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OF  
LUSAKA

**SCHOOL OF MEDICINE AND HEALTH SCIENCES**

**CHALLENGES OF SICKLE CELL ANAEMIA ON ADOLESCENT'S SOCIAL LIVES:  
A PHENOMENOLOGICAL STUDY AT UNIVERSITY TEACHING HOSPITALS IN  
LUSAKA**

**BY**

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**A dissertation submitted to the University of Lusaka in partial fulfillment of the  
requirements of a Degree in Bachelor of Science in Public Health**

## DECLARATION

**Name of student and ID: SIMON BANDA\_BSPH19217791**

I declare that this dissertation is my creative work and to the best of my acquaintance has not been presented for a degree in any other institution.

**Signature:**  \_\_\_\_\_

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## **ABSTRACT**

### **Background**

SCD/SCA is a hereditary condition affecting the shape of the red blood cells. The Zambian Ministry of health acknowledges SCA/SCD to be a public health concern. In consideration of the World Health Organization (WHO) objectives of health care system in Zambia it is vital for health providers to be client oriented and view SCD/SCA in a holistic view. However, not much evidence has been shown about supportive networks to improve social networks of sickles within Zambia, there is lack of adequate information for parents with children who are sicklers and their social lives, in addition the Ministry of Health and its cooperating partners have not done much to influence policies that foster health education with regards to SCA and its social effects in policy formulation. Therefore this research was done at UTHs with the motive of assessing social challenges that adolescents who are affected by SCA experience in their lives and the social supportive programs considered to improve the social wellbeing of sicklers.

### **Methodology**

The study adopted the qualitative approach and utilized phenomenological study design. With the sample size of 11 sicklers and their respective caregivers selected through purposive sampling. Data collection was done through methods of focus group discussions and interviews and was analyzed through methods of narrative and interpretive phenomenon Analysis.

### **Results**

This study established the consideration that believes that in most cases of SCD/SCA it is perceived to be concerned with physical and biological challenges without considering other related challenges such as social challenges in the lives of sicklers particularly adolescents. The results indicated that some participants had shared their stories with emotional outlook as a result of negative experiences that they encountered in relation to their medical condition. On the other hand the other participants gave different views and they believe that their social lives are normal and some participants had little knowledge about their condition. The results also presented the views that acknowledges the need for social supportive programs.

## **Conclusion**

In the end conclusions were made that some adolescents' sicklers have a negative view of their social life experiences as a result of their medical conditions while others believe that their social lives are normal. Social media platforms such as WhatsApps have shown significance in playing the role of common social supportive groups for many sicklers and their caregiver. In addition this research found gaps in an attempt to evaluate available literature concerning the topic of interest; in globally and regional contexts most authors implemented different methodologies. In the local context there was little done about the study hence leaving a huge gap.

## **DEDICATION**

I dedicate this dissertation to me, my dearest mum (Audrey Mwenda Chungu) and my sister (Elina Mwenda), my family and my friends.

## **AKNOWLEDGEMENT**

First and foremost I am grateful and thankful to the Lord almighty for giving me strength, guidance and the knowledge I needed to pursue this Bachelor's Degree of Health Science in Public Health.

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## ACRONYM

focused group discussion .....	(FGD) -----	13
No Date.....	(n.d.)-----	7
Sickle cell anemia.....	(SCA) -----	7
sickle cell disease.....	(SCD) -----	7
social learning theory.....	(SLT)-----	15
United States of America.....	(USA)-----	8
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## CHAPTER ONE: INTRODUCTION

### 1.0 Background

American Red Cross Research (n.d.), presented the origin of mutation that causes sickle cell disease (SCD) as originating thousands of centuries ago in Africa. It emerged and became recognized by different tribal languages of Africa long before it was discovered in western medicine. It is believed that although SCD affects the populations all over the world of various backgrounds, African ancestry population has the highest prevalence of people affected with SCD (American Red Cross, n.d). Sickle cell anemia is a specific and most common type of SCD which involves two sickle cell genes (Laurence, 2017).

Sickle cell anemia (SCA) is a genetic blood disorder that affects the shape of the red blood cells whose function is to carry oxygen from the lungs to all parts of the body. Normally red blood cells are round and flexible which makes it easy to movements through the blood vessels, on the contrary the red blood cells in sickle cell anemia are sickle shaped like a crescent moon. The sickled cells turn out to be inflexible and sticky causing blockage of the blood flow. It is for this reason that most individuals living with sickle cell anemia tend to have lack of enough oxygen in their bodies resulting into fatigue and body pains (Mayo Clinic, 2022). New born babies who have sickle cell anemia may not show symptoms for some months and when symptoms begins to show, they might present signs and symptoms such as, extreme pain, jaundice, tiredness due to anemia, swollen feet and hands. Sickle cell anemia can also affect the immune system causing high risks of attracting bacterial infections. Other effects can be seen when a sickler is growing older such as stunted growth as well as more serious medical complications that arise due to lack of enough oxygen into the organ tissues this also increases risks of developing liver damage, stroke and so on (Cleveland Clinic, 2022).

Living with sickle cell anemia is associated with many effects in one's life and to one's family members, overall people with sickle cell anemia experience biological, physical, mental as well as social challenges. In some cases people with sickle cell anemia are stigmatized and discriminated in various ways. It can be slightly easier for adults to cope on the other hand adolescents mostly experience mental breakdowns and social challenges as they perceive themselves to be different from their peers in schools, families and the society at large. This study ventured into assessing

social challenges that adolescents living with sickle cell anemia experience in their daily lives and the support systems that have influenced the coping mechanisms.

### **1.1 Statement of the Problem**

In 1910 the United States of America (USA) established the first description of sickle cell on an African young man. Since then a lot of work was devoted in research and study to understand the disorder. Within the 40years of these descriptions, the epidemiology and pathophysiology of SCA have been noticeable. Although there has been a lot of knowledge concerning the disease there has been low identification of means to improve the care of people living with SCA (Matina, 2019). It is estimated that about 300,000 babies are born with SCA each year and it's common throughout the population of African countries catering about 75% of the population living in the sub-Sahara of Africa (Sinkala, 2018).

The Zambian Ministry of health has perceived sickle cell disease as a public health concern in which it is believed that about 20-25% sickle cell traits are carried and passed on in the population and about 1-2% of babies are born with the disease within the country (Kings Health partners, 2021). The University Teaching Hospitals (UTHs) and the Arthur Davison Children's Haematology Clinic of Zambia have admitted about 16 thousand Sickle cell patients of which the majority of them are adolescents (Kings Health partners, 2021). In most cases of Sickle cell anaemia is perceived to be concerned with physical and biological challenges such as slow growth, jaundice, body pains and so on .It can be observed even from recent publications that there is more focus on the physical and biological measures of sickle cell anemia been implemented such as sickle cell newborn screening programs, medical care and treatment services. However the disease has social challenges in the daily life of a person this aspect has not been assessed by most researchers and health care givers. For there is more to effects of sickle cell anemia other than the biological and physical effects. There is less consideration about adolescent's social life, once they are treated and discharged from a health facility back to their various societies. The study aim was to assess social challenges of Sickle cell anaemia in the daily lives of adolescent, at the University Teaching Hospital in Lusaka, Zambia. It is through researches like this that will contribute to a holistic view of understanding sickle cell anemia in health care systems as well as individuals with similar interests and concerns.

## **1.2 Justification/Rationale**

Psychological complications of sickle cell anemia such as severe depression, stress, low self-esteem and so on are public health concerns. With respect to the World Health Organization (WHO) objectives of health care system in Zambia that supports enhancing responsiveness to patient's expectations by being client oriented this means that adolescents with SCA should be taken care of holistically. However, not much evidence has been shown about supportive networks for adolescents social lives affected with SCA within Zambia, there is lack of adequate information for parents with children who are sicklers regarding on how they can enhance their social lives, on the other hand the Ministry of Health and its cooperating partners have not done much to influence policies that foster health education with regards to SCA and its social effects in policy formulation. By considering social dimension that influence adolescent's everyday lives as a country, it will enable the healthcare system to identify challenges of SCA in the aspect of social life and make possible interventions to protect, promote and prolong the lives of sickles. Therefore this research was done with the motive of assessing social challenges that adolescents who are affected by SCA experience in their social lives, as well as for academic purposes.

