PSYCHIATRIC MORBIDITY AMONG CHILDREN AND ADOLESCENTS AGED LESS THAN 17 YEARS WITH SICKLE CELL DISEASE AT MOI TEACHING AND REFERRAL HOSPITAL, ELDORET-KENYA

KENYA

BY

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DECLARATION

I declare that this thesis is my original work and has not been presented in any other university or institution of higher learning for consideration for any certification. This research thesis has been complemented by referenced sources duly acknowledged. Where text, data (including spoken words), graphics, pictures or tables have been borrowed from other sources, including the internet, these are specifically accredited and references cited using current APA system and in accordance with anti-plagiarism regulations.

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Supervisor's declaration

This research has been submitted for consideration with our approval as university supervisors.

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DEDICATION

This thesis is dedicated to:

God the creator of the Universe,

My homeland Kenya, the most beautiful country in the world

The great fore fathers of our nation and the heroes of our country's second liberation

Moi University School of Medicine; the foundation of knowledge

The prestigious Friends School Kamusinga my alma mater, the island of hope and the home I loved to be.

My great parents Edward Waswa Kisiang'ani and Electine Ayiela Wabuyabo who never stop giving of themselves in innumerable ways

My dearest wife Maurine Chepchirchir Limo, who leads me through the valley of darkness with light of hope and support

My beloved siblings Purity, Faith, Bella, Eugene, Eldridge and Laura who stand by me when things look desolate

My beloved daughter Zara Chebet Ayiela whom I love with all my heart

My friends who encourage and support me, with special mention to Dr Benjamin Induswe, Dr Kelvin Orare and Tony Kibiwott Chemweno

All the people in my life who touch my heart both knowingly and unknowingly, I dedicate this research.

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LIST OF ABBREVIATIONS

AMPATH	Academic Model Providing Access to Healthcare
APA	American Psychiatric Association
CBCL	Child Behavior Checklist
CDI	Children's Depression Inventory
ChIPS	Children's Interview for Psychiatric Syndromes, Child
DBD	Disruptive Behavior Disorders Rating Scale
DSM	Diagnostic and Statistical Manual
DISC-IV	Diagnostic Interview Schedule for Children
GDP	Gross Domestic Product
HRQL	Health Related Quality of Life
HB	Haemoglobin
IREC	Institutional Research and Ethics Committee
Ksh	Kenyan Shillings
MTRH	Moi Teaching and Referral Hospital
MINI-KID	Mini-International Neuropsychiatric Interview for children and Adolescents
OCD	Obsessive Compulsive Disorder
PedQL	Pediatric Quality of Life Inventory

P-ChIPS	Children's Interview for Psychiatric Syndromes, Parent
PTSD	Post Traumatic Stress Disorder
PG	Post Graduate
PSY	Psychiatry
PHIS	Pediatric Health Information System
SCD	Sickle Cell Disease
SM	School of Medicine
TRF	Teacher Report Form
USD	United States Dollar
WHO	World Health Organization

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ABSTRACT

Background: There is growing interest in mental illnesses associated with chronic medical conditions. Several studies suggest higher rates of psychiatric disorders in medically ill than in non-medically ill. Sickle cell disease (SCD) is associated with significant psychological implications on both patients and their caregivers. This could be due to financial implications and frequent hospital visits that come with the disease. SCD is a group of inherited red blood cell disorders characterized by an abnormal protein in red blood cells. Little is known about the burden of mental illness among children and adolescents attending the SCD clinic at Moi Teaching and Referral Hospital (MTRH). Factors such as, family income, age and sex among others were explored for association with psychiatric morbidity in this group.

Objective: To describe the psychiatric morbidity and the factors associated with psychiatric morbidities among children and adolescents with sickle cell disease attending MTRH Sickle cell clinic.

Methods: This was cross-sectional study. The study was conducted at the MTRH Sickle Cell Clinic. 298 respondents were recruited into the study by random sampling from a sampling frame from the SCD clinic records. Data was collected over a year between August 2020 and August 2021. Investigator designed questionnaire was used to collect sociodemographic data while the Minikid (Mini-International Neuropsychiatric Interview for children and Adolescents) tool that has been used locally and validated against the WHO designed Composite international diagnostic interview was used to screen psychiatric illnesses. Pretesting was done in the pediatric oncology clinic.

The dependent variable was a psychiatric diagnosis such as schizophrenia.

The independent variables were the age, sex, net monthly income of caretakers, the living status (who the participant lives with), number of hospital admissions and whether patients have encountered a mental health expert. Descriptive bivariate analysis was used to establish the association between psychiatric morbidity and potential factors.

Results: Of the participants, 129(43.3%) had one or more psychiatric diagnosis. The screened diagnoses were major depression (22%), panic disorders (18%), separation anxiety (16%), manic hypomanic episodes (15%), PTSD (10%), OCD (8%) and agoraphobia (6%).

Bivariate analysis showed a statistically significant association between depression and the number of hospital admissions (P=0.015). Panic disorders significantly associated with sex (P=0.015), who the respondents lived with (P=0.005) and the number of hospital admissions (P=0.033).

Conclusion: There is a high burden of mental illness in children and adolescents with SCD in MTRH SCD clinic especially depression and anxiety disorders. Association exists between number of previous hospital admissions, who the child lives with and gender with psychiatric morbidity.

Recommendation: Screening of SCD patients for psychiatric conditions. Minimize hospital admissions through improved outpatient care of SCD patients. Improve on modifiable sociodemographic characteristics of SCD patients that are associated with psychiatric morbidities through government policies and programs.

CHAPTER ONE

1.0 Introduction and General Background

There has been progressive growing interest in mental health conditions associated with many pediatric and adolescent medical illnesses and their effects on medical outcomes, especially adherence to treatment and quality of life. Many of the studies exploring these associations suggest high rates of psychiatric symptoms or disorders among adolescents with chronic conditions when compared with non– medically ill adolescents(Ivan Pless, 1971).This is one of the earliest studies to explore psychiatric morbidity among children with chronic illnesses.

Sickle cell is a lifetime disease and it is associated with significant psychological implications on both the children diagnosed with the disease and their caretakers. This is attributed to the financial implications and the often-frequent hospital visits and admissions associated with this disease (Bakare et al., 2008). Sickle cell disease is responsible for both acute and chronic complications , as well as disturbances in psychosocial development including low self-esteem, negative feelings and depression (Gernet et al.,2011; Lambotte et al.,2017).

Previous studies (Jerrell, Tripathi, & McIntyre, 2011) have demonstrated a higher prevalence of mental illnesses among children with sickle cell disease and among their parents compared to controls. Sickle cell disease can result in a host of physiological, cognitive, and psychosocial comorbidities, including chronic and acute anemia, infection, stroke, severe pain episodes, delayed puberty, and academic underachievement (Schatz and Puffer ,2006). Depression is one of the most common complications of chronic illnesses (Patten et al.,2005; Chapman, Perry, Strine, 2005), and childhood depression is a medical problem that can have serious consequences if

it is unrecognized and untreated (Doglan, 1990). The majority of available studies have shown that children with Sickle cell disease have a higher risk of depressive symptoms (Jerrell, Tripathi, Mcintyre,2011), although some studies failed to show significant levels of anxiety and depression (Alao and Cooley,2001) In a previous study, approximately half of the children and adolescents with sickle cell disease were diagnosed with either dysthymia (90%) or major depression (10%) (Jerrell, Tripathi, Mcintyre,2011).

