). Although adequate statistics on the exact spread and the rate at which these haemoglobinopathies occur is finite, there is no reason to be uncertain about the current and futhure global burden they pose (Williams and Weatherall, 2012).

Inherited haemoglobin disorders is a common monogenic diseases. About three hundred thousand to four hundred thousand children are born with haemoglobin disorders yearly and about ninety percent of these births can be found in countries with low gross national income (Williams and Weatherall, 2012).

Variants in haemoglobin come from gene abnormalities affecting the α-globin genes and thousands of these Haemoglobinopathies have been identified, with about 5% the population of the world being carries. The prevalence of haemoglobinopathies (the α- and β-thalassaemias, HbS, HbC and HbE) can be attributed to the malaria protection they offer (Flint *et al.*, 1993). Among these haemoglobinopathies Thalassaemias is the commonest followed by sickle cell anaemia. Even though there are more thalassaemia carriers than that of SCD, there is a high occurrence of sickle cell genes in some areas leading to a high prevalence. (World Health Assemby, 2006).

Sickle cell anaemia, an autosomal recessive disease, which comes about when a point mutation occurs on codon 6 of the βeta-globin chain. This brings about the haemolytic and VOC complications seen in patients with sickle cell disease. The pathophysiology is complex and made up of exogenous and endogenous dysfunctions but the main incident in the pathogenisis is the polymerization of the sickle haemoglobin (HbS). These causes cellular alterations including membrane changes and shortened life span of the red blood cell which in due cause blockage and damages the organs that are infracted. Also, there is adherence of RBCs to the vessel's endothelium. Proinflamatory events coupled with nitric oxide release also occur in the pathogenesis of this disease (Darghouth *et al.*, 2017).

A combination of haemolytic and vaso-occlusion bring about the basic clinical manifestation of SCD and its associated complications of which some are very life threatening (Ansong *et al.*, 2013). SCD complications can be categorized into four main groups, namely vaso-occlusive complications; haemolysis and haematological complications; organ dysfunction and infections. (Frimpong, 2016)

Until recently, SCD treatment has been limited, but several encouraging novel therapeutic agents are being developed (Darghouth *et al.*, 2017). Biomedical technology has introduced the use of gene therapy and stem cell transplantation in the management of SCD in developed countries (Ansong *et al.*, 2013). The complex nature of the disease makes it difficult for a single therapy to prevent or reverse all SCD complications (Darghouth *et al.*, 2017). In general, a combination of preventive and symptomatic therapies are used in the management of SCD (Ansong *et al.*, 2013).

This can be achieved by programs that combine therapy, genetic counselling and carrier detection thus World Health Organization has recommended the global implementation of the services mentioned above. This has however been difficult to develop.(Modell, 2011)

2.1. Demographic characteristics of children with sickle cell disease

Demographics refers to statistical data about the characteristics of a population, such as age, gender and residence of the people being studied. (Webster's New World College Dictionary, 2014). There is a dearth of research to determine the socio-demographic distribution and impact of sickle cell patients in Ghana. The demographic characteristics that would be studied are level of education, marital status, family size, income, and place of residence. These indicators are important in the determination of the morbidity patterns children with SCD present with to the hospitals that warrant admission. People's choice of healthcare and reaction towards health care differ socio-demographically, culturally and socioeconomically and this has a significant consequence on their health seeking behaviour (Jacobs *et al.*, 2011)

2.1.1. Level of education

Education is essential and has an intense effect on population health. Researches done over the years in developing countries have established educational as a significant predictor of health. Lack of education is a proven barrier to healthcare. (López-noval and Pugno, 2010). A study done in Karachi on education and health seeking behaviour enforced the point that education has a remarkable association with health seeking behaviour of the persons studied. A study conducted in Ethiopia on the barriers to healthcare utilization, observed that education influences the

utilization of healthcare services. It was also found out that that mothers who were educated utilized the healthcare services available to them (Girma, Jira and Girma, 2011). Results from a research done by Nils Braakmann (2008) on the relation between education, health and health related behaviour in Newcastle did not find any evidence to support higher education and health seeking behaviour (Hester, 2008). Education is critical and influences how people make decisions to attend hospitals and use the services provided. Education was not an important predictor of healthcare in a study on the factors that influence healthcare utilization in South Africa *(Abera, Ncayiyana and Levin, 2017).*

2.1.2. Marital status

Marital status was seen to have a strong association with health seeking behaviour among urban households than rural. In a study in Esera, it was found out that married people living in urban households sought care eleven times more than the single. Similar findings on marital status and health seeking behaviour were made in Mongolia and Jamaica (Begashaw and Tesfaye, 2016). This was contrary to a study in Ethiopia which observed that marriage affect health service utilization (Aweke, 2005).

2.1.3. Place of residence

This refers to where a person lives. A study in Ethiopia, the health seeking behaviour of families was 58.4%, the urban dwellers sought healthcare about two times more than the rural dwellers. Comparing the above study to an earlier study done in Amara region of the same country, there was an increase in how both rural and urban residences sought care. The study in Amara showed

that the health seeking behaviour of families was about 30% in rural and 52% in urban households. This was due to improved access to hospitals and health information delivery by health extension workers.(Begashaw and Tesfaye, 2016)

In Salman and Hassan's study in Ethiopia on causes of hospital admissions among children with SCD, 51.87% were from urban and 48.13% were from the rural communities(Salman and Hassan, 2015).

A descriptive cross-sectional study performed on 155 SCD patients at a referral centre in Brazil on the demographic and socioeconomic characteristics sickle cell disease patients and their compliance to treatment, showed that many of the study population were poor and lived far from the referral centres (Fernandes *et al.*, 2015). People living in urban area are receptive to new ideas and are open to trying new treatment methods thus maintain a regular check-up schedule. Contrary to this, people living in the rural regions do not like change thus stick to traditional practices. Thus they do not adhere to regular check-ups and visits.

2.1.4. Socioeconomic status

A study conducted in brazil on the demographic and socioeconomic characteristics patients with SCD, majority of the participants who were caregivers had only attended primary school. About 55.3% of them had regular jobs and about half had income up to the Brazil minimum wage which is about 240 dollars. A third of the participants were not on any government social benefit program. In this study, unemployment and low income contributed to complications of sickle cell disease, blood transfusions and admissions were associated (Fernandes *et al.*, 2015).

The study on health care utilization among rural and urban households in Ethiopia showed that monthly income of households affected routine hospital visits. This was similar to other researches from Congo Republic, Georgia India and Mongolia. The study showed that income was a predictor of rural residents health care seeking behaviour but it did not affect the health seeking behaviour of urban resident. This finding could be due to the employment in the urban regions than rural.(Begashaw and Tesfaye, 2016).

Grima et al found out that people belonging to the medium and low socioeconomic groups sought healthcare 3.5 and 2.6 times more than the people who fall in the high socioeconomic group. This was attributed to the availability of free healthcare services for poor people living in Ethiopia. Also, people in the high class group are generally healthier. (Girma, Jira and Girma, 2011)**.** But studies performed in Brazil revealed that the low socioeconomic class sough healthcare less than the high socioeconomic class. (Kwazulu-natal *et al*., 2005)

In a study on the prevalence of painful crisis, the sickle cell patients in steady state who also belonged to the upper socioeconomic class was remarkably higher than the number of such children in crisis. Among the studied SCA subjects, 50% of children in crisis belonged to the lower class families. Implying that children with caretakers with low income experience crisis more that those who belong to the upper and middle classes.(Yauba M Saad *et al*., 2015).

A study on healthcare seeking behaviour and its related factors conducted in Ethiopia revealed that factors such a family size contributed to inappropriate health seeking behaviour. Participants from

larger families showed less appropriate health seeking behaviours. This was attributed to the fact that parents and guardians with large families had more responsibilities which served as a hindrance to visiting healthcare facilities when their children fell ill (Senbeto *et al.*, 2013).

2.2. The contribution of episodes of illness to default for reviews

A meta-analysis review, conducted in Cincinnati by Crosby et al., 2012, found a clinic appointment nonadherence rate of 40% in paediatric sickle cell groups. This was similar to earlier studied done in the United States of America which found noncompliance rates for appointments in the sickle cell clinic to be 36%–44%. In this study approximately half said that they always make their clinic appointments and the half had missed at least one appointment (Crosby *et al.*, 2012).

Visiting the hospital on a regular basis helps the doctor identify pending health problems which leads to early interventions and better health outcomes. It has been found out that people who did not visit hospitals or take their review dates seriously begin to adhere once they fall ill and are admitted. Everyone is afraid of death thus circumstances that bring them close to death have an effect on how they obey advice form health care workers. Adherence to treatment is associated with life-threatening diseases.(Boateng and Flanagan, 2006) It has been found out that patients discharged from hospitals after a life-threatening episode of illness adhere to their medication and review visits.

Begashaw and Tesaye in a study on health care utilization pointed out that perceived severity was significantly associated with visits to the health facility. That those with severe acute illnesses utilized healthcare and were compliant than those with chronic illness but in stable state

(Begashaw and Tesfaye, 2016). Severity of a disease has a strong association with acceptable health seeking attitudes. Families with serious illnesses were more likely to seek health care as compared to people who do not have severe illnesses. People with acute illness also exhibited good health seeking behaviour than chronic illnesses in both rural and urban areas. A major factor that influences how people seek health is acute duration of illness. This is similar to findings made in Ethiopia and Jamaica. The patients' personal preferences, fears towards these diseases conditions and its outcomes determine how they seek care. This finding is also dissimilar with findings from Congo that revealed that people who had chronic ailments had a high likelyhood of seeking a healthcare than those whose illness were acute. Also, a research done in Kenya showed that patients with chronic illness sought care than those with acute illnesses. (Muture *et al.*, 2011)

A transverse study by Yauba et al on anaemic crisis among sickle cell children in Nigeria showed that out of 87 children in crisis, 32 had anaemic crisis whiles 55 had pain crisis giving a prevalence of 36.8 and 63.2 respectively. (Yauba M Saad *et al.*, 2015).

