PREVALENCE AND FACTORS THAT AFFECT TRANSITION FROM PAEDIATRIC TO ADULT SERVICES AMONG ADOLESCENTS WITH SICKLE CELL DISEASE IN WEBUYE COUNTY HOSPITAL

BY

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STUDENTS' DECLARATION

I certify that this dissertation is my original work and has not been presented for the award of a degree in any other university.

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DEDICATION

I dedicate this study to all adolescents with Sickle Cell Disease in Kenya and around the world.

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ABBREVIATIONS

AYA	Adolescent and Young Adult
CHD	Congenital Heart Disease
CF	Cystic Fibrosis
CKD	Chronic Kidney Disease
FGD	Focus Group Discussion
Hb	Haemoglobin
HbAS	Haemoglobin AS
HbS	Sickle Haemoglobin
HbSS	Haemoglobin SS
HIV	Human Immunodeficiency Virus
IBD	Inflammatory Bowel Disease
RBC	Red Blood Cell
SCA	Sickle Cell Anaemia
SCD	Sickle Cell Disease
SCT	Sickle cell Trait
SLE	Systemic Lupus Erythematosus
SMART	Social-ecological Model of Adolescent and Young Adult Readiness to Transition
WCH	Webuye County Hospital
WHO	World Health Organization

ABSTRACT

Background: New advances in medicine in the last thirty years have made it possible for children with sickle cell disease to live past their childhood period. Children with Sickle Cell Disease (SCD) are now surviving well into their adolescent years and ultimately transitioning from paediatric to adult services. Adolescents with sickle cell disease must learn how to navigate the dynamic health care system besides dealing with the societal stigma associated with Sickle Cell Disease. In view of ensuring good health care outcomes and continuity of care for adolescents with SCD, transition should be well understood and given priority.

Study Objectives: The study sought to determine the proportion of adolescents with SCD who transition from paediatric to adult services and those who attend at least two scheduled adult clinic visits thereafter at Webuye County Hospital (WCH) and to explore the factors that affect successful transition from paediatric to adult services among adolescents with SCD.

Study design: We employed a mixed method study approach in which we conducted both retrospective cohort study and cross-sectional survey.

Methods: We included all eligible adolescents with SCD aged between 12-19years enrolled in paediatric and adult medical outpatient clinics at WCH between January 2015 and April 2020. We obtained socio-demographic and clinical characteristics from the patient physical files. Different variables were analysed using STATA version 12.0 and quantitative data was summarised into frequencies, proportions and measures of central tendency and p value of <0.05was considered significant.

Adolescents with SCD in active care and those lost to follow up were contacted via telephone and invited to the hospital to participate in the study.

Focus group discussions and in-depth interviews were conducted for adolescents still in active care and those lost to follow up respectively to explore the factors affecting transition to adult services. Key informant interviews were conducted among healthcare workers using open ended questions interview guides. Qualitative data was transcribed and translated accordingly, and scripts coded into emerging themes.

Results: A total of 80 adolescents with SCD (55% male) with a median age of 16 (IQR 14-17) years were enrolled in the study. 68 (85%) out of the 80 adolescents were living in Bungoma county with 58.5%living in villages adjacent to the hospital. The median age at first enrolment to the paediatric clinic was 7(IQR 5-8) years with an overall duration of

follow-up of 9(IQR 8-11) years. Out of the 80 adolescents, 65(81.3%) had a positive sickling test as the mode of SCD diagnosis.

In general, 50 (62.5%) out of the 80 adolescents had ever attended adult medical outpatient clinic at least once after attaining the age of 12 years giving a prevalence of ever transitioning to adult services of 62.5% (95% CI 51.3, 73.7). 1(2%) transitioned at the appropriate age of transition as per the hospital protocol while 49 (98%) adolescents had delayed transition.

Out of the 50 adolescents who had transitioned to adult care services, 8 (10%) were still in active care and had attended more than two scheduled appointments in the adult medical outpatient clinic giving a prevalence of sustained successful transition in adult services of 10% (95% CI 3.8, 16.3)

The factors perceived by the adolescents and healthcare workers as barriers to transition included: lack of transition knowledge, financial constraints, fear of leaving paediatric clinic, stigma, poor preparedness to transition and negative first time encounters at the adult clinic. Facilitators to transition included early preparation to transition, good family support and positive first -time encounters at the adult clinics.

Conclusions and Recommendations: Two thirds of the adolescents with SCD had ever transitioned to adult services with majority having delayed transition. Sustained successful transition was poor with barely a quarter of the adolescents in active care in the adult services. Significant barriers to transition include: lack of transition knowledge, financial constraints, poor preparedness to transition, negative first -time experiences in the adult clinics, stigma and fear of leaving paediatric clinic. Major facilitators are: Good family support, positive first time encounters at adult clinic and early preparation.

Based on the findings from the study, we recommend a transition program that will address structural and interpersonal issues of adolescents and healthcare providers to ensure successful transition outcomes.

1.0 CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW

1.1 Introduction

Sickle Cell Disease (SCD) is a huge public health concern that mostly affects people of African, Asian and Mediterranean descent [(1)]. Every year, more than 300,000 babies are born with SCD in the world with more than half of these births recorded in the Sub-Saharan Africa[(2)]. In Kenya the burden of SCD is experienced in the malaria endemic zones of the Coastal and Western parts. About 80% of children with sickle cell disease live in western Kenya[(3)].

Owing to medical advances in the last three decades, diseases such as SCD that were usually severe and fatal in childhood have been transformed to long-term chronic conditions in resource rich countries[(4)].The use of prophylactic penicillin, hydroxyurea, vaccination and blood transfusion has markedly increased the life expectancy of children with SCD who survive to adulthood. In Sub-Saharan Africa, a region with limited medical advancement, the high mortality rate of children with SCD lessened the need for adult-oriented medical care. However, early screening and improved medical services are rapidly taking shape contributing to improved survival of children with SCD into their late adolescence[(5)]. Inevitably, these patients ought to transition from paediatric to adult healthcare services.

Transition from paediatric to adult care for chronic illnesses happens to coincide with adolescence, a period characterized by rapid physical and psychosocial changes. Adolescence is a period of growth experienced between the ages of 10 and 19. Adolescence is one of the most difficult phases in life. Even the well composed adolescent battles with issues of identity, autonomy, sexuality, and relationships. Questions on identity, purpose in life and relationships often preoccupy the minds of most adolescents. Common to this phase are also eating disorders, substance abuse and violent behaviours that can lead to acute health problems or even long-term health complications later in life[(6)].

Adolescents with SCD usually tend to face multiple tragedies as they have to battle with issues arising from adolescence, as well as those of the SCD itself. Unpredictable painful crises, teasing from peers associated with physical appearance e.g. jaundiced eyes, several hospital admissions due to disease progression and academic difficulties are some of the major challenges that adolescents with SCD face during this vulnerable phase of life[(7)].This can be very stressful for them to handle all at once and can lead to poor health outcomes if the transition process is poorly tackled. In this study we aim to determine the proportion of adolescents with SCD who successfully transition to adult services and the factors that affect their transition from paediatric to adult services.

1.2 Literature Review

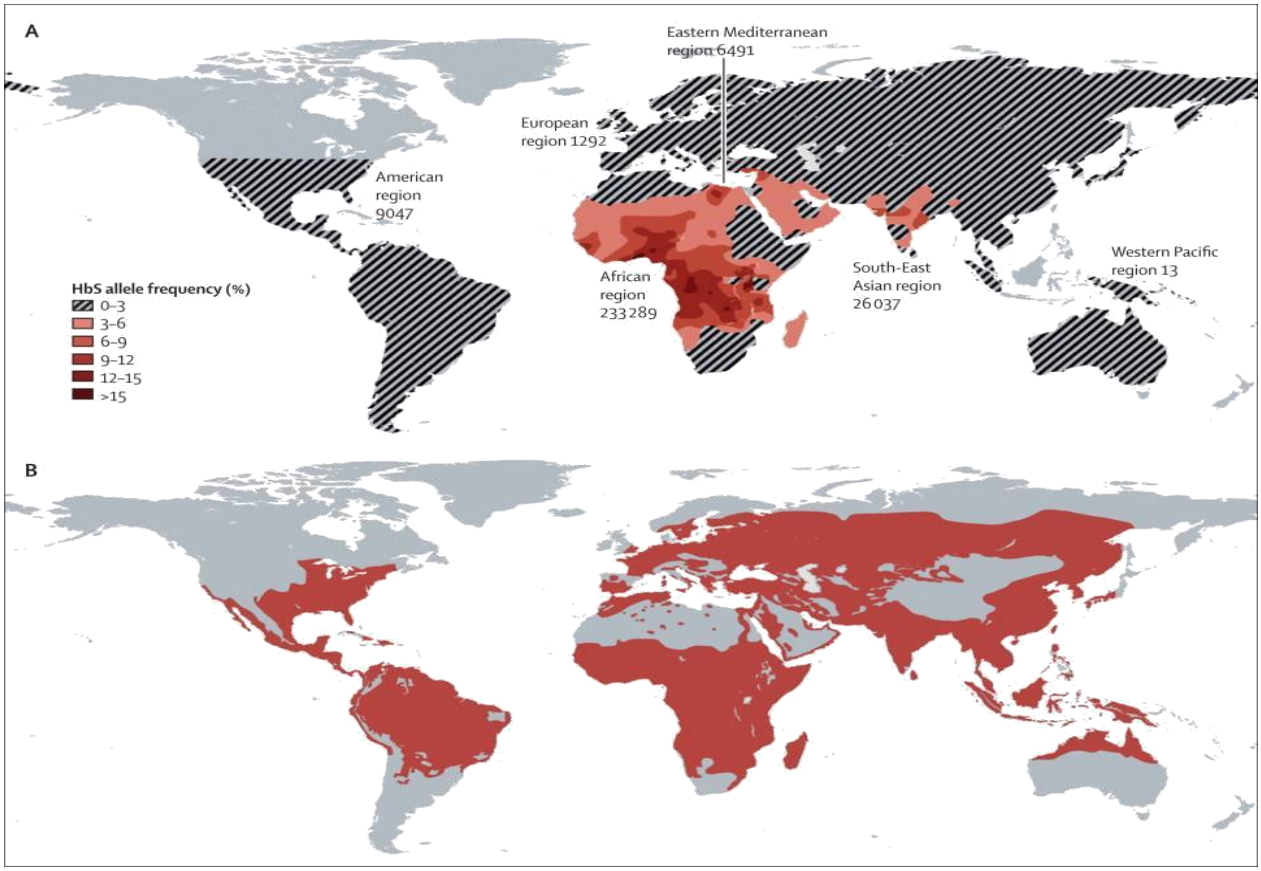
1.2.1 Epidemiology of Sickle Cell Disease

Globally more than 4.4 million people are affected with SCD and over 43 million have Sickle Cell Trait (SCT)[8]. SCD also called Sickle Cell Anaemia (SCA) is very common among the people of Sub Saharan Africa, India and Middle East regions. Migration of people has resulted to occurrence of the SCA gene which is now frequently found in the American Continent [9].

Sub-Saharan Africa has quite a substantial burden of SCD with the bulk of the disease experienced in malaria endemic zones. High prevalence rates of SCT, approximately 10-45%, are experienced around equatorial Africa and the incidence decreases markedly in the North and South African regions to approximately 1-2%. This distribution shows that SCT confers protection against malaria. However this advantage has also led to high rates of defective gene in the malaria endemic zones [9].

In West African countries such as Nigeria and Ghana, SCT rate is about 15-30%, while in the East African region, Uganda has a frequency rate of as high as 45% in the Baamba tribe [9].

In Kenya, several studies have been conducted to determine prevalence of SCD in the malaria endemic zones of Coastal and Western Kenya. In a population based cross sectional survey in 2013, Foote et al showed the prevalence of Haemoglobin SS (HbSS) and Haemoglobin AS (HbAS) to be 1.6% and 17.1% respectively in preschool children in western Kenya. Similarly, Komba et al in 2009 reported the prevalence of SCD to be 1.6% in a hospital-based surveillance comparative study in Kilifi District, Coastal Kenya [8]. The global distribution of SCD is shown in *Figure 1* below.



Source: Science Direct

Figure 1: Map of global distribution of Sickle Cell Disease

1.2.2 Overview of Sickle Cell Disease

Sickle cell disease is a genetic blood disorder that occurs when sickling of the red blood cells occurs due to inadequate oxygen resulting to vascular injury, obstruction of the smaller vessels of the circulatory system, chronic anaemia and organ dysfunction.

SCD results from a single point mutation on the B-globin subunit of the Haemoglobin (Hb) (replacement of glutamic acid with valine in the 6^{th} position) leading to a defective form of haemoglobin called Sickle Haemoglobin (HbS). If a person inherits two copies of HbS mutations, he/she is homozygous (HbSS) and is said to have the disease whereas a sickle cell carrier inherits only one defective HbS from either parents (HbAS) and do not manifest clinical disease[(1)].

HbS polymerises under low oxygen states like stress resulting in deformed Red Blood Cells (RBC) with a characteristic sickle shape.The deformed RBCs block the small blood vessels of circulation leading to ischaemia and infarction of the tissues and chronic anaemia which maninests clinically as sickle cell disease crises.

SCD affects several organs in the body and patients present with various clinical manifestations and complications which worsen over time. Painful crisis is the most common presentation of SCD and occurs due to microvascular obstruction leading to tissue infarction. Other SCD crises include acute chest syndrome, sequestation crisis, aplastic crisis and hemolytic crisis. Significant proportion of adolescents with sickle cell disease will begin to experience signs and symptoms of complications that were earlier on latent such as kidney disease, pulmonary hypertension and increased cerebral infarcts[(7)]. Closer monitoring and continuous care with the healthcare providers is therefore crucial at this stage. Additionally, patients with SCA have increased risks of infections, cardiomyopathy and hepatic diseases. If SCD is left untreated, early mortality is inevitable. *Table 1* below shows a summary of clinical manifestations of SCD in paediatric patients.

Table 1: Clinical manifestations of paediatric Sickle cell disease

Paediatric SCD	
Infants	**Children**
Pain in chest, abdomen, and limbs/joints Dactylitis Anaemia Mild jaundice Enlarged spleen Fever Frequent upper respiratory infections	Pain (acute or chronic) Acute anaemia Infections Jaundice Poor nutritional status and growth Academic failure Delayed puberty

Effective management of SCD begins with early identification of the disease in the new-borns through neonatal screening. This allows for prompt commencement of prophylactic penicillin and pneumococcal vaccinations which aid to prevent significant infections(10). SCD education for parents and family should then be initiated and continue throughout childhood. Initial education should be centred on genetics and inheritance of the disease, need for prophylactic penicillin and importance of vaccinations. Later in the childhood phase, education on identification and early medical intervention on vaso-occlusive crises should be initiated. Discussions on the possible treatment options such as hydroxyurea, transfusions and stem cell transplant should also be done at this stage. As the affected child grows to adolescence, education should focus on SCD and its complications and acquisition of skills that will allow them navigate through the healthcare systems, especially during transition from paediatric to adult care.

Patients with SCD are prone to serious life-threatening bacterial infections and as such, preventive measures such as prophylactic penicillin and vaccinations (pneumococcal, H. influenza, meningococcal and influenza) should be initiated. Regular follow-ups with healthcare providers ensures comprehensive care such as transcranial doppler ultrasonography that help identify children who are more likely to develop primary strokes as well as screening for other end organ damage. In addition, use of hydroxyurea reduces the incidences of vaso-occlusive crises and frequent hospitalizations. Serial transfusion significantly reduces the risk of primary and secondary strokes [(10)].

1.2.3 Transition of Adolescents from Paediatrics to Adult Healthcare Services

Transition is a multifaceted vibrant process involving movement of adolescents from paediatric-oriented to adult-oriented healthcare systems while addressing their medical, psychosocial and educational/vocational needs[(4)]. Transition progress varies for each adolescent and their families and should therefore be individualized. If well-co-ordinated, transition will ensure optimization of health for adolescents with chronic illnesses and make it easy for them to attain their maximum potential[(11)].

In contrast to transfer, (a single-time activity of moving somebody or something from one place on to the next) transition is a life changing process which individuals, their families and healthcare providers experience together, and for which actions should be put in place to increase the chances of success.