In a Saudi Arabian study, the prevalence of sickle cell in the various regions is reported to be as follows: Qatif (Eastern region) 0.170; Gizan (Southern region) 0.103; Mecca (Western region) 0.025 and Alula (Northern region) 0.081 (El-Hazemi 1992). Given the number, severity and unpredictability of complications associated with sickle cell disease adolescents are potentially at risk for poor psychosocial adaptation and quality of life (Al-Haidar 2003). In one of the first reports of depression and sickle cell disease in children (Morgan and Jackson 1986), employing the Children Depression Inventory (CDI), reported significantly higher depression scores among adolescent with SCD than their healthy peers. (Seigel et al., 1990), in their study of sickle cell disease, asthma, diabetes and normal control subjects found that 65% of patients had depression scores in the moderate-to-severe range, versus 13% of the controls. Similarly another study reported that adolescents with sickle cell disease had higher frequency and more severe depression than the adolescents with cystic fibrosis, spina bifida and diabetes mellitus (Key et al., 2001).

Sickle cell disease is an inherited red blood cell disorder. Individuals with sickle cell disease have an abnormal protein in their red blood cells as a result of substitution of glutamic acid for valine on the hemoglobin chain. In the Kenyan set up, sickle cell disease is common in the Lake Victoria region and in the Coastal regions (Wanjiku et

al., 2019). The prevalence is generally higher in malaria endemic regions. Since the disease runs in families, there is a global consensus that couples planning to have children should undergo genetic testing and counselling.

Some of the early signs and symptoms of sickle cell disease are swelling of the hands and feet; symptoms of anemia, such as fatigue, or extreme tiredness; and jaundice. With time, sickle cell disease can result in a range of complications including but not limited to infections, delayed growth, and episodes of pain, called pain crises. Majority of individuals with sickle cell disease

are pain-free between crises. However, adolescents and adults may also suffer chronic, ongoing pain. Over a lifetime, sickle cell disease can harm a patient's organs including the spleen, brain, eyes, lungs, liver, heart, kidneys, penis, joints, bones, or skin. (Maakaron, 2021)

Sickle cell disease usually results in anemia. However, the primary symptomatic feature of sickle cell disease is pain. Children with sickle cell disease go through a chronic disease with onset in early childhood resulting in serious complications later in life (Levenson, 2008).

These children with sickle cell disease are at an increased risk of developing mental health problems including anxiety, depression and psychological difficulties such as low self-esteem (Dumaplin ,2006).

Due to the chronicity of the illness, there is significant distress both among the children with sickle cell disease and their parents or caretakers which has a negative psychological impact on both these groups (Kain and Mayes, 1996).

Furthermore, frequent problems of pain episodes, removal from normal family and social surroundings, and frequent or long hospital stays during the pain episodes may bring negative outcomes to the normal development of a child and adolescent at stages of emotional, socio-behavioral, cognitive, and academic progress and contribute significantly to diminished psychosocial performance, altered intra- and interpersonal relationships, and poor quality of life (Caldas, Pais-Ribeiro, Carneiro 2004; Edwards, Scales, Loughlin, Bennett , 2005)

Psychological problems that more often than not complicate chronic physical illness in children and adolescents with sickle cell disease are common. Mental health liaison services to this vulnerable population in developing countries are however limited. Many of these children go through their physical illness with little or no access to mental health services (Bakare MO, Omigbodun, Kuteyi, Meremikwu , 2008)

These children with sickle cell disease are at increased risk of developing internalizing problems such as depression and anxiety as a result of their illness, and often show neuro-cognitive impairments and learning difficulties, disturbed interpersonal relationships, low self-esteem, and maladaptive coping patterns (Hijmans, Grootenhuis and Oosterlaan, 2009; Collins, Kaslow, Doepke and Eckman, 1998)

Psychiatric morbidity in earlier studies has been shown to be higher among patients with sickle cell disease than in the general population (Benton, Boyd, Ifeagwu, Feldtmose, & Smith-Whitley, 2011).This could be because these children are growing to ages where psychiatric diagnoses begin to appear or simply because of the pain and suffering as a result of the physical symptoms of sickle cell disease.

Currently the only cure for sickle cell disease is bone marrow transplant. This is an expensive procedure and only a small number of people who have sickle disease are able to afford the transplant. Research has established effective management options that can reduce symptoms and prolong and improve quality of life.

Early diagnosis and consistent medical follow up to prevent complications contribute to improved well-being. This is a life-long illness and severity of the disease varies widely from patient to patient.

In Africa, the psychosocial experience of children/adolescents living with sickle cell disease is poorly documented (Lukoo et al.,2015; Mbassa et al.,2001). Little is known about the burden of mental illnesses among children attending Moi Teaching and Referral Hospital sickle cell clinic and in Kenya at large. There is no single study of psychiatric morbidity among children and adolescents with sickle cell disease in Kenya.

There is a myriad of risk factors associated with mental illness in children with sickle cell disease which need to be explored. These include the sociodemographic factors ranging from the education status of parents/caretakers, age of diagnosis, income level of parents and even the sex of the children.

To address the burden of mental health in sickle cell disease, concerned parties including governments, healthcare workers and the patients need to unite for a working solution. There is an urgent need for awareness about mental health and sickle cell disease, which has been missing in majority of many government programs. All hospitals and health centers that house sickle cell clinics should have psychiatrists or clinical psychologists to handle the important part of mental health

which by and large affect the general outcomes of the medical management of these patients.(Khalifa et al., 2014)

1.1 Statement of the research problem

Sickle cell disease like many other chronic illnesses is associated with psychiatric morbidity such as depression and anxiety. Many of these psychiatric conditions go undiagnosed and consequently untreated because of the stigma and the high rates of disability associated with these chronic illnesses (Jenerette, Funk, & Murdaugh, 2005). Greater focus is directed to the management of the physical symptoms of the illness with little focus on the psychological impact of the illness.

With this study, the burden of psychiatric morbidity in children and adolescents with sickle cell disease was established. Factors associated with psychiatric morbidity in children and adolescents with sickle cell disease were also studied. Predictors of mental illness in these children and adolescents with sickle cell disease will be known and therefore timely interventions instituted.

The World Health organization defines health as a state of complete physical, mental and social well-being and not merely absence of disease or infirmity. If this study had not been done, psychiatric morbidity and factors associated with psychiatric morbidity in children and adolescents with sickle cell disease may never have been known. These individuals will therefore not be considered healthy at least by the World Health Organization definition of health(WHO, 2018)

Furthermore, there will be more informed clinical practice therefore managing these children and adolescents holistically. There will also be profound benefits to the patients since mental illnesses will not go untreated even as physical symptoms of sickle cell disease are dealt with by clinicians.

1.2 Justification

Given the growing number of children with sickle cell disease and the reduced levels of mortality it is important to define the magnitude of psychiatric morbidity among patients with sickle cell and also describe its potential predictors in the population. (Amirkhanyan & Wolf, 2003) (Lorine et al., 2015)

Sickle cell disease is a condition associated with stigma and mental illnesses among the children who are patients .There are a number of factors associated with stigma including these children's' smaller stature, delayed milestones and their frequent hospitalization.(Jadoon, Yaqoob, Raza, Shehzad, & Choudhry, 2010).