In a study by Salman and Hassan, 2015, Vaso-occlusive crisis was the most common cause of hospital admissions of patients with a percentage of 73.84. Infections were second to the acute painful crisis with a prevalence of 9.28%. Acute Chest Syndrome and Acute Splenic Sequestration Crisis were the third and fourth cause of admission with a percentage of 8.02 and 6.32 respectively (Salman and Hassan, 2015). Brown et al 2013, also found pain crisis as the most common crisis associated admission and aplastic the least common. Vaso-oclusive crisis was present in 61.5% followed by hyperhaemolytic crisis (29%) then splenic sequestration. Associated infections were septicaemia, malaria, acute osteomyelitis, urinary tract infection and septic arthritis (Brown, 2013).

In a research by Jain et al in 2013, acute febrile illness was the most common cause of admissions with severe anaemia and acute painful events being the second and third causes of admission. ACS, stroke, acute splenic sequestration and dactylitis accounted for the rest. Morbidities like, priapism , avascular necrosis of the bones and leg ulcers were not seen (Jain *et al.*, 2013). In children living with chronic diseases, healthcare barriers affect their primary healthcare experiences thus the severity of the disease (Seid, 2017)

2.3. Healthcare Access

Continuous care is a significant determinate of health of any child born with SCD. Quality access to healthcare breeds desirable health outcomes in children with this disease.

An individual's characteristics, the type of disease and access to health services contributes to good health seeking behaviour. Representative studies on curative and preventative services often identify the following as related factors to health seeking behaviour; availability of healthcare service, price of the service, quality, residence health views, and personal characteristics of the users (Begashaw and Tesfaye, 2016). The prevalence of health seeking behaviour in Ethiopia was 38.7%. The long travel distance to health centres, financial barriers and cultural practices were the main reasons why people did not seek health care.

Countries under The World Health Organization agreed to the universal coverage concept in 2005, but countries with low income not been able to achieve this because of many impediments that hinder healthcare access. Caretakers on children with sickle cell experience various elements of

barriers to access to healthcare. These access barriers include affordability of health care, geographical accessibility, availability, and acceptability. (Jacobs *et al.*, 2011)

It is a fact that among certain groups of children with sickle cell disease, access and sociodemographic indicators such as poverty, low levels of education among parents, absence of insurance, unemployment and unmet health care contribute to poor quality of healthcare and make the children vulterable to poor health coutcomes. (Seid, 2017). The barriers to access to healthcare in children include geographical access; financial barriers; lack of knowledge and awareness barriers; sociocultural, ethnicity- related and language barriers.

2.3.1. Geographical barriers

A study on healthcare utilization in Ethiopia found out that distance was a barrier for the people living in rural areas. Physical proximity to healthcare facilities affects the utilization of the services (Begashaw and Tesfaye, 2016). The findings above were similar to earlier findings made by Girma et al., in Jimma, another suburb in Etiopia. About 76.7% of the cases who lived 10 kilometres or more from a health facility did not seek healthcare.(Girma, Jira and Girma, 2011)

Long travel time and long travel distance to hospitals serve as major stumbling blocks to healthcare in many areas. Families living in rural communities face longer travel times than families in urban communities. People living in the rural residence seek medical care less than the people living in the cities, and this is because of the difference in the journey and time to get to these health facilities. A retrospective study showed rural community members had to travel two to three times

the distance of their urban counterparts just to seek medical care thus most residents living in the rural regions do patronise modern medical care. (Chan, Hart and Goodman, 2006)

Urban and rural locations differ in transit options which affect access to health care. Syed et al., 2013 studied the effects of cost, distance to healthcare providers, availability of transit and travel burden by distance and time. The study found out that transportation contributed to people not seeking health. This collectively suggested that transportation might be associated with reduced healthcare utilization and missed appointments. (Seid, 2017)

Two main geographical barriers are identified when it comes to geographic access to healthcare: deplorable health facilities in the rural and the lack or absence of the needed healthcare providers. Some villages do not even have primary health care providers. In areas where there is a medical officer people still have to go to town for further investigation as the needed equipment are not available. People had difficulties traveling to town for management due to the distance.('Geographic Access to Health Care for Rural Medicare Beneficiaries - Chan - 2007 - The Journal of Rural Health - Wiley Online Library', no date)('Geographic Access to Health Care for Rural Medicare Beneficiaries - Chan - 2007 - The Journal of Rural Health - Wiley Online Library', no date)('Geographic Access to Health Care for Rural Medicare Beneficiaries - Chan - 2007 - The Journal of Rural Health - Wiley Online Library', no date)(Chan, Hart and Goodman, 2006).

In a research conducted by Boateng et al., 2006, which analysed data gathered by the 2015 Ghana Demographic and Health Survey came out with a finding that geographic access to health services is relevant to how people use healthcare services. (Boateng and Flanagan, 2006).

2.3.2. Financial barriers

People who have not been registered under any health insurance program experience financial barrier to healthcare, principally among the poor. A study by Abera et al, 2017, found out that individuals with insurance visited health facilities more than people without insurance. This finding was similar to previous studies done in other places. The travel cost for families in the rural area is double the cost of families in the urban areas.(Abera, Ncayiyana and Levin, 2017).

In instances where health care services are readily available, people are not able to access them because of the cost involved. The cost involved in seeking healthcare maybe grouped direct cost which includes the fees charged in the health facility; indirect cost such as cost of transportation and opportunity cost which includes the loss of wages. The opportunity cost for seeking healthcare is higher for poorer families because their source of income is from labour, thus looking after sick children prevents them from working and getting money. This puts pressure on families and cause delay in seeking healthcare or not seeking healthcare at all. Thus, even with the introduction of health insurance most families find it difficult seeking healthcare. The lack of money is the most serious problem in obtaining healthcare.

Grima et al.2011, observed in North West Ethiopia that even though service related factors like perceivedcost of transport cost of treatment were predictors of health services utilization. They also found out that poverty led to people self-medicating with over the counter drugs and using traditional methods. For people living in middle and low income countries, lack of financial resources serves as a primary healthcare barrier.(Girma, Jira and Girma, 2011)

Financial barriers experienced by many people include informal and formal payments, tests, cost of medication and transportation cost. Guardians of children living with chronic diseases usually

experience major difficulties in paying for health services rendered to their wards as most of them are unemployed. This poor economic state makes it difficult for them to pay for hospital services.

Some guardians have not registered their wards under the national health insurance scheme despite their entitlement to free primary health care. Referral to bigger facilities become a burden to the family and they would have to pay for every single cost of services rendered in the bigger facilities form consultation cost to payment of drugs. Children of mothers who do not attend antenatal clinics suffer most when they develop sickle cell related crisis in their early age.

However, many resarchers have found poverty to be the most important healthcare barrier in relation to children.

2.3.3. Sociocultural barriers

Mothers educational status has been proven to be a very strong independent cause of poor health outcomes in children. Women are the ones who usually bring sick children to hospitals. Besides poverty they face various gender-related barriers that also prevent them from seeking healthcare. The major one is the male partner dominance. This affects women and children's access to not only healthcare but other community services.

Cultural, religious and linguistic barriers affect access to health services as people identify with their own and feel comfortable around them thus breeds some mistrust which has negative consequences on seeking healthcare. Religious beliefs, traditional remedies, the lower position of women and early marriages reinforce the sociocultural barriers.

Some parents also fear the orthodox management given to their ward may harm them thus indulge in traditional remedies do not help the child. Many parents and guardians living in rural areas take their wards to the nearest traditional healer or prayer house for concoctions and delay seeking medical help until all methods tried have failed. (Chan, Hart and Goodman, 2006)

Children default reviews on account of many reasons. Many parents and guardians living in rural areas take their wards to the nearest traditional healer or prayer house for concoctions and delay seeking medical help until all methods tried have failed. This results in a power imbalance and leads to their subjugation to the older generation. Being at the bottom end of a low resourced household, the child's healthcare maybe the least considered and priority is likely to be given to others. In addition, many health events that occur in these children need specialized treatment and procedures by specially trained doctors example paediatric haematologist or just a paediatrician. There is a deficit in doctor to patient ratio in middle and low-income countries (Chan, Hart and Goodman, 2006).

2.3.4. Lack of knowledge

Low education status is an important barrier to accessing health services. Improved education is associated with basic health habits. Educated people get better jobs which ensures better living conditions thus they enjoy good health. Majority of rural area inhabitants cannot read, write and speak English thus shun away from hospitals.

Low demand for health services is related to low levels of knowledge and awareness on health. To adequately care for children care givers must know when and where to seek care. Delays health care seeking has contributed to 70% of deaths among children. Information on health may not

reach marginalized and poor populations because of a myriad of reasons like low education, limited health outreaches in these areas, cultural barriers, linguistic barriers and distance to health centers.

In a research conducted by Jacob et al., 2015 on primary healthcare and its barriers among sickle cell disease children. About one third of the parents also said they experienced barriers in navigation skills which included, knowing how to make the system work for them and needing to be more savvy about healthcare.(Jacob, Childress and Nathanson, 2016)

2.3.5. Other access related factors

In a study conducted by Crosby et al., 2012 about half said they always make their clinic appointments and the half had missed at least one appointment. When the participants were asked specifically about the barriers participants reported inability to take time off, waiting too long and competing activities as the top barriers. (Jacob, Childress and Nathanson, 2016)

In a research by Jacob et al., 2015 on health care barriers faced by children with SCD. About a third to half of the guardians assessed reported that they experience access barriers such as seeking permission from work, long waiting times and having to meet other family needs.(Jacob, Childress and Nathanson, 2015)

2.4. The role of healthcare workers and default for reviews

In Sub-Saharan African countries, of which Ghana is inclusive, people have raised concerns about the manner and way health service workers communicate and relate towards patients in the healthcare facilities. Some workers, especially some nurses treat their client unfairly. They

sometimes act in abusive manners towards their patients, act rudely towards them or offer immediate and quality care to patients who look rich. In a study in Nigeria by Reis et al. that a greater number of health workers engaged in unethical behaviour and showed discriminatory attitudes towards people living with chronic diseases. (Reis *et al.*, 2005).