## **1.3 General objective**

To assess the challenges of Sickle cell anaemia on adolescent's social lives admitted at University Teaching Hospitals in Lusaka.

## **1.4 Specific objectives**

- I. To assess specific challenges of Sickle cell anaemia on the social lives of adolescents at UTHs.
- II. To explore ways in which adolescents with sickle cell anaemia cope and maintain their social lives.
- III. To assess appropriate social lives supportive programmes implemented for adolescents living with sickle cell disease at UTHs.

## **1.5 Research Questions**

- I. What are the challenges of sickle cell anaemia on the social lives of adolescents admitted at UTHs?
- II. How do adolescents with sickle cell disease at UTHs cope and maintain their social lives?
- III. What appropriate social life supportive programmes have been implemented for adolescents living with sickle cell disease at UTHs?

## CHAPTER TWO

### 2.0 LITERATURE REVIEW

#### 2.1 Introduction

Literature review is a section of academic works presenting knowledge and understanding of the educational literature on a particular topic placed in context (University of Edinburgh, 2022). In this chapter, the study focused on critical evaluation of different author's publications by reviewing their available writings and methodologies that they used on the topic of sickle cell anemia and its effects on the social lives of adolescents. The study also identified gaps, connections, criticized, compared and contrasted the works of these authors on the topic of interest of this research. The structure of this literature review flows from the perspective of the global to regional perspective and then to the local perspective. Note that the words Sickle cell disease (SCD) and Sickle cell anemia (SCA) were used interchangeably by many authors reviewed in this literature.

#### 2.1.2 Global perspective

SCA is known for affecting millions of people globally (Wastnedge et al., 2018). This is to say that the disease has affected different individuals world wide and many have suffered its effects in various ways such as mentally, emotionally, socially and physically in which these effects interlink in most situations. The Sickle Cell Anemia News (2018), highlighted that one of the common effects of SCA in adolescents is severe emotional breakdown (Bionews, 2018). Effects such as emotional breakdown has contributed largely to SCA adolescent's social withdraws, aggression, low self-esteem, suicidal thoughts and so on.

Bulgin, Tanabe, and Jenerette (2018), argued that societies globally are found of uneducated individuals with regards to SCD information, hence they form personal typical negative views about people with SCD such as stigmatizing sicklers to be weak, lazy and false pretence of illness this can result in adolescents with SCD to feel degraded and have status loss. This can also apply in their households were family members are illiterate about SCD challenges, as they do not perseve the disease to be a life threatening illness if poorly managed. Stigma of SCD can therefore lead to psychological effects such as social isolation, stress, depression, anxiety suicidal ideation as well as suicidal attemps (Bulgin; Tanabe; Jenerette , 2018). The authors made much emphasis on the stigmatization of adolascents with SCD as a social challenge in United States of America (USA).

Yalinie et al. (2018) agrees with Bulgin, Tanabe and Jenerette (2018) on the aspect of psychosocial impact particularly stigmatization in SCD adolescent's social lives in various societies. However in their findings of a descriptive qualitative design with semi structured interviews the authors stated that the Participants perceived the use of digital self-management as an effective social supportive program. Hence adolescents' and their care givers should take an individualistic step of having access to digital self-management programs that focus on providing appropriate educational guidance that can enable adolescents have access to information enhancing social support through the use technology like smart phones (Yalinie et al., 2018).

In an integrative narrative review conducted by Brenda, Ann-Louise and Susan (2018), they argued that SCD influences the multiple sides of an adolescent's life. There has been connection of perceptions in the experience of living with SCD and living with other chronic diseases, however there are crucial differences in relationship dynamics and healthcare experience. Therefore there is a need for further exploration in the understanding of this phenomenon of experiences in adolescents living with SCD and their social supportive needs. There is also a need of multi collaboration in developing SCA adolescent's wellbeing through promotion of peer supportive networks by nursing care, Researchers, communities and health care providers at large (Brenda, Anna-Louise, Susan, 2018).

In a cross-sectional study conducted by Castro Spinola and Marcos Viana in Brazil it was concluded that due to cognitive disabilities in adolescents living with sickle cell that has affected various aspects of their lives, there is a need for policy formulation and strategy establishments in the areas of education, healthcare and social assistance that will improve the overall health status of adolescents living with SCA (Castro.; Viana, 2019).

India is one of the contries that has experienced high prevelences of SCA varing from tribe to tribe. Vineet Raman, Tanya Seshadri, Sangeetha Joice and Prashanth Srinivas (2021), on a systematic review obseved that indian researches focused on epidemiology and biomedical corncens of SCA, yet there is little information and knowledge on implementations of programmes in the southen and northeast india that focus on sociol determinants and support of the disease (Vineet Raman et al., 2021).

### **2.1.3 Regional perspective**

Management of sickle cell anemia has been a public health problem in developing countries. According to the world health organization WHO, more than 300,000 of 500,000 annual births with sickle cell genes globally live in Africa specifically in the Sub-Sahara region (Ndour et al, 2022).

David Muthahi Kambasu, Joseph Rujumba, Herve Monka Lekuya, Deogratias Munube and Ezekiel Mupere (2019), in a mixed approach involving cross-sectional study design and interinterviews and focused group discussion (FGD), done at Mulago National Referral Hospital in Kampala Uganda, findings through a focused group discussion (FGD) were that all the adolescents with SCA and their care givers in their sample size talked about how SCA has affected them and stigma contributing to social challenges that they face in their daily lives. Some adolescents stated that they have experienced stigma based on how they look hence facing social exclusion from their peers and limited participation in community and household activities. In the discussion of the research the authors highlighted that despite the varieties of researches done on SCD/SCA in Sub-Sahara Africa, there has been insufficient of information on the impact of the disease on emotional, school, physical and social wellbeing of adolescents living with the disease (Kambasu et al., 2019).

Atim et al. (2019), argues that it is not only adolescents but also their caregivers should be considered as they both experience psychosocial challenges and have poor coping mechanisms. Interventions for psychosocial challenges should be implemented with the aim of reducing negative thoughts and feelings in SCA adolescents and their caregivers as well as promoting appropriate coping mechanisms both internal (behavioral and cognitive) and external (community support, family support, and health facility-related support). Supportive programmes can be done through involvement of various key players such as clinics, hospitals and community based settings (Atim et al., 2019).

Julie et al. (2021) argues for stigma been one of the major challenge that degrade people with SCD. In addition the authors agrees with Atim et al on the aspect of negative societal attitudes not only affecting adolescents with SCD but as well the caregivers like parents with feelings of blaming themselves, and financial burdens. There is a need for SCD social supportive programs not only for sickles but including the families, caregivers and the communities at large with the aim of reducing stigma in the region (Julie et al., 2021).

Seham Mohamed Abd Elaziz and Rawia Abd Elghany Mohamed based their argument on strengthening self-management programs as a way to empower adolescents' with SCD to cope with Physical, emotional and social challenges through educational programs (Seham, Rawia, 2019).

Maria Berghs, Bola Ola, Anna Cronin De Chavez, Bassey Ebenso (2020) acknowledged the application of social determinants of sickle cell that affects Sub-Sahara Africa. In their research they posed queries to say;

*“Why SCD remains a low priority on global health agenda?, why are more resources not invested to save lives and ensure holistic care of people with SCD?, Why are policies focused more on shifting towards development of genomic cures instead of assuring better healthcare for people across the life-course?.”*

The authors concluded that forgoing international and local inequalities seems to be narrow focused in healthcare systems concerning SCD and its effects. Public health concerns continue to perceive SCD as purely a biomedical problem that requires to be prevented through medical advances, early detection, interventions in infancy. Berghs et al. (2020) therefore, argues that there is need to implement considerations of social determinants of health to SCD as it will help in policy formulation not only to perceive SCD as a burden of disease to be prevented but to be viewed in a holistic approach that will also ensure better health and wellbeing in the lifetime of all sicklers (Berghs et al., 2020).