This is a population that has not been reached before in terms of mental health services especially in the African set up. Studies have been done on the psychiatric morbidity in many other chronic illnesses such as cancer, Human Immunodeficiency Virus and chronic kidney disease but very little has been done in sickle cell disease.

This study was done at the Moi Teaching and Referral Hospital-Eldoret. This is a national referral hospital with its catchment area being Western Kenya including the lake region where sickle cell disease is a major concern. Very little is known about psychiatric morbidity in children and adolescents with sickle cell disease in Moi Teaching and Referral hospital and in Kenya.

Cross sectional studies are used to determine prevalence. They are relatively quick and easy but do not permit distinction between cause and effect(Mann, 2003). The prevalence of psychiatric morbidity in children and adolescents attending Moi Teaching and Referral Hospital sickle cell clinic is not known. This guided the researcher's decision to choose a cross sectional study design.

Understanding psychiatric morbidity and factors associated with this psychiatric morbidity will ensure no mental illness goes untreated in these patients. There will therefore be reduced morbidity and mortality due to mental illnesses further improving outcomes.

Many previous studies have looked at specific mental health conditions such as depression and anxiety in patients with sickle cell. My study using the Mini Kid (Mini-International Neuropsychiatric Interview for children and Adolescents) tool explored a wide range of psychiatric diagnoses including suicide, obsessive compulsive disorder, conduct disorders, eating disorders, drug and substance use disorders among others that have not been studied by earlier researchers.

The aim of this study was to determine the prevalence of psychiatric morbidity among children and adolescents with sickle cell disease attending the sickle cell clinic at the Moi Teaching and Referral Hospital. The researcher also intended to explore the factors associated with psychiatric morbidity among children and adolescents with sickle cell disease attending the sickle cell clinic at Moi teaching and Referral Hospital.

1.3 Study significance

By achieving the specific aims, it was anticipated to establish the true burden of psychiatric morbidity, the factors associated with these psychiatric morbidities and the undiagnosed mental health problems in children and adolescents living with sickle cell disease.

This information will provide a more holistic approach to children and adolescents with sickle cell disease. This will ensure we not only address the physical complains of these children but also address their psychological problems.

Moi Teaching and Referral Hospital is a national referral hospital serving the Western region including the lake region. These are regions where this condition is a major concern and it was appropriate to do the study here.

With very little known about psychiatric morbidity in children and adolescents with sickle cell disease, a cross sectional study was an appropriate initial study to pave way for more studies.

1.4 Research question

What is the prevalence of psychiatric morbidity among children with sickle cell disease?

What are the factors associated with psychiatric morbidities among children and adolescents with sickle cell disease?

1.5 Study objective

1.5.1 Main objective

To describe the psychiatric morbidity and the factors associated with psychiatric morbidities among children and adolescents with sickle cell disease at The Moi Teaching and Referral Hospital Sickle cell clinic.

1.5.2 Specific objectives

1. To estimate the prevalence of psychiatric morbidity among children and adolescents with sickle cell disease.
2. To assess the factors associated with psychiatric morbidity among children and adolescents with sickle cell disease.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Sickle cell disease

The sickling disorders are a group of inherited diseases of the hemoglobin molecule. These disorders result in chronic hemolytic anemia, increased susceptibility to infection, frequent acute 'crises,' and progressive organ damage as a result of vaso-occlusion by the sickle erythrocytes. The disease is due to the substitution of valine for glutamic acid at position 6 of the β globin chain. This substitution allows hemoglobin S molecules to polymerize when deoxygenated. The polymerized hemoglobin S distorts the erythrocyte into the characteristic 'sickle' shape and induces membrane changes in the cells that lead to potassium and water loss, resulting in erythrocytes that are dehydrated and poorly deformable. There are also membrane changes that permit adhesion of the erythrocyte to vascular endothelium. As a result, occlusion of the microcirculation ensues, leading to ischemia and infarction and, ultimately, producing end-organ failure (Johnson, 2016).

Approximately 5% of the world's population carries trait genes for hemoglobin disorders, mainly, sickle-cell disease and thalassemia (WHO, 2011). Most of these are found in Africa or are people of African descent.

Sickle cell disease (SCD) is caused by mutations in the β-globin gene that lead to the production of abnormal forms of the β-subunit of hemoglobin. It is the commonest life-threatening genetic disorder among people of African heritage and is also common in populations hailing from the Indian subcontinent, the Mediterranean basin, and the Middle East (Dennis and Chao , 2020)

Age at diagnosis of sickle cell disease can be variable. In a retrospective study done by (Brown, 2010) at the University College Hospital Ibadan on children with sickle cell disease who attended the children's outpatient department of the hospital between June 2000 and June 2009, 457 children were studied (Male: Female ratio 1.1:1). Median age at diagnosis was 2.0 years (2.5 months - 14.0 years).

A case control study in a western European country (Hijmans, Grootenhuis et al., 2009) that examined behavioral and emotional problems in children with sickle cell disease, the mean age of study participants was 12.3 years.

In a Nigerian case control study (Iloeje 1991) that looked at the prevalence of psychiatric morbidity among children and adolescents with sickle cell disease, the mean age of study participants was lower at 9.63 years.

The global male to female ratio of sickle cell disease is 1:1. No sex predilection exists since sickle cell is not an X linked disease (Maakaron Medscape, 2021). A Saudi Arabian case control study (Amir, Tawfiq et al 2010) with 110 participants with sickle cell disease and 202 participants without sickle cell disease, the males were dominant accounting for 90(81.8%) in the children with sickle cell disease while girls accounted for 20(18.2%). Another case control study done in Egypt (Bakri, Ismail et al., 2014) exploring the behavioral impact of sickle cell disease in young children with repeated hospitalizations had 35 children recruited in the study. The male accounted for 18(51.4%) while the female accounted for 17 (48.6%). Both studies were conducted in a hospital set up and not in a community set up.

In 2008, The United Nations estimated that there were between 20 and 25 million people worldwide living with sickle cell disease, of which 12–15 million lived in

Africa. Approximately 75–85% of children born with sickle cell disease are born in Africa,

Furthermore, a National Demographic Health Survey done in Nigeria in 2018, which included testing for sickle cell disease, 10% of the children aged 6 months to 5 years with severe anemia were also shown to have sickle cell disease. In an 11-year chart review of stroke cases at Senegal's only pediatric hospital, children with sickle cell disease, the majority of them were diagnosed at mean onset age of 6 years, which accounted for 38%. Even in high-resource countries such as Germany, the lack of universal early screening places sickle cell disease children at unacceptably high risk. Most children in a recently established national sickle cell disease registry were discovered after 1 year of age, usually by presenting with symptoms (Oron et al., 2020).