In a study by Anderson, it was observed that health staff in a Ghanaian hospital distanced themselves from certain groups of patients because of their educational status. They determined the people who needed quality care on account of their level of education. Thus the uneducated population referred to as "villagers" were treated with discourtesy and impatience, given less time and information. They shouted on them, ordered them around and sometimes accused of lying. (Andersen, 2004)

A study by Van Der Geest and Sarkodier titled fake patients: a study experiment on Ghana hospitals; revealed Ghanaians generally felt that health workers in health facilities were rude and unfriendly (Geest and Sarkodie, 1998).In a research by Jacob et al., 2015 on barriers to primary healthcare in children living with sickle cell disease. It was found out that about a third of the parents expressed concern about the lack of communication within the healthcare system. It was also difficult to get a doctor pay attention to you and address all your concerns. (Jacob, Childress and Nathanson, 2016). Dapaah et al. 2016, in a study on a study on the behaviours and attitudes of staff in the health service and the use of health facilities in two hospital in Kumasi found of that with the exception of a few, health workers were generally friendly towards the patients in clinic encounters (Dapaah, 2016).

In a research done in Ethiopia, they found a low prevalence of l health seeking behaviour, which was 38.7%. They observed unfair and inefficient healthcare delivery. The quality of healthcare received by the rural population was poor compared to the urban population. (Begashaw and Tesfaye, 2016)

CHAPTER THREE

3.0 Methodology

3.1. Study design, methods and Data collection methods and tools

A descriptive cross sectional design was used for this research which involved the administration of questionnaire at Komfo Anokye Teaching Hospital from April 2018 to June 2018.

3.2. Data collection tools and techniques

A structured questionnaire was administered to selected parents and guardians of children with sickle cell disease at the sickle cell clinic of the Komfo Anokye teaching hospital. The questions focused on the demographic factors and barriers to health care experienced prior to receiving healthcare.

3.3. Profile of study area

The study was conducted at the Sickle cell cliniclocated at Komfo Anokye Teaching Hospital which is in Kumasi in the Ashanti region, Ghana. This hospital is located in the heart of Kumasi in a culturally rich lively suburd called Bantama. Kumasi is the Ashanti regions capital city.

The last census conducted in reported there were 4.78 million people living in the Ashanti Region. The region has a t 24,389 square kilometres land area which constitute about 10.2% of Ghana's total area, making it the third largest region. This makes the Ashanti region third to the Northern region and Brong-Ahafo regions. In terms of population density, the region comes third, after Greater Accra and Central region, with a density of 148.1 persons per square kilometre. About

14.8% of the total Akan population reside in the Ashanti region. It has 27 administrative districts; the Bantama Sub-metro is under the Kumasi metropolitan Assembly.

The hospital is about 250km from the capital city of Ghana Accra. It is north to Accra. The hospital is easily accessible to every on in and out of Kumasi because of its location. The road network and the numerous commercial activities near the hospital help in its accessibility. It is located near the Kejetia market with has a big bus terminal which buses trooping in from all over the Ashanti region and beyond. This hospital is Ghana's second largest hospital with a 1,200 bed capacity. It is a referral centre for hospitals located in the middle and northern sector of Ghana and also the neighbouring towns in Burkina Faso and La Cote D'Ivoire.

The history of the KATH goes back to 1904, where this health facility was constrcted on a hill overlooking the bantam town in 1940. That hospital was called African and European Hospital; it had an African department that took care of the Ghanaians and a European section that catered for the whites in Ghana at that time. Top government workers were occasionally treated at the European section. Due to migration and population increase in Kumasi, there was a need to build a new hospital thus the was a relocation of th44e European section to Kwadaso military quarters and KATH was built in 1954055. It was named Komfo Anokye in remembrance of the great fetish priest, who did many things for the Ashanti Kingdom.

In 1975, the hospital became a teaching hospital, which was used by the medical students of

Kwame Nkrumah University of Science and Technology (KNUST) then known as University of Science and Technology. Currently it is the only hospital of this kind in the Ashanti region and still the second largest Ghanaian teaching hospital. It is now the training centre for members of the Ghana Post Graduate College of Physicians and Surgeons. It also a centre for training midwives and nurses from Kumasi and other training schools. It also a center for training biomedical scientist and pharmacy students from KNUST.

Kath has two non-clinical directorates and 12 clinical directorates and. The directorates are child health, medicine, emergency medicine, polyclinic, intensive care, obstetrics and gynaecology, diagnostics, trauma and orthopaedics, surgery, EENT, anaesthesia, oncology, oral health, domestic and technical services. About 3,909 people work in KATH, with 9.4%doctors, 42.2% nurses and midwives, 0.2% top management, 3.8% administration and Finance. 1.3% physician assistants, 3.8% pharmacist and pharmacy technicians. 10.9% clinical support and 5.6% allied health staff. (KATH Annual Report 2013).

The paediatric sickle cell clinic is under the child health directorate and is one of the subspecialist clinics of the directorate alongside clinics like Asthma clinic, paediatric HIV clinic, Cardiology clinic and Renal clinic. The clinic was started in 1992 and sees about 5000 children between the ages of 0-14 years every year. Clinic days are Mondays, Tuesdays, Thursdays and Fridays where about 170 children, both old and new cases are seen. The clinics staff strength is as follows: 4 specialist, 4 residents, 4 house officers, 4 nurses and 2 data entry officers.

3.4. Study Population

The population were parents or guardians of sickle cell patients on the sickle cell register at KATH from January 2018 to March 2018.

Inclusion criteria for factors that contribute to default in reviews

- Care givers of children with SCD enrolled onto the KATH Register Care givers of children under 14 years.

Exclusion criteria for factors the contribute to default in reviews

- Caregivers of children above 14 years

3.5. Study variables

Independent variables: Age, sex, educational background, religion, place of residence, occupation, family size, family income, ethnicity, marital status, residence sickle cell genotype.

Dependent variable: The dependant viable is default from clinic over a period of 12 months.

Table 1: Definition of variables for the study

Variable	**Operational definition**	**Indicator**	**Scale of measurement**	**Objective addressed**
Demographic factors				One
Age	The length of time someone has existed	0 to4 years 5 to 9 years 10 to14 years	Ordinal	

Sex	Biological differentiation of male and female	Male Female	Binary
Place of residence	Place one stays	Urban Rural	Binary
Socioeconomic status	Social class or standing of an individual or group.	Low class Middle class High class	nominal
Haemoglobin Genotype	Types of hemoglobin	Hb SC Hb S, Hb S/ β°-Thalassemia	Nominal
Family size	The total number of people in family	Number of people in the family	Discrete
Family income	The incomes made by people in a family	Income received	Discrete
Marital status	A state of being married or unmarried	Single Married Widowed Divorced Other (…….)	Nominal
Educational background	All the education and individual has undergone	Never attended Primary education Completer Secondary education Tertiary education	Nominal

Occupation	A profession or job	Farmer	Nominal	
		Government employee		
		Housewife		
		Merchant		
		Private employee		
		Self employed		
		Student		
Ethnicity	A persons cultural group	Akan Dagomba Ewe Fante Ga Gonja Hausa Nzema	Nominal	
Residence	A persons home	Urban Rural	Binary	
Episodes of illness	Any illness associated with children with SCD	Vaso-occlusive crisis	Nominal	Two
		Anaemia		
		Malaria		
Vaso- occlusive crisis	Painful complication of sickle cell	Yes	Binary	
		No		
Haemolytic crises	The breakdown of RBS in a short period	Yes	Binary	
		No		
Hand- foot syndrome	Swelling and pain in the palms and hands.	Yes	Binary	
		No		

Acute Chest Syndrome	Complication of SCD characterized by Severe chest pain	Yes No	Binary	
Admissions	If the child has been admitted to the	Yes No	Binary	
Access barriers				
Access barriers Geographical location	Where the health facility is situated	Not far	Ordinal	Three
Geographical location Financial barriers	Where the health facility is situated	Far Very far Yes	Ordinal Binary	
Financial barriers Sociocultural barriers	Money contributing to not seeking healthcare	No Yes	Binary	
Sociocultural barriers Lack of knowledge	The way of living contributing to not seeking healthcare Lack of education contributing to not seeking healthcare.	No Yes	Binary	
Lack of knowledge	Lack of education contributing to not seeking healthcare.	No 	Binary	
Health staff related barriers	How health personnel relate to you being the reason for not seeking health care.		Binary	Four
Behaviour of health staff	How health personnel relate to you being the reason	Yes No		

	for not going to the hospital			

3.6. Sample size and sampling techniques

Respondents would be care givers of sickle cell patients enrolled onto the sickle cell clinic register. The participants would be selected by simple random sampling and the sample size was calculated using the Yamane formula for proportions thus:

Diagram 3.1: Formula for population proportion

$$n = \frac{z^2 p(1-p)N}{z^2 p(1-p)Ne^2}$$

Where n = sample size z = confidence interval corresponding to a level of confidence. Calculated as 1.96 based on confidence interval of 95% p = population proportion, estimated to be 50% for the maximum sample size

N = population size. This is determined to be 400 based on clinic attendance estimates from the KATH Sickle Cell Clinic for a 3-month period.

e = precision or error limit estimated as 5%

Source: Yamane (1967:258)

This will yield a minimum sample size of 132.

A non-response of 20% was added making the sample size 152

3.7. Pretesting

Ten questionnaires were pretested on some care givers of sickle cell patients who attend the Maternal and Child Health hospital in Pampaso in Kumasi on a sickle cell clinic day. This was done to test for the validity and reliability of the tool used in data collection. This pretesting ensured that an option called "others" was added to the questionnaire to so that some of the conditions which were not included in the options section were captured. This enabled us capture call the conditions presented by these children and not only the major crisis they faced. The pretesting also enabled as classify the ages of the children well.