#### **2.1.4 Local perspective**

Moraes, Ngomah-Moraes, and Munsaka (2019), states that there is a major psychological concern that comes with social challenges of SCA in adolescents as they are prone to depression, anxiety, self-concept and challenges of not being accepted socially. Due to the disease complications such as small stature, stunted growth and delayed physical development sickles can have low self-esteem and poor relation with peers as well as limiting their abilities to participate in activities like sports physical education programs and so on. The authors therefore states that school environment helps adolescents to make sense of their conditions as well as a supportive networks for coping mechanism, this makes school environment to be an important phase of adolescent's social lives. In the authors' phenomenological study they agree that, there is a need for social support of adolescent learners living with SCA. Adolescents and their parents prefer keeping information about the condition unrevealed with fear of been side lined and stigmatized in their educational

journey. Therefore, there is need for relevant sectors not just the ministry of health but also the ministry of education to consider enhances supportive networks of adolescents' learners with SCA through teachers and parents (Moraes et al., 2019).

Simwangala et al. (2022) argues that the quality of life physical, socially, emotionally and academically in adolescents living with SCA is influenced by their neurocognitive deficits hence considerations should be based on future large-scale research of neurocognitive impairments with respect to improving quality of life in these adolescents as well as adults. The authors' emphasis on the aspect of regular assessments on sicklers for neurocognitive deficit as an early diagnosis that will enable sicklers to access adequate support, information and medication. The authors also argue for neurocognitive rehabilitation programs especially for adolescents with SCA, by the community healthcare facilities to enhance continuous learning and developments (Kabuwa et al., 2022).

## **2.2 Theoretical framework**

With respect to the reviewed literature on social challenges of adolescents living with SCA such as social exclusion, stigmatization, depressive symptoms due to the feeling of being different and not socially acceptable as well as a need for social supportive networks and programs. This research was guided by Social cognitive theory. Social cognitive theory (SCT) was developed from social learning theory (SLT) by Albert Bandura in the 1960s, it came to be called the SCT in 1986. The theory is concerned with occurrence of learning in a social context with dynamics and reciprocal interactions of the person, environment and behavior. The theory points much emphasis on internal and external social reinforcements that socially influence people's behavior (Lamorte, 2019).

Social cognitive theory also emphasis on the maintenance of adopted behaviors, SCA effects on adolescents lives is a complex phenomenon that does not only require initiation of particular behaviors to promote and improve health of sicklers however there is need for maintenance of these behaviors in the society as a goal of public health. SCT was developed with five constructs, in which the sixth one was latter added on (ibid).

Reciprocal determinism construct gives the understanding of how interaction of person, environment and behavior are shaped. Adolescent with life long illness like SCA can feel the need to have sense of belonging and acceptance by their peers in different aspects of their lives despite

their condition. Environmental setups like schools, churches, communities and societies at large play key roles in sharpening social interaction stimulus and promotes social dimension of wellbeing.

Adolescents with SCA ought to have behavioral capabilities in order to cope with daily life challenges. This means that sickles have to be provided with information about SCA on the things they are supposed to do and not to, this can be done through educational social supportive programs.

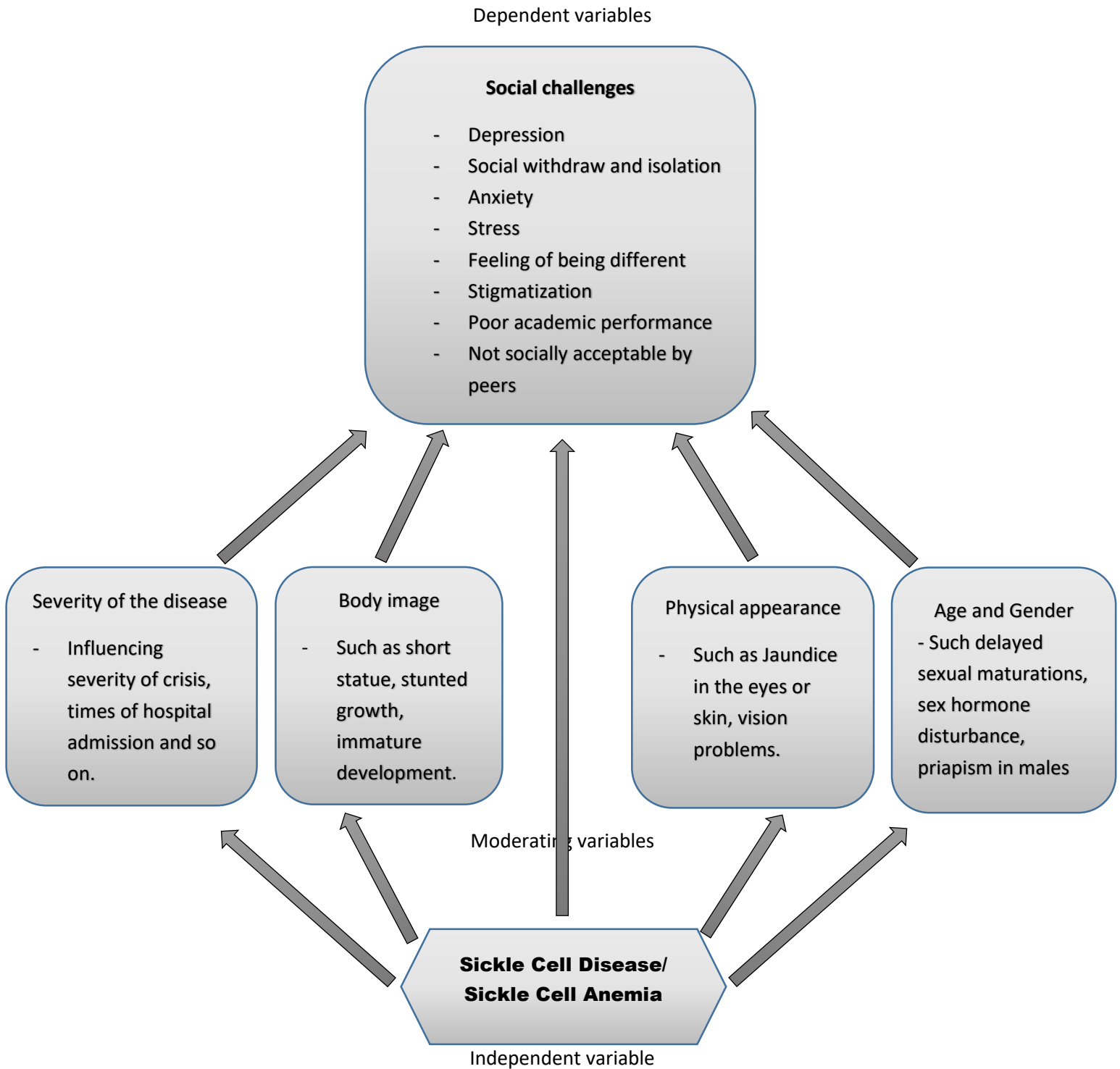
Observational learning is one factor that can be used to sharp people's behavior, in the end it should not only be adolescents with SCA being observant of what works for them to cope with daily life challenges but it should also be the concern of key players such the family, caregivers, communities and the healthcare system. Observation of how SCA affects adolescent's academic performance due to low school attendance sets a clear indicator for public health interventions.

Reinforcement, it's through this construct that determine how adolescents with SCA perceive themselves, like in the aspects of academic performance adolescents who tend to do well and get good grades tend to be more confident about themselves despite living with lifelong illness and pain, this can be the opposite to adolescents who have poor performances in their academics which can be a huge contribution to social isolation and expressing depressive symptoms.