Sickle cell disease is a major genetic disease that negatively impacts individuals in Sub-Saharan African countries (WHO, 2015). According to the World Health Organization (WHO, 2015) the disease upsets hemoglobin. This results in frequent pain and medical problems that in turn negatively affect the patients' education, employment, and psychosocial development (WHO**,** 2015). The World Health Organization further noted the highest prevalence of hemoglobin AS in Africa as occurring "between latitudes 15^0 North and 20^0 South, ranging between 10 and 40 % of the population in some areas. Prevalence levels decrease to between 1 and 2 % in North Africa and less than 1 % in Southern Africa" (WHO, 2015). Ghana, Nigeria, Cameroon, Republic of Congo, and Gabon have prevalence rates of between 20 and 30 % while it is as high as 45 % in some parts of Uganda (WHO, 2015;Loureiro, Rozenfield,2005). The reason the sickle cell has maintained such high prevalence levels in tropical Africa is because the sickle cell trait partially protects against

malaria (WHO, 2015; Modell and Darlison ,2008). However, individuals who are homozygous for gene S do not have defense against malaria and consequently suffer from severe sickle cell disease, with a lot of them dying before attaining the age of procreation (WHO, 2015). Such HbSS individuals usually die from an infection or severe anemia (Quinn, Rogers, McCavit, Buchanan,2010). Those who survive into adulthood remain susceptible to exacerbations of the disease and its medical and psychosocial complications (Buchanan,2010). With the present lack of cure, many adults with sickle cell disease are believed to live in fear of early death or have death anxiety and many other psychological complications such as depression and low self-esteem (Annie , 2005). There are effective treatments using painkillers for the sickle cell pain. Other complications of sickle cell disease are treated using antibiotics. Rest, balanced diet, folic acid supplementation and high fluid intake, plus occasionally needed aggressive procedures like transfused blood and operation are used (Montalembert, 2008). However, psychological difficulties accompany these medical complications and treatments. According to (Levenson et al., 2008) psychological complications and "psychiatric issues are common in sickle cell disease"

2.2 Psychiatric morbidity

There have been tremendous improvements in the management of sickle cell disease globally. This has resulted in better disease outcomes and increased life expectancy among sickle cell patients. Childhood mortality from sickle cell is decreasing and the mean age of death is increasing (Quinn, Rogers, McCavit, & Buchanan, 2010). Despite these advances, children and adolescents with Sickle cell disease continue to face many challenges of living with a chronic condition that requires lifelong medical management that may place them at risk of psychiatric symptoms and disorders. Studies focusing on children and adolescents with sickle cell disease suggest greater

risks for psychosocial difficulties and depressive and anxiety symptoms in children with sickle cell disease compared to the children and adolescents in the general population (Benton, Boyd, Ifeagwu, Feldtmose, & Smith-Whitley, 2011)

Like many other chronic illnesses Sickle cell disease is a physical condition with a myriad of possible mental health problems such as adjustment disorders, depression, suicide and post-traumatic stress disorder, emotional and behavior problems. Studies have demonstrated an increased rate of emotional and behavioral problems, as well as increased probability of a psychiatric disorder in children with a chronic illness compared with children without a chronic illness. (Hysing, Elgen, Gillberg, & Lundervold, 2009). There is further evidence that most patients with chronic illnesses suffer from significant psychiatric morbidity, highlighting the need for routine screening to improve psychological outcomes in such cases. This was evidenced by a case control study on the psychiatric morbidity in Egyptian children with Acute Lymphoblastic Leukemia (Khalifa et al., 2014).

Major Depressive Disorder is known as unipolar depression as those with it appear to have a single extreme of a depressed mood rather than expressing both mania and depressed mood alternatively. Major depressive disorder affects different individuals differently (Kumaraswamy, 2013). The effects on different individuals include losing weight, troubled sleep, heightened irritability, and the onset of guilt feelings, oversleeping, overeating, and pronounced agitation (Marcus, Yasamy, van Ommeren, Chisholm, and Saxena, 2012). Most individuals with major depressive disorder lose interest in their daily engagements and feel worthless, hopeless, weak, tired, helpless, or hurt. Even though the onset of major depressive disorder can be at any given age, it commonly sets in when one is in his or her early 20s (Sarokhani et al., 2013). Over the years, the average age at which one is likely to develop major depressive disorder

has been reducing. Those with blood relatives with the disorder are more likely to suffer than those without cases of the disorder in their families (Sarokhani et al., 2013).

Depression in sickle cell disease is more prevalent than in the general population, indeed it is consistent with that of other chronic illness of prevalence of 20-30% [Hasan, Hashmi, Alhassen, Lawson, Castro, 2003). Demographic variables such as: education, gender, social support and unemployment are predictive of depression [Hasan, Hashmi, Alhassen, Lawson, Castro ,2003). Interventions should be carried out to ensure adequate social support and close and healthy relationship with friends and families to minimize risk for depression. Depression is associated with frequency of sickle cell crises, increased healthcare utilization services and hospitalizations for pain crises and presence of chronic/near daily pain (Jenerette, Funk and Murdaugh 2005). Depressive symptoms may be a challenge to recognize in sickle cell disease populations as they present with different symptoms than the general population.

(Kaur, Deepti, and Lal 2014) noted in their study that persons suffering from major depressive disorder have the condition recurrently following various courses like among the children and adolescents with sickle cell disease. Some individuals experience major depressive disorder bouts or depressive episodes regularly, at times with spans of several years between the successive bouts. The regularity of the bouts appears to increase as one grows older and older. According to (Marcus et al. 2012), many of those who have major depressive disorder have in the past experienced the dysthymic disorder. Those with major depressive disorder and dysthymic disorder concurrently are described as suffering double depression and they have a heightened likelihood of developing other depressive episodes (Sarokhani et al., 2013). They face

significant difficulties in their quests to recover from depressive episodes fully. When they are hospitalized, they are highly likely to be hospitalized for long to get over the related symptoms. These patients are treated using different approaches including drug therapy, psychotherapy, family therapy, existential therapy, Electro-Convulsive Therapy, and Standard Transcranial Magnetic Stimulation (Siever, 2008)

(Mohammad et al., 2016) noted that the comorbidity of the two sets of disorders presents grave effects, including making the courses of the disorders increasingly chronic, hurting social relationships, and increasing suicidal tendencies especially in young people. Many researchers and clinicians view the two sets of disorders as being just different expressions of the same disorder at present. That view is informed by the actuality that the genetics related to depression and anxieties are rather comparable. At the same time, that view is informed by the actuality that the neurobiological foundations related to depression and anxieties are rather comparable (Bhatia & Munja, 2014). The biological vulnerability that one has relating to anxiety is comparable to the biological vulnerability that one has relating to depression

(Vincent and Alyson 2004) argued that depression and depressive episodes are largely interpersonal problems stemming from or causing poor social skills. The foremost researcher to link depression to poor social skills was (Lewinsoh 1974), who defined social skills or competencies as simply being behavioral expressions that are affirmed by others. According to him, social skills deficit makes one highly susceptible to depression development.

Anxiety disorders and depression owing to social skills deficits may develop several years later in some cases (Bhatia & Munja, 2014). This fact presents marked opportunities for preventing the onset of depression before it sets in those who seek

medical attention for anxiety disorders. For instance, students who seek medical attention for anxiety disorders can be assisted to steer clear of the development of depression through the related interventions, including teaching them cognitive skills and social skills (Mohammad et al., 2016)..