In 2001, a consensus policy statement on health care transition for adolescents and young adults with chronic health conditions was crafted and subsequently recommended by the America Academy of Paediatrics, the America Academy of Family Physicians and the American College of Physicians-American Society of Internal Medicine. In the interest of ensuring successful transition to adult-centred health care systems, the policy statement advocates for competent health care workers to be involved in the transition, portable and accessible medical summaries for smooth transfer of care, current transition plans with involvement of the patient and their families, affordable and comprehensive health insurance and the equal standards for primary and preventive health to be applied to adolescents and young people with chronic condition.[(11)]

1.2.4 Two Different Worlds: Paediatric versus Adult Healthcare Services

Understanding the uniqueness of paediatric and adult services is an important aspect in transitioning adolescents with chronic diseases. Striking differences in terms of extent of decision-making processes, psychosocial supports and family involvement are apparent between the two systems.

Paediatric care is usually considered as more „caring" with healthcare workers being actively involved in the patient"s management, ensuring adequate follow-up and adherence to medications. Additionally, there is a lot of parental involvement in decision making and consent processes and care includes both family and interdisciplinary team. Relationships between the health care providers and patients are well established due to the more time taken in the system.[12]

On the contrary, adult care centres focuses on the individual. The patient makes his/her own decision concerning the treatment plan and disease management, with minimal familial involvement. Unlike in paediatric centres, issues on sexuality and future plans such as career and independence are usually discussed in adult centres.[13]

1.2.5 Approach to Transition in Adolescents with Sickle Cell Disease

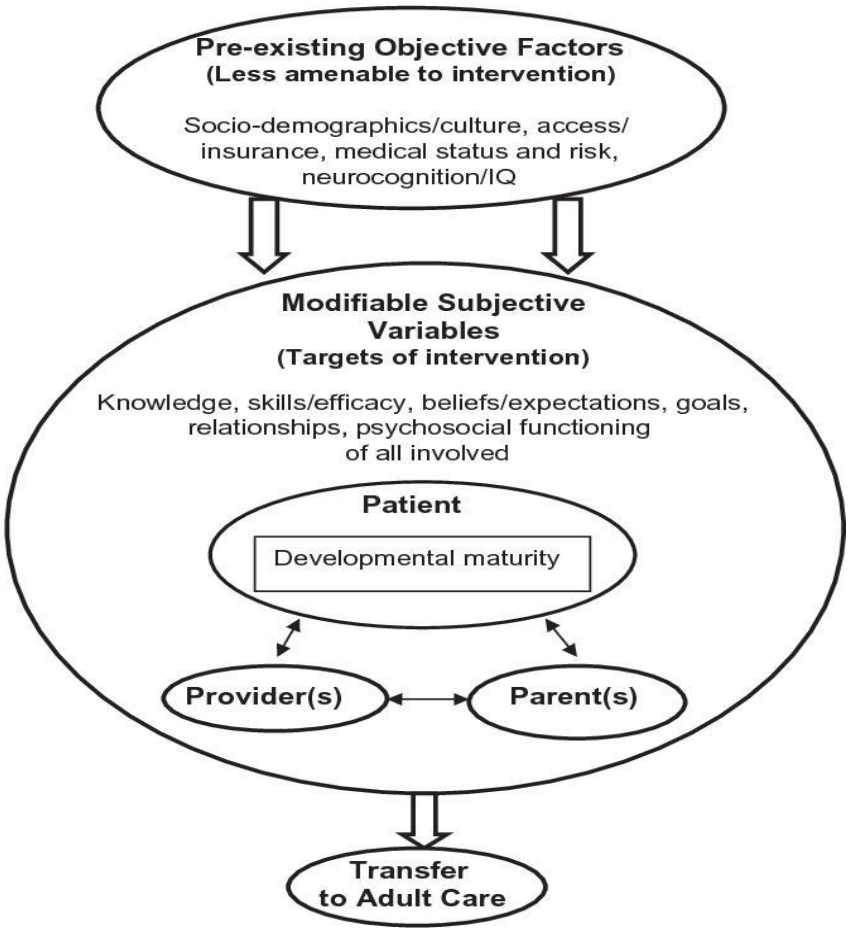
A well planned transition to adult care yields good health outcomes in Adolescent and Young Adults (AYAs) and allow them to take responsibility of their disease and other adult roles. On the contrary, poor transition processes result in poor health outcomes such as lack of adherence to medications, increased hospitalizations and poor quality of life in general[14] .

The Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART) was developed in 2011 by Schwartz et al in United States (US) in order to address the complex dynamic and socio-ecological issues of transition in AYA beyond the usual norm of a patient"s age, knowledge and skills. The development of the model was informed by several theories and studies, specialist advice and pilot data collection within childhood cancer survivorship programs. The SMART model as shown in *Figure 2* below brings to light a deeper understanding of transition from a social-ecological point of view, including several stakeholders (patients, parents, and health care workers) with pre-existing objective factors less amenable to intervention such as socio demographics/culture and subjective factors like skills and beliefs that may be modified with interventions in a medical setting[14].

The SMART model was initially applied to paediatric cancer survivors" population. Over the years, several studies have been done on the applicability of the model to other AYA with chronic illnesses. Mulchan et al in 2016 in the US did a study to determine the applicability

of SMART model in AYA with SCD. The team conducted semi-structured interviews among 14 AYA with SCD (14-24years old) and 10 clinical experts. Emerging themes showed that SMART model was applicable in SCD. Some of the themes specific to SCD included health care navigation skills and pain management (subjective variables) and societal stigma (objective factors) [15].

Similarly, in 2017 in the US, Jerlym et al conducted a study on perspectives of young adults with SCD on Paediatric to Adult care transition. Nineteen AYA with SCD (18-30 years) were recruited in Focussed Group Discussions (FGDs) and filled in brief questionnaires about transition topics. Emerging themes were consistent with SMART components. Knowing SCD complications, understanding medications and choosing adult providers (modifiable subjective variables) were among the key topics suggested by young adults to be included in transition programs [16].



Source: Schwartz et Al, 2011)

Figure 2: Social-ecological Model of Adolescent and Young Adult Readiness to Transition (SMART)

1.2.6 Barriers to Successful Transition from Paediatric to Adult Healthcare Services

Several factors have been described in literature as barriers to successful transition in adolescents with chronic diseases globally. Gray et al conducted a systematic review in August 2017 using the SMART model to summarize the literature on barriers to transition from Paediatric to Adult Care across paediatric illness populations in the United States of America. Examples of the paediatric illnesses captured included Diabetes, Cancer, Asthma, Sickle Cell Disease (SCD), Chronic Kidney Disease (CKD), Congenital Heart Diseases (CHD), Human Immunodeficiency Virus (HIV), Systemic Lupus Erythematosus (SLE), Inflammatory Bowel Disease (IBD), Cystic Fibrosis (CF), Epilepsy and transplant patients. Fifty-seven articles from various databases were retrieved. The selected articles were in English, focussed on transition from paediatric to adult healthcare, included AYA < 25years, a chronic disease group, presented original data on barriers to transition and had to have been conducted in the United States .[17]

Out of the 57 articles selected, 25 used qualitative method (mean sample size 111.83), 24 quantitative method (mean sample 17.40) and 8 had mixed methods (mean sample size 81.72). SCD, HIV, Cancer, Diabetes and IBD were the most common chronic illnesses identified. Based on status of transition, 29 studies included pre-transfer AYA and twenty one studies post transfer AYA. The mean age of adolescents ranged from 14-22 years.

Several barriers to transition from Paediatric to Adult health care were identified under different categories as summarized in *Table 2* below.

Table 2: Barriers to Transition from Paediatric to Adult healthcare- A systematic review by Gray et al. (2018)

Category	Barriers	Number of studies
Socio-demographics/Culture	-Unstable living conditions -Age at transition -Low parent education -Poverty	4
Access/Insurance	-Difficult obtaining a local qualified adult provider -Long distance accessing adult provider -Difficult finding adult provider who accepted public insurance cover	28
Health Status/Risk	-Exposure to infection -Complexity/instability of the AYA‟s condition	11
Neurocognition/IQ	-Cognitive /Developmental delay	7
Development	-Developmental immaturity -Pressure to take responsibility too soon by the paediatric providers	10
Skills/Efficacy	-Providers being unable to adequately support transition -Lack of time/funding/staff or training in transition issues -Lack of an established transition protocol -Limited institutional support, -Poor provider assessment of AYA skills	23
Belief /expectations	-Poorer quality of care in the adult setting care -Lack of expectations for moving to adult care. -Adult providers are less caring/ knowledgeable than paediatric providers -Perceived stigma from adult providers -Medical follow-up in adult care was not a priority/not needed	23
Knowledge	-Lack of AYA/caregiver knowledge about medication/illness or the transition process -Lack of provider knowledge of young adults/paediatric-onset illnesses	10
Goals	-Desire to remain in paediatric care.	5
Relationships	-Fear of leaving paediatric providers and environment. -Hesitancy in developing relationships with adult providers. -Difficulties letting go of long-standing relationships by paediatric providers -Disjuncture in the relationship between paediatric and adult providers -Helicopter/over involved parents -Overly accommodating and engaging paediatric providers	38
Psychosocial Functioning	-Unstable life circumstances -Denial of illness -Problematic mental health substance use issues	19

In a 2004 study done by Telfair et al in the US on transition to adult care for adolescents with SCD, 172 adolescents with aged 14 years and older still in paediatric care within SCD programs across the United States were enrolled. In this national survey, structured questionnaire interviews were used to collect data. The adolescents worried about i) leaving familiar paediatric healthcare provider with whom they had built longstanding relationships ii) lacking information regarding transition to adult care and iii) fear that adult clinicians may not comprehend their needs.[18]

A similar study was done by Hauser et al in 1999 on transitioning adolescents with sickle cell disease to adult-centred care in Chicago, USA. This was a single institution study where FGDs with 22 adolescents, their parents and eight healthcare workers were conducted separately. Leaving paediatric healthcare workers and settings, adult clinicians who may or may not be acquainted with managing sickle cell disease, and starting new family roles were some of the major concerns raised by the adolescents and their parents. Practitioners affirmed the need for transitioning that prepares the adolescents and their parents for adult-oriented care[19].

Focusing on providers perspectives on transitioning adolescents and young adults with SCD, Stollon et al interviewed thirteen SCD experts from both adult and paediatric departments at the Children‟s Hospital of Philadelphia. The team sought to find out their encounters in taking care of adolescents and young adults with SCD. Several barriers to transition were identified. Among these were Socio-demographic factors such as poverty and challenging home life which impacted on the psychological functioning of these adolescents and eventually negative transition outcomes[20].

Neurocognitive deficits due to stroke and its sequelae directly affected patients‟ ability to understand and manage their own diseases and generally find their way through the systems. Negative experiences in the emergency department especially before establishment of good rapport with adult caregivers affected consequent appointments and follow-ups. Lastly, complexity of the skills and the level of health literacy expected of AYAs with SCD was considered as a barrier. Difficulty in explaining sickle cell pain and where it is manifesting in a believable and articulate manner while in pain, adequate health literacy and the need to be proficient in planning and problem solving appropriately was found to be rampant.[20]

In assessing transition readiness in adolescents with SCD and their caretakers in Ghana, Miriam et al interviewed a total of 46 children paired with 46 adults. Insufficient knowledge on SCD and self-management was identified as barriers to transition and attributed to

younger age of child participants and cultural practises among other factors. Additionally, most study participants were not aware of a transition to adult care by the age of 15 years[5].

1.2.7 Facilitators to Successful Transition from Paediatric to Adult Healthcare Services

Factors that contribute towards successful transition from paediatric to adult care in adolescents with chronic conditions include i) early preparation before transition ii) a structured written program to guide transition process iii) a principal healthcare provider from paediatric services to organize the process iv) involvement of parents during transition v) patient‟s ability to understand and manage their condition.[21]. Stollon et al identified some of the facilitators to successful transition from the health care providers perspectives through the following categories[20]:

1.2.7.1 Positive Relationships between Patients and Providers

Paediatric providers strongly agreed that trusting relationships between patients and healthcare providers contributed to successful transition. Creating an environment where the providers and patients freely discuss the patient‟s disease and management, transition process and any other concerns was more likely to lead to successful transition and good outcomes post-transition. Adult providers emphasized that the adolescents and young adults would benefit from the assistance of social workers while navigating the adult systems.

1.2.7.2 Family Support: Positive Relationships and Parent Skills

Participants described family members who were supportive of their children with SCD, but who emphasized independence and self-management as a priority in other areas of the child‟s life as well as with regard to health care contributed to their successful transitions. Participants also emphasized that parents provide support by encouraging the patient to learn independence, but remaining present as a safety net in times of difficulties.

1.2.7.3 Developmental Maturity

Participants agreed that developmental maturity was one of the contributors to a successful transition. Adolescents and young adults who were developmentally mature were motivated to take responsibility of their lives and the disease. In addition, quality of life and health care utilization were some of the measures of success that were pointed out in the study.

Table 3: Summary of studies showing Facilitators and Barriers to Transition from Paediatric to Adult healthcare in AYA with SCD

Study Title, Author, Year & Country	**Study type** **Study Population** **Study setting**	**Results**
Transition to adult care for adolescents with sickle cell disease: results of a national survey. Telfair et al.2004. USA	Cross-sectional 172 adolescents with SCD aged 14 yrs+ still in paediatric care - SCD programs across USA.	**Barriers:** -Fear leaving familiar setting -Inadequate knowledge of adult care providers with regards to their needs. -Lack of information relating to their transition to adult care. -Sickle cell program needed to help with transition process.
Transitioning adolescents with sickle cell disease to adult-centred care. Hauser et al. 1999. USA.	Cross-sectional Adolescents & their parents -22) practitioners n= 8) -Sickle Cell Clinic, University of Illinois at Chicago.	**Concerns:** -Leaving a familiar setting and -physician whom they trusted. -Going to an adult provider who may or may not be familiar with managing sickle cell disease. -Establishing new family roles. Practitioners affirm the need for transitioning that prepares the adolescents and their families for ACC.
Transitioning adolescents and young adults with Sickle cell disease from paediatric to adult healthcare: Provider‟s perspectives Stollon et al, USA 2016	Cross-sectional Paediatric providers=7 Adult providers=4 -Children‟s Hospital of Philadelphia	**Barriers**: -Negative experiences in Emergency Department -Challenging home life -Neurocognitive deficits in AYA. **Facilitators:** -Positive relationship between patients and providers -Good family support -Developmental maturity
Assessment of transition readiness in adolescents with Sickle cell disease and their caretakers, a single institution experience. Kwarteng-Siaw et al-Ghana 2017	Cross-sectional Adolescents and their parents=46 -Ghana‟s Komfo Anokye Teaching Hospital Sickle Cell Clinic (KATH SCC)	**Barriers**: -Lack of knowledge about SCD -Unaware of the transition process.

2.0 CHAPTER TWO: STUDY JUSTIFICATION, RESEARCH QUESTIONS AND STUDY OBJECTIVES

2.1 Study Justification

The magnitude of SCD in Kenya is experienced in malaria endemic regions of coastal and western Kenya, with high prevalence rates of up to 17.1% in Western Kenya. New advances in managing patients with SCD in the last thirty years have transformed SCD from a severe illness of childhood to a chronic lifelong condition with increased life-expectancy into adulthood in developed countries. Early screening and improved medical services is rapidly taking shape in the Sub-Saharan countries such as Kenya which is contributing to improved survival of these children into their late adolescence. Consequently, these adolescents must transition from paediatric to adult services.

Transition from paediatric to adult services for adolescents with SCD happens to coincide with adolescence, a vulnerable period in life characterized by both physical and psychosocial changes. This is a double tragedy as they have to battle with challenges attributed to the adolescent phase and SCD itself. This can be wearing to most of these adolescents and can result to loss of follow ups and poor transition outcomes.

With the increasing population of adolescents with SCD, clear guidelines and programs ought to be put in place in the health care systems to ensure smooth transition to adult services. In depth understanding of factors that affect transition from paediatric to adult services among these adolescents will help develop a comprehensive care tailored to their needs.

Currently there is scarcity of literature on factors that affect transition from paediatric to adult services in adolescents with SCD in Kenya.

2.2 Study Utility

Currently, no studies have been done in Kenya on prevalence and factors that affect transition from paediatric to adult services in adolescents with SCD. This study will give insight to the healthcare providers working with SCD adolescents on facilitators and barriers to transition and thus help to ensure smooth transition to adult services. Identification of factors that affect transition from paediatric to adult services in adolescents with SCD will be useful to guide policy and practice around adolescent transition with a view of optimizing transition and health outcomes.