Expectations refer to the anticipated outcomes due past behaviors in both adolescents living with SCA and there interactive environment. Society's knowledge, attitude and perception on the topic of SCA in adolescents plays a key role in anticipating future benefits and consequence. This means that if the effects of SCD are not viewed in a holistic approach by public health, the expectations will continue to be increased stigmatization, social isolation, suicidal rates, poor interpersonal relations, stress, and anxiety and so on.

Self-efficacy refers to level of confidence that sicklers can poses on the bases of their ability to perform a particular behavior successfully. Self-efficacy in tells the capacities that adolescents with SCA can perform in a specific aspect of their lives such as not been socially acceptable but still having the confidence of having to do well in their lives and contribute positively to their various societies (Nickerson, 2022).

## 2.2.1 Conceptual Framework



Source: Ghimire (2016)

**Figure 1.0:** Showing Sickle cell Disease influencing social challenges in various aspects of adolescent's lives.

### **2.3 Conclusion**

In the end of the review of available literature on the topic of challenges that are associated with SCA in adolescents daily social lives. Conclusions were made that in globally and regional perspective, similar studies on the topic were conducted multiple times with similar recommendations of implementing social support programmes for adequate knowledge for adolescents living with SCA and their communities. However most similar studies done global and regional were much focused on stigmatization being the main social challenge in adolescents with SCD. In addition most similar researches globally and regional adopt different methodologies most of them adopted quantitative approach as well as systematic review and cross sectional study designs. Bulgin, Tanabe and Jenerette (2018), phenomenon like SCD experiences needs to be fully understood in depth by explorations in a qualitative way. In local perspective it was observed that there was a huge gap in the similar studies, there was little done about this topic in the zambian perspective one reviewed article relates to this study in way that it acknowledges the social challenges of SCA in adolescent's as well as the study methodology of adopting a qualitative approach, phenomenological study design and interpretive phenomenon data analysis. However the article only considered the education aspect of adolescent's social life living with SCA. As for this research focused on many aspects of adolescent's social life and not only academics.

## **CHAPTER THREE: METHODOLOGY**

### **3.0 Introduction**

A research methodology is a process or techniques used to identify, select process and analyze information about a topic (Univesity of the Witwatersrand Johannesburg, 2022). This chapter presents the methodology that was used in this study, and it is structured as follows; Study Approach and study design that was used, study site, study population/targeted population that was used based on inclusions and exclusion criteria, sampling techniques, sample size determination, methods adopted for data collection, data analysis considered and ethical considerations.

### **3.1 Study Approach**

This study adopted the qualitative approach, this approach involves non-numerical data collection and analysis with aim of understanding concepts, opinions and experiences of certain phenomenon (Bhandari, 2020). The purpose for adopting qualitative approach for this study was to gain subjective insight and deep understanding of opinions that adolescents living with SCA can present with respect to challenges that they face in their social lives.

### **3.2 Study design**

The Phenomenological study design was used in this study. It is a study that aims at exploring experiences of individuals relating to a particular phenomenon. It also focuses on how individuals perceive the world around them, and their experiences as they go through a phenomenon (Gumberg Library, 2022). This study design sets emphasis on questions like “what is this experience like? What does this experience mean? How does this lived experience present itself to an individual? With this study designs, the study therefore attempted to answer the research questions about social challenges faced by adolescents living with SCA/SCD and their experience that may include thoughts, imaginations, perceptions, memories, and emotions or feelings.

### **3.3 Study site**

The study was conducted at Hematology ward of University Teaching Hospital (UTH) both at the children’s and a few participants from the adult hospital. UTH is a government hospital located along nationalist road in Lusaka, Zambia. The hospital was established in 1934, it is a main referral tertiary hospital in Zambia (University Teaching Hospital, n.d). UTH together with the Arthur Davison Children’s Haematology Clinic of Zambia are said to have admitted approximately 16

thousand Sickle cell patients of which the majority of them been adolescents (Kings Health partners, 2021).

### **3.4 Study population/Target population**

The study focused on adolescents with SCA both admitted and outdoor patients.

The inclusions criteria were; patients ranging from the age of 16-19 years old as they may have experienced different events in their social lives and are likely to share their perceptions. It also considered all patients from the selected age range, regardless of language, tribe and gender. The participants were Zambian citizens only as the research was based on the interest of national level.

The study also considered the views of sicklers respective caregivers mostly parents as they showed interest in the study.

The exclusion criteria were; adolescents from the age of 14 and less as they might not have experienced certain events as well as they might be younger to communicate effectively.

### **3.5 Sampling techniques**

The study used a purposive sampling method to recruit participants. A purposive sampling is a non-probability method of sampling in which the researcher choose appropriate participants from the population based on his/her own judgments with respect to the topic being researched on (Alchemer, 2021). Purposive sampling may include different types, for this study the type of purposive sampling that was used is the homogeneous purposive sampling which involves identifying individuals in a population that have common characteristics or features (Formplus , 2022). It is for the reason that this study explored views from the particular population which is adolescents with SCA/SCD.

### **3.6 Sample size determination**

The sample size for the population set to be 15, however this study was done with the sample size of 11 sicklers and 5 caregivers (parents). The rationale for the stated sample size was based on the statement made by Interq intern, Sakshi Shetty (2018), stating that the appropriate sample size for a qualitative study is between 10-30 participants, as this sample size can still yield extremely applicable results. It can also be anticipate that exceeding 15 participants might reach a point of saturation. Point of saturation refers to the point in research process were no new information is discovered in data analysis (Sandra et al., 2017).

### **3.7 Data collection methods**

Focus group discussions (FGD) has been termed as an often used qualitative data collection method to acquire an in-depth understanding of social issues. It involves obtaining data from a selective group in form of a discussion about a particular topic (Tobias et al, 2018). Data was collected through recordings of focus group discussions of 4 participants. The study also included interviews of 7 participants. The interviews were based on both semi-structured and unstructured questions. Semi-structured interviews are normally open-ended questions with the benefit of allowing flexibility of information in order for easy comparison among respondents. On the other hand unstructured interviews are not set however the questions are based on the response of a participant from the previous question in relation to the topic (George, 2022).

### **3.8 Data analysis**

Narrative data analysis refers to analytical method normally used by qualitative researchers to interpret texts or visual data that contain form of stories that people tell to organize and make sense of their lives (Figgou.; Pavlopoulos, 2015).The study used Narrative analysis to explore real life stories and experiences of both caregivers and adolescents living with SCA and how they made sense out of their social lives. The study also utilized Interpretive Phenomenon Analysis (IPA) as a backup data analysis to understand the insights of social life events of adolescents living with sickle cell. IPA is a qualitative data analysis that aims to deliver detailed examination of people's lived experience on different events (Smith;Osborn, 2015).

### **3.9 Ethical considerations**

These are a set of principles that guided the research process and practices. In view of considering sensitivity of this research based on the focus that it was dealing with adolescents with a medical condition of SCA/SCD, ethical approval was obtained from the University of Lusaka Research Ethical Clearance Committee and the Zambia National Research Authority. Permission to carry on the research was also obtained from the Lusaka Provincial Health Office of the Ministry of Health and the site administrative of UTH. Furthermore permission from every participant and their respective care givers was considered through signing of informed consent forms that were distributed to the targeted population. The research adhered to the ethical principles of Autonomy in which informed consent was given to the participants based on their interest to participate at their free time. The information that was obtained from participants was treated with confidential

at all cost, by not disclosing any identity e.g... Names, specific age, residential area or any other related information that can give clues to the identity of the participants and the care givers. Furthermore personal information was not disclosed to any third part without the participants concern. The study observed the principle of beneficence by making sure that maximum good came out of it by educating and encouraging sicklers to take care of themselves in whatever activities they engage themselves in. the other consideration was the principal of non-maleficence which aims at minimizing causing harm at all cost be it in ways of asking questions etc.