Since psychological symptoms have implications for physical complaints in sickle cell disease, the implications are that psychological symptoms are known to contribute to vaso-occlusive crisis and other physical complaints. For example, major depression was reported to increase sickle cell chronic disease patients' burden of physical illness and symptoms, their functional disabilities and medical costs [WHO, 2011]. Some researchers reported that it is better to consider psychological variables as contributing to the onset of sickle cell pain. For example, (Pell et al., 2007) found that higher levels of kinesophobia were associated with greater psychological distress. Their findings suggest that, it could be psychological distress that increased kinesophobia or kinesophobia increased psychological distress since the analysis was correlational. The psychological symptoms that were associated with higher levels of kinesophobia were Phobic Anxiety, Psychoticism, Somatization, Anxiety, Obsessive-Compulsive, Interpersonal Sensitivity, and depression. Some research found that psychological problems that sickle cell disease patients most frequently encountered are increased anxiety, depression, social withdrawal, aggression, poor relationships, and poor school performance (Anie, Green, 2012).

Elsewhere, it was found that stigmatization in sickle cell disease for pseudo-addiction to opioid analgesics was also related to anxiety and depression (Dahman, et al.,2008; Elanderet al.,2004). Depression was found to powerfully predict physical and mental health-related quality of life than was genotype (Dahman, et al., 2008). Depression in

sickle cell disease individuals is associated with increased emergency room treatments, hospital admissions, chronic pain flares, sickle cell crisis, and higher levels of related psychological disorders.

Another importance of examining psychological symptoms is that symptoms of fatigue, appetite disturbance, and irritability are present both in sickle cell anemia and in clinical depression. Patients with the most clinically severe pain also show the greatest prevalence of depression [Hasan et al., 2003].

An association between anxiety, poorer health-related quality of life, and more pain in sickle cell disease has established (Dahman BA et al.,2008). Therefore, (Levenson et al., 2007) concluded that anxiety and depression predicted more daily pain and poorer physical and mental quality of life in adults with sickle cell disease. These findings point out the importance of recognizing and treating psychological symptoms, particularly anxiety and depression, in adults with sickle cell disease.

Bipolar mood disorder is a severe mental disorder that involves changes in mood, cognition and behavior. It can be divided into three broad subgroups: Bipolar 1 mood disorder- (characterized by episodes of mania and depression); Bipolar 2 mood disorder (hypomania and depression) and a heterogeneous group that is sometimes referred to as ‘spectrum disorders’, which includes Bipolar Mood Disorder-NOS (Not Otherwise Specified), cyclothymia, and other less well-defined Bipolar Mood Disorder-like syndromes (Akiskal et al., 2000; American Psychiatric Association (APA) 2000, 2013). The worldwide prevalence of all manifestations of Bipolar Mood Disorders is about 4% (Angst, 1988). The peak age of onset is 15–25 years, but the incidence remains quite high throughout early and mid-adult life (Merikangas et al., 2011). It is suggested that cases with adolescent or adult onset typically present

with similar symptom profiles for each phase of the disorder e.g. manic, hypomanic, depressive and mixed episodes (where depressive and manic symptoms occur simultaneously), and that the frequency of different types of episodes are also comparable (e.g. depressive episodes are common; mixed states are relatively rare) (Angst, 1988). There have been some variations reported in these characteristics by age of onset, but overall cases presenting in adolescence or adulthood are usually regarded as having 'adult-pattern' Bipolar Mood Disorder with distinct episodes (Carlson, 2011; Merikangas et al., 2011; Douglas and Scott ,2014).

A study (Kwoba et al., 2017) looking at the prevalence of psychiatric morbidity in a community sample in western Kenya found 191 (45%) of the participants had one or more mental disorders. Of these, 66(15.7%) had anxiety disorder, 53(12.3%) had major depressive disorder while 49(11.7%) had alcohol and substance use disorder. The study further found out that having a mental condition was associated with age less than 60 years and having a medical condition.

In sickle cell disease, like in other chronic illnesses, more focus is usually directed to the treatment of physical symptoms. Less attention is usually directed to the emotional and the psychosocial aspect of sickle cell disease. The chronicity of sickle cell disease could impair the quality of life of patients and caregivers. This is attributed to the financial implications of treating a family member with sickle cell, frequent hospital visits and difficulty in coping with the disease (Wonkam et al., 2014).

Psychiatric morbidity has been shown to worsen outcomes in the treatment of sickle cell disease. Comorbid depression in sickle cell disease is associated with adverse course and outcomes. In a retrospective cohort study in North Carolina, forty-six

percent of the sickle cell disease cohort was diagnosed with a depressive disorder. Compared with the controls, the sickle cell disease cohort with depression had more acute vaso-occlusive pain and acute chest syndrome visits per year, developed more complications with related organ damage, and incurred significantly higher outpatient, acute (emergency + inpatient), and total sickle cell disease care costs. This demonstrated the need for early diagnosis and treatment of psychiatric morbidities to improve patient outcomes (Jerrell, Tripathi, & McIntyre, 2011).

The implications of knowing the nature of psychiatric problems of children and the pervasiveness or otherwise of such problems are obvious: more relevant therapeutic strategies can be incorporated into the over-all management of such patients. The finding of higher rates of behavioral problems among older children than younger ones means that preventive efforts should be commenced early and directed at the younger children with SCD.

Such measures include maintaining adequate hydration, giving appropriate vaccines and maintaining optimal hemoglobin levels to avoid crises especially those associated with neurological complications (Iloeje, 1991)

Behavioral and social-emotional functioning is affected by presence of sickle cell disease. Studies have shown increased internalizing problems such as depression and anxiety and distorted social functioning compared to children without sickle cell disease(anxious/depressed mean,54.5, SD 5.7 compared to mean 52.6 SD 4.6 in healthy controls)(Bakri, Ismail, Elsedfy, Amr, & Ibrahim, 2014; Hijmans et al., 2009). This was a case control study in a Western European country. A Child Behavior Checklist (CBCL), Teacher Report Form (TRF) and Disruptive Behavior Disorders rating scale (DBD) were distributed among caregivers and teachers of 119 children

with sickle cell disease aged 6–18 years and among caregivers and teachers of 38 healthy siblings.

Studies on externalizing disorder such oppositional defiant disorders and conduct disorder are more mixed, with some studies showing evidence of increased externalizing problems for youth with sickle cell disease, while others have found no differences or even decreased externalizing problems compared to similar peers without sickle cell disease (Bakri et al., 2014; Noll, Kiska, Reiter-Purtill, Gerhardt, & Vannatta, 2010).This is a demonstration of the complex interrelation between pediatric and adolescent sickle cell disease and behavioral outcomes viz a viz psychiatric morbidities in this population. This further highlights the need for further evaluation of the nature of sickle cell related behavioral problems.

Children with sickle cell disease experience cognitive deficits across several domains including memory, language and attention when compared to healthy peers and normative samples (Hijmans, Fijnvandraat, et al., 2011; Steen et al., 2005).

The world health organization has put in place several strategies to improve outcomes of sickle cell disease in Africa. It recognizes the fact that governments need to apply a holistic approach in the management of patients living with sickle cell. Apart from early diagnosis and physical treatment of symptoms, the WHO is looking at the psychological aspect of managing these patients. It is recommending establishment of patient support groups in addition to ensuring access to genetic counselling services which are still poorly accessed in Africa (WHO, 2010).