2. 3 Research Questions

Among children with SCD receiving care at Webuye County Hospital:

a) What proportion of adolescents with Sickle cell disease transition from paediatric to adult services?

b) What proportion of transitioned adolescents attend at least two scheduled adult clinic visits thereafter?

c) What are the factors that affect successful transition from paediatrics to adult services among adolescents with sickle cell disease?

2.4 Study Objectives

a) To determine the proportion of adolescents with SCD that transition from paediatric to adult services in WCH.

b) To determine the proportion of transitioned adolescents with SCD who attend at least two scheduled adult clinic visits in WCH.

c) To explore the factors that affect successful transition from paediatric to adult services at WCH among adolescents with SCD as informed by the adolescents with SCD and healthcare providers.

3.0 CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Study Design

We employed a mixed method study approach in which we conducted:

a) A retrospective cohort study design to determine the proportion of adolescents with SCD that transition from paediatrics to adult services and those who attend at least two scheduled adult clinic visits thereafter through abstraction of medical records.

b) A cross-sectional survey in which we conducted focus group discussions and in-depth interviews among adolescents with SCD and key informant interviews for health care workers to explore the factors that affect successful transition from paediatric to adult services at WCH.

3.2 Study Site and Setting

Setting: The study was conducted at Webuye County Hospital situated along the Eldoret – Bungoma Highway in Bungoma county, Western Kenya. It is a public hospital situated in a 37-acre land with an immediate catchment population of 60,894 people. Majority of the people living in the region are the Bukusus and Tachoni sub-tribes whose main economic activity is subsistence farming and livestock keeping. About 14% of the residents in Bungoma County have no formal education and 5.6% of the population in Webuye town are unemployed according to the Kenya National Bureau of Statistics (KNBS), 2013 and Society for International Development (SID), 2013.

Site: WCH is a high volume level IV hospital with a bed capacity of 217 beds and bed occupancy of up to 150 %. The daily patient turnover is about 150-200 patients, majority being children. It has both inpatient and outpatient services and serves as a referral facility to the surrounding hospitals in the region. The hospital has one paediatric ward which admits both medical and surgical conditions of children below 12 years.

The children are first triaged at the Paediatric Triage at the Maternal and Child Health (MCH) department after which those who require admission are admitted to the ward after initial stabilization. The Paediatric Ward has a bed capacity of 46 beds with bed occupancy of 111 %. Common cases admitted include pneumonia, malaria and SCD. For adult services, the hospital has two medical wards; female and male wards which admit adults and children above 12 years with medical and surgical conditions. Triage is done at the casualty department before admission to the wards. Hypertension and Diabetes related comorbidities are common cases admitted in these wards.

Paediatric outpatient clinic runs every Thursday from 8am -2 pm. Children below 12 years are followed up here and mainly comprises sickle cell disease patients. Other conditions on follow-up in the clinic include cerebral palsy, cardiac diseases and epilepsy. On average, 20-30 patients are reviewed on each clinic daily, with approximately 7-10 adolescents with SCD. A family medicine consultant heads the clinic and leads a team comprising of family medicine residents (post-graduate doctors), medical and clinical officers, a nurse and a nutritionist. On average 3- 4 clinicians are present to review patients on each clinic per day. Upon arrival of the patients, health talks are given by the nutritionist on duty that day before actual review of patients commences. Documentation on patients‟ progress is done manually on patients‟ hard copy files. Once the patients are reviewed by clinicians, they are sent to collect medicine at the pharmacy and then to records office to get the next clinic appointment date. Patients‟ files are returned to the records room by the nurse once clinic is done.

The medical outpatient clinics run every Monday and Friday from 8am -2 pm. Adults and children above 12 years with medical conditions are reviewed here. The Monday clinic is mainly for hypertensive patients and the Friday clinic for Diabetes cases alongside other cases. About 50- 70 patients are reviewed on a normal clinic day, majority being adults. On average, 3- 5 adolescents with SCD will attend either the Monday or Friday clinics. Two consultation rooms are available with one waiting area that accommodates both adults and adolescents attending clinic. The medical team is made up of a family physician, family medicine residents (postgraduate doctors), medical and clinical officers, a nurse and a nutritionist. Health talks are given before review of patients. Documentation of patients‟ progress is done manually on the patients‟ hard copy files. Once the patients are reviewed by clinicians, they are sent to collect medicine at the pharmacy and then to records‟ office to get the next clinic appointment date. Patients‟ files are returned to the records room by the nurse once clinic is done.

3.3 Key Case Definitions and Outcomes of Interest

- Confirmed diagnosis of Sickle Cell Disease – defined as positive sickling test and/ or presence of sickled red blood cells on peripheral blood film
- Adolescent- an individual between ages 10-19 years
- Transition - defined as adolescent attended adult medical outpatient clinic at least once after attaining the age of 12 years.
- Successful sustained transition- defined as adolescent attended at least two scheduled appointments in adult medical outpatient clinic after transition.

- Appropriate age of transition -defined as adolescent who transition to adult medical outpatient clinic at 12-13years.
- Delayed transition-defined as adolescent who transition to adult medical outpatient clinic at 14-19 years
- Lost to follow up- defined as adolescents who did not return for care in clinics for a period of 3 months or more since their last documented appointment date.

3.4 Factors of Interest

Factors that affect transition from paediatric to adult services were explored in the following categories:

3.4.1 Social Demographic Factors

Age at last visit to the hospital, sex, physical location.

3.4.2 Clinical Factors

Age of enrolment to care in years, mode of SCD diagnosis, overall duration of care at the hospital, status at last contact per medical record.

3.4.3 Transition Related Factors

Age at visit to adult medical outpatient clinic, number of visits and status of follow-up.

3.5 Phase I: Retrospective Cohort Study Methods

3.5.1 Study Population

3.5.1.1 Inclusion criteria

- Confirmed diagnosis of Sickle Cell Disease
- Adolescents who achieved the age 12+ years during the period 2015 – 2020.
- Enrolled in paediatric outpatient clinics in WCH between January 2015 and April 2020**.**

3.5.1.2 Exclusion Criteria

- Any adolescent who per the file died or dropped out of care before age 12 years.
- Missing patient file.

3.5.2 Sample Size Determination

Sample size was based on the first primary objective to determine the proportion of adolescents with Sickle Cell Disease that transition from paediatric to adult services in WCH. According to health records estimates in WCH, approximately 100 eligible adolescents with SCD were enrolled between January2015- April 2020. A representative sample was drawn from this finite population and sample size was determined as follows: Where

n; = sample size with finite population correction,

N = size of the target population = 100

Z = Z statistic for 95% level of confidence = 1.96

P = Estimated transition to adulthood= 50% (no available data)

d = margin of error = 5%

$$= \frac{100 \text{ x } 1.96^{2} \text{ x } 0.50\text{x } 0.50}{0.05^{2}(100\text{-}1) + 1.96\ 2 \text{ x } 0.50\text{x } 0.50}$$

n = 80

A minimum of 80 adolescents with SCD was sampled to estimate transition within 5% level of precision.

3.5.3 Study Procedure Retrospective Cohort Arm - Retrieval and Abstraction of Medical Records of Adolescents

The principal investigator identified two clinical officers working in the paediatric department as research assistants and trained them on the scope of the study, the use of medical abstraction forms, and ethical aspects of the study. Potential adolescents with SCD under care in paediatric clinic between January 2015 and April 2020 were identified by their hospital number from the admission register at the paediatric clinic. We then approached the records officer who assisted in retrieval of physical files from the records office.

The research assistants assigned a study number on each file and a corresponding adolescent medical abstraction form that captured factors of interest of the study. Additionally, a master study register that contained the details of patient‟s hospital name, assigned study number, phone contact and physical address was set up. This master study register was particularly important in tracing adolescents categorised as lost to follow-up and in recruiting adolescents in active care to participate in focused group discussions and in-depth interviews. The data collected from medical abstraction form included:

- Socio-demographic characteristics: Age, gender, physical location (county,

- Clinical characteristics: Mode of SCD diagnosis, age at first enrollment to paediatric clinic, age at first visit to adult clinic, duration of follow-up in clinics, and status of follow up.

3. 6 Phase II: Qualitative Methods- Adolescent Arm

3.6.1 Study Population

3.6.1.1 Inclusion Criteria for Adolescents

Adolescents with SCD aged 12-19 years enrolled in paediatric and adult medical outpatient clinics in WCH.

- Informed consent for those >18years
- Parents /guardian consent and child assent for those <18years
- Confirmed diagnosis of Sickle Cell Disease

3.6.1.2 Exclusion Criteria for Adolescents

- Adolescents with SCD who decline to give consent and assent.

3.6.2 Factors of Interest Affecting Adolescent Transition

Potential barriers and facilitators to transition were explored in the following domains:
Adolescent related factors:

- Age at transition, gender, proximity to the hospital, family support, financial constraints and relationships.

Healthcare system related factors:

- Communication among HCW and adolescents, clinic setting, firs-time encounters with adult clinicians, preparation to move to adult clinics and communication between HCW in paediatric and adult services.

3.6.3 Study Procedures

3.6.3.1 Adolescent Focused Group Discussion Procedures

The study was conducted during the nationwide nurse‟s strike and both the paediatric and adult clinics were not operational. This interfered with the regular follow up of the adolescents in the clinics. Potential study participants were identified from the master register that was set up during the retrospective cohort study. Adolescents categorised as those in active care were contacted via telephone by the principal investigator and trained research assistants and invited to the hospital to participate in the study. Convenience sampling was done and adolescents who consented were recruited in the focus group discussions

We conducted two focus group discussions among adolescents with SCD in active care in WCH to explore the factors affecting successful transition. The adolescents were handled in two groups: Those who had ever transitioned to adult service as one group, and those who had delayed to transition and still come to paediatric services in another FGD. Prior to the discussions, we allocated different numbers to the participants with which we referred to them to ensure confidentiality. The discussions were held in a closed room in the hospital in a circular sitting arrangement. The principal investigator led the discussions using the FGD tool guide and the research assistants took notes and helped with tape recording. Discussions continued to a point of information saturation with an average time of 30-45 minutes. Upon conclusion of the discussions, we assured the participants of confidentiality and appreciated them for participating in the study.

3.6.3.2 Adolescents who were lost to follow-up – Tracing and In-depth interview procedures

For the adolescents 12years and older lost to follow-up, we obtained contacts from the master register from the retrospective cohort study and contacted them and their parents by telephone and for those still leaving within the county, we invited them to return for care at WCH. The principal investigator then invited them to participate in the study, and for those that gave assent/consent, we conducted in depth interviews with them.

3.7 Phase III: Cross-sectional Survey- Health Care Workers Arm

3.7.1 Study Population

3.7.1.1 Inclusion Criteria for Health Care Workers

- Health care workers caring for patients with SCD at WCH. (Doctors, Nurses and social worker.)
- Healthcare workers who had worked with adolescents with SCD in paediatric and adult medical outpatient clinics for a minimum of 3 months.

3.7.1.2 Exclusion Criteria for Health Care Workers

- Health care workers who declined to give consent

3.7.2 Study Procedures

3.7.2.1 Healthcare workers Key Informant Interviews Procedures

We conducted Key Informant Interviews with healthcare providers caring for adolescents with SCD for a minimum of three months from both paediatric and adult services. Face to face in-depth interviews with six healthcare providers in the hospital premises were

conducted. We contacted the heads of paediatric and adult clinics to help us identify potential study participants. We then used snowball sampling method where we asked each participant to suggest other potential participants. The snowball sampling method ensured that we recruited participants who are identified and recognized by their colleagues as key stakeholders in the field.

The principal investigator obtained informed consent from the healthcare providers prior to setting a suitable time and place for conducting the interviews. An interview tool guide was used for the discussion. The interviews focused on answering the third research question on factors that affect transition of adolescent with SCD from paediatric to adult services. The principal investigator wrote down notes during discussions alongside tape recording. The interviews lasted approximately 30 minutes. We assured the participants of confidentiality and appreciated them for participating in the study.

3. 8 Data Management and Analysis

3. 8.1 Quantitative Data

Data was obtained from medical abstraction forms attached on individual files of eligible study participants. Data was then entered into password protected Microsoft Access data entry platform and stored in a hard disk. Data was then cleaned for any errors before analysis was done using STATA version 12.0. Discrete variables were summarized as frequencies and percentages and continuous variables as medians and inter quartile ranges.

3. 8.2 Qualitative Data

The Focus Group Discussions and in-depth interviews were audio recorded, transcribed and translated accordingly. The word document was imported into *ATLAS.ti* version 8.0, and scripts coded into emerging themes. Quotes were selected to describe the perceptions and experiences of adolescents with SCD and the health care providers regarding transition from Paediatric to Adult services.

3.9 Quality Assurance

The following measures were taken for quality assurance:

- Adherence to the inclusion and exclusion criteria.
- The research assistants were trained on the scope of the study and use of case record forms to ensure uniformity in data collection.
- Focus group discussions and in-depth interviews were conducted in a language familiar to the participants.
- The principal investigator did daily assessment of data

3.10 Measures Undertaken to Minimize the Risk of Covid-19 Transmission

The following infection prevention control measures were taken per the Kenyan ministry of health / WHO guidelines and protocols.

The principal investigator and research assistants:

- Alcohol-based sanitizers and hand washing were used before and after contact with the participants.
- Surgical masks were worn at all times. N95 masks were used in participants suspected to have respiratory illnesses.
- Minimal time with participants was taken (not more than 60 minutes) to avoid the risk -of being exposed.

Participants:

- All participants had their temperatures taken using a non – contact thermometer.
- Alcohol-based sanitizers/hand washing were availed to the participants to be used before and after coming in contact with them.
- Participants were advised to put on a 3ply surgical face mask provided by the principal investigator during the face to face interactions.
- Participants were advised to maintain social distancing at least 1.5 meters during focused group discussions and key informant interviews.

3.11 Ethical Consideration

- Ethical approval was sought from Kenyatta National Hospital /University of Nairobi research and ethics committee before commencement of the study.
- Permission was sought from WCH to conduct the study and access medical records of adolescents with SCD**.**
- The purpose of the study was carefully explained to the adolescent with SCD, their family and healthcare workers caring for them. Informed consent was obtained.
- Belmont Principles was used to ensure justice to participants and respect of their autonomy. All adolescents were given an equal chance to participate in the study.
- Confidentiality was strictly observed throughout the study period by the principal investigator and research assistants. Study participants were given identification numbers and no names were used.

4.0 CHAPTER FOUR: RESULTS

4.1 Screening and Enrolment

We identified 95 potential study participants from the admission register found in paediatric outpatient clinic between January 2015 and April 2020 using their specific identification file number. We then approached the records‟ s officer for retrieval of physical files from the records‟ department from which we screened for eligibility, further identifying cases that fulfilled our inclusion criteria, specifically should have achieved the age of 12 years or older during the study period and had record of visiting the hospital up to the age 12 years.

We excluded 10 adolescents whose files were missing and 5 adolescents who per the files had dropped out of care before age 12 years as these children did not reach the age at which they could have experience the main outcome of interest of potentially transitioning out of paediatric to adult services. After exclusions, we remained with 80 adolescents with complete data on key variables, for whom we then abstracted detailed data for the retrospective cohort analysis as shown in figure 3.

4.2 Descriptive Characteristics of the Retrospective Cohort of Adolescents with Sickle Cell Disease at Webuye County Hospital

Out of the 80 adolescents, 36 (45%) were females and 44 (55%) were males. Regarding physical location, 68 (85%) out of 80 adolescents were living in Bungoma county,10 (12.5%) in Kakamega county and 2 (2.5%) in Trans-nzoia county. 47 (58.8%) out of 80 adolescents were living in villages adjacent to the hospital while 33 (41.2%) in distant villages far from the hospital. At their last contact with the hospital most of the adolescents were in their mid-adolescence with a median age of 16 years (IQR: 14.0-17.0). Their age distribution at last visit was as follows: 7 (12-13yrs), 43 (14-16yrs) and 29 (17-18yrs) as shown in table 4 below.