## CHAPTER FOUR: RESULTS

### 4.0 Introduction

This section involves presentation of the key findings in relation to the topic as well as the relationship with other literatures. In addition this sections presents the study limitations that are relevant and should be noted. Considering the research problem that was established in this study in which it is believed that The Zambian Ministry of health perceive the issue of SCD/SCA to be a public health concern considerations that 20-25% have the disease and about 1-2% of babies are born with it within the country (Kings Health partners, 2021). This study established the consideration that believes that in most cases of SCD/SCA it is perceived to be concerned with physical and biological challenges without considering other related challenges such as social challenges in the lives of sicklers particularly adolescents.

### 4.1 Results

After carrying the study through a focus group discussion and open ended interviews with adolescent sicklers and their respective care giver (mothers), the results indicates that about 8 participants have shared their stories with emotional outlook as a result of negative experiences that they encountered in relation to their medical condition. On the other hand the other 3 participants gave different views and they believe that their social lives are normal as most of their social network such as families and friends are well informed about this medical condition hence they treat them with love and care. The results below presents the detailed views and options of participants with respect to the topic of interest. Note that due to ethical considerations to maintain confidentiality and privacy the participant were coded by numbers and are presented that way through out data analysis.

#### **Theme 1: Perceived their social life to be normal**

##### Participant 1

When I was a bit younger, I barely knew what sickle cell anemia was, hence I can say I used to feel free. Now that parents seat me down to tell me about my medical condition and why we always visiting the hospital and sometimes get admitted for a long time. I tend to experience a lot of pain and doctors call it crisis.

*At first I did not want to believe because I was scared that I will die, I have slowly come to understand a lot of things about me. I have barely experienced negativity from my social life as my mum and dad and my siblings love me and care for me and they don't like it when I get a bed in a hospital. Some of my school friends and teachers knows about me being sickle cell, so my teachers don't let me do big things of school preventive maintenance. My mother is my support and I tell her everything about how I feel about being a sick.*

As a parent it has been difficult for me and his father, because many are times he experiences crisis in the middle of the night. "Once in time it happen when I was not around home had gone for work related then he got sick, I was terrified and so I had to get permission and rushed home". Nowadays he has developed in terms of school, and I can tell that he is embracing self-acceptance and does not withdraw in his social life. I have accessed some form of SCD/SCA program through WhatsApp group and they are helpful in one way or another because we share information with other caregivers.

#### Participant 2

Living with sickle cell is hard, feeling joint pains, wearing warm clothes always, taking folic acid and hydroxiria. But my friends don't laugh at me because everyone thinks am just normal the way I look. I have told a few friend about my condition and they accept me the way I am and they understand why I sometimes get sick and don't come to school.

*I haven't have much crisis recently since grade 10, I am in grade 12, and I hope I will finish school without getting sick. I want to be a doctor as well so that I can be helping people with sickle cell that's why I like the research you are doing and letting people talk about it to know more about the sickle cell. The only time I feel like am accessing some form of support is when we talk about it with my parents and my friends, I do feel bad sometimes for being like this but I don't normal withdraw from my family and friends.*

#### Participant 3

I don't know any supportive programs for sickle cell except the one on WhatApp that my auntie told to me join, a lot of people that have sickle cell are part of the group and they talk about how they get depressed because of sickle cell and that they get stigma from their friends and families. I do learn a lot from them because they give opinions about what to do with this situation. I can agree that having more supportive groups can help people that are depressed with stigma from

sickle cell. Doctors should support these groups and encourage people with sickle cell to be part of the groups.

*I know some of the people on mother's side who have sickle cell, they like talking to me about it and that's how I get to understand some of the things about sickle cell. It is easy for me to open up and tell them how I feel that's why I don't really feel isolated and feel different.*

As a parent I feel the pain of my daughter whenever she has a crisis and body pains it's difficult to manage this condition because it is unpredictable she gets sick even when least expects it. I have seen her get stressed just not knowing if it has anything to do with her sickle cell condition. She opens up to her auntie who is also a sickler her auntie understands her better with this condition and she encourages her to always take care of herself.

## **Theme 2: Perceived their social life to be affected due to SCD/SCA**

Participant 4

This condition has affected my school performance as I tend to miss classes continuously. "Abanandi bala nseka imimonekele" the quotation is a Bemba statement which means my friends make fun about how I look thin and small.

*These days I prefer my own company because I don't have many friends so I just stay in the house and watch TV and press my phone. I don't manage to talk about my sickle cell sickness with people. "Nda unfwa insoni". I just think some people find it fun to know ones disabilities like not able to do sports like my friends. I have not seeing any supportive programs for SCD/SCA.*

Participant 4 gave her view of experience living with sickle cell disease not been easy as an adolescent who is beginning to know and understand how the world works around her. The quotation "nda unfwa insoni" is also a Bemba statement which means I feel imbalanced or rather am not comfortable talking about my sickle cell condition with people as they may have views that can have negative effects on my mental health. In addition the caregiver of the participant gave her view about her experience raising a sickler.

*It has been a bad experience for me financial burden I think a lot about my daughter whenever I look at her. Takwete aba nakwe aikalafye eka (doesn't have many friends, seats*

*alone) most times and I get worried as a parent. I know she is a adolescent hence she need a social life with friends that can influence her positively. Another thing I feel like schools should consider helping sicklers in terms of providing making up classes for them as they miss a lot in academics and it affects their performances.*

#### Participant 5

*For me this experience has been hard and traumatizing I always ask myself questions why me? Will this end? Or will I die? I was supposed to be in 12 by now but am in grade 10 because I sick a lot. When I passed my grade 9, I didn't like my results because I didn't do well because I was missing class every day. I have staying home for almost a year because mom wanted to transfer me to another school. I have friends but just a few because some tease me at school. I do want to be part of my friends but I get imbalanced sometimes coz am a quite person and I don't people talking bad about me so I spend more time alone. Sometime my siblings joke about me being lazy and weak. I have no problem talking about it with my parents and my best friend they understand me. My uncle made me join a WhatsApp group for sickle cell as a supportive group, it is helpful sometimes they tell us how to take care of ourselves and they tell us stay away from friends who drinks alcohol and smokes because it is not okay for our health. I like searching about sickle cell on internet that's how I see other supportive program web sites.*

I am always listening to when she wants to speak about it because sometimes she becomes depressed and isolate herself from her social life even from the family in the house. She talks about how she feels bad because her friends are in grade 12 and some finished school already.” I have noticed that when she opens up to express how she feels, she feels good and accepts the situation and continue her medication which she hates so much” we have WhatsApp groups as some form of supportive programs where share information with other parents of sicklers its helpful.

#### Participant 6

Growing up didn't really matter living with sickle cell, but in my late teen I have had a different experienced, I get teased that I don't grow. I do experience body pains even during classes at school. Most of my friends drink and smoke but I don't because I know I am not supposed to drink or smoke so I usually fond by myself when my friends make plans about drinking alcohol. Sometime I don't feel like part of my friends because I do different things and keep my own

company. I have had girls who have teased me for being shot and its depressing when people cannot accept you socially. I do WhatsApp groups that talk about sickle cell. The groups are helpful because I see a lot of people expresses their feelings and help each other to feel better about the sickle cell condition.

*I wish to join the military after I write my grade 12 but my parents have discouraged me that it can't be possible for me as I don't have enough blood and I don't have to do heavy activities. I do get depressed sometimes people discriminate me like am weak and I can't perform activities as normal boys do. Sometimes I do sit and just wish I had someone to talk to about my life and my feelings. This interview is very helpful because I have never talked to someone about sickle cell like this. I agree to making more supportive programs were people with sickle cell can get to seat and talk about how they can live with sickle cell in the society out there.*

#### Participant 7

*I heard about my condition when I was young I never really paid attention to it because I was not sure what it is. I came to understand about my condition in recent years when I was brought for review by my mum. I do get disturbed especially after I heard people with sickle cell don't live a long life that makes me get scared and think too much. I am young and I want to achieve a lot and become lawyer when I grow up. When it comes to people out there some friends don't say anything and school friends tease me saying "aka kulwala lwala" (meaning the one who always gets sick) and they get scared for me it makes me feel bad because it is not my fault and they are to know that. Mum always tell me to ignore my friends whatever they say and because am intelligent I can do better things.*

As a parent I am always disturbed with my daughter's condition because it never looked good in any one's eyes. I have heard my friends and neighbors say disturbing things about the condition of my child such as "uyu mwana aka endo kula ba mai bake bazaka vutika kumu sunga". The quotation above is a Zambian Nyanja language which means (when this child grows up, the mother will suffer taking care of her).