3.8. Data Handing

A data manager and two research assistants helped in the administration of the questionnaires. These personals were trained. Data were then entered into the Stata software version 13 for analysis. The principal investigator carried a data verification process by randomly selecting ten questionnaires and comparing it with the data on the software. Data collected were anonymized to protect the patients identify. Soft copies of data were protected by a password on the laptop of the reseacher. The soft copies were backed up on and kept under in safe place together with the hard copies. The data is accessible to only the researcher and the research assistants only. Stata software version 13 was used to compute for standard deviations and means for continuous variables. The Stata software was also used to generate frequency tables for categorical variables. This software was also used to test the hypothesis firstly by conducting univariate analysis for contributing factors like sex, age, haemoglobin genotype, residence, level of education and family income. Further analysis was done on the significant ones. A multivariate analysis involving logistic regression was done to determine their statistical significance and also to compute the odds ratio. Demographic variables including age, sex, genotype and place of residence were all adjusted

for. Categorical variables were presented in pie charts and frequency tables whiles logistic regression outputs were presented in tables.

3.9. Ethical Review Process

Ethical approval was sought from the committee on Human Research, Publications and Ethics at Kwame Nkrumah University of Science and Technology. The Komfo Anokye Research and development department and the Child health Department also gave approval. Doctors in charge and staff of the sickle cell clinic gave their support. Anonymity of patients was ensured by providing patient ID without necessarily using their names.

3.10. Assumptions

Source of data reflect the actual situation over the period of study.

3.11. Data analysis plan

Statistical analysis was performed on data retrieved from the medical records and guardians using STATA program, version 12.1 and results presented in frequencies, percentages and descriptive statistics. Univariate and multivariate analysis was done to determine statistical significance for appropriate variables of interest.

CHAPTER FOUR

4.0 RESULTS

Introduction

This chapter presented the results of the data collected from one hundred and fifty caregivers of children with sickle cell diseases. The analysis was done using descriptive statistics (frequencies with percentages), mean with standard deviation and independent chi-square test (chi-square value and p-value).

4.1. Demographic Characteristics of the Study

This section presented the demographic characteristics of the study.

From Table 4.1, about 42% of the participants (n=146) were females. The ages of the children were between 1 year and 14 years with a mean of 6.93 and standard deviation of 4.06. Majority of the children had SS genotype (69%), about 28% had SC genotype and 2% had beta thalassemia. Fathers were the main primary care givers with a percentage of 76 followed by mothers. Only 3% of care givers had never attended school, 47% had completed primary education, 39% completed secondary education and 22% had completed tertiary education. Many of the care givers were government employees (62%) and majority of the female caregivers were housewives. The maximum family size recorded was 7 and minimum was 2, the median family size was 4.5.

Majority of the participants were Akan representing 87%. Majority of the participants were also Christians (87%), the rest were Muslims. Most of participants live in urban settings (87%).

Table 4.1: Demographic characteristics of children with SCD

	Frequency	Percentage
Sex		
Female	62	42.47

Male	84	57.53
Total	**146**	**100**
Sickle cell disease genotype		
Bthal	3	2.05
Sc	42	28.77
Ss	101	69.18
Total	**146**	**100.00**
Primary care giver Father		
	112	76.71
Mother	31	21.23
Other	3	2.05
Total	**146**	**100.00**
Educational Level		
Completed secondary education	39	27.08
Never attended	3	2.08
Primary education	69	47.92
Tertiary education	33	22.92
Total	**144**	**100.00**
Occupation		
Farmer	7	4.79
Government employee	91	62.33
Housewife	27	18.49
Merchant	7	4.79
Private employee	11	7.53
Self	2	1.37
Student	1	0.68
Total	**146**	**100.00**

Source: Field Study, 2018

Table 4.3: Frequency with Percentage of Ethnicity, Religion, Marital Status, Residence Categorization

Characteristic	Frequency	Percentage
Ethnicity Akan		
	123	84.25
Ewe	6	4.11
Other	17	11.64
Total	**146**	**100**
Religion Christian		
	132	90.28
Muslim	14	9.72
Total	**146**	**100**
Marital Status		
Divorced	3	2.08
Married	121	84.03
Single	14	9.72
Widowed	6	4.17
Total	**146**	**100**
Residence Categorization		
Rural	18	12.33
Urban	128	87.67
Total	**146**	**100**

Source: Field Study, 2018

Table 4.2: Descriptive Statistics of Age, Family Size and Income of study population

Variable	N	Mean	Std. dev.	Min	Max
Age	145	6.93	4.06	1.0	15.0
Family size	146	4.38	1.20	2.0	7.0
Income	123	1,619.11	962.526	200.00	6,000.00

Source: Field Study, 2018

Table 4.4 presented the association between the demographic characteristics and default for review. The study used independence chi-square test to measure the association; p-value < 0.05

indicates significant association and p-value > 0.05 indicates insignificant association (no association) between demographic characteristics and default for review.

The test results revealed that level of educational and marital status had significant association with default for review. From the results (Table 4.4), the chi-square value and p-value for educational level and default for review was 8.045 (degree of freedom of 3) and 0.045 <0.05 respectively. This indicates there is significant association between educational level of participants and default to review. Children's guardians who have never attained any formal education are more likely to default (p-value 0.0450). Marital status and default to review had significant association; thus, children of single guardians are more likely to default reviews than children with both parents (p-value of 0.022 < 0.05) (Table 4.4).Creating dummies for marital status where 1 is married and 0 is otherwise (never married, widow, and divorced). It was found out that, single guardians of children with sickling cell were more likely to default reviews (using married as reference), odds ratio 1.747 (C.I: 0.703, 4.340).

The following demographic characteristics of the participants had no significant association with default for review; sex, genotype, primary care giver, religion and residence category. The p-values of the chi-square were all statistically insignificant (p-value > 0.05). This meant the associations between these demographic characteristics and default for review are the same across categories. There was no clear or significant direction with regards to default for review.

The sample population has a higher average family size (4.3). Running logistic regression model to predict the family size on default to reviews, there was a significant influence of family size to default to review. The larger the family size the more likely they were to default reviews, odds ratio of 1.40 with a p-value of 0.039< 0.05. Income had no influence on default to review.

Table 4.4: Relationship between Demographic Characteristics and Default for Review

Variable	Category	Default		Chi-Square	
		Yes N(%)	No N(%)	Value (df)	p-value
Sex	Male	45(53.6)	39(46.4)	0.701(1)	0.403
	Female	28(45.2)	34(54.8)		
Genotype	B'thal	2(66.7)	1(33.3)	0.343(2)	0.842
	SC	21(50)	21(50)		
	SS	50(49.5)	51(50.5)		
Primary Care Giver	Father	54(48.2)	58(51.8)	3.175(2)	0.204
	Mother	16(51.6)	15(48.4)		
	Others	3(100)	0(0)		
Educational Level	Never	3(100)	0(0)	8.045(3)	0.045
	Primary	39(56.5)	30(43.5)		
	Secondary	18(46.2)	21(53.8)		
	Tertiary	11(33.3)	22(66.7)		
Religion	Christian	63(48.5)	67(51.5)	0.113(1)	0.584
	Muslim	6(42.9)	8(57.1)		
Marital status	Never married	8(57.1)	6(42.9)	9.665(3)	0.022
	Widowed	6(100)	0(0)		
	Divorced	0(0)	3(100)		

	Married	57(47.1)	64(52.9)		
Residence category	Rural	12(66.7)	6(33.3)	0.208(1)	0.207
	Urban	61(47.7)	67(52.3)		

Source: Field Study, 2018

4.2. The relative contribution of episodes of illness to default for reviews

This section measured the default for review and the episodes of illness.

Half of the participants said they had ever defaulted reviews and half said they had never defaulted.

From Figure 4.2 below, the number of times the participants have defaulted review over the past 12 months was demonstrated and the results revealed out of the 73 participants that had defaulted review, 49 percent of them had defaulted two times and 45 percent defaulted once.

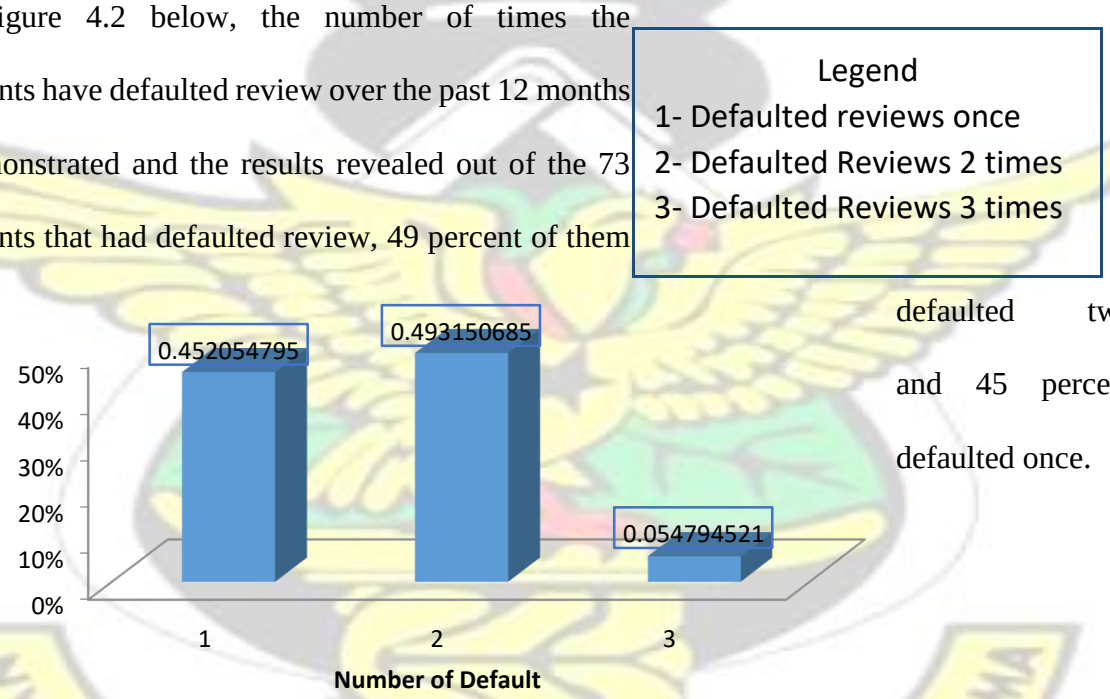

Figure 4.1: Default Times

Source: Field Study, 2018

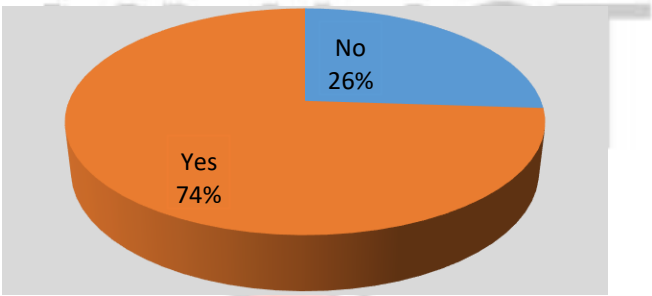

Figure 4.2: Hospital Admissions over the past 12 months

Source: Field Study, 2018

The study found out whether the participants have been admitted to the hospital before. The results revealed that, 108 patients representing 74 percent had been admitted and managed for a complication of sickle cell. The number of admissions ranged from one to four giving a mean admission rate of 1.38.