Table 4: Socio-Demographic Characteristics of the study population N= 80 (As per medical abstraction form

Variable	Detail	N (%)
Sex	Male Female	44 (55.0) 36 (45.0)
Age at last visit to the hospital (Years)	Median (IQR) 12-13 14-16 17-18	16 (14.0-17.0) 7 (8.9) 43 (54.4) 29 (36.7)
Physical Location: County	Bungoma Kakamega Trans-nzoia	68 (85.0) 10 (12.5) 2 (2.5)
Villages	Adjacent (<1hr by public transport) Distant (>1hr by public transport)	47 (58.8) 33 (41.2)

4.3 Clinical Characteristics of the Study Population

Mode of diagnosis of Sickle Cell Disease: The diagnosis of Sickle cell disease for the adolescents was made through either a positive sickling test or presence of sickled red blood cells on a peripheral blood film. Out of the 80 adolescents, 65 (81.3%) had a positive sickling test,7 (8.8%) had a positive peripheral blood film while 8(10.0%) had both. Of note, per their medical records, no adolescent had haemoglobin electrophoresis test report for diagnosis.

The age at 1st enrolment to the paediatric clinic among the adolescents was as follows: 4 (0-2years) 18 (3-5years) 43 (6-8years) 15(9-11years) and the median age was 7years (IQR 5.0-8.0). Overall duration of follow-up from time of enrolment into care to last contact with hospital was a median of 9 years (IQR 8.0-11.0). Status at last contact per medical records showed 24(30%) were in active care, 13 (16.3%) transferred out, 30 (37.5%) lost to follow-up and 13(16.3%) had died as shown in the table 5 below.

Table 5: Clinical characteristics of the children/adolescents with Sickle Cell Disease at Webuye county Hospital

Characteristic	Subgroup	Frequency or median	Percentage or interquartile range
Mode of diagnosis	Sickling test only Positive blood film Sickling test and PBF(Both)	65 7 8	81.3 8.8 10.0
Age of enrolment to care. (years)	Median (IQR) 0-2 3-5 6-8 9-11	7 4 18 43 15	5.0-8.0 5.0 22.5 53.8 18.8
Overall duration in care at WCH (years)		9	8.0-11.0
Status at last contact per medical record	Active care Transferred out Lost to follow-up Dead	24 13 30 13	30.0 16.3 37.5 16.3

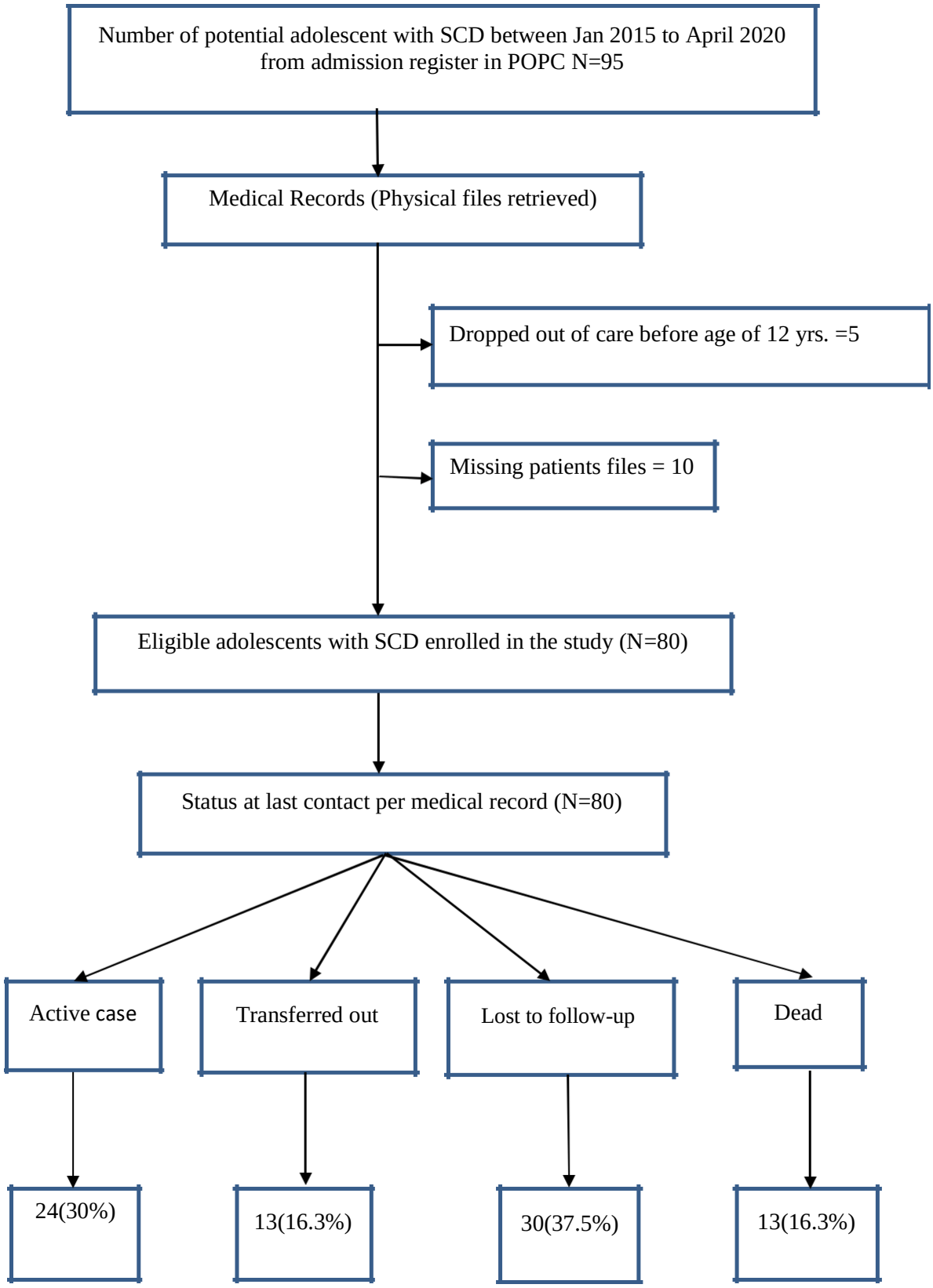


Figure 3: A flowchart showing screening and enrolment and status of follow-up of the adolescent with SCD in the retrospective cohort.

4.4 Objective One: Transition of Adolescents with Sickle Cell Disease from Paediatric to Adult Services in WCH

From the medical records we determined if each adolescent had ever attended the adult outpatient clinic after attaining the age of 12 years in keeping with the hospital protocol for transition out of paediatric services. Out of the 80 adolescents enrolled in paediatric outpatient clinic who had achieved the age of 12+ years during the study period (January 2015- April 2020), 50 had ever attended adult medical outpatient clinic at least once after attaining the age of 12 years and hence transitioned to adult care services giving a prevalence of ever transitioning of 62.5% (95% CI 51.3, 73.7).

Thirty adolescents had no record of attending the adult outpatient clinic by their last recorded contact with WCH, giving a prevalence of non-transition of 37.5% (95%CI 26.3, 48.8) Tracing by telephone was done to determine the current status of these 30 adolescents, and detailed results on their status will be provided in separate section of the results.

4.4.1 Age of Transition out of Paediatric to Adult Services

Appropriate age for transition per WCH protocol is 12-13 years. Per their medical records, the 50 adolescents had their first adult clinic (transition) visit at a median age of 15 years IQR (15-16). More specifically, their first visit in adult clinic was documented to have occurred at the following ages: 1(13yrs), 2 (14yrs), 4 (15yrs), 19 (16yrs), 20 (17yrs) and 4 (18yrs) as shown in figure 4 below.

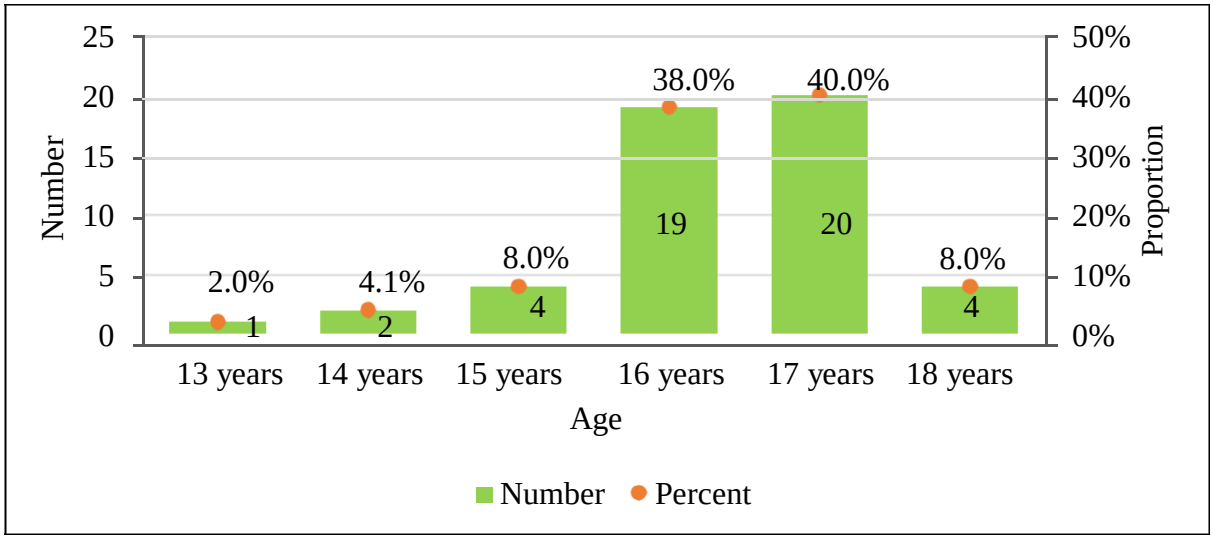


Figure 4: Age in years at first transition to adult care services among 50 adolescents with SCD, given as percent of all transiting at each given age

4.5 Objective 2: Proportion of Adolescents That Had Successful Sustained Transition in the Adult Care Services

We further reviewed the medical records to determine if adolescents continued to attend adult clinic after their first transition visit to gain insight into whether they were sustained in care after their first adult clinic experience. Out of the 50 adolescents who had transitioned to adult care services only 8 (10%) were still in active care and had attended more than two scheduled appointments in the adult medical outpatient clinic and therefore successfully transitioned. This gives prevalence of successful sustained transition in adult services of 10% (95% CI 3.8, 16.3).

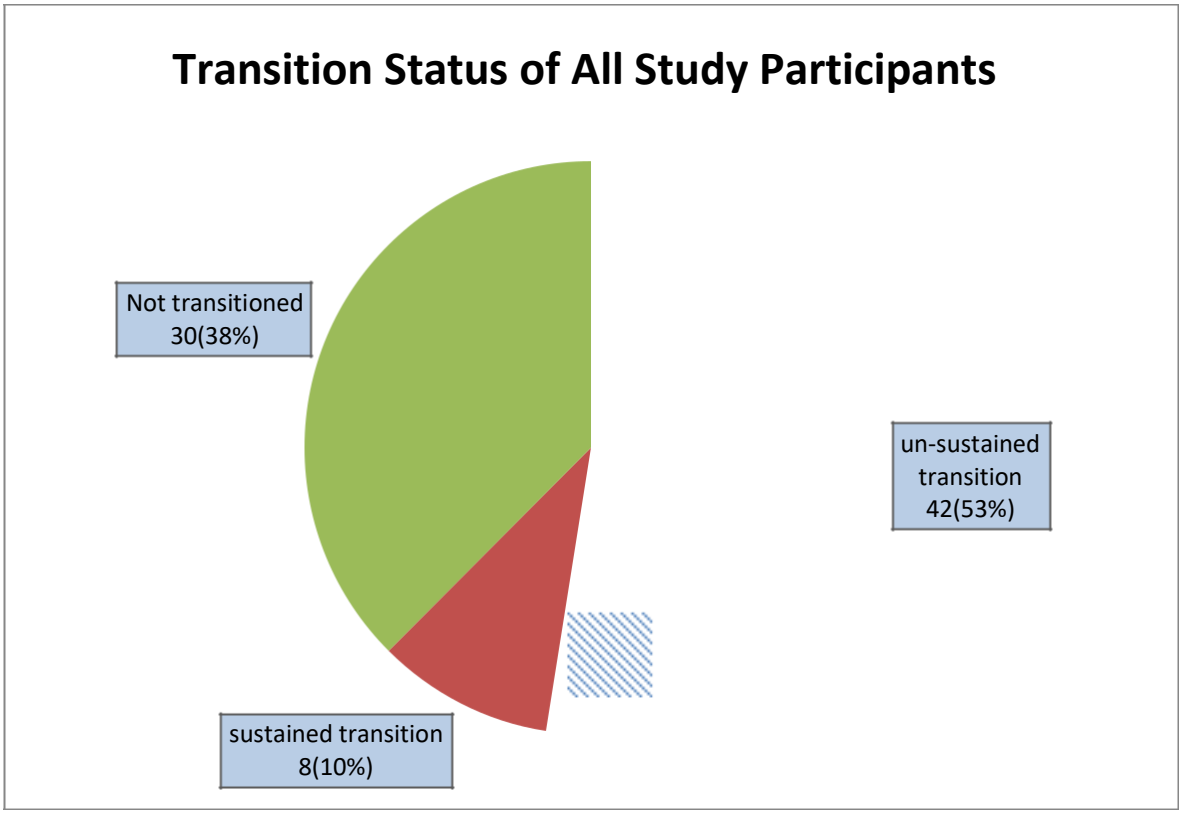


Figure 5: Transition status of all study participants

4.6 Adolescents Status of Follow-Up at the Time of Study. (As Per Medical Abstraction Records)

Of the 30 adolescents that had not transitioned to adult clinic, we categorized their status of follow-up as; those in active care, transferred out, lost to follow-up or dead after tracing. 16 (53.3%) out of 30 adolescents were still attending paediatric clinic and therefore still in active care. Upon contacting the caregivers of the remaining adolescents,8 (26.7%) had transferred to the nearest hospital (Bungoma county and referral hospital and 6 (20%) had attained the age of 12 years but had died before transition.

Of the 50 adolescents that had ever transitioned to adult clinic, 8 were still in active care.42 adolescents had dropped out of care after their initial visit to the adult clinic. After contact tracing via the telephone,7 (14%) had died,5 (10%) transferred out and 30 were lost to follow-up as shown in the figure 6 below.

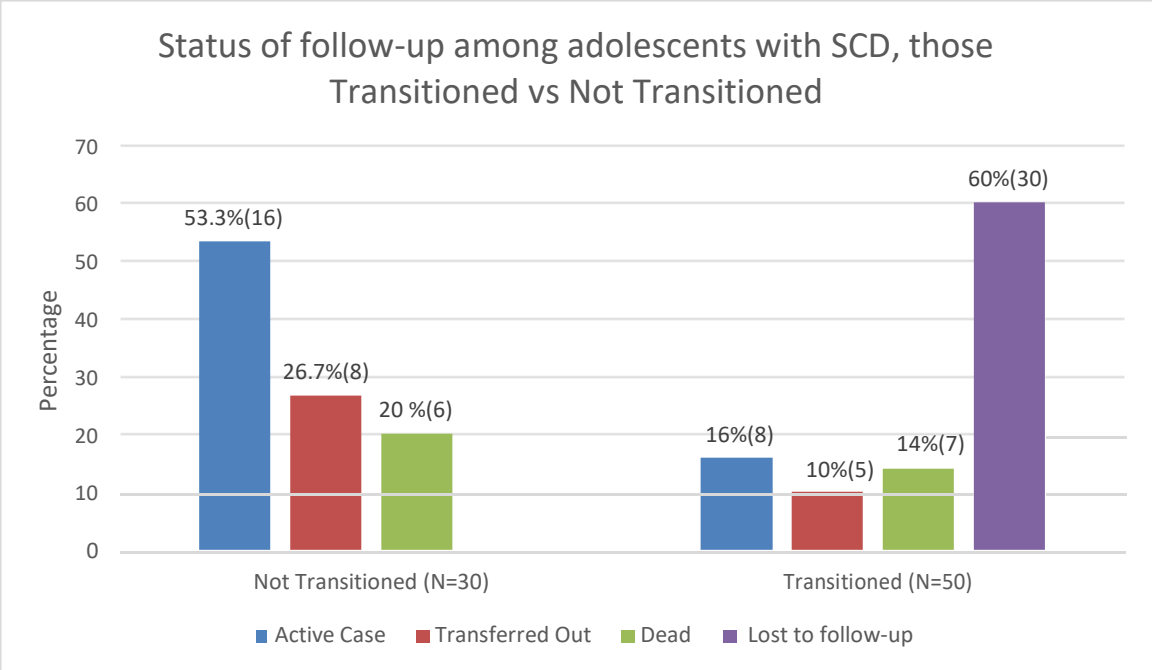


Figure 6: Status of follow-up of adolescents with SCD at time period of study

4.7 Objective Three: Factors that affect transition from paediatric to adult services among adolescents with sickle cell disease

4.7.1: Retrospective Cohort Data- Evaluation of factors associated with ever transitioned versus those who did not transitioned

We first analyzed data from the retrospective cohort to identify any factors associated with transition. As indicated in table 6 below, more male adolescents had transitioned (62%) compared to female adolescents (43%) but the difference was not statistically significant**. (**2.1 vs1.0, p=0.104). There was no significant difference in the median age at enrollment in paediatric clinic amongst those that had transitioned compared to those that did not transition (p=0.856). Physical location influenced transition outcomes as those adolescents who lived adjacent to the hospital were more likely to transition than those who lived far (66.0% versus 56.7%, p=0.047*).* With regard to status of follow-up, more adolescents who had not transitioned were still in active care (53.3%) compared to adolescents who had transitioned (16.0%) P= <0.001. More adolescents 26.7% had transferred out before transition compared to after transition (10%) but this was not statistically significant (p=0.05). No significant difference in the number of adolescents who died before and after transition (p=0.48). None of the adolescents was lost to follow before transition compared to 30(60%) adolescents who were lost to follow up after transition (p=<0.001).