As a parent I have accepted my child the way she is and I strongly recommend supportive programs in these communities because many people don't have enough knowledge about this condition of sickle cell. People say anything anyhow without them knowing that they are destroying other people and I believe that the more people get educated about these conditions and accept sicklers

the way they are the more children and adults having sickle cell will be saved just like how HIV/AIDs was now its being accepted and it saves a lot of people. Again more health workers who understand sickle cell in different angles should be engaged in providing social supportive services.

#### Participant 8

I feel pain when it's cold and that's how I get sick, it has being a long time since I was come here to be admitted I just come here for checks ups and blood transfusion. Some friends have made fun of me, and some just asks why I have yellow eyes.

*Sometimes in school I separate myself from friends because they play excessive games, mother said I am not supposed to play such games. I think a lot about sickness and I wish I was fine I am scare that I can die. I don't talk to anyone about it I feel shy, so I just keep it to myself. I am not sure about supportive programs I have never head of them and I don't know how they can help I feel shy so I don't think I can be going to supportive programs.*

#### Participant 9

My mom always tells me that am different so I am not supposed to do some things that my friends do, I can't do heavy work at home because mother tells me to take enough rest and eat a lot of vegetables. My brother's tease me saying am a weak soldier. A few friends at home have told me that am sick so they cannot lay their hands on me because I can die. I feel bad some times as it feel like they are pitying me.

*I know I am sick but I never want people to look at me like I cannot do anything because I will get sick. I don't talk about my condition with anyone because I have insecurities about it. I don't like to be bullied as they always do at school because I am small. I support supportive programs because that way people with sickle cell can get to interact with each other and talk about their lives to teach others how to live and help depression in people with sickle cell. For now I don't go to any of those supportive programs but I have a friend at school who is also sick of sickle cell we do talk about it and I understand him better when he gets sick than anyone else in class.*

### **Theme 3: Insufficient knowledge about SCD/SCA and its challenges in the social context**

Participant 10

“I don’t know much about sickle cell so I don’t know what to say, I just feel body pains sometimes”

Participant 11

*I have never paid attention to how people see me because I have sickle cell, I do get sick and miss classes sometimes but I never really understand that its sickle cell I have actually come to understand a lot about this disease after interacting with you and all these other patients. I have never told any of my friends that am sick so I don’t not know if I do get stigma or not. I would like to be part of supportive programs so I can learn more about sickle cell and how to live with it I didn’t know enough because I don’t know anyone with sickle cell at home or school so no one talks about it.*

## CHAPTER FIVE: DISCUSSION

### 5.0 Discussion

Considering the study's statement of the problem and its objectives and specific research questions in relation to other literatures this study can agree in the line of the studies done in global view such as the study done by Bulgin, Tanabe, and Jenerette (2018) systematic review and Yalinie et al. (2018) in which the authors acknowledged stigmatization and discrimination among people with the condition of SCD/SCA. Stigmatization and discrimination can refer to the discrediting, degrading, and shaming of a person as a result of possessing certain characteristics or attributes. Stigma and discrimination can carry forms such as public-stigma involving negative attitudes from the social setting, self-stigma referring to negative attitude and perception within an individual. These type of stigma have elements such as prejudice, labeling, social isolation, stereotyping, rejection, status loss, ignorance, low self-esteem and so on (Muhammad et al, 2021). Furthermore on a global scale this study can be compared and be in agreement with an integrative narrative review conducted by Brenda, Ann-Louise and Susan (2018) in which they concluded that SCD/SCA affects various aspects of adolescent's life that requires supportive needs hence the issue of supportive programmes should not be ignored and the need to multi-collaborate in improving SCD/SCA wellbeing.

In the regional perspective the study can be in relation to the study of Atim et al. (2019) and Julie et al. (2021) in which they connect in the aspect of acknowledging that not only do sicklers are being affected in their social lives, care givers such as parents or guidians as they carry different burdens such as financial, pscological and mental, as it was also observed in the results of this study. The authors concluded supportive programmes should consider caregives involvement for better managements and treatment of SCD/SCA at house level. This study argued against the idea of Seham et al (2019), in which the aurtherors argued for strengthening self-management programs as a way to empower adolescents' with SCD to cope with Physical, emotional and social challenges through educational programs as this studies focus was to support the pesrpective of mult-collaboration to improve wellbeing of sicklers. However as observed in the results presented there is an incrisease in the use of digital platforms such as social media like WhatsApp groups that most sicklers use as an effective programe for social supportive network.

In the local pespective the study by Moraes, Ngomah-Moraes, and Munsaka (2019), acknowledged major psychological concern that arise as social challenges of SCA in adolescents as they are prone

to depression, anxiety, self-concept and challenges of not being accepted socially as in line with the results of this study. The authors further stated that school environment should be utilized as supportive networks to help adolescents make sense of their conditions and a coping mechanism.

The relevance of this study can be placed on the emphasis that it is a study that has been done in different perspectives be it globally, regional and local with similar context of SCD/SCA in adolescents and their social lives. However with the detailed analysis and evaluation there has been some gaps identified among this study and other literatures. In the globally and regional perspective, similar literatures have results that acknowledge the various aspects of social life that tends to be affected in adolescents' lives due to SCD/SCA.

In zambian perspective it can be concluded that there is a weakness in the information about this topic. The study by Moraes, Ngomah-Moraes, and Munsaka (2019), which had results relating to this study and adopted similar methodology of qualitative approach, phenomenological study design and interpretive phenomenon data analysis. The gap can be identified on the scope as the authors focused on the education aspect of adolescent's social lives living with SCA on contrary with this study as it focused on many aspects of adolescent's social life and not only academic aspect.

### **5.1 Limitations**

The research limitations signify the weaknesses in the in various aspects of the research be it the study approach, study design, the methodology or other external factors that may influence outcomes and conclusions of the research (Paula T. Ross,; Nikki L Bibler Zaidi, 2019). The study encountered several limitations some anticipated, others were not anticipated. The major limitations that were considered in the study includes;

Delayed approval from the various bodies such as the Lusaka Health Office Ministry of Health as well as the site administrative offices. It is for this reason that some potential participants from the targeted population were not recruited as they got discharged from the site. The other anticipated limitation was having young sicklers at the children hospital that did not meet the inclusion criteria, however a few met the required age range and were recruited in the study. On the other hand at the adult hospital not much adolescents were identified only a few got recruited and participated in the study. This limitation led to not meeting the desired sample size but a reduction. Language barrier was another limitation to consider, this is due to some languages that participants were

comfortable with in order to communicate effectively. Some languages were not easy to interpret throughout data analysis.

It is beyond the scope of this study to address the questions of having supportive programs and if the current supportive programs are effective because it's a subjective topic with different views from different participants. In addition it is also beyond the scope of this study to address the aspect of how sicklers cope with their condition in respect to their social life, most participant did not find a proper way to answer the question of "what do you do to maintain your social life or how do you cope in your everyday life living with this condition?" It can be concluded that most participants interacted with had not given the above question a thought.

## **CHAPTER 6: CONCLUSION AND RECOMMENDATIONS**

### **6.0 Conclusion**

In the end conclusions can be made by considering the research questions of the study that includes what the challenges sickle cell anemia had on the social lives of adolescents admitted at UTH. How do adolescents with sickle cell disease at UTH cope and maintain their social lives? And what appropriate social life supportive programs have been implemented for adolescents living with sickle cell disease at UTH? After conducting the study the questions were answered as; there are various challenges that adolescents with SCD/SCA experience in their daily lives in the social context. Some of these challenges include stigma, discrimination, rejection, isolation and so on. The other research question addressed the issue of coping in the social context, it was observed during the study and in the results of the study that it's through self-acceptance that many sicklers cope with the condition and try to live a normal life by maintaining their social lives with family and friends. The final research question involved the issue of assessing supportive programs that were implemented by both health providers and personal. The study concludes that there has not been enough supportive programs however there has been the system of using social media platform such as WhatsApp to form groups that are SCD/SCA related to provide and share information and support people with this condition and their respective caregivers.