It was found out that patients who were admitted once were trice more likely to default reviews referenced to those admitted more than once (2 or more) (OR=3.556, p-value = 0.122 > 0.05, CI: 0.712, 17.763).In other words, there is less likely for patients who have been admitted more than once to default (OR=0.281 with p-value = 0.122>0.050, CI: 0.056, 1.405).

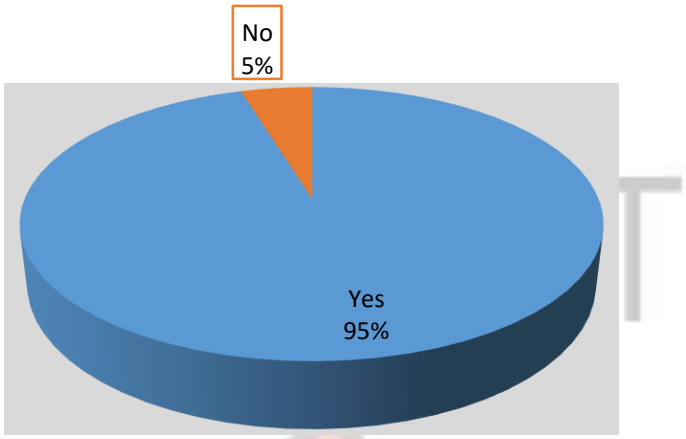

Figure 4.3: Admission Influence

Source: Field Study, 2018

The study inquired from the participants whether their admission influenced compliance to reviews. Ninety-five (95) percent of the participants said admissions influenced the default while four percent were not affected by the admissions. The results suggested hospitalization of sickle cell patients influence their compliance to review.

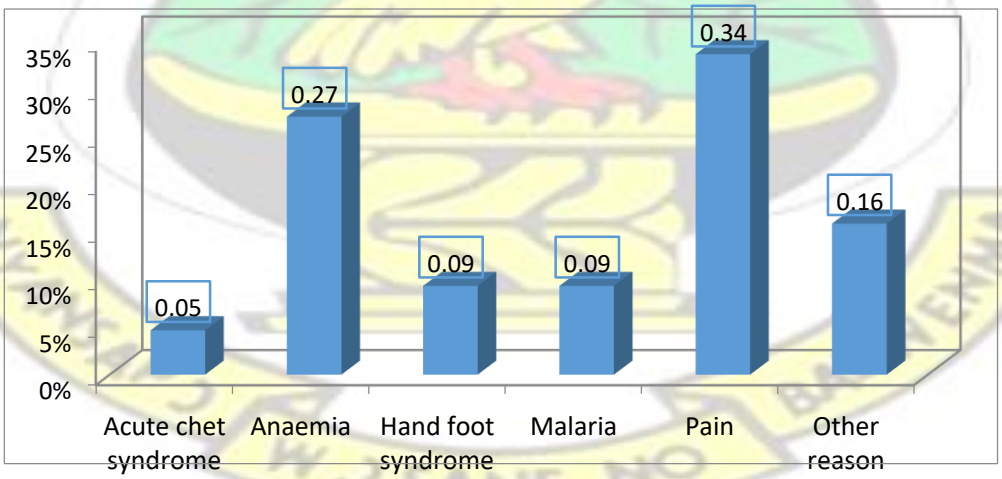

Figure 4.4: Reasons for Admission

Source: Field Study, 2018

The main reasons identified to be the reasons for the sickle patients' admission were anaemia, pain crisis, malaria and hand foot syndrome. From Figure 5.4 above, 34 percent of the reasons was pain and 27 percent was anaemia.

4.3. Barrier factors such as healthcare access contributing factor to default for reviews The study aimed at assessing the barrier factors such as access to healthcare as a contributing factor to default for review and this section assessed these barrier factors. Long travel time to health facility was not a contributing factor to default for reviews. Almost all the participants indicated long travel time to health facility was not a factor that contributes to default of reviews. Traveling long distance to health facility has been established as one of the major access barriers in many communities. The study population was dominated by urban dwellers. The assertion that the participants do not understand the need for healthcare was disagreed suggesting that they understand the need for healthcare services. This meant understanding the need for healthcare had no contributing effect on default for review.

Table 4.5: Healthcare Access factors

Access factors	Yes		No		N(%)
	N	Percentage	N	Percentage	
Long travel time to health facility	1	0.7	145	99.3	146(100.0)
High transportation cost	3	2.1	142	97.9	146(100.0)
High cost of healthcare (user fee)	40	27.4	106	72.6	146(100.0)
Taking care of household responsibilities	1	0.7	145	99.3	146(100.0)
Taking time off work	12	8.2	134	91.8	146(100.0)
Taking care of to the needs of other family members	19	13.0	127	87.0	146(100.0)
Not having national health insurance card	2	1.4	144	98.6	146(100.0)
Husbands/ family heads do not agree you bringing child to hospital	1	0.7	145	99.3	146(100.0)
Not understanding the need for healthcare	0	0.0	146	100.0	146(100.0)
Long wait times to see doctor	18	12.3	128	87.7	146(100.0)

Multiple Responses

Source: Field Study, 2018

Table 4.6: Correlation Coefficient and p-value of Access factors and Default Rate

	Default	
	Coefficient	**p-value**
Long travel time to health facility	0.083	0.319
High transportation cost	0.048	0.563
High cost of healthcare (user fee)	0.461**	0.000
Taking care of household responsibilities	0.083	0.319
Taking time off work	0.150	0.071
Taking care of the needs of other family members	.224**	0.007
Not having national health insurance card	0.000	1.000
Husbands/ family heads do not agree you bringing child to hospital	0.083	0.319
Not understanding the need for healthcare	.[a]	-
Long wait times to see doctor	0.292**	0.000

. Correlation is significant at the 0.01 level (2-tailed); *. Correlation is significant at the 0.05 level (2-tailed);* ***a*. Cannot be computed because at least one of the variables is constant.* **Source: Field Study, 2018**

Needing to take care of household responsibilities and husbands/family heads not agreeing to you bringing child to hospital are not factors contributing to default for review. Taking care of the needs of other family members was also not a factor contributing to default for review.

The results showed clearly that, all the access factors had no relation with default for review. This suggested the participants in the study especially those who defaulted reviews are not influence by any of the access factors.

However, there was a significant number of the participants who said they defaulted due to high cost of healthcare (user fee). It was indicated by about 27.4 percent of the participants.

Table 4.10 below presented independence chi-square test (of association) between high cost of healthcare and default for review.

Table 4.7: Crosstab and Chi-Square Test for High cost of healthcare (user fee) and Default

High cost of healthcare (user fee)	Default		Total	Chi-Square Value	P-value
	No	Yes			
No	68	38	106	28.959	0.000
	64.2%	35.8%	100.0%		
Yes	5	35	40		
	12.5%	87.5%	100.0%		
Total	73	73	146		
	50.0%	50.0%	100.0%		

Source: Field Study, 2018

The result (Table 4.10) showed there was significant association between respondents who indicated high cost of healthcare (user fee) and default for review. The chi-square value was 28.959 and p-value of 0.000 < 0.05 showed significant association. From the distribution in Table 4.10, 40 out of 146 participants said high cost of healthcare contributed to default for review. It was seen that, 35(87.5%) out of the 40 participants who said high cost of healthcare contributed to default also indicated they default for review.

4.4. Health staff related factors contributing to default for reviews among SCD children in

KATH

This section measured the health staff related factors contributing to defaults for review among sickle cell disease children at KATH. The study identified various health staff related factors purported to contribute default for review among sickle cell disease children. Descriptive statistics (frequencies with percentages) were used to establish these health related factors' contribution to default for review among sickle cell disease children.

Table 4.8: Health staff related factors

Health staff related factors	Yes		No		Total
	N	Percentage	N	Percentage	
Providers giving as little service as possible	1	0.7	145	99.3	146
Impatient providers	2	1.4	142	98.6	144
Intimidating providers	0	0.0	146	100.0	146
Rude office staff	2	1.4	144	98.6	146
Uncaring office staff	2	1.4	144	98.6	146
Providers do not listens to parent/child effectively	2	1.4	144	98.6	146
Questions are not answered	0	0.0	145	100.0	146
Being judged based on how one looks	0	0.0	146	100.0	146
Providers not paying attention to clients	0	0.0	146	100.0	146
Attitude of health staff	2	1.4	143	98.6	146
Health staff do not provide confidentiality	1	0.7	144	99.3	146
Not prompt in attending to patients	1	0.7	143	99.3	146

Source: Field Study, 2018

Table 4.9: Coefficient of Health staff related factors and Default Rate

	Default
	Coefficient
Impatient providers	0.000
Rude office staff	0.118
Uncaring office staff	0.118
Providers do not listens to parent/child effectively	0.000
Attitude of health staff	0.000
Health staff do not provide confidentiality	-0.083
Not prompt in attending to patients	-0.083

Source: Field Study, 2018

All the participants in the study disagreed with the following assertions; intimidating providers, questions are not answered, judging providers and providers rushing child/parent through the consultation. Similarly, the assertion that respondents feeling like providers give little health service was disagreed by all the respondents except one. In-patient providers, uncaring and rude staff and providers not listening to the parent/child effectively were all not health staff related factors affecting default. The other health staff related issued that were found not to contribute to default for review were attitude of health staff, health staff do not provide confidentiality and not prompt in attending to patients.