2.3 Prevalence of psychiatric morbidity in children with sickle cell disease

According to a study conducted in United States, between 70,000-100,000 individuals live with sickle cell disease while approximately 3 million have sickle cell trait. A study (Gil et al., 2015), reported that negative mood was associated with increases in same day pain and decreased social activity, while increases in positive mood were associated with decreases in pain, less health-care use, and more activity participation in adolescents with sickle cell disease (aged 13 to 17 years).

On other hand (Lallinger et al., 2015) found out the association between daily stress and mood with pain, various types of social support, depression, and quality of life in children with sickle cell disease. The prevalence of depression in children with sickle cell disease was 13%, a finding consistent with previous studies ***(ibid).*** In another study done by (Jerrell et al., 2015) shows that the prevalence of depression in children and adolescents with sickle cell disease was 10%. According to a study by (Noll et al., 2007), on depression in a group of children aged 8–15 with sickle cell disease using the Child Depression Inventory reported that no differences were found between children with sickle cell disease and healthy children (the control group).

According to a study done in Nigeria by (Iloeje, 1991), found out that prevalence rates of psychiatric morbidity in children with sickle cell disease was 26.2 per cent. On the other hand, according to the study done by(Sehlo and Kamfar ,2015), Eight (13%) of the 60 children with sickle cell disease had CDI and CDI-P scores of more than 12 (CDI mean score 14.50 ± 1.19, CDI-P mean score 14.13 ± 1.12), and were diagnosed as having clinical depression using the diagnostic interview DISC-IV. For group I, Health Related Quality of Life (HRQL) was poor across all Pediatric Quality of Life Inventory (PedsQL 4.0) domains in both self- and parent-reports ($P < 0.001$) compared with group II (the controls)

A number of epidemiological studies have demonstrated that although children with chronic illnesses are at an increased risk of a psychiatric morbidity compared to the general population, only a minority show any signs and symptoms of a psychiatric disorder. (Pless & Roghmann, 1971; Rutter, Tizard & Whitmore, 1970). The available evidence suggests that sickle cell disease seems to follow this pattern. This should however be taken with caution as presence or absence of a psychiatric disorder represents a limited evaluation of the psychological impact of a chronic illness and sickle cell disease in this case.

In a Saudi Arabian case control study (Mostafa, Amr, Tawfik, Amin, and Hablas, 2010) consisted of 110 adolescents with sickle cell disease and a convenient sample of 202 adolescents without sickle cell disease as controls. The study revealed 29% of participants with sickle cell disease and 32% of participants without sickle cell disease met criteria for one or more psychiatric symptoms. Adolescents with SCD showed higher prevalence of adjustment (9.1% in respondents with sickle cell disease and 3% in respondents without sickle cell disease) and anxiety disorders (17.3% in patients with sickle cell disease and 16% in controls) compared to their peers.

In a cross-sectional study at the Comprehensive Sickle Centre at the Children's Hospital of Philadelphia (Benton, Boyd, Ifeagwu Fieldmose, Smith –White 2011) found the frequency of Psychiatric diagnosis to be 50%. 40 children aged 12-19 years attending the sickle cell disease clinic were evaluated for a psychiatric diagnosis using the Children's interview for Psychiatric Syndrome, Child (ChIPS) and parent (P-ChIPS). 20(50%) of the respondents met criteria for a DSM-IV psychiatric diagnosis. Attention –deficit/ hyperactivity disorder (n=16, 40%) was the most frequent diagnosis followed by oppositional defiant disorder (n=9, 22.5%) and conduct disorder (n=7, 17.5%). There was however few individuals with internalizing

disorders (Major depressive Disorder (n=5, 12.5%)). 3 individuals (7.5%) screened positive for generalized anxiety disorder.

A cross sectional Nigerian study (Anie,Feyijimi et al., 2010) had a total study sample of 408 adolescents and adults with adolescents accounting for 155(38%) of the respondents. 54% of the adolescents demonstrated depressive feelings while 7% demonstrated anxiety feelings.

Psychiatric morbidity has been shown to be higher in populations with chronic illnesses compared to those without. Prevalence of mental disorders in the community with disease was found to be 68% compared to 48% without disease (Kwoba et al., 2017). Out of 201 children/adolescents included, a drop in self-esteem was noted in 76.1%, anxiety 29.9%, depression 5.5% and a negative impact on daily life in all cases. There were significant negative consequences at 39.3%. A cross sectional study (Engoba, Moyen et al.,2021) exploring the psychological experience of children and adolescents with sickle cell disease in University Hospital of Brazzavile, found that of the 201 participants included, 76.1% had a drop in self-esteem, 29.9% had anxiety while 5.5% had depression.

A cross sectional study in Nepal (Sharma et al., 2021) exploring psychiatric morbidity among 140 children and adolescents with sickle cell disease attending a psychiatric clinic at Lumbini Medical College and Teaching Hospital found the most common psychiatric diagnosis to be conversion disorder (29, 20.7%) followed by depressive disorder (25, 15.6%).

Reported rates of psychiatric diagnoses vary across studies. Differences in methodology, including use of parent and child report measures, checklists, parent reports only, observational scales, symptom rating scales, small sample sizes, and

biased ascertainment, may contribute to the wide variations in rates of psychopathology

2.4 Factors associated with psychiatric morbidity

A myriad of factors including age, gender and socioeconomic status may influence the adolescent's vulnerability to exhibit psychosocial difficulties.

Advanced age, duration of illness, use of upper-level analgesics, number of complications and hospitalizations, and occurrence of complications were associated with psychological disorders (Kwoba et al 2017).

A cross sectional study done on Saudi Arabian children and adolescents with 110 subjects with sickle cell and 202 subjects without sickle cell disease revealed that male gender and high family income were independent protective factors while frequent pain episodes served as an independent risk factor for the development of psychiatric morbidity. (Amr, Tawfik, Hatem, & Hablas, 2010).

A study looking at association of social environmental factors with cognitive function in children with sickle cell disease established that when considered collectively, mothers' financial stress emerges as the strongest and most consistent predictor of cognitive function, which may reflect the overwhelming difficulty of raising a chronically ill child in a low-income home environment (Yarboi, Compass, White et al 2015).

Family income is therefore an important predictor of psychiatric morbidity according to available evidence. The proportion of Kenyans living below the poverty line (less than 1.19 USDs a day) was 35.6% in the year 2016/17 having reduced from 43.6% in 2005/6. (World Bank, 2018). Kenya is considered a low income country with a GDP per capita of 1838.28 USDs (World Bank, 2020). This is important as it affects

healthcare financing and will determine healthcare access by the children and adolescents with sickle cell disease.