Table 6: Comparison between adolescents who transitioned versus those who did not transition

Variable	Transition to adult clinic		OR (95% CI)	P value
	Yes (n=50)	No (n=30)		
Gender				
Male	31 (62.0)	13 (43.3)	2.1 (0.8-5.4)	0.104
Female	19 (38.0)	17 (56.7)	1.0	
Age at enrolment in years				
Median (IQR)	7 (4-8)	7 (5-9)	1.0 (0.8-1.3)	0.856
Category, n (%)				
>=Median	32 (64.0)	18 (60.0)	1.2 (0.5-3.0)	0.721
<Median	18 (36.0)	12 (40.0)		
Physical location				
Adjacent to the hospital	33 (66.0)	13 (43.3)	2.5 (1.0-6.4)	0.047
Distant to the hospital	17 (34.0)	17 (56.7)	1.0	
Status of follow-up				
Active care	8(16.0)	16(53.3)	0.17(0.1-0.5)	< 0.001
Transferred out	5(10.0)	8(26.7)	0.3(0.1-1.0)	0.05
Dead	7(14.0)	6(20.0)	0.7(0.2-2.2)	0.48
Lost to follow-up	30(60.0)	0.0		<0.001

4.7.2 Cross-Sectional Survey among adolescents still in care and those who had dropped out of care but successfully traced

4.7.2.1 Recruitment

A total of 54 potential adolescents were identified from the medical records, 24 in active care and 30 as those lost to follow-up. The rest of the adolescents had either died or transferred out to the nearest facility. Phone numbers of the eligible adolescents were retrieved from the master register and adolescents and their caregivers were invited to the hospital to participate in the study.10 out of the adolescents in active care declined consent and 27 of out of the adolescents lost to follow-up were not successfully traced. In all, 17 adolescents consented to participate in the study. (Figure 7)

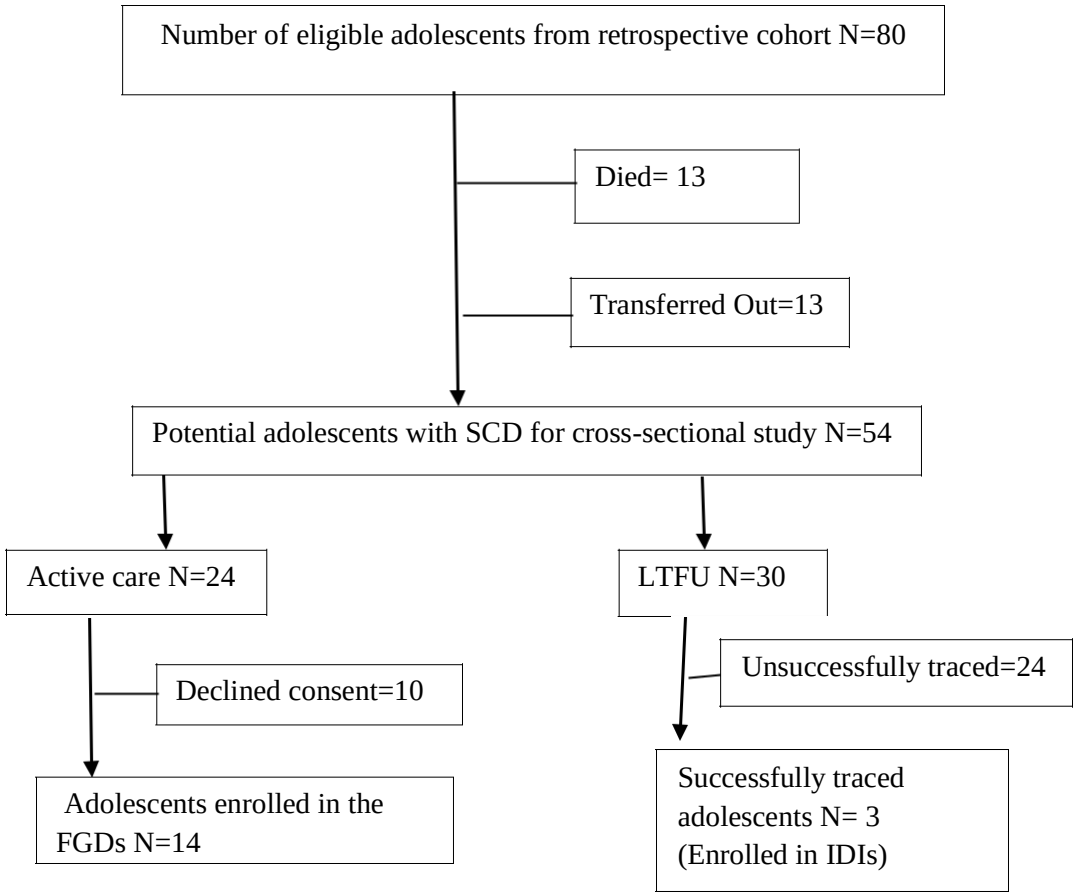


Figure 7: A flow chart showing number of adolescents enrolled in the cross-sectional study.

4.7.3 Adolescents Perspectives on Transition to Adult Care

a) Focused Group Discussions

i) Characteristics of the adolescents in the FGDs.

We identified adolescents for inclusion into 2 major focused group discussions, group A and B. The groups were based on those that had transitioned to adult services and those with

delayed transition and still receiving care in the paediatric clinic. A total of 14 participants consented to participate in the FGDs. 6 out of 14 adolescents had transitioned to adult services and were placed in group A while the remaining 8 adolescents were still in receiving care in the paediatric clinic and were placed in group B. Group A comprised of 2 males and 4 female adolescents aged between 14-17years. Group B comprised of 3 male and 5 female adolescents aged between 12-15 years. The table 7 below shows characteristics of participants in FGDs.

Table 7:Characteristics of participants in FGDs N=14

Group		**Transitioned**	**Not transitioned**
Age-Group		14- 17 years	12-15 years
Sex	Male	2	3
	Female	4	5
Total		6	8

ii) Adolescent perspectives on barriers and facilitators to transition from paediatric to adult Services

The focused group discussions were audio recorded and data was analysed by reading the transcripts numerous times to identify major themes. The following themes emerged as facilitators and barriers affecting transition to adult services as shown in the table 8 below.

Table 8:Adolescent FGD's Findings with emerging Themes

Factors	Barriers	Facilitators
Patient and family	-Fear of leaving paediatric clinic -Financial constraints -Lack of transition knowledge.	-Good family support
Healthcare system/Health care worker.	-Negative first- time encounters at the adult clinic -Poor preparedness to transition	-Early preparation to transition. -Positive first -time encounters at the adult clinic

Barriers to successful transition from paediatric to adult services

We explored several barriers to transition to adult clinic among adolescents with SCD during FGDs. The major concerns for the adolescents included fear of leaving paediatric clinic, financial constraints, negative first- time encounters at the adult clinic and poor preparation to transition. Below are the common themes that emerged during FGDs with quotes:

1. Lack of transition knowledge

Lack of transition knowledge was perceived by the adolescents to be one of the factors that affect successful transition to adult care. The adolescents reported that they needed to be given detailed information about transition process. They needed to understand the reasons for transition. Most of them stated that they had not been informed about transition to the adult clinic and what to expect after transition.

Responses from adolescents during FGDs:

"*I was only told during my last clinic visit in paediatric clinic that the next visit I'll move to adult clinic because I was then 12 years. No one had explained this to me before and I was really scared."* FGD A, Female 14 years: Transitioned

"I was not told early that I will move to the adult clinic. Daktari only told me once when I was 12years that I will need to move to the adult clinic during the next visit. I did not know what to expect" FGD A, Male 16years: Transitioned

2. Fear of leaving paediatric clinic

The adolescents stated that they were more comfortable at the paediatric clinic than in the adult clinic. Most of them reported that they were used to the doctors and nurses in paediatric clinic who were more of friends and therefore moving to the adult clinic felt strange and out of place. Some adolescents felt that they were still young and should only transition when they are16 years of age.

Responses from adolescents during FGDs:

"We should transfer to adult clinic when we are more mature like 16years" FGD B, Female 12 years: Not transitioned.

"For me it was difficult to say goodbye to the doctors and nurses who have been attending to me from the time i was young. They were like my friends and I felt like they knew me better" FGD A, Female 16years: Transitioned.

3. Negative first- time encounters at the adult clinic

Negative first-time encounters at the adult clinic was perceived to be a contributing barrier to successful transition to adult care. Most of the adolescents stated that the clinicians in paediatric clinic were friendly and approachable compared to adult clinic. Majority of them disliked the long queues in the adult clinic and the fact that they had to sit at the same waiting area with the elderly patients.

Responses from adolescents during FGDs:

"I felt uncomfortable sitting in the same area with old patients. Some of them were like my grandparents" FGD A, Female 14 years: Transitioned.

"The adult clinic was always full of other patients.it took long for me to the seen by the doctor I felt like leaving some days" FGD A, Male 16 years: Transitioned

"The doctor I first met in the adult clinic was not nice to me. He seemed to be in a hurry, He did not even ask me how I was doing" FGD A, Female 16 years: Transitioned

4. Financial constraints

The adolescents pointed out that the doctors‟ fee is a lot more in the adult clinic compared to paediatric clinic. The consultation fee at the paediatric clinic is 20 shillings while in adult clinic is 120shilling money which is hard to come by and yet most of the times they‟re required to also buy drugs.

Responses from adolescents during FGDs:

"At the paediatric clinic we used to pay 20/= while at the adult clinic is 120/= and this is a lot of money and still one has not paid for the drugs" FGD A, Male 16years: Transitioned.

"The doctor's fees in adult clinic should be similar like that of children's clinic. It's difficult sometimes to get money for doctor's fee, transport and drugs" FGD B, female 15 years: Not transitioned

5. Poor preparedness to transition

It was evident from the discussions that most adolescents had hardly been communicated to about transition. Most of them stated that they were only told once about moving to the adult clinic.

Responses from adolescents during FGDs:

"The doctors should start preparing us early when we are around 10 about moving to adult clinic" FGD A Female, 12years: Transitioned

Facilitators to transition from paediatric to adult services

We identified a few factors during discussions as facilitators to transition to adult clinic among the adolescents with SCD. The adolescents stated that good family support, early preparation to transition and positive first -time encounters at the adult clinic contributed greatly in making the transition process easy.

Here are some of emerging themes with quotes:

1. Good family support.

Some of the adolescents stated that they had good family support and this helped them to continue coming to the adult clinic.

Responses from adolescents during FGDs:

"My parents helped me a lot. They gave me money for transport to come to clinic" FGD A Female 13 years: Transitioned.

"My mum has been very supportive throughout. She has always been reminding me of clinic dates and importance of taking my drugs." FGD A Female 14years: Transitioned.

2. Early preparation to transition

The adolescents reported that early preparation to transition would make the transition process easier. Some of the participants suggested that the transition process should begin as early as 10 years so that when they reach 12, they"re prepared psychologically to transition to adult clinic**.**

Responses from adolescents during FGDs:

"The doctors should start preparing us early when we are around 10 about moving to adult clinic" FGD A Female, 12years: Transitioned

"When I was 11 years the doctor at paediatric clinic had explained to me that at 12years I will move to the adult clinic, this prepared me psychologically." FGD A, Female 14 years: Transitioned.

3. Positive first -time encounter at the adult clinic.

Positive first -time encounter at the adult clinic was stated as a facilitator by the adolescents. Some of the adolescents reported that their first encounter in adult clinic was good because they met friendly nurses and doctors and this motivated them to attend the subsequent clinics.

Responses from adolescents during FGDs:

"The doctor that I found there when I first attended the adult clinic was nice to me and this motivated me to come for the next clinic visit" FGD A, Female 16 years: Transitioned

4.7.4 In- Depth Interviews for Adolescents Lost To Follow-Up

We were able to trace 3 adolescents who had transitioned to adult services but got lost to follow up afterwards. We obtained their contacts from the master register from the retrospective cohort study and contacted them and their parents by telephone and invited them to return for care at WCH. The three adolescents were all males of ages 15 -17 years. Two were living in Kakamega county while one in Bungoma county. We conducted in-depth interviews with the adolescents after they gave informed consent and assent. Below are some of the themes that emerged during the in-depth interviews.

Barriers to transition

1. Financial constraints

Financial constraint was one of the reasons why transition was a challenge for these adolescents.

The adolescents echoed what had been said in the FGDs concerning the high consultation fee in the adult clinic compared to paediatric clinic and therefore they opted to buy drugs from nearby chemists instead of coming to the hospital.

The adolescents also reported that it was difficult to find transport money to come for clinic visits since their parents were poor and they came from large families

Responses from In-depth interviews:

"My father is a casual labourer and my mother farms in the shamba. We are 13 children at home and most of them are in school. It is difficult most of the times to get money for transport to come for clinic since the little money that my father gets goes into school fees for my other siblings. I'm forced to stay at home during clinic dates and just buy drugs from the nearby chemists." IDI, 17 years male.

2. Lack of transition knowledge.

The adolescents stated that they were not informed adequately about transition to adult clinic. They reported that the doctors did not tell them what to expect in the adult clinic and most of them were not prepared to leave paediatric clinic.

Responses from In-depth interviews:

"The doctor in the paediatric clinic told me I think twice or once that once I reach 12 years I will move to adult clinic. He did not tell me much about the adult clinic." IDI. 15 years male.

3. Negative first- time encounters at the adult clinic

Negative first -time encounters at the adult clinic was stated as a barrier to transition. The adolescents reported that they preferred paediatric since the doctors were friendly and knew more about their condition compared to healthcare workers in adult clinic.

Responses from In-depth interviews:

"I was more comfortable attending the paediatric clinic because I feel like the doctors and nurses were friendly and knew more about my condition. The adult clinic is always full of patients and the doctors are in a hurry to see the patients." IDI, 15 years male

Facilitators to transition

1. **Early preparation to transition**

The adolescents reported that the doctors should start telling them early about transition to adult clinic. They also stated that they should take time and explain to them about what to expect in the adult clinic.

*Responses from the in-depth interview*s:

"*The doctors at the paediatric clinic should start telling us about transition to adult clinic early. We should be told more about the adult clinic and what to expect"* IDI, 17years male.

2. Positive first-time encounters at the adult clinic.

The adolescents agreed that positive first -time encounter at the adult clinic will encourage them to come to clinic. They stated that the doctors at the adult clinic should try and be friendly and that they should have their own sitting area separate from the elderly patients.

*Responses from the in-depth interview*s:

"Doctors at the adult clinic should be friendly to us and also we should have our own waiting area separate from the old patients" IDI, 16 years male.

4.8 Health Care Workers Key Informant Interviews

A total of 6 healthcare workers consented to participate in the key informant interviews. The 6 key informants represented the fields of paediatrics, medicine, nursing and social work and had worked in the paediatric and adult clinics for a period of at least 3 months in webuye county hospital (table 9).