Further conclusions about this study can be made by reflecting to the methodology used for data collection, presentation and analysis. The study utilized qualitative with the acknowledgement that the phenomenon of sickle cell and lived experience is subjective and takes the views and opinions of the respondents. IPA and narrative analysis were used to effectively present the views and opinions of respondents with respect to events, moments, memories as well as stories that they experience in their social lives.

## **6.1 Recommendations**

With a concise acknowledgement of the results and limitations to this study recommendations can be made that;

1. Future research should consider adopting similar methodology for all scales be it global, region or local perspective. This is due to the weakness identified in the review of available literature in which most adopted different methodologies.
2. The huge gap was identified in the local perspective that indicates that there is little information about this study compared with the global and regional perspective, hence is a relevant suggestion to encourage sickle cell researchers to consider similar research and publications.
3. Practitioners should consider the holistic view of managing and treating people with SCD/SCA by considering effective ways of improving social lives through social supportive programs.
4. The public in general should be educated about sickle cell awareness and encouraged to be of support to sicklers in various social settings.
5. The use of smartphone or rather social media platforms to implement social supportive programs can subjectively be said to be effective hence should be strengthened. In addition the suggestion can be posed to encourage implementation of physical social supportive programs be it in schools, admission health sites, in communities and so on.

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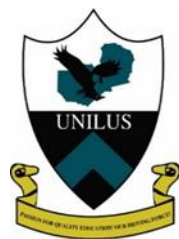
## Appendix

### Interview guide

1. What is the experience of living with SCA/SCD like?
2. Can you tell me the experience of living with SCA/SCD in the social context?
3. Can you explain how you cope with the effects of SCA/SCD, such as discrimination, stigma, stress, the feeling of being different?
4. How do you try to maintain your social life?
5. What/who do you consider your social supportive network in your SCA/SCD journey?
6. What do you think about delivery of community based social supportive programs for sicklers?
7. Have you accessed social supportive programs before? If yes how are the program's effectiveness?

Note: some questions are not included in the interview guide as they are unstructured and they are determined by the response of the interviewee

Informed consent



UNIVERSITY  
OF  
LUSAKA

TITLE OF STUDY;

**CHALLENGES OF SICKLE CELL ANEMIA ON ADOLASCENTS SOCIAL LIFE: A PHENOMOLOGICAL STUDY AT UNIVERSITY TEACHING HOSPITAL IN LUSAKA**

PRINCIPAL INVESTIGATOR;

NAME: **SIMON BANDA**

ADDRESS: **Chalala**

PHONE: 0971061411

EMAIL: sylentnaz@gmail.com

**General things you should know about research studies**

You are being asked to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, at any time. Deciding not to be in the study or leaving the study before it is done will not affect your relationship with your health care providers. You are not forced to be in the research study to receive health care. You are free to ask questions at any time. If you decide to take part in this study, you are required to sign or thumbprint this consent form.

Please read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information.

Research studies are designed to obtain new knowledge that may help other people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

## **PURPOSE OF STUDY**

Sickle cell disease/Sickle cell anemia SCD/SCA traits are known to be carried by about 20-25% of the population and about 1-2% of babies are born with the disease within the country. Living with SCD/SCA is associated with many effects in one's life and to one's family members, despite effects such as biological and physical, there are other effects such as social in which there are less considerations taken. The study aims to assess social challenges of SCD/SCA in the daily lives of adolescent, at the University Teaching Hospital in Lusaka, Zambia.

## **STUDY PROCEDURES**

- The study will involve 15 participants and will be based on a 7-10 minutes interviews with 7 participants, and other participants will be asked to take part in a focus group discussion for at least 25-30 minutes.
- The study is anticipated to take about 2 to 3 days. If you agree to take part in this study, everything for the study can be done in one day.
- For data collection tools, the study will involve note writing and audio recordings only
- The study will not involve looking at any of your medical records.
- If you agree to take part in this study, you will be asked a series of questions about the challenges of sickle cell on your social life.

## **BENEFITS**

There may not be any direct benefit to you from participating in this study. However we hope that the information obtained from this study may help you in terms of self-assessment and encourage self-care. The results of this study may also help to improve social supportive programs for sicklers in different communities in Zambia.

## **RISK**

- Some of the questions may upset you and how you feel about being a sickler.
- You can decide to skip questions or refuse to answer any questions that you do not want to answer, and you may terminate your involvement at any time if you choose.
- There may be a small chance that someone outside of the study may overhear our conversation by accident. We will do everything in our power to stop this from happening.

**CONFIDENTIALITY**

Every effort will be made to keep your personal information confidential. Your study information will be identified by a code to protect your privacy. Any publication about the study findings will not use your name, location and age. The findings may be reviewed by the supervisor, representatives of the University of Lusaka Research Ethics Committee and the Zambia National Research Authority. Participant data will be kept confidential except in cases where the researcher is legally obligated to report specific incidents such as abuse and suicide risks.

**COMPENSATION**

There will not be any form of compensation for this study. However if the participant will require form of transport to come and participate for interview or focus group discussion, the researcher will not be restricted to help and provide transport. It will also be the responsibility of the researcher to provide transport even after the participant has withdrawn from the study in the process of an interview or focus group discussion.

**CONTACT INFORMATION**

If you have questions at any time about this study, or you experience adverse effects as the result of participating in this study, you may contact the researcher whose contact information is provided on the first page.

**CONSENT**

I have read and I understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant’s signature..... Date.....

Investigator’s signature..... Date.....

Witness’s signature..... Date.....

### Work plan

ACTIVITY	2022 AUG	2022 SEP	2022 OCT	2022 NOV	2022 DEC	2023 JAN	2023 FEB	2023 MAR	2023 APR	2023 MAY
Proposal writing										
Proposal defending										
Proposal submission										
Waiting for ethical approval from school ethical committee and the NRA										
Preparation of tools and assistants										
Requesting and waiting form permission from the site respective bodies										
Data collection										
Data analysis										
Dissertation writing										
Dissertation submission										

Work Budget

Budget Category	Unit Cost (K)	Multiplying Factor	Total Cost (K)
<b>1. Personal</b>	<b>Dairy wage &amp; per diem</b>		
		<b>Number of staff &amp; days</b>	
- Researcher	100	1 x 7 days	700
- Assistant	50	1 x 7 days	700
		<b>Sub total</b>	<b>1400</b>
<b>2. Transport</b>			
- 50 for researcher		3 days	150
- 50 per assistance		2 x 10 days	100
- 35 per participant		1 day	210
		<b>Sub Total</b>	<b>460</b>
<b>3. Supplies and stationery</b>	<b>Cost per item</b>		
		<b>Number of items</b>	
- Photocopying	- 1.0 per page	3 pages	3
- Pens	- 5	4	20
- Pencils	- 2	2	4
- Printing	- 3	2	4
- Binding	- 30	55	165
- Data storage devise (flash disk)	- 50	2	160
		1	50
		<b>Sub Total</b>	<b>352</b>
<b>Total</b>			<b>2212</b>
10% incidentals			500
<b>GRAND TOTAL</b>			<b>2712</b>

Unilus Ethical Clearance letter

**SCHOOL OF MEDICINE AND HEALTH SCIENCES LEOPARDS HILL  
CAMPUS**

Plot No. 37413, Off Alick Nkhata Mass Media. P. O Box 36711, Lusaka.  
Phone: +260211258505, 258409 Fax +260211233409; Cell +260976075850,961917862,  
E-mail:unilus@zamnet.zm,ictar@zamnet.zm

**SCHOOL OF MEDICINE AND HEALTH SCIENCES  
RESEARCH ETHICS COMMITTEE**

Ref no: IORG0010092-2023/064

Date: 15<sup>th</sup> DECEMBER, 2022

SIMON BANDA - BSPH19217791

**Re: RESEARCH TITLE: CHALLENGES OF SICKLE CELL ANAEMIA ON  
ADOLESCENT'S SOCIAL LIFE: A PHENOMENOLOGICAL STUDY AT UNIVERSITY  
TEACHING HOSPITAL IN LUSAKA**

The above research was submitted to the research ethics committee for review. The study has no major ethical problems and is approved subject to the following:

1. The study cannot be changed without express permission of the UNILUS Research ethics committee
  2. Approval from the Lusaka District health Management or equivalent health authorities should be sought.
  3. The study tools should be added.
  4. An informed consent form should be attached and filled by all study participants (If dealing with primary data)
  5. The risks and benefits should be included in the consent form.
  6. Ensure before commencement that approval is sought from ZNHRA
- Congratulations and the committee wishes you success in your work.