A higher level of parent support was significantly associated with decreased depressive symptoms, demonstrated by lower Child Depression Inventory (CDI) scores (Sehlo and Kamfar BMC Psychiatry 2015).This was a case control study with 120 participants. Of these 60 had sickle cell disease and 60 had no sickle cell disease and were the controls. The researchers used the children's Depression Inventory (CDI) and children's Depression Inventory-Parent (CDI-P) to screen for depression in the participants. The study revealed that 8(13%) of the children had CDI and CDI-P scores of more than 12 (CDI mean Score 14.50±1.19, CDI-Pmean score 14.13±1.12) and were diagnosed with clinical depression. Better quality of life was shown by the associated higher total Pediatric Quality of Life(PedsQL 4.0) self-scores of children with SCD ($B = -1.79$, $P = 0.01$ and $B = 1.89$, $P = 0.02$ respectively). This study concluded that higher levels of parent support were significantly associated with decreased depressive symptoms and better quality of life in children with sickle cell disease.

In an Egyptian case control study with 35 children with sickle cell disease and 35 matched controls without sickle cell disease (Mohammed Bakri et al, 2014) showed children who have sickle cell disease had statistically significant behavioral changes on child behavior checklist compared to the control group: Anxiety/depression (65.2 vs. 55.1; $P < 0.001$), somatic complaint (66.7 vs. 54.4; $P < 0.001$) withdrawn (63.4 vs. 53.2; $P < 0.001$), aggressive behavior (60.4 vs. 56; $P=0.04$), and internalizing symptoms (64.7 vs. 51.5; $P < 0.001$), respectively. The study concluded that children with SCD who had history of repeated hospitalization are at an increased risk of

developing behavioral problems. Psychological counseling, social support, and proper pain management could minimize these behavioral consequences.

A retrospective cohort design study in the US(Matthew. Myrvik, Lisa, Burks, Raymond, Hoffman, 2012) using the Pediatric Health Information System(PHIS) had a total of 5825 patients. The study found the mean hospital admission rate to be 1.9 admissions per patient per year. The study further concluded that pediatric patients with sickle cell disease and a history of a mental illness have a longer length of stay in hospital and higher admission rates for management of vaso- occlusive events. In fullness of time, these study findings demonstrate that mental health poses an obstacle in the management of sickle cell disease.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study area

The study area was the Moi Teaching and Referral Hospital situated in Eldoret town, Uasin Gishu County. It is located along Nandi Road in Eldoret town. Moi Teaching and Referral Hospital is one of the four national referral hospitals in the country. Its catchment area is mainly western Kenya and neighboring countries such as Uganda. It serves a population of about 24 million people. The sickle cell clinic is situated in Chandaria building of the MTRH. The clinic runs every Thursday from 8am. The clinics are run by medical officers with training in sickle cell and specialists in hematology. This team is supported by nurses trained in hematology and care of patients with sickle cell disease. Being a teaching hospital, Moi University medical students, Moi University registrars, Kenya Medical training college students and nursing students from Baraton University of East Africa also attend these clinics.

3.2 Study population

The study population was all the children and adolescents attending the sickle cell clinic at the Moi Teaching and Referral Hospital. The Moi Teaching and Referral Hospital sickle cell clinic is following approximately 500 patients. Of these about 400 are children and adolescents between the age of 6 and 17 years. Every Thursday (sickle cell clinic day) a maximum of 30 patients are booked for the clinic.

3.3 Study design

The study design was a cross sectional study to investigate psychiatric morbidity in children and adolescents with sickle cell disease attending the sickle cell clinic at Moi Teaching and Referral Hospital.

3.4 Sample size

One of the main objectives of the study is to estimate the burden of psychiatric morbidity in children with sickle cell seen in sickle cell clinic at Moi Teaching and Referral Hospital. The sample size was calculated using a sample size formula for estimating a single proportion as described by Lemeshow (Lemeshow, Klar, & Lwanga, 1990). A study done in Nigeria (Iloeje, 1991) found the prevalence of psychiatric morbidity in children with sickle cell to be 26.2%. This prevalence study (Iloeje 1991) was chosen because by the time the researcher was preparing the proposal, there were very limited studies that explored multiple psychiatric morbidities like this one. Most of the available studies looked at single psychiatric morbidities such as depression and anxiety and did not explore multiple psychiatric diagnoses.

$$n \geq \left[\frac{Z_{\alpha/2}}{d}\right]^2 .pq$$

Where: - n= minimum sample size

$Z_{\alpha/2}$= Critical value for standard normal distribution at α-level of significance (α=0.05, $Z_{\alpha/2}$=1.96)

P= estimated prevalence of psychiatric morbidity = 26.2% (from a study done in Nigeria by (Iloeje , 1991)

d= margin of error at 5%

q=1-P

Substituting the above,

$$n \geq \left[\frac{1.96}{0.05}\right]^2 \times 0.262 \times 0.738 = 297.12$$

A minimum of 298 participants with sickle cell disease were recruited into the study. The sample size was adjusted by 20% for non-response and a final figure of 350 respondents was reached.

3.5 Sampling procedure

Random sampling technique was used to select participants until the sample size was achieved. The sickle cell clinic follows a total of 500 patients. Of these about 400 are between the age of 6 and 17 yrs. The minimum sample size was 298. It was adjusted by 20% for non-response. Using a sample frame from the sickle cell clinic records, the patients in the desired age group (6-17yrs) had all their names and hospital numbers written on separate pieces of paper rolled and put in one jar. The names were mixed thoroughly and then picked randomly until the sample size was achieved. All the 350 names and hospital numbers that were picked were well typed and printed on a piece of paper. On every clinic day, Thursday, at least 7 patients who appear on the typed list were selected. A verbal assent was sought from the child or adolescent and later on written consent was sought from their caretakers. The child or adolescent would then be recruited into the study. Every patient who participated in the study had a blue sticker fixed on their file and marked so that she/he is not selected more than once during a revisit. Any child or adolescent that would decline to participate was skipped and another participant selected from the printed list. This was done until the minimum sample size of 298 was achieved.

3.6 Inclusion/exclusion criteria

3.6.1 Inclusion

Children and adolescents with a confirmed diagnosis of sickle cell (HB electrophoresis) attending the Moi Teaching and Referral Hospital sickle cell clinic at Chandaria centre.

3.6.2 Exclusion criteria

Severely ill patient that is unable to participate in the study.

3.7 Data collection tools

Questionnaires were used to obtain sociodemographic data of the patients and the MINI KID screening instrument used to screen psychiatric conditions in children and adolescents. The MINI KID is a structured clinical diagnostic interview designed to assess the presence of DSM-V and ICD-10 psychiatric disorders in children and adolescents aged 6 to 17 years. The interview was administered to the child/adolescent together with the parent(s) although it can be administered without parents in the adolescents. The MINI KID follows the structure and format of the adult interview (MINI) which has been validated against the structured clinical interview for DSM-III-R and against the WHO –designed Composite International Diagnostic Interview. This tool has been used locally in Nairobi (Okumu, 2008) and Eldoret (Njuguna 2020). Like its adult counterpart the MINI-KID is organized in diagnostic sections and modules. Using branching tree logic, the instrument asks 2-4 screening questions for each disorder. Additional symptom questions within each disorder are asked only if screening questions are positively endorsed. All questions are in binary “yes/no” format. Discrepancies between parent and child reports are resolved at the item (individual question) level by asking for further input from the

child and parent and using clinical judgement to break ties. Diagnostic criteria are summarized and documented within each disorder section and on a summary sheet. The disorder screens for 24 DSM-V and ICD-10 psychiatric disorders and suicidality and takes approximately half an hour to conduct. The MINI KID has been shown to generate reliable psychiatric diagnoses in children and adolescents in much shorter periods (Sheehan et al., 2010).