None of the health staff related factors identified from literature was found to contribute to default for review among sickle cell disease children.

CHAPTER FIVE

5.0 DISCUSSION

5.1. Demographic characteristic and default for reviews

The study revealed that children of guardians who had never attained any formal education defaulted more. All study participants who had never attended school defaulted reviews. This is similar to observations made by Grima and Abera who found out that there was a positive association between education and healthcare utilization. Educated people understand the consequences of defaulting reviews thus comply with scheduled visits. The study finding on education was contrary to that of Braakmann who found no link between higher education and health seeking behaviours of sickle cell patients. All the participants in braakmann's study had some level of education; there were no illiterates in his study.

The study also illustrated that children of guardians who had never married were statistically more likely to default reviews. This study finding was in line with that of Begashaw and Tesfaye who stated that the married sought healthcare more than the unmarried. Even though there was a significant association between the never married population and default. In general, there is no association between single parenting and default by sickle cell patients. This finding is contrary to that of Aweke, 2005 who observed that marriage affected healthcare utilization.

The sample population has a higher average family size (4.3) compared to the Kumasi Metropolitan household size which is 4.2 (GSS, 2014). Running logistic regression model to predict the family size on default to reviews, there was a significant influence of family size to default to review. The larger the family size the more likely they were to default reviews, odds ratio of 1.40 with a p-value of 0.039.

Using income as a determinant of default, there was no significant influence. The availability of national health insurance has made it possible for both the rich and the poor to seek healthcare. Thus cost of consultation is not a hindrance to seeking health.

5.2. Contribution of episodes of illness to default for reviews

Compliance to treatment in terms of adherence to scheduled review dates was 50%. This is in consonance with the study of Crosby (2012) where 50% of the study population had ever defaulted reviews. Majority of patients who were admitted had defaulted with a percentage of 54.6. It was found out that those who were admitted once were 3 times more likely to default (OR = 3.557) this is however not statistically significant (p-value = 0.122 >0.05). There is a less likely for patients who have been admitted more than once to default. (OR=0.281 with p-value = 0.122>0.050). Ninety-five percent of participants said the admissions influence their compliance to reviews. This could be due to children developing crisis when caretakers do not stick to scheduled visits. Children who had defaulted had run out of their medications thus were susceptible to morbidities associated with sickle cell disease. The burden admissions bring to the patients and family members make guardians comply to review dates. The results suggested hospitalization of sickle cell patients influenced their compliance to review.

Pain crisis were the common cause of hospital admissions among the study population. The other main reasons identified as causes of admission among sickle cell patients were anaemic crisis, infections like malaria and hand foot syndrome. This is similar to observations made by Brown 2013, Salman and Hassan but contrast observation by Jain et al, and Yaube et al. The former stated that febrile illness was the main cause of morbidity followed by anaemic crisis then painful events whiles the latter observed that the common cause of morbidity among sickle cell children was

anaemia followed by pain crises. Jain also observed that leg ulcers, priapism and avascular necrosis were not seen, these morbidities were also not seen in this study. Infections were not part of the top three causes of morbidity among children living with sickle cell. In contrast to what we found in this current study, some other studies have identified infections as the leading cause of admissions in children with SCD in Ghana. Children with sickle cells disease are susceptible to infections due to immune deficit opsonin defect, impaired splenic function and many others but lower rates of infections were recorded. In most developed counties VOC and other forms of crisis are the major causes of admission while in developing countries infections have been the major cause of admissions. The postulated reason for this distinction has been the early introduction of pneumococcus vaccine and penicillin V prophylaxis. Even though this study was conducted in a developing county we find pain crisis being the major cause of hospitalizations among these children. I opine that the same reason may apply to KATH since they ensure the administration of pneumococcus vaccine and penicillin vaccine alongside education of the guardians in the management of children with SCD. The findings of this current study was also contrary to that of Konotey Ahulu who noted that the common cause of admission was malaria, it is possible that introduction of treated mosquito nets have influenced the place of malaria as a common cause of morbidity among these patients.

5.3 Barrier factors such as access to healthcare as a contributing factor to default for reviews

The study aimed at assessing the barrier factors such as healthcare access as a contributing factor to default for review. Long travel time to health facility was not a contributing factor to default for reviews. Almost all the participants indicated long travel distance to health facility was not a factor that contributes to default of reviews. The study population was dominated by urban dwellers thus

the health status of Sickle Cell Disease children in the rural areas cannot be assessed. KATH was the only hospital to have a sickle cell clinic up until the second quarter of 2018 where leaders of Kath trained a few hospitals in Kumasi to start these clinics. It could be that majority of the children in rural areas have not been diagnosed and educated on the need for regular reviews or those who have been diagnosed might not be attending any clinic. It could be that the children in the rural areas have been diagnosed but attend normal clinics where they are seen by nurses, physician assistants or doctors. More studies have to be conducted to know the level of care children with Sickle Cell Diseases in the rural regions receive and comprehensive care points must be established in the rural areas The study findings were however in line with observations made by Boateng et al who found out that living in the city was strongly related to physical access to healthcare.

Geographic accessibility of hospitals has a direct effect on healthcare utilization.

Not having a health insurance card was not a cause for default in reviews. This study finding is line with findings made by Abera et al. With the exception of 2 participants almost all the participants were enrolled into the National Health Insurance Programme. The insurance caters for their consultation and basic medication and this gives the caretakers some form of financial relief.

However, there was significant number of the participants who said they defaulted review due to high cost of healthcare. There is a positive relationship or association between high cost of health care and default rate (correlation coefficient of 0.461 and p-value=0.000 < 0.05). The higher the healthcare cost the more likely to default. Even though SCD is covered under insurance scheme, all laboratory investigation and some drugs have to be purchased by the caretakers and this could be the reason behind this finding. Travel cost was also not a contributor to default. Most of the participants of this study were educated, belonged to the middle socio economic class and were urban dwellers, cost of transportation to Kath is not expensive as the Hospital is relatively close to them. Cost of transportation was less expensive.

The assertion that the participants do not understand the need for healthcare was disagreed suggesting that they understand the need for healthcare services. This meant understanding the need for healthcare had no contributing effect on default for review. The members of the sickle cell clinic at KATH especially the nurses take their time to explain the condition to caretakers whenever a child is diagnosed and enrolled into their clinic. They continue to educate members on what they are supposed to do, why they are supposed to take their medication and also how they are supposed to take care of their wards. This has created a good and solid knowledge base thus they understand the need for healthcare. Also majority of the participants were educated which made it easy to understand the condition.

Needing to take care of household responsibilities and husbands or family heads not agreeing to send wards to hospital are not factors contributing to default for review. As well as, taking care of the needs of other family members was also not a factor contributing to default for review. The results showed clearly that, majority the access factors had no relation with default for review. This once again can be attributed to education and urbanization.

5.4 Health staff related factors and default of patients

None of the health staff related factors were causes for default in review. The research revealed that healthcare workers providing services to children with sickle cell disease generally showed positive behaviours and attitudes towards patients who visited the clinic. This finding was not in line with the observations made in most researches in this literature that health care workers treat their patients in a rude and unfriendly manner. These positive findings are striking against the assertion made by Van Der Geest and Sarkodie that, in Ghana, the patients feel health workers in hospitals are rude and unfriendly, as previously indicated. They also fall contrary to observations

made by Reis et al who said health workers showed discriminatory attitudes and engaged in unethical behaviours. These findings are also contrary to the study done by Andersen who pointed out that health workers in Ghanaian use educational level to distance themselves from certain patient groups. It could be argued that since almost all the participants were educated, the health workers were not rude to them. Even though majority of the caregivers were educated and lived in the urban areas, the non-educated and those from the rural areas did not have any issue with the way the health staff related to them.

These findings are however in line with that of Dapaah et al., who's study found out that with the exception of a few, health staff generally related well with their clients. Health personnel have evolved thus they now identify their patients as their clients they have to serve.

It was made obvious that health workers assigned to the sickle cell unit went beyond their duty in the care for their patients. The healthcare team at the sickle cell clinic have the passion for the job. They warmly receive the clients to the unit during review days, addressing them politely, advising clients on the dos and don'ts of the condition and sometimes give them their contact to call when they face any problem. They work hard and educate the caregivers the disease and how to manage it. Many reasons contribute to the positive attitudes and behaviours exhibited by the health staff, it is worth noting that sickle cell is a chronic disease and all patients with sickle cell have to be enrolled into a clinic for comprehensive management. The sickle cell unit in KATH knowing this has trained their workers to exhibit behaviours that would make patients always want to come back. The health staff have done well in relating to the clients in a favourable manner.

5.5 Limitations of the Study

The research was only conducted in the sickle cell clinic in Komfo Anokye Teaching Hospital thus findings could not be generalized to the whole sickle cell disease population in Ghana. The results however can still be generalized to the Ghanaian population thus enabling health care providers plan useful interventions.

The study population was dominated by urban dwellers thus I did not get the true picture of the health status and level of default among Sickle Cell Disease children in the rural areas.

In this study I relied on self- reported answers, these answers may be subjected to recall and reporting bias. Unidentified confounders and predictors for default for reviews are still possible. Further research is needed to improve upon these limitations.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSIONS

The research identified educational status and marital status have a significant association with default for reviews. There larger the family size the more likely they were to default reviews. Majority of the children were females with most of them living urban areas. Haemoglobin gynotype SS was the most common heamoglobinopathy. Majority of the caregivers had had some level of education, only 3% never attended school. Fathers were the main care givers. The mean age, family size and income were 6.93, 4.38 and 1,619 respectively.