Table 9: Characteristics of key informants N=6

	Paediatrics	Adults
Designation		
Family Physician	1	0
Medical officer	1	0
Nurse	2	1
Social worker	0	1
Sex		
Male	2	1
Female	2	1
No. of years working with adolescents		
0-3	1	0
4-7	2	0
8-11	1	1
12-15	0	1
Age (years)		
25-30	1	0
31-35	0	0
36-40	1	0
41-45	2	0
46-50	0	2

4.8.1 Health Care Workers Key Informant Findings

Analysis of the individual key informant interviews yielded data on barriers and facilitators to transition to adult clinic as well as recommendations to successful transition. The following are the common themes that emerged during the interviews:

Health Care Workers Perceptions on Barriers to Transition from Paediatrics to Adult Services

1. **Lack of transition knowledge**

The healthcare workers interviewed each agreed that there was no standard way of communicating to the adolescents about transition to adult clinic at the hospital. All of them stated that communication about transition was dependent on the healthcare worker seeing the patient. Lack of transition protocol greatly contributed to this. Most of the healthcare workers also reported that there was no proper hand over of patients once they"ve transitioned to adult clinics.

Responses from healthcare workers during KII's:

"We must develop guidelines where now it is not determined by who you meet but everybody in that clinic knows that maybe by the moment the children are 10 years, we start talking about transition and the things to expect" KII, Family physician.

"I also think they feel like they have been pushed to another hospital all together, because I don't think we have very good communication between the paediatric and the adult medical outpatient clinic." KII, Adult clinic nurse.

2. Negative first -time experiences in the adult clinic

The healthcare workers reported that there was no special clinic for adolescents with SCD once they transition to adult services. Both the adolescents and the adult patients share the same clinic days and this makes the adolescents feel out of place. Some of the health care workers stated that the adolescents did not like the long queues in adult clinic.

Responses from healthcare workers during KII's:

"R: You see in the adult clinic there are old people there because we don't separate them so they feel intimidated by the older patients and they feel out of place being seen by the same doctor who is seeing these very old patients, so I feel their age and the age of these older patients really affects them" KII, Paediatric nurse.

"R: The medical outpatient clinic is a bit slow compared to the paediatric outpatient clinic, so they are almost used to the express clinic in the paediatric outpatient clinic, so when you shift them to the medical outpatient clinic, they usually feel like it is going to be a waste of time" KII, Medical officer.

3. Fear of leaving paediatric clinic

The health care workers described the fear and resistance of the adolescents to leave paediatric clinic as a barrier to transition. In the paediatric clinic, the adolescents were used to their doctors whom they had formed strong bonds and they were not willing to break the bonds. Some of the HCW also stated that the adolescents felt young and not mature enough to transition to adult clinic.

Responses from healthcare workers during KII's:

"There are some who do not want to transition to the adult clinic and they feel that maybe they should transit when they are 18 years of age" KII, Paediatric nurse.

"Most of the sickle cell patients have a class below the normal age group, they have issues with education so at 12 years when they are supposed to transition, they are so young even to understand about the disease and the transition process" KII, social worker.

"Sickle cell children don't grow like others, their growth rate is minimal so when you tell them to move into the adult clinic, they still feel that they are young and should still remain in the paediatric clinic" KII, Paediatric nurse.

4. Financial constraints

The healthcare workers reported that the cost implications when adolescents are transferred to the adult clinic posed a major challenge to transition. These included the high consultation fee and the cost of medication at the adult clinic.

Responses from healthcare workers during KII's:

"Drugs in the medical outpatient clinic are expensive compared to the paediatric outpatient clinic. Most of them do not have NHIF, they pay from out of pocket. So some of them will opt to buy drugs from nearby chemists using money they'd have used on transport to come for clinic…and that's how we lose some of them." KII, Medical officer.

5. Stigma

Stigma associated with SCD was pointed out as a barrier to transition to adult clinic during interviews. The healthcare workers reported that due to the stigma, children suffering from sickle cell disease are not easily accepted in the community because of the burden of treatment and hence can miss clinic attendance. Some of the HCW also stated that emotional stress experienced during the adolescence period coupled with stigma from peers may affect transition of these adolescents.

"Immediately when an adolescent patient start realizing that they're suffering from SCD, there are a number of mental issues or torture and other social issues that come up and when this child is not prepared properly there is a tendency that the child will refuse to come to the clinic" KII, Paediatric nurse.

Health care workers perceptions on facilitators to transition from paediatric to adult services.

1.Early preparation to transition

All healthcare workers reported that the transition process will be made easier if preparation of the adolescents and their caregivers started early and this will also improve adherence to clinic visits and minimize lost to follow up.

Responses from healthcare workers during KII's:

"We have to start early preparation by counselling them (both parents and children) on why they have to transfer from the paediatric to adult clinic. We should equip them with knowledge and also what to expect in the adult clinic." KII Family physician

"We have to talk to the adolescents and their parents that at a certain age the children will transition from the children to the adult clinic, and this has to start early enough" KII, Paediatric nurse.

2. Good family support

The healthcare workers stated that adolescents who had good family support had better transition outcomes and were attending adult clinic compared to the adolescents who had little or no family support**.**

Responses from healthcare workers during KII's:

"In my experience working with the adolescents with SCD here at the clinics, I've observed that adolescents who have supportive parents and those that are involved in their children's disease management were doing well clinically, they hardly missed their clinic dates and had better transition outcomes." KII, Adult clinic nurse.

3. Positive first -time encounters at the adult clinic

Positive first -time encounters at the adult clinic for the adolescents with SCD was agreed by health care workers as a facilitator to transition to adult clinic as this will encourage them to come for the subsequent clinic visits in the adult clinic.

Responses from healthcare workers during KII's:

"When these adolescents come to the adult clinic, let us engage them to get to know how they are doing, their adherence patterns and get to know their challenges and give them feedback on their status" KII, Social worker.

"When they come to the clinic you have already transitioned them, let us give the adolescents first priority to be seen first or since there are 3 rooms let us allocate them one room exclusive for them" KII, Paediatric nurse.

Table 10: Summary of KII finding: Factors that affecting transition from paediatric to adult clinics among adolescents with SCD.

Factors	**Barriers**	**Facilitators**
Patient/family	-Financial constraints -Lack of transition knowledge	-Good family support
Healthcare system/Healthcare worker	-Negative first-time experiences at the adult clinic	-Positive first-time encounters at adult clinic -Early preparation to transition
Community	-Stigma	

5.0 CHAPTER FIVE: DISCUSSION

Over the years, the high mortality rate of children with SCD had lessened the need for adult-oriented medical care in the Sub-Saharan Africa. However, with the advent of early screening for hemoglobinopathies and improved medical services, most of the children with SCD are surviving beyond the childhood period into adolescence. [5]

At Webuye county hospital, we sort to find out the prevalence of adolescents with SCD that transition from paediatrics to adult services and also explore the factors that affect successful transition. To our knowledge this is the first study in Kenya to find out the prevalence of adolescents with SCD that transition to adult services.

5.1 Prevalence of Ever Transitioning To Adult Clinic

Our study found the prevalence of ever transitioning to adult services among adolescents with SCD to be 62.5% (95% CI 51.3, 73.7). Out of the 50 adolescents that ever transitioned to adult services, 1(2%) adolescent had transition at the appropriate age of transition (12-13years) as per the hospital protocol and 49 (98%) had transitioned after the age of 14 years and therefore had delayed transition. None of the adolescents had early transition to adult services. Thirty adolescents had no record of attending the adult outpatient clinic by their last recorded contact with WCH, giving a prevalence of non-transition of 37.5% (95%CI 26.3, 48.8).

After in-depth search on literature review, we found no previous studies done on prevalence of transitioning adolescents with SCD to adult care. However, we found the prevalence in our study to be slightly higher compared to a study done by Grewal et al on transitioning the HIV infected adolescents/youth to adult care in Kenya which was at 50% (95% CI 40-59) [(22)]. Another Canadian study by Graham et al on prevalence of transitioning young adults with complex congenital heart disease showed the prevalence of ever transitioning to be 47% which was slightly lower in comparison to our study[(23)].

Additionally, a slightly lower prevalence of 49% in comparison to our study was noted among the adolescents and young adults with mental health issues transitioning to adult mental health services in the UK [(24)].

Several studies have been done on approach to transition in adolescents with SCD from paediatrics to adult care. A US study by Sobota et al on transition from paediatric to adult care for sickle cell disease showed that the most common criteria used for transferring patients to adult care was age (100%) and pregnancy (70%) [(25)]. Transition to adult SCD care typically occurred later with cut off ages of 18-22 years. This was contrary to our study

where the cut off ages were 12-13 years. The high percentage (98%) of delayed transition in our study could attributed to by the early cut- offs ages for transition to adult care. Additionally, the high consultation fee at the adult services and fear of leaving paediatric clinic as echoed by adolescents in the FGDs and in-depth interviews could be contributing factors to delayed transition.

5.2 Prevalence of Successful Sustained Transition to Adult Services

Out of the 50 adolescents who had transitioned to adult care services only 8 (10%) were still in active care and had attended more than two scheduled appointments in the adult medical out -patient clinic and therefore successfully transitioned. This gave a prevalence of successful sustained transition in adult services of 10% (95% CI 3.8, 16.3). 42 adolescents had dropped out of care after their initial visit to the adult clinic.

After contact tracing via the telephone 7(14%) had died,5 (10%) transferred out and 30(60%) were lost to follow-up. Of the 30 adolescents that had not transitioned to adult clinic,16(53.3%) adolescents were still attending paediatric clinic and therefore still in active care,8(26.7%) had transferred to the nearest hospital and 6(20%) had attained the age of 12 years but had died before transition.

Although extensive literature has been devoted to the issue of transition from paediatric to adult services, little is mentioned on prevalence of successful sustained transition to adult services among adolescents with chronic illnesses [26]. An international Delphi study done by Suris et al on key indicators to successful transition recognised patient not lost to follow up and attending scheduled visits in adult care as essential and very important indicators of successful transition[26].

Likewise, some authors consider that attendance at the first two appointments in adult care should be considered as an indicator of good continuity of care [27]. The later indicator is consistent with the definition of successful transition in our study where the adolescents ought to have attended at least two scheduled appointments in the adult clinic.

As indicated by Paul et al, transition is common but good transition is rare with reports indicating that only between 22-47% of youth make a successful transition to adult care. The findings in our study findings were slightly lower where we had poor successful sustained transition at 10%.

The percentage of adolescents lost to follow up after transition was high at 60% in our study. This prevalence was slightly higher compared to a UK study where 50% of adolescents with Congenital Adrenal hyperplasia (CAH) were lost to follow up after transition to adult

services[27].In view of the indicators for successful transition reported in the international Delphi study[26], the high percentage(60%) of adolescents lost to follow up could point towards poor successful transition.

5.3 Adolescents Perspectives on Transition: Barriers and Facilitators to Transition

Adolescents with SCD transitioning from paediatric to adult care have several concerns that requires the attention of those responsible for planning their health care provision. Similar to the systematic review on barriers to transition from paediatric to adult care by Gray et al [17], the themes that emerged from the focused group discussions and in-depth interviews as barriers to transition included adolescents fear of leaving paediatric clinic, lack of transition knowledge, negative experiences in adult clinic, financial constraints and poor preparedness to transition.

The adolescents expressed concerns of not being prepared adequately to transition to the adult clinic and the negative first- time experiences at the adult clinic. This could be some of the reasons for the high percentage (60%) of adolescents lost to follow-up after transition to adult care. They also reported the fear of leaving paediatric clinic and ending longstanding relationships built with the paediatric healthcare workers. This findings were similar to a study done by Telfair et al on transitioning adolescents with SCD[18].Regarding financial constraints, the adolescents reported the challenges in coming to the adult clinics due to lack of transport money and the high consultation fees at the adult clinic. This could be a plausible reason why we had more of adolescents (53.3%) in active care in the paediatric clinic compared to adolescents (16%) attending the adult clinic. This findings were consistent with a study Mennito et al on assessing transition readiness in adolescents with SCD[28]

Facilitators to transition as pointed out by the adolescents were good family support, early preparation to transition and positive first -time encounters at the adult clinics. This findings were consistent with previous studies done on transitioning adolescents with SCD.[22][19]

5.4 Healthcare Perspectives on Transition: Barriers and Facilitators

In summary, the health care workers identified barriers to transition as lack of transition knowledge, financial constraints, fear of leaving paediatric clinic, stigma and negative first-time encounters at the adult clinic as barriers to transition. Facilitators to transition included early preparation to transition, good family support and positive first -time encounters at the adult clinics. (table 10)

Several studies have been reported on facilitators and barriers to transition from the health care workers perspectives. One study identified the following barriers to successful transition: limitation in developmental maturity and skills, neurocognitive deficits and negative experiences with adult healthcare workers [20]. Our study adds on this by identifying additional barriers to transition as lack of transition knowledge, financial constraints and stigma.

In general, both paediatric and adult health care workers discussed similar themes related to barriers and facilitators to transition among adolescents with SCD. One reoccurring theme in the interviews was lack of transition knowledge among adolescents with SCD. This barrier is consistent with literature on barriers to transitioning adolescents with SCD suggesting that continual education of the adolescents is needed. [17],[18],[19] ,[5]. Paediatric HCW can promote adolescents transition readiness by starting transition preparation in early adolescence[29], seeing the adolescent alone for part of the visit[23],and regularly assessing transition readiness[21].Additionally, a transition program to be put in place to facilitate smooth transition to adult care[18].

Another theme of transition barrier that greatly affected adolescents with SCD is the challenge of financial constraints and the high cost of accessing adult services. This is consistent with another study done in a rural community[28]. This could be attributed to the high unemployment and poverty rate in Bungoma county, given that majority (68%) of the adolescents live in this area.

Despite these challenges that affected successful transition to adult services, the participants also reported positive stories of successful transition. Thus our results support other literature emphasizing the importance of early preparation to transition, good family support and positive first -time encounters at the adult services [22],[18][20].

5.5 Study Strengths

- This is the first study in East Africa to give insight on factors that affect transition to adult services among adolescents with SCD in a rural community. It also gives the prevalence of ever transitioning and successful transition in adolescents with SCD.
- Use of qualitative approach from both Healthcare workers and adolescents with SCD gave added insights on factors affecting transition to adult services.
- Although not a huge percentage, adolescents lost to follow up were traced and reasons for LTFU were established.

5.6 Study Limitations

- Our sample size for the cross-sectional study was small, however we achieved thematic saturation.
- Our study site was a low resource setting facility hence the study participants did not have the ideal SCD confirmatory test-Hb electrophoresis
- We were unable to interview the adolescents age <12 years who were soon to transition to adult services and find out their knowledge, concerns and perspectives on the transition process because of COVID-19 pandemic and nurses' strike.

5.7 Conclusions

- Two thirds of the adolescents with SCD had ever transitioned to adult services.
- More than three quarters of the adolescents had delayed transition with majority transitioning after the age of 16 years.
- Sustained transition was poor with barely a quarter of the adolescents in active care in the adult clinic and more than half of the adolescents lost to follow-up after transition to adult services.
- Barriers to transition from paediatric to adult services include: lack of transition knowledge, financial constraints, negative first -time experiences in the adult clinics, stigma, poor preparedness to transition and fear of leaving paediatric clinic.
- Good family support, positive first- time encounters at adult clinic and early preparation are the facilitators to transition from paediatric to adult services.

5.8 Recommendations

- There is need to have a transition program for adolescents with SCD to guide with transition process from paediatric to adult services and to improve outcomes of successful transition.
- Webuye county Hospital to set up adolescent- friendly clinic for adolescents with SCD to improve successful transition outcomes
- There is need for strategies to overcome financial constraints and access to the hospi

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APPENDICES

Appendix I: Study Timelines

	2020				2021				
Activity	Mar-April	May-June	July-Sept	Sept-Dec	Jan-Mar	Mar-April	May-Aug		
Proposal development									
ERC approval									
Initial data collection									
Study modification									
Data collection									
Data analysis									
Results presentation									
Dissertation write-up									
Submission of dissertation									

Appendix II: Study Budget

Item	Cost (Kshs)
Printing and photocopy	10,000
Tape recorder and batteries	5,000
PPEs/Sanitizers	5,000
Research assistants	20,000
Statisticians	75,000
Contingency fund (10% of budget)	10,000
Total	**125,000**

Appendix III: Waiver of Informed Consent for Retrospective Data Abstraction

Study Title: Prevalence and Factors that affect Transition from Paediatrics to Adult services among Adolescents with Sickle cell disease in Webuye county Hospital

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Introduction

I am a post graduate student at the University of Nairobi pursuing a master of medicine degree in Paediatrics and Child Health. I am doing a study on Prevalence and factors that affect transition from Paediatric to Adult care among adolescents with Sickle Cell Disease in Webuye County Hospital. Improvement in the medical management of sickle cell disease has made it possible for children with Sickle cell disease to survive into adolescent years. As such these adolescents have to transition from Paediatric to Adult services. It is important to know the exact numbers of adolescents with SCD who transition to adult care and those who remain in care thereafter as this will inform approach to transition process and improve healthcare outcomes.