Researcher designed questionnaire was developed. The questionnaire was pre tested on children and adolescents attending the oncology clinic at the Moi Teaching and Referral hospital.

The questionnaire and the MINI KID were administered in person by the interviewer or with trained assistants in order to clarify any questions not understood by the respondent.

3.8 Study procedure

Any patient who met the criteria to participate in the study was identified in the clinic using the sampling frame. The patient was then allowed to see the clinician and go through the consultation process. Once through with the consultation, a verbal ascent was obtained from the patient. From here a written consent was obtained from the caretaker who had accompanied the patient to the clinic. The patient and the caretaker were then directed to a private room where they were helped fill the questionnaire and the tool used in data collection. The data was collected by the researcher with the help of assistants who were trained on the use of the MINI-KID tool. The researcher with the help of assistants enrolled at least 7 patients every Thursday (Sickle cell Clinic Day). This translated into 28 respondents in a month and at least 336 respondents after a year which is above the minimum number of the sample size (298). The

assistants were selected from medical students who have rotated in psychiatry, psychology students and psychology interns at Moi Teaching and Referral Hospital.

3.9 Measures

The dependent variable was absence or presence of a psychiatric diagnosis such as schizophrenia, major depression, bipolar mood disorder, attention deficit hyperactivity disorder, adjustment disorder among others.

The independent variables were the age, sex, net monthly income of caretakers, the living status i.e., alone, with both parents, with a single parent or with foster parents, the number of previous hospital admissions and whether or not these patients have ever encountered a mental health expert.

3.10 Data management and analysis

The completed questionnaires and Mini Kid tools were checked for completeness and consistency on a daily basis by the researcher before entering into the Epidata data base in the computer. From Epidata the data was exported to software for statistical computing and data analysis (R Core Team, 2015) for analysis. Categorical variables such as sex, diagnosis, and living status were summarized as frequencies and the corresponding percentages and results presented in tables and charts.

Numerical variables such as age, monthly income, number of previous hospital admissions were summarized using measures of central tendencies (mean or median) and the corresponding measurers of dispersion (standard deviation or inter quartile range (IQR). Bivariate analysis was used to establish the association between psychiatric morbidity and the potential factors.

3.11 Ethical considerations

Approval to conduct the study was sought from the Institutional Research and Ethics committee (IREC) Moi University. Authority from the Moi Teaching and Referral Hospital Management Team and The Academic Model Providing Access to Healthcare (AMPATH) was also sought. Signed informed consent from the parent/guardian of the children was obtained after a clear explanation of the purpose of the study. Confidentiality of the participants was maintained. The completed data collection forms were kept under key and lock cabinet accessible only to the researcher. Computerized data was protected by use of passwords. A verbal assent was obtained from children aged 7 years or more in addition to the consent from the parents or guardians before inclusion into the study

3.12 Expected outcome

This is the data analysis matrix showing comparison/analysis and expected outcomes.

	Factors (variable) psychiatric morbidity	Factors (independent variables)	Prevalence estimated of psychiatric morbidity	Assessment and expected outcome	Recommendations points
	Children and adolescents	1. Number of hospital admissions 2. Who the child lives with 3. Net family income (monthly) 4. Age 5. Sex			
1	Major depressive episode				
2	Suicidality				
3	Manic and hypomanic episodes				
4	Panic disorder				
5	Agoraphobia				
6	Separation anxiety				
7	Social phobia				
8	Obsessive compulsive disorder				
9	Post-traumatic disorder				
10	Alcohol use disorder				
11	Non-alcohol substance use disorder				
12	Tic disorder				
13	Attention deficit/hyperactivity disorder				
14	Conduct disorder				
15	Oppositional defiant disorder				
16	Psychotic disorders				
17	Mood disorders				
18	Anorexia nervosa				
19	Bulimia nervosa				
20	Binge eating disorder				
21	Generalized anxiety				

CHAPTER FOUR

4.0 RESULTS

4.1 Socio-demographic Characteristics of the Respondents

Table 1: Demographic characteristics

Variable	(N=298)
Age (years)	
6-8	100 (33.6%)
9-11	52 (17.4%)
12-14	89 (29.9%)
15-17	57 (19.1%)
Sex	
Male	147 (49.3%)
Female	151 (50.7%)
Net Income	
0-2999	106 (35.6%)
3000-5999	109 (36.6%)
6000-8999	5 (1.7%)
More than 9000	78 (26.1%)
Live with	
Both parents	186 (62.4%)
One parent	83 (27.9%)
Foster parents	7 (2.3%)
Other relatives	22 (7.4%)
When sickle cell disease diagnosis was made (years)	
Less than 1 year ago	14 (4.7%)
1-5 years ago	138 (46.3%)
6-10years ago	71 (23.8%)
More than 10years ago	75 (25.2%)
Admission times	
Never	13 (2.1%)
1-5	120 (41.2%)
6-10	46 (15.8%)
More than 10	119 (40.9%)
Mental health expert encounter	
Yes	35 (11.7%)
No	263 (88.3%)

A total of 298 respondents participated in the study. A large proportion, 100(33.6%) respondents were between ages (6-8) years. The mean age of our respondents was 10.53 years. There were 50.7 %(151) female and 49.3% (147) male respondents respectively. Table 1 result indicates that a majority of the respondents 62.4% (186) lived with both parents while the least 2.3% (7) lived with foster parents. A large proportion of the respondents, 46.3% (138) were diagnosed with sickle cell disease between 1-5 years ago. Most of the respondents 41.2% (120) had 1-5 admission times while 2.1% (13) had never had a hospital admission. 88.3% (263) of them had never had a mental health expert encounter with only 11.7 %(35) having encountered a mental health expert.

4.2 Sickle cell disease diagnosis

Table 2: Sickle cell disease

Sex	**When diagnosis with sickle cell disease was made**				**Total**
	Less than 1 year	1-5 years	6-10years	More than 10years	
Male	6(45.5%)	65(47.5 %)	33(46.5%)	42(56.0%)	147(49.3 %)
Female	8(54.5)	73(52.5 %)	38(53.5%)	33(44.0%)	151(50.7 %)
Total	14	138	71	75	298

The results in Table 2 indicate that 151 of the respondents diagnosed with Sickle cell disease were female while the least 147 were male. A higher frequency 138(46.3%) of respondents were diagnosed with sickle cell disease between 1-5 years ago whereby female respondents had a higher proportion 52.5 % (73) while male 47.5% (65) were the least. Respondents diagnosed with sickle cell disease less than 1 year ago reported the lowest frequency at 4.7%. Among the 14 respondents, female respondents had a higher proportion 54.5% while male 45.5% had a lower proportion. This implies that

most of the respondents with sickle cell disease were diagnosed with sickle cell dissease between 1-5 years ago while minority attending the sickle cell clinic were diagnosed with the illness less than a year ago.

4.3 Prevalence of psychiatric morbidity in children and adolescents with sick cell disease

Of the 298 participants in the study, 129 (43.3%) met criteria for one or more psychiatric diagnosis while 169(56.7%) did not meet criteria for any psychiatric diagnosis.