Half of the participants had ever defaulted reviews. Participants who were admitted were 2 times more likely to default scheduled reviews. Seventy four percent of the children had been admitted and managed for a complication of SCD. The main reasons for admission were pain crisis, anaemia, malaria and had foot syndrome. Hospitalization of SCD patients influenced their compliance to reviews.

Hospital access factors such as long travel time, tending to needs of other family members, not having national health insurance cards and not understanding the need for healthcared were not causes of default for reviews. However, there were a significant number of participants who defaulted reviews because of high cost of healthcare.

Health workers providing services to children with sickle cell disease generally related well towards clients. Health staff related factors like impatient providers, rude staff and health staff not providing confidentiality did not contribute to default for reviews.

6.2 RECOMMENDATIONS

1.1.1. Patients and Relatives

Continuous education is needed to adequately equip caretakers and client on the need to adhere to scheduled visits. 50percent of the study participants defaulted reviews thus more education must be done on the benefits and dangers of default.

1.1.2. KATH and staff

Staff of the KATH Sickle cell clinic should continue with the comprehensive care they offer children living with sickle cell disease. In terms of education, up to date treatment and also encouraging patients to adhere to scheduled visits.

Clinicians and other staff involved in the management of children living with sickle cell should be equipped with current and relevant information in the care of these children. Clinicians' should also help other hospitals set up sickle cell clinics so children living with sickle cell disease in any part of the country can have access to quality health care.

1.1.3. Ministry of Health

The ministry of health should allocate funds and resources to the setting up of sickle cell clinics in selected hospitals all over Ghana; this would help in widespread comprehensive SCD care. They should also formulate polices for the management of sickle cell patients in Ghana like compulsory screening of the new-born in all facilities. This would ensure early detection and children with SCD can be enrolled into SCD clinics.

REFERENCES

Abera, A., Ncayiyana, J. and Levin, J. (2017) 'Health-care utilization and associated factors in Gauteng province , South Africa', *Global Health Action*. Taylor & Francis, 10(01). doi: 10.1080/16549716.2017.1305765.

Andersen, H. M. (2004) '"Villagers": Differential treatment in a Ghanaian hospital', *Social Science & Medicine*, 59(10), pp. 2003–2012. doi: 10.1016/j.socscimed.2004.03.005.

Ansong, D. *et al.* (2013) 'Sickle Cell Disease : Management Options and Challenges in Developing Countries'. doi: 10.4084/MJHID.2013.062.

Aweke, A. (2005) 'Faculty of Medicine Department of Community Health By ':, (June).

Ballardini, E., Tarocco, A. and Marsel, M. (2013) 'Universal neonatal screening for sickle cell disease and other haemoglobinopathies in Ferrara, Italy.', *Blood transfusion = Trasfusione del sangue*. SIMTI Servizi, 11(2), pp. 245–9. doi: 10.2450/2012.0030-12.

Begashaw, B. and Tesfaye, T. (2016) 'Healthcare Utilization among Urban and Rural Households in Esera District: Comparative Cross-sectional Study', *American Journal of Public Health Research*, 4(2), pp. 56–61. doi: 10.12691/ajphr-4-2-3.

Boateng, J. and Flanagan, C. (2006) 'Women ' s Access to Health Care in Ghana : Effects of Education , Residence , Lineage and', *Ghanaian Women's Access to Health Care*.

Brown, B. (2013) 'Morbidity and mortality pattern in hospitalized children with sickle cell disorders at the University College Hospital , Ibadan , Nigeria', 40(1), pp. 34–39.

Chan, L., Hart, L. G. and Goodman, D. C. (2006) 'Geographic Access to Health Care for Rural Medicare Beneficiaries', *The Journal of Rural Health*. Wiley/Blackwell (10.1111), 22(2), pp. 140–146. doi: 10.1111/j.1748-0361.2006.00022.x.

Crosby, L., Barachi, I. and Meghan, E. Crosby, L. E. *et al.* (2012) 'Integrating interactive web-based technology to assess adherence and clinical outcomes in pediatric sickle cell disease', *Anemia*, 2012. doi: 10.1155/2012/492428.

Dapaah, J. M. (2016) 'Attitudes and Behaviours of Health Workers and the Use of HIV / AIDS Health Care Services', 2016.

Darghouth, D., Madalinski, G. and Bovee, P. (2017) 'Pathophysiology of sickle cell disease is mirrored by the red blood cell metabolome', 117(6), pp. 1–4. doi: 10.1182/blood-2010-07299636.The.

Fernandes, T., Medeiros, T. and Alves, J. (2015) 'Socioeconomic and demographic characteristics of sickle cell disease patients from a low-income region of northeastern Brazil', *Revista Brasileira de Hematologia e Hemoterapia*, pp. 172–177. doi: http://dx.doi.org/10.1016/j.bjhh.2015.03.013.

Flint, J., Harding, M., Boyce, A. and Clegg, J. (1993) '8 The population genetics of the haemoglobinopathies', *Bailli?re's Clinical Haematology*, 6(1), pp. 215–262. doi: 10.1016/S0950-3536(05)80071-X.

Frimpong, E. (2016) 'Pattents of illness among sickle cell disease accessing care at the Komfo Anokye Teaching Hospital, Kumasi, Ghana.'

Geest, S. V. A. N. D. E. R. and Sarkodie, S. (1998) 'THE FAKE PATIENT : A RESEARCH EXPERIMENT IN A GHANAIAN HOSPITAL', 47(9), pp. 1373–1381.

'Geographic Access to Health Care for Rural Medicare Beneficiaries - Chan - 2007 - The Journal of Rural Health - Wiley Online Library' (no date).

Girma, F., Jira, C. and Girma, B. (2011) 'Health services utilization and associated factors in jimma zone, South west ethiopia.', *Ethiopian journal of health sciences*, 21(Suppl 1), pp. 85–94. doi: 10.4314.

GSS (2014) 'Kumasi metropolitan', (District Analytical Report-Kumasi Metropolis), pp. 1–92.

Hester, J. (2008) 'Progressivism, Suffragists and Constructions of Race: Evelyn Greenleaf Sutherland's Po' White Trash', *Women's Writing*, 15(1), pp. 55–68. doi: 10.1080/09699080701871443.

Jacob, E., Childress, C. and Nathanson, J. D. (2015) 'Barriers to care and quality of primary care services in children with sickle cell disease'. doi: 10.1111/jan.12756.

Jacob, E., Childress, C. and Nathanson, J. D. (2016) 'Barriers to care and quality of primary care services in children with sickle cell disease', *Journal of Advanced Nursing*, 72(6), pp. 1417–1429. doi: 10.1111/jan.12756.

Jacobs, B. *et al.* (2011) 'Addressing access barriers to health services : an analytical framework for selecting appropriate interventions in low-income Asian countries'. doi: 10.1093/heapol/czr038.

Jain, D. *et al.* (2013) 'Morbidity pattern in hospitalized under five children with sickle cell disease', (September), pp. 317–321.

Kwazulu-natal, N. *et al.* (no date) 'CENTRE FOR SOCIAL SCIENCE RESEARCH Health Seeking Behaviour in', (116).

López-noval, B. and Pugno, M. (2010) 'Understanding the Relationship between Education and Life Satisfaction'.

Modell, B. D. M. (2011) 'WHO | Global epidemiology of haemoglobin disorders and derived service indicators', *Who*. World Health Organization. Available at: http://www.who.int/bulletin/volumes/86/6/06-036673/en/ (Accessed: 3 July 2017).

Muture, B., Keraka, P. and Kimuu, P. (2011) 'Factors associated with default from treatment among tuberculosis patients in nairobi province , Kenya : A case control study'.

Piel, F. B., Steinberg, M. H. and Rees, D. C. (2017) 'Sickle Cell Disease', *New England Journal of Medicine*, 376(16), pp. 1561–1573. doi: 10.1056/NEJMra1510865.

Reis, C., Heisler, M. and Amowitz, R. (2005) 'Discriminatory Attitudes and Practices by Health Workers toward Patients with HIV/AIDS in Nigeria', *PLoS Medicine*. Edited by S. Benatar. Public Library of Science, 2(8), p. e246. doi: 10.1371/journal.pmed.0020246.

Salman, Z. A. and Hassan, M. K. (2015) 'Hospitalization Events among Children and Adolescents with Sickle Cell Disease in Basra , Iraq', 2015.

Seid, M. (2017) 'Barriers to Care and Primary Care for Vulnerable Children With Asthma'. doi: 10.1542/peds.2007-3114.

Senbeto, M., Tadwsse, S., Tadesse, T. and Tesfahun, M. (2013) 'Appropriate healthseeking behavior and associated factors among people who had cough for at least two weeks in northwest Ethiopia : a population-based cross-sectional study'.

Serjeant, G. R. (2013) 'The Natural History of Sickle Cell Disease', pp. 1–11. Society, A. (2016) 'STATE OF SICKLE'.

Webster's New World College Dictionary, 2014 (2014) *Demographics dictionary definition | demographics defined, Fifth Edition*. Available at: http://www.yourdictionary.com/demographics (Accessed: 3 July 2017).

Williams, T. N. and Weatherall, D. J. (2012) 'Health burden of the hemoglobinopathies', *Cold Spring Harb Perspect Med*, 2, pp. 1–14. doi: 10.1101/cshperspect.a011692.

World Health Assemby, 2006 (2006) 'FIFTY-NINTH WORLD HEALTH ASSEMBLY Sickle-cell anaemia Report by the Secretariat', (April).

Yauba, M., Abiodun, A. and Olufemi, O. (2015) 'Prevalence of painful and anaemic crises among children with sickle cell anaemia in a tertiary hospital : A crosssectional study', 3, pp. 1783–1786.

'Geographic Access to Health Care for Rural Medicare Beneficiaries - Chan - 2007 - The Journal of Rural Health - Wiley Online Library' (no date).

Andersen, H. M. (2004) '"Villagers": Differential treatment in a Ghanaian hospital', *Social Science & Medicine*, 59(10), pp. 2003–2012. doi: 10.1016/j.socscimed.2004.03.005.