Benefits

The study is a retrospective study and we are requesting for a waiver of informed consent in order to be able to access the information necessary for this study.

Practicality

This research would not be able to be done without a waiver because we are analyzing already documented data prior to the time of collection of data and getting informed consent of the subjects is not feasible either from the fact that contact information may be missing, have changed and the subject may live too far from the site of the study.

Risk

The research will cause no risk to the patient as we will not come into contact with them. The waiver of consent will be used to collect data already documented. Coding of data will be used to prevent the primary risk that is breach of confidentiality.

Confidentiality

Rights and welfare of the subject will be respected by abstracting identifiable personal data and omitting any unnecessary data. This will further more prevent any breach of confidentiality.

Problem/Question

If any problem or question about the study, you can contact the principal investigator by contacting;

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Lead Supervisor:

Prof. E. M. Obimbo

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The Chairperson,

KNH-UON ERC Committee

Tel 2726300/2716450 Ext 44102

Email uonknh-erc@uonbi.ac.ke

Investigator Signature: _____ Date: _____

Appendix IV (a): Consent form for parents/guardians of participants less than 18 years and adolescents above 18 years – Focused Group Discussion.

Study Title: "Prevalence and Factors that affect Transition from Paediatrics to Adult service among adolescents with Sickle cell disease in Webuye County Hospital".

Principal Investigator:

Dr. Millicent N. Wanyama

Tel: 0722530852

Email: millysabina@gmail.com

Supervisors:

Prof. E. M. Obimbo

Dr. Nyambura Kariuki

Dr. Paul Laigong

(Department of Paediatrics and Child Health, University of Nairobi)
Tel: 0721257746

Introduction

I am a post graduate student at the University of Nairobi pursuing a Master of Medicine Degree in Paediatrics and Child Health. I am doing a study to find out the factors that affect transition from paediatric to adult service among adolescents with Sickle cell disease in Webuye County Hospital.

Improvement in the medical management of sickle cell disease has made it possible for children with Sickle cell disease to survive into adolescent years. As such these adolescents have to transition from paediatric to adult services. It is important to understand the possible barriers and facilitators to transition from paediatrics to adult care so as to ensure continuity of care, better health outcomes and reduce lost to follow up incidences.

You are requested to participate in a group discussion as part of the study. This is on voluntary basis. You are allowed to take some time and think about this, and even consult friends and family if you so wish. In case you don"t understand or need clarifications with regards to this consent frame please feel free to seek help from the principal investigator or any of the research assistants.

Scope of the Study

The aim of the Focus Group Discussions is to allow you to share your views and experiences on the transition process, what made it easier or harder for you during and after transition and how best we can improve the process. Your input will be highly regarded and will help in developing transition programs and guidelines to ensure smooth transition process.

Focus Group Discussions will consist of 6-8 adolescents with sickle cell disease of the age group bracket. The venue of discussion will be communicated to you. Discussions will take 30-45 minutes and participants will be asked questions around the transition process. We shall record and take notes of your responses during discussions to allow for further analysis.

Please take note of the following:

Participation is voluntary

Confidentiality shall be maintained at all times. Prior to the discussions, we shall allocate different numbers to the participants with which we shall refer to them.

Refusal to participate in the study will not be held against you and it will not influence the services you are entitled to in this hospital

Risks

There will be no dangers to your health since we will not give you any medicine or perform any procedures on you, only questions will be asked. None of your rights will be infringed during this research**.**

Benefits

The results of the research will be shared with you and your healthcare providers and will help ensure a smooth transition for the adolescents with sickle cell disease from paediatric to adult services.

Consent to Participate in the Study

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counsellor. I have had my questions answered by him or her in a language that I understand. The risks and benefits have been explained to me. I understand that I shall be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw it any time. I understand that all efforts shall be made to keep information regarding me confidential. By signing this I have not given up my legal rights as a participant in this research study

I voluntarily agree to participate in this research study: Yes……No……

Name of participant…… Date ……...

Signature /Thumb stamp……..

Researcher's Statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given his/her consent

Name of researcher…… Date…….

Signature of researcher……

Should you have any questions about your rights as a research participant, feel free to get in touch with any of the following:

Principal Investigator:

Dr. Millicent N. Wanyama

Tel 0722530852

Email millysabina@gmail.com

Lead Supervisor:

Prof. E. M. Obimbo

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The Chairperson,

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Tel 2726300/2716450 Ext 44102

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Appendix IV (b): Consent Form for Parents/Guardians of Participants Less Than 18 Years and Adolescents above 18 Years-Focused Group Discussion (Swahili Version)

Fomu ya Idhini kwa wazazi wa washiriki <18years na vijana juu 18 years. Kifunguo

Mimi ni Dkt Millicent Wanyama, mwanafunzi katika Chuo Kikuu cha Nairobi ninayesomea Shahada ya Afya na Magojwa ya Watoto. Nafanya utafiti juu ya mambo ambayo yanaadhiri mpito kutokana na huduma kwa watoto na huduma kwa watu wazima miongoni mwa vijana walio na ugonjwa wa Sickle Cell katika hospitali Kuu ya Kaunti ya Webuye.

Hii fomu ya kupata idhini ni kwa ajili ya vijana walio na ugonjwa wa Sickle Cell katika hospitali ya Kaunti ya Webuye ambao tunawakaribisha kushiriki katika utafiti. Nitakupa taarifa na kukukaribisha kwa utafiti huu. Kunaweza kuwa na baadhi ya maneno ambayo huelewi, tafadhali uliza na mimi nitachukua muda kukueleza na kama una maswali baadaye, waweza bado kuniuliza

Sababu ya utafiti

Watoto wengi ambao wanaugua ugonjwa wa Sickle Cell sasa wanaishi kati ya watu wazima kutokana na mazindulizi mapya dhidi ya uboreshaji wa afya katika ugonjwa wa sickle cell. Imekuwa muhimu sana kuelewa kipindi hiki cha mpito kutoka huduma kwa watoto kwa huduma ya watu wazima ili kuhakikisha vijana hawa wanaendelea kupata huduma za afya na kudumisha afya njema.Tunataka kujua ni mambo yapi ambayo hufanya kuhama kutoka huduma kwa watoto kwa huduma ya watu wazima rahisi au vigumu kwa vijana wa sickle cell.

Maandalizi ya Utafiti

Lengo la majadiliano ya kikundi inayolenga nikuwezesha vijana wa sickle cell kutueleza mambo yapi ambayo hufanya kuhama kutoka huduma ya watoto kwa huduma ya watu wazima rahisi au vigumu.Tutatilia maanani maoni yako na pia itatuwezesha kuboresha mpito kutoka kwa huduma ya watoto kuenda kwa huduma ya watu wazima.Majadiliano ya kikundi itakuwa na vijana wa sickle cell kati ya 6-8 na yatachukua dakika 30-45.Maswali kuhusu mpito yataulizwa. Tutarekodi majadiliano hayailikutuwezesha kufanya utafiti zaidi. Ni chaguo lako kushiriki au la. Usipochagua kushiriki, bado utapokea huduma zote katika hospitali hii.

Tafadhali elewa yafuatayo

Kushirika ni kwa hiari yako. Habari kukuhusu ambayo tutakusanya katika utafiti huu utakuwa wa siri.

Utafiti wetu hautamdhuru mtoto wako kwa njia yeyote.

Nimesoma /nimesomewa maelezo haya na nimepewa nafasi ya kuuliza maswali kuhusu hayo maelezo.Nimeidhini kwa hiari kushiriki utafiti huu.

Jina la mshiriki.....Tarehe.....

Sahihi ya mshiriki.....

Nina uhakika kuwa nimemsomea na mwakilishi fomu hii, na kwa kadri ya uwezo wangu nilihakikisha kwamba mimmi kama mshiriki nimeelewa. Nilithibitisha kuwa mimi kama mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti huu na kuyajibu vyema kwa kadri ya uwezo wangu.Mimi nathibitisha kwamba mwakilishi hakulazimishwa kutoa kibali.

Jina la Mtafiti/Mtu wa kuchukua kibali.....Tarehe.....

Sahihi ya Mtafiti/Mtu wa kuchukua kibali.....

Mtafiti Mkuu:

Dkt Millicent N Wanyama,

Nambari ya simu 0722530852

Barua pepe: millysabina@gmail.com

Msimamizi Mkuu:

Prof. E. M. Obimbo,

Nambari ya simu +254-20-4915046

Barua pepe: eobimbo@yahoo.com

Kamati ya maadili ya hospitali kuu ya Kenyatta:

Nambari ya simu 2726300 Ext. 44102

Barua pepe**: uonknh_erc@uonbi.ac.ke**

Appendix V(a): Assent Form for Participation in the Study-Focused Group Discussion

Study Title: "Prevalence and Factors that affect Transition from Paediatrics to Adult service among adolescents with Sickle cell disease in Webuye County Hospital".

Principal Investigator:

Dr. Millicent N. Wanyama

Tel: 0722530852

Email: millysabina@gmail.com

Supervisors:

Prof. E. M. Obimbo

Dr. Nyambura Kariuki

Dr. Paul Laigong

(Department of Paediatrics and Child Health, University of Nairobi)
Tel: 0721257746

Introduction: We want to give you information regarding something we are doing called a research study. A research study is when people collect a lot of data to learn more about a topic. I Millicent Wanyama am doing a study to learn more about adolescents with Sickle Cell Disease who are moving out of paediatric to adult care. After we provide you with sufficient information, we will inquire if you"d like to take part in this study or not.

Reason for doing this study: We need to find out what challenges you face as you move from paediatric to adult clinics. We are collecting data from many of the young boys and girls like you to help us know these challenges.

If you decide to Take Part in the Study

If you say yes to take part in the study, the following will happen:

We shall have a Focused group discussion where we shall allow you to share your experience moving from paediatric to adult clinic. We shall ask you questions only regarding what you think. It is not an examination, so feel free to answer the way you want. There is no right or wrong answer.

If You Have Any Questions

You can ask now. You can ask later or any time. You can speak to me or someone else.

Is it necessary to be in this study?

No, you don"t. Nobody will punish if you decide not to take part in the study. In the event you choose to take part in the study, please let us know. If you decide not to participate in the study also let us know. You can inform us now or later on. The investigator will give you a copy of this assent to keep.

I have explained the investigation to ……. (print name here) in a language he/she can understand and the child has given assent to take part in the study.

Name of participant…… Date ……...

Signature /Thumb stamp……..

Name of researcher…… Date…….

Signature of researcher……

Should you have any questions about your rights as a research participant, feel free to get in touch with any of the following:

Principal Investigator:

Dr. Millicent N. Wanyama

Tel 0722530852

Email millysabina@gmail.com

Lead Supervisor:

Prof. E. M. Obimbo

Tel +254-20-4915046

Email eobimbo@yahoo.com

The Chairperson,

KNH-UON ERC Committee

Tel 2726300/2716450 Ext 44102

Email uonknh-erc@uonbi.ac.ke

Appendix V (b): Assent Form for Adolescents with Sickle Cell Disease Less Than 18 years transition Study Assent Form- Focused Group Discussion (Swahili Version)

Fomu ya Idhini kwa vijana chini ya umri wa miaka 18

Kifunguo

Hii fomu ya kupata idhini ni kwa ajili ya vijana walio na ugonjwa wa Sickle cell katika hospitali ya kauti ya Webuye ambao tunawakaribisha kushiriki katika utafiti. Mimi ni Dk Millicent Wanyama ,mwanafunzi katika chuo kikuu cha Nairobi ninayesomea shahada ya afya na magojwa ya watoto.Mimi nafanya utafiti juu ya mambo ambayo yanaadhiri mpito kutoka huduma kwa watoto kwa huduma ya watu wazima miongoni mwa vijana walio na ugonjwa wa sickle cell katika hospitali ya kauti ya webuye. Nitakupa taarifa na kukukaribisha katika utafiti huu.

Kwa nini tunakutana na wewe?

Sisi tunataka kukueleza kuhusu kitu tunafanya kinaitwa utafiti.Utafiti ni wakati madaktari wana kusanya mengi ya habari kujifunza zaidi kuhusu jambo fulani.Tunachofanya ni utafiti tujifunze zaidi kuhusu vijana walio na ugonjwa wa sickle cell ambao ni kipindi cha mpito kutoka huduma kwa watoto kwa huduma ya watu wazima.Baada ya sisi kukueleza zaidi kuhusu utafiti huu,sisi tutakuuliza kama ungependa kuwa katika utafiti huu au hapana.

Kwa nini tunafanya utafiti huu?

Tunataka kujua ni mambo yapi ambayo hufanya kuhama kutoka huduma kwa watoto kwa huduma ya watu wazima rahisi au vigumu kwa ajili yenu.Sisi tutapata habari hii kutoka kwa kura ya wavulana na wasichana kama wewe.

Nini kitatokea kwako kama wewe utachagua kuwa katika utafiti huu?

Kama wewe utakubali,mambo haya yatafanyika: Tutakuwa na majadiliano ya kikundi inayolenga ambayo itakuruhusu kutueleza mambo yapi ambayo hufanya kuhama kutoka kwa huduma ya watoto kwa huduma ya watu wazima rahisi au vigumu.Maswali yatakuwa kuhusu nini unafikiria.Hakuna majibu sahihi au haki kwa sababu huu si mtihani.

Je, una maswali yeyote?

Unaweza kuuliza maswali wakati wowote,unaweza kuuliza sasa,unaweza kuuliza baadaye.unaweza kuzungumza nami au unaweza kuzungumza na mtu mwingine.

Je, ni lazima niwe katika utafiti huu?

Hapana, si lazima uwe katika utafiti huu. Hakuna mtu atakayekulazimisha kama hutaki kufanya hivyo.Kama unataka kuwa katika utafiti huu, tuambie na kumbuka unaweza sema ndiyo sasa,na kubadilisha baadaye ijapokuwa hutaki kuendelea na utafiti huu. Ni kwa hiari yako.

Nimesoma /nimesomewa maelezo haya na nimepewa nafasi ya kuuliza maswali kuhusu hayo maelezo.Nimeidhini kwa hiari kushiriki utafiti huu.

Jina la mshiriki.....Tarehe.....

Sahihi ya mshiriki.....

Nina uhakika kuwa nimemsomea mwakilishi fomu hii,na kwa kadri ya uwezo wangu nilihakikisha kwamba mshiriki ameelewa.

Nilithibitisha kuwa mshiriki alipewa nafasi ya kuuliza maswali kuhusu utafiti huu na kuyajibu vyema kwa kadri ya uwezo wangu.Mimi nathibitisha kwamba mwakilishi hakulazimishwa kutoa kibali.

Jina la Mtafiti/Mtu wa kuchukua kibali..... Tarehe.....

Sahihi ya Mtafiti/Mtu wa kuchukua kibali.....

Mtafiti Mkuu:

Dkt Millicent N Wanyama,

Nambari ya simu 0722530852

Barua pepe: millysabina@gmail.com

Msimamizi Mkuu:

Prof. E. M. Obimbo,

Nambari ya simu +254-20-4915046

Barua pepe: eobimbo@yahoo.com

Kamati ya maadili ya hospitali kuu ya Kenyatta:

Nambari ya simu 2726300 Ext. 44102

Barua pepe**: uonknh_erc@uonbi.ac.ke**

Appendix VI: Consent form for participation in the study – Health Care Workers

Study Title: Prevalence and Factors that affect Transition from Paediatrics to Adult services among Adolescents with Sickle cell disease in Webuye County Hospital

Principal Investigator:

Dr. Millicent N. Wanyama

Tel: 0722530852

Email: millysabina@gmail.com

Supervisors:

Prof. E. M. Obimbo

Dr. Nyambura Kariuki

Dr. Paul Laigong

(Department of Paediatrics and Child Health,University of Nairobi Tel 0721257746)

Introduction

I am a post graduate student at the University of Nairobi pursuing a master of medicine degree in Paediatrics and Child Health. I am doing a study to find out the factors that affect transition from paediatric to adult service among adolescents with Sickle cell disease in Webuye County Hospital. Improvement in the medical management of sickle cell disease has made it possible for children with Sickle cell disease to survive into adolescent years. As such these adolescents have to transition from paediatric to adult services. It is important to understand the possible barriers and facilitators to transition from paediatrics to adult care so as to ensure continuity of care, better health outcomes and reduce lost to follow up incidences.