Prof Kasonde Bowa

MSc(Glasgow),M.Med(UNZA),FRCS(Glasgow),FACS,FCS,DPH(LSTMH),MPH(UCL)

Chairman- UNILUS REC

Professor of Urology and Consultant Urologist

Executive Dean

University of Lusaka and University Teaching Hospital School of Medicine and Health Sciences.  
**SCHOOL OF MEDICINE AND HEALTH SCIENCES LEOPARDS HILL  
CAMPUS**

Plot No. 37413, Off Alick Nkhata Mass Media. P. O Box 36711, Lusaka.  
Phone: +260211258505, 258409 Fax +260211233409; Cell +260976075850, 961917862,  
E-mail: unilus@zamnet.zm, ictar@zamnet.zm Date:

15<sup>th</sup> DECEMBER, 2022

.....  
.....  
.....  
**PERMISSION FOR SIMON BANDA - BSPH19217791 TO CONDUCT A RESEARCH  
STUDY AT YOUR FACILITY/ INSTITUTION/ORGANIZATION**

Reference is made to the above subject matter

The University of Lusaka, School of Medicine and Health Sciences here by requests for permission for **SIMON BANDA** Public Health Student to conduct research at your facility/ institution/ organization, entitled; **CHALLENGES OF SICKLE CELL ANAEMIA ON ADOLESCENT'S SOCIAL LIFE: A PHENOMENOLOGICAL STUDY AT UNIVERSITY TEACHING HOSPITAL IN LUSAKA.** The research is in partial fulfillment of the requirements for the degree of Bachelor of Science Public Health. This is purely for academic purposes and information gained in such a way will not be used in the public domain without prior authorization from the institutions/ organizations involved.

The research topic has been cleared by the University of Lusaka, School of Medicine and Health Sciences Research Ethics Committee as per the attached copy. Data collection is expected to be done from **1<sup>st</sup> January, 2023 to 31<sup>st</sup> March, 2023.**

The University of Lusaka avails itself of this opportunity to review to your office the assurances of its highest considerations and looks forward to your timely and favorable response.



Prof Kasonde Bowa

MSc(Glasgow),M.Med(UNZA),FRCS(Glasgow),FACS,FCS,DPH(LSTMH),MPH(UCL)

Chairman- UNILUS REC

Professor of Urology and Consultant Urologist

Executive Dean University of Lusaka and University Teaching Hospital School of Medicine and Health Sciences.

NHRA approval

NATIONAL HEALTH RESEARCH AUTHORITY

NATIONAL HEALTH RESEARCH AUTHORITY

Lot No. 18961/M, off Kasama Road, Chalala, P.O. Box 30075, LUSAKA

Ref No: NHRA000029/24/01/2023  
2023 Tell: +260211 250309

Email [znhrasec@nhra.org.zm](mailto:znhrasec@nhra.org.zm)

Date: 24th January  
[www.nhra.org.zm](http://www.nhra.org.zm)



The Principal Investigator,

Simon Banda,

UNILUS,  
Lusaka, Zambia.

Dear Mr. Banda,

**Re: Request for Authority to Conduct Research**

The National Health Research Authority is in receipt of your request for ethical clearance and authority to conduct research titled “**Challenges of Sickle cell Anemia on Adolescents Social life: A Phenomenological study at University Teaching Hospital.**”

I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA bi-annually from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, University leadership, and all key respondents.

Yours sincerely,  
Acting Director/Chief Executive Officer

Ms Sandra Chilengi-Sakala, National Health Research Authority

MoH approval

All correspondence should be addressed to the  
Provincial Health Director  
Telephone: +260 211 256813  
Fax: +260 211 256814  
Telephone: +260 211 256815  
Cell: +260 974 787873  
+260 963 908260



REPUBLIC OF ZAMBIA  
**MINISTRY OF HEALTH**

In Reply please quote:

File No.:.....  
**LSKPHO/101/8/1**

Lusaka Provincial Health Office  
P.O. Box 32573  
LUSAKA

14<sup>th</sup> February, 2023

Mr. Simon Banda  
UNILUS  
LUSAKA

**RE: PERMISSION TO CONDUCT RESEARCH**

Lusaka Provincial Health Office is in receipt of your letter requesting for permission to conduct a study titled "**Challenges of Sickle Cell Anaemia on Adolescents' Social life: A Phenomenological Study at University Teaching Hospital in Lusaka**"

My office is glad to inform you that it has no objection to your request provided that;

1. The relevant Institution Director where the study is being conducted are fully appraised;
2. Progress updates are provided to Lusaka Provincial Health Office and the District Health Office biannually from the date of commencement of the study;
3. The final study report is cleared by NHRA before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by NHRA, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted.

Kindly ensure minimum interruption in health service delivery at selected health facilities.

By copy of this letter, the District Health Office / Institution are advised to allow you undertake the above-mentioned research and provide you with the relevant support.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'Dr. Consy Mwale'.

Dr Consy Mwale  
Provincial Health Director  
LUSAKA PROVINCE

CC. Senior Medical Superintendent- UTH  
District Health Director – Lusaka District

UTHs approval

Telephone: (260) 211 253947  
Fax: (260) 211 250305  
Email: info.childrens@uth.gov.zm



In reply please quote:

No:.....

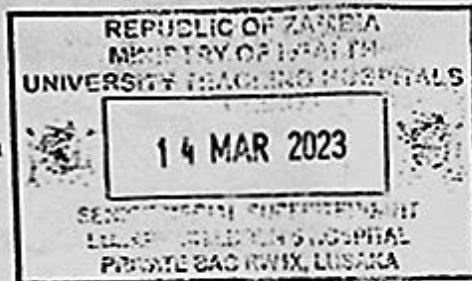
REPUBLIC OF ZAMBIA

# MINISTRY OF HEALTH

OFFICE OF THE SENIOR MEDICAL SUPERINTENDENT  
UNIVERSITY TEACHING HOSPITAL  
CHILDREN'S HOSPITAL  
PLOT NO. 3541, NATIONALIST ROAD  
PRIVATE BAG RW IX  
LUSAKA, ZAMBIA

14<sup>th</sup> March 2023

Mr Simon Banda  
Unitus  
LUSAKA



Dear Mr S. Banda,

**RE: PERMISSION TO CONDUCT RESEARCH: YOURSELF**

Reference is made to your letter dated 27<sup>th</sup> February, 2022, in which you are seeking permission to conduct research entitled "Challenges of Sickle Cell Anaemia on Adolescent's Social Life: A Phenomenological Study at University Teaching Hospital in Lusaka"

Having obtained the necessary ethical approvals, I am pleased to inform you that permission has been granted. You may proceed with commencement of data collection in accordance with the terms outlined in your LAMUBREC/NRHA approvals.

Wishing you all the best in your research

Kind regards

Dr M. Mwenechanya  
SENIOR MEDICAL SUPERINTENDENT  
UTHS