Ansong, D. *et al.* (2013) 'Sickle Cell Disease : Management Options and Challenges in Developing Countries'. doi: 10.4084/MJHID.2013.062.

Aweke, A. (2005) 'Faculty of Medicine Department of Community Health By ':, (June).

Begashaw, B. and Tesfaye, T. (2016) 'Healthcare Utilization among Urban and Rural Households in Esera District: Comparative Cross-sectional Study', *American Journal of Public Health Research*, 4(2), pp. 56–61. doi: 10.12691/ajphr-4-2-3.

Boateng, J. and Flanagan, C. (2006) 'Women ' s Access to Health Care in Ghana : Effects of Education , Residence , Lineage and', *Ghanaian Women's Access to Health Care*.

Brown, B. (2013) 'Morbidity and mortality pattern in hospitalized children with sickle cell disorders at the University College Hospital , Ibadan , Nigeria', 40(1), pp. 34–39.

Chan, L., Hart, L. G. and Goodman, D. C. (2006) 'Geographic Access to Health Care for Rural Medicare Beneficiaries', *The Journal of Rural Health*. Wiley/Blackwell (10.1111), 22(2), pp. 140–146. doi: 10.1111/j.1748-0361.2006.00022.x.

Dapaah, J. M. (2016) 'Attitudes and Behaviours of Health Workers and the Use of HIV / AIDS Health Care Services', 2016.

Darghouth, D., Madalinski, G., Bovee, P. and Ying, X. (2017) 'Pathophysiology of sickle cell disease is mirrored by the red blood cell metabolome', 117(6), pp. 1–4. doi: 10.1182/blood2010-07-299636.

Fernandes, T., Medeeiros, T., Alves, J. and Bezerra, J. (2015) 'Socioeconomic and demographic characteristics of sickle cell disease patients from a low-income region of northeastern Brazil', *Revista Brasileira de Hematologia e Hemoterapia*, pp. 172–177. doi: http://dx.doi.org/10.1016/j.bjhh.2015.03.013.

Flint, J., Harding, M., Anthony, J. and Clegg, J. (1993) '8 The population genetics of the haemoglobinopathies', *Bailli?re's Clinical Haematology*, 6(1), pp. 215–262. doi: 10.1016/S0950-3536(05)80071-X.

Frimpong, E. (2016) 'Pattents of illness among sickle cell disease accessing care at the Komfo Anokye Teaching Hospital, Kumasi, Ghana.'

Geest, S. V. A. N. D. E. R. and Sarkodie, S. (1998) 'THE FAKE PATIENT: A RESEARCH EXPERIMENT IN A GHANAIAN HOSPITAL', 47(9), pp. 1373–1381.

Girma, F., Jira, C. and Girma, B. (2011) 'Health services utilization and associated factors in jimma zone, South west ethiopia.', *Ethiopian journal of health sciences*, 21(Suppl 1), pp. 85–94. doi: 10.4314.

GSS (2014) 'Kumasi metropolitan', (District Analytical Report-Kumasi Metropolis), pp. 1–92.

Hester, J. (2008) 'Progressivism, Suffragists and Constructions of Race: Evelyn Greenleaf Sutherland's Po' White Trash', *Women's Writing*, 15(1), pp. 55–68. doi: 10.1080/09699080701871443.

Jacob, E., Childress, C. and Nathanson, J. D. (2015) 'Barriers to care and quality of primary care services in children with sickle cell disease'. doi: 10.1111/jan.12756.

Jain, D., Bagul, A. and Shah, V. (2013) 'Morbidity pattern in hospitalized under five children with sickle cell disease', (September), pp. 317–321. 1429.

Kwazulu-natal, N. Ardinton, C. and Working C. (2005) 'CENTRE FOR SOCIAL SCIENCE RESEARCH Health Seeking Behaviour in', (116).

López-noval, B. and Pugno, M. (2010) 'Understanding the Relationship between Education and Life Satisfaction'.

Modell, B. D. M. (2011) 'WHO | Global epidemiology of haemoglobin disorders and derived service indicators', *Who*. World Health Organization. Available at: http://www.who.int/bulletin/volumes/86/6/06-036673/en/ (Accessed: 3 July 2017).

Muture, B. N. *et al.* (2011) 'Factors associated with default from treatment among tuberculosis patients in Nairobi province, Kenya : A case control study'.

Piel, F. B., Steinberg, M. H. and Rees, D. C. (2017) 'Sickle Cell Disease', *New England Journal of Medicine*, 376(16), pp. 1561–1573. doi: 10.1056/NEJMra1510865.

Reis, C. *et al.* (2005) 'Discriminatory Attitudes and Practices by Health Workers toward Patients with HIV/AIDS in Nigeria', *PLoS Medicine*. Edited by S. Benatar. Public Library of Science, 2(8), p. e246. doi: 10.1371/journal.pmed.0020246.

Salman, Z. A. and Hassan, M. K. (2015) 'Hospitalization Events among Children and Adolescents with Sickle Cell Disease in Basra, Iraq', 2015.

Seid, M. (2017) 'Barriers to Care and Primary Care for Vulnerable Children with Asthma'. doi: 10.1542/peds.2007-3114.

Senbeto, M. *et al.* (2013) 'Appropriate health-seeking behavior and associated factors among people who had cough for at least two weeks in northwest Ethiopia: a population-based cross-sectional study'.

Serjeant, G. R. (2013) 'The Natural History of Sickle Cell Disease', pp. 1–11.

Webster's New World College Dictionary, 2014 (2014) *Demographics dictionary definition | demographics defined, Fifth Edition*. Available at: http://www.yourdictionary.com/demographics (Accessed: 3 July 2017).

Williams, T. N. and Weatherall, D. J. (2012) 'Health burden of the hemoglobinopathies', *Cold Spring Harb Perspect Med*, 2, pp. 1–14. doi: 10.1101/cshperspect.a011692.

World Health Assemby, 2006 (2006) 'FIFTY-NINTH WORLD HEALTH ASSEMBLY

Sickle-cell anaemia Report by the Secretariat', (April).

Yauba M Saad *et al.* (2015) 'Prevalence of painful and anaemic crises among children with sickle cell anaemia in a tertiary hospital: A crosssectional study', 3, pp. 1783–1786.

APPENDIX A

QUESTIONNAIRE FOR DATA COLLECTION ON FACTORS THAT CONTRIBUTE TO DEFAULT AMONG CHILDREN WITH SCD AT KATH.

Questionnaire on Factors that influence default among children with Sickle Cell Disease	
Study ID: _____ Date: __/__/____	
Section 1: Socio demographic factors	
Age	.....
Sex of child with SCD	☐ Male ☐ Female
SCD Genotype	☐ SS ☐ SC ☐ Other (.....)
Number of times child has been hospitalized over the past 12 months	☐ 1 ☐ 2 ☐ 3 ☐ More than 3 times
Primary care giver of child	☐ Mother ☐ Father ☐ Other (.....)
Educational status of care giver	☐ Never attended ☐ Primary education ☐ Completer Secondary education ☐ Tertiary education
Occupation of Care taker	☐ Housewife ☐ Farmer ☐ Government employee ☐ Student ☐ Merchant ☐ Others (.....)
Family size:	☐ 2 ☐ 3 -5 ☐ More than 5

Family income:	.....
Ethnicity:	☐ Akan ☐ Ewe ☐ Ga ☐ Other (.....)
Religion:	☐ Christian : ☐ Muslim ☐ Other (.....)
Marital status	☐ Single ☐ Married ☐ Widowed ☐ Divorced ☐ Other (.....)
Residence:	☐ Urban (.....) ☐ Rural (.....)
Section 2: Episodes of illness	
Please tick on each row to indicate the answer that best suits you.	
How many times have you defaulted reviews over the past 12 months?	☐ 1 ☐ 2 ☐ 3
Has your ward been admitted to the hospital before? 1. If yes, has that influenced compliance to reviews? 2. How many times has you ward been admitted? 3. Why was your ward admitted	☐ Yes ☐ No ☐ Yes ☐ No ☐ Pain episodes ☐ Malaria ☐ Anaemia ☐ Pneumonia ☐ Acute Chest Syndrome ☐ Meningitis ☐ Splenic Sequestration ☐ UTI ☐ Stroke ☐ Arthritis ☐ Hand –foot Syndrome ☐ Pharyngitis ☐ Septicaemia ☐ Others (.....)
4. **Section3: Access factors**	
5. Please tick on each row to indicate the answer that best suits you.	Has this stopped you from bringing your ward for scheduled reviews?
Long travel time to health facility	☐ Yes ☐ No
High transportation cost	☐ Yes ☐ No
1. High cost of healthcare (user fee)	☐ Yes ☐ No
2. Taking care of household responsibilities	☐ Yes ☐ No

3. Taking time off work	▢Yes	▢ No
4. Catering to the needs of other family members	▢Yes	▢ No
5. Not having national health insurance card	▢Yes	▢ No
6. Husbands/ family heads do not agree you bringing child to hospital	▢Yes	▢ No
7. Not understanding the need for healthcare	▢Yes	▢ No
8. Long wait times to see doctor 9.	▢Yes	▢ No
10. **Section 4: Health staff related factors**		
Please tick on each row to indicate the answer that best suits you.	Has this stopped you from bringing your ward for scheduled reviews?	
Feeling like providers do not pay attention to you	▢Yes	▢ No
Impatient providers	▢Yes	▢ No
1. Providers being intimidating	▢Yes	▢ No
2. Providers being rude	▢Yes	▢ No
3. Staff not showing care	▢Yes	▢ No
4. Providers do not listens to parent/child effectively	▢Yes	▢ No
5. Questions are not answered	▢Yes	▢ No
6. Judgment based on appearance, ancestry, or accent	▢Yes	▢ No
7. Rushing guardians through clinic	▢ Yes	▢ No
	▢ Yes	▢ No
8. Attitude of health staff	▢ Yes	▢ No
	▢ Yes	▢ No
9. Health staff do not provide confidentiality		
10. Not prompt in attending to patients		

Appendix B

Komfo Anokye Teaching Hospital on the map