You are requested to take part in the research study. This is on voluntary basis. You don‟t have to make an immediate decision on whether to participate in this study. In case you don‟t understand or need clarifications with regards to this consent frame please feel free to seek help from the principal investigator or any of the research assistants.

Scope of the Study

The scope of the study is to find out the factors associated with transition of adolescent with sickle cell disease from paediatric to adult services. What has been your experience working with adolescents with sickle cell disease and how best can we improve transition. This research will gather the perspectives of health care workers on their experiences with transition as well as their input on what should be done in order to improve the process. You

will be provided with an open-ended questionnaire which will last approximately 20minutes. Your name will not appear on the forms, only a number will identify you. Only the principal investigator and the research assistants will have access to this information.

We shall also invite some of you to participate in Key Informant Interviews which will a one on one interview at a venue convenient to you in the hospital. Participants will be asked questions around the transition process and this will last approximately 30- 45 minutes. We shall record and take notes of your responses during the interview to allow for further analysis.

Please take note of the following:

Participation is voluntary

Confidentiality shall be maintained at all times. Prior to the interview, we shall allocate identification numbers to the participants with which we shall refer to them.

Refusal to participate in the study will not be held against you and it will not interfere with your work in the hospital.

Risks: There will be no dangers to your health, only questions will be asked. None of your rights will be infringed during this research**.**

Benefits: The results of the research will be shared with you and other health care providers at the paediatric and medical outpatient clinics. The outcomes of the study will help ensure a smooth transition for the adolescents with sickle cell disease from Paediatric to Adult services.

Consent to Participate in the Study

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counsellor. I have had my questions answered by him or her in a language that I understand. The risks and benefits have been explained to me. I understand that I shall be given a copy of this consent form after signing it. I understand that my participation in this study is voluntary and that I may choose to withdraw it any time. I understand that all efforts shall be made to keep information regarding me confidential. By signing this I have not given up my legal rights as a participant in this research study

I voluntarily agree to participate in this research study: Yes……No……

Name of participant…… Date ……...

Signature ……..

Researcher's statement

I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given his/her consent

Name of researcher…… Date…….

Signature of researcher……

Should you have any questions about your rights as a research participant, feel free to get in touch with any of the following:

Principal Investigator:

Dr. Millicent N. Wanyama

Tel 0722530852

Email millysabina@gmail.com

Lead Supervisor:

Prof. E. M. Obimbo

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The Chairperson,

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Appendix VII: Adolescent Medical Records Abstraction Form

Study Title: "Prevalence and Factors that affect Transition from Paediatrics to Adult services among Adolescents with Sickle cell disease in Webuye County Hospital"

Study ID No: ……. Date …. /……/……

1. DOB: ……Age in years…….
2. Gender: Male……Female……

   Physical Location:

   County……..……

   Sub County……

   Village……

   3 Date at first enrolment to Paediatric outpatient clinic…….

   Age in years…….

3. Mode of SCD diagnosis.

   a) Positive sickling test……. b)positive PBF……c) Both……..

4. Age at first visit to Adult medical outpatient clinic

   a) 12 years…….. **b**) >12 years…… (specify)…….

5. Pattern of visits in Paediatric outpatient clinic:

   a) Adhered to the scheduled appointments? Yes…….. No……

   b) Weekly…….. (specify)…….

   c) Monthly…….. (specify)…….

   d) Years……. (specify)…….

6. Pattern of visits to Adult medical outpatient clinic:

   a) Adhered to the scheduled appointments? Yes…….. No……

   b) Weekly…….. (specify)…….

   c) Monthly…….. (specify)…….

   d) Years……. (specify)…….

7. Status of Adolescent follow-up:

   a) In active care…….

   b) Transferred Out……

   c) Lost to Follow up……..

Appendix VIII (a): Focussed Group Discussion Tool: Not Transitioned (English Version)

Study Title: "Prevalence and Factors that affect Transition from Paediatrics to Adult services in Adolescents with Sickle cell disease in Webuye County Hospital".

Study Group Number: _____ Focus Group category: _____

Study Site: _____ Number of participants: _____

Moderator: _____ Notes taker: _____

Date_____ Start time: _____ End time: _____

Instructions to the facilitators*:* Begin by introducing yourselves. Ensure the participants are feeling comfortable. Ask the participants to introduce themselves using their initials and ages. Thank them for accepting to take part in the discussion, reconfirm their consent for participation and reassure them of confidentiality. Request them for permission to tape record the session and take notes.

Standard procedure for discussion.

a) You will do the talking during the discussion. I may approach to give your input in case I haven"t heard from you.
b) We will not call you by name, but by pre-allocated numbers so as to keep your identity confidential.
c) There are no wrong answers.
d) Everyone's views are important and will be respected.
e) Whatever is said here will remain here.
f) In the course of this discussion, we will be using a recording device and taking notes. **Guide questions for FGDs for adolescents with SCD still in Paediatric care**.

a) What does transition mean to you?
b) Has your healthcare provider communicated to you about moving to adult care when you reach 12 years old?
c) What are some things you think would be important to know in order to have a good transition? How would knowing these things be helpful?
d) What do you think will make your transitioning into adult care difficult?
e) What do you recommend that will make the process of transitioning more easy and successful for you?

Closing session*:* The moderator of the session will ask if there are any additions or questions to what has been discussed. If none, the session will be closed by thanking everyone for their participation. Refreshments will then be served afterwards.

Appendix VIII(b): Focussed Group Discussion Tool: Not Transitioned (Swahili Version)

KIAMBATISHO: Kiungo cha mjadiliano wa umakini: vijana walio kwenye huduma ya watoto

Kichwa cha somo: "**Maambukizi na sababu zinazoadhiri kutoka huduma za watoto na watu wazima kati ya vijana wanaoadhirika na ugonjwa wa Sickle cell kwenye hospitali ya kaunti ya Webuye"**

Nambari ya somo ya kikundi: _____ Jamii ya kikundi cha umakini: _____

Tovuti ya somo: _____ Idadi ya washiriki: _____

Msimamizi: _____ Mweka kumbukumbu: _____

Tarehe:_____ Mwanzo: _____ Mwisho: _____

Masharti kwa mwezeshaji*:* Anza kwa kujitambulisha. Hakikisha kuwa washiriki wamepumzika. Washauri washiriki wajitambulishe kwa kutumia herufi za kwanza za majina yao pamoja na miaka yao.

Washukuru kwa kujihusisha kwenye mjadiliano, hakiki idhini yao ya kushiriki na uwajulishe kuhusu usiri wa ushiriki wao. Waombe ruhusa ya kurekodi vipindi hivyo kwenye mkanda na kitabu.

Utaratibu wa kawaida wa mjadiliano:

a) Utafanya sehemu kubwa ya mjadiliano. Ninaweza kukaribia kupokea pembejeo lako iwapo sijaskia kutoka kwako.

b) Hatutakuita kwa jina lako binafsi, ila kwa nambari zilizopeanwa mwanzoni ili kuhakikisha kuwa usiri wa kitambulisho chako umezingatiwa.

c) Hakuna majibu mabaya .

d) Maoni ya kila mtu ni muhimu na yataheshimiwa.

e) Kitakacho semwa hapa kitabaki hapa.

f) Kwenye mwendo wa mjadiliano huu, tutatumia kiungo cha kurekodi na kuandika kumbu kumbu.

Mwongozo wa maswali ya FGDs ya vijana wanaougua Sickle cell walio kwenye huduma ya watoto.

a) Mpito unamaanisha nini kwako?

b) Je, mhudumu wako wa afya amekueleza kuhusu kuhamia kwenye vifaa vya watu wazima utakapo hitimu umri wa miaka 12?

c) Ni mambo gani unayoyaona yaliyo muhimu kujulishwa ili uwe na mpito laini? Ujuzi wa mambo hayo utakusaidia vipi?

d) Unadhani ni mambo gani yanayo weza kufanya mpito wako uwe mgumu?

e) Ungependekeza nini ili mpito wako uwe laini na kamilifu kwako?

***Mwisho wa kipindi**:* Msimamizi wa kipindi atauliza iwapo kuna maswali ama mambo ya kuongezea juu ya yaliyojadiliwa. Iwapo hakuna lolote , kipindi hicho kitafungwa kwa kushukuru kila mtu kwa kushiriki. Vinywaji vitaletwa baada ya kipindi hicho.

Appendix IX (a): Focussed Group Discussion Tool: Transitioned (English Version)

Study Title: Prevalence and Factors that affect Transition from Paediatrics to Adult services in Adolescents with Sickle cell disease in Webuye County Hospital.

Study Group Number: _____ Focus Group category: _____

Study Site: _____ Number of participants: _____

Moderator: _____ Notes taker: _____

Date_____ Start time: _____ End time: _____

Instructions to the facilitators*:* Begin by introducing yourselves. Ensure the participants are feeling comfortable. Ask the participants to introduce themselves using their initials and ages. Thank them for accepting to take part in the discussion, reconfirm their consent for participation and reassure them of confidentiality. Request them for permission to tape record the session and take notes.

Standard procedure for discussion.

a) You will do the talking during the discussion. I may approach to give your input in case I haven‟t heard from you.

b) We will not call you by name, but by pre-allocated numbers so as to keep your identity confidential.

c) There are no wrong answers.

d) Everyone's views are important and will be respected.

e) Whatever is said here will remain here.

f) In the course of this discussion, we will be using a recording device and taking notes.

Guide questions for FGDs for adolescents with SCD already transitioned to Adult care.

a) What do you understand by transition?

b) When did your healthcare provider communicate to you about transition?

c) What does it mean to be ready for transition?

d) What made it easier for you to move to Adult clinic?

e) What made it difficult for you to move to Adult clinic?

f) What advice would you give to adolescents who are preparing to transition to adult ca

g) What do you recommend that needs to change to improve transition process?

Closing session: The moderator of the session will ask if there are any additions or questions to what has been discussed. If none, the session will be closed by thanking everyone for their participation. Refreshments will then be served afterwards.

Appendix IX (b): Focussed Group Discussion Tool: Transitioned (Swahili Version)

Kiambatisho: Kiungo cha mjadiliano wa umakini: Vijana walio kwa huduma ya watu wazima.

Kichwa cha somo: "Maambukizi na sababu zinazoadhiri kutoka huduma za watoto na watu wazima kati ya vijana wanaoadhirika na ugonjwa wa sickle cell kwenye hospitali ya kaunti ya Webuye"

Nambari ya somo ya kikundi: _____ Jamii ya kikundi cha umakini: _____

Tovuti ya somo: _____ Idadi ya washiriki: _____

Msimamizi: _____ Mweka kumbukumbu: _____

Tarehe:_____ mwanzo: _____ Mwisho: _____

Masharti kwa mwezeshaji*:* Anza kwa kujitambulisha. Hakikisha kuwa washiriki wamepumzika. Washauri washiriki wajitambulishe kwa kutumia herufi za kwanza za majina yao pamoja na miaka yao.

Washukuru kwa kujihusisha kwenye mjadiliano, hakiki idhini yao ya kushiriki na uwajulishe kuhusu usiri wa ushiriki wao. Waombe ruhusa ya kurekodi vipindi hivyo kwenye mkanda na kitabu.

Utaratibu wa kawaida wa mjadiliano:

- **a)** Utafanya sehemu kubwa ya mjadiliano. Ninaweza kukaribia kupokea pembejeo lako iwapo sijaskia kutoka kwako.
- **b)** Hatutakuita kwa jina lako binafsi, ila kwa nambari zilizopeanwa mwanzoni ili kuhakikisha kuwa usiri wa kitambulisho chako umezingatiwa.
- **c)** Hakuna majibu mabaya .
- **d)** Maoni ya kila mtu ni muhimu na yataheshimiwa.
- **e)** Kitakacho semwa hapa kitabaki hapa.
- **f)** Kwenye mwendo wa mjadiliano huu, tutatumia kiungo cha kurekodi na kuandika kumbu kumbu.

Mwongozo wa maswali ya FGDs ya vijana wanaougua sickle cell walio kwenye huduma ya watoto.

a) Mpito unamaanisha nini kwako?

b) Je, mhudumu wako wa afya amekueleza kuhusu kuhamia kwenye vifaa vya watu wazima utakapo hitimu umri wa miaka 12?

c) Ni mambo gani unayoyaona yaliyo muhimu kujulishwa ili uwe na mpito laini? Ujuzi wa mambo hayo utakusaidia vipi?

d) Unadhani ni mambo gani yanayo weza kufanya mpito wako uwe mgumu?

e) Ungependekeza nini ili mpito wako uwe laini na kamilifu kwako?

***Mwisho wa kipindi**:* Msimamizi wa kipindi atauliza iwapo kuna maswali ama mambo ya kuongezea juu ya yaliyojadiliwa. Iwapo hakuna lolote , kipindi hicho kitafungwa kwa kushukuru kila mtu kwa kushiriki. Vinywaji vitaletwa baada ya kipindi hicho.

Appendix X: Key Informant Tool Guide

Study Title: Prevalence and Factors that affect Transition from Paediatrics to Adult services in Adolescents with Sickle cell disease in Webuye county Hospital

Study Number: _____ Key informant category: _____

Study Site: _____ Notes taker: _____

Moderator: _____

Date_____ Start time: _____ End time: _____

Guide questions for key informant interviews for healthcare providers caring for adolescents with SCD.

Introduction: I will introduce myself and the aim of the study before beginning the interview. Thank the participant for agreeing to be interviewed and assure them of confidentiality.

a) What is your current job title?

b) How many years have you been in practice caring for adolescents and young adults?

c) How does the transition process work in your clinic?

d) What do you think are some unique challenges for adolescents with Sickle Cell Disease preparing to transition to adult care? What of the adolescents who have already transitioned?

e) What are the facilitators to successful transition from paediatric to Adult care?

f) Is there communication between paediatric and adult healthcare providers before and after transition of adolescents with SCD to adult care?

g) Are there guidelines /protocols for transition in your clinic?

h) What are some of the things that will improve transition?

Closing session: Ask for any final comments or additional information. Thank them for participating in the study.

Appendix XI: KNH/UoN-ERC Letter of Approval

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Ref: KNH-ERC/A/353

15th October 2020

Dr. Millicent Nanjala Wanyama
Reg. No.H58/11112/2018
Dept. of Paediatrics and Child Health
School of Medicine
College of Health Sciences
University of Nairobi

Dear Dr. Wanyama

RESEARCH PROPOSAL – PREVALENCE AND FACTORS THAT AFFECT TRANSITION FROM PAEDIATRIC TO ADULT SERVICES AMONG ADOLESCENTS WITH SICKLE CELL DISEASE IN WEBUYE COUNTY HOSPITAL (P209/03/2020)

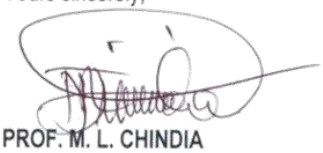
This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 13th October 2020 – 12th October 2021.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
g. Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website**http://www.erc.uonbi.ac.ke**

Yours sincerely,



PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Dean, School of Medicine, UoN
The Chair, Dept. of Paediatrics and Child Health, UoN
Supervisors: Prof. Elizabeth Maleche Obimbo, Dept.of Paediatrics and Child Health, UoN
Dr. Nyambura Kariuki, Dept.of Paediatrics and Child Health, UoN
Dr. Paul Laigong, Dept.of Paediatrics and Child Health, UoN

Appendix XII: Certificate of Plagiarism

Turnitin Originality Report

PREVALENCE AND FACTORS THAT AFFECT TRANSITION FROM PAEDIATRIC TO ADULT SERVICES AMONG ADOLESCENTS WITH SICKLE CELL DISEASE IN WEBUYE COUNTY HOSPITAL by Millicent Nanjala Wanyama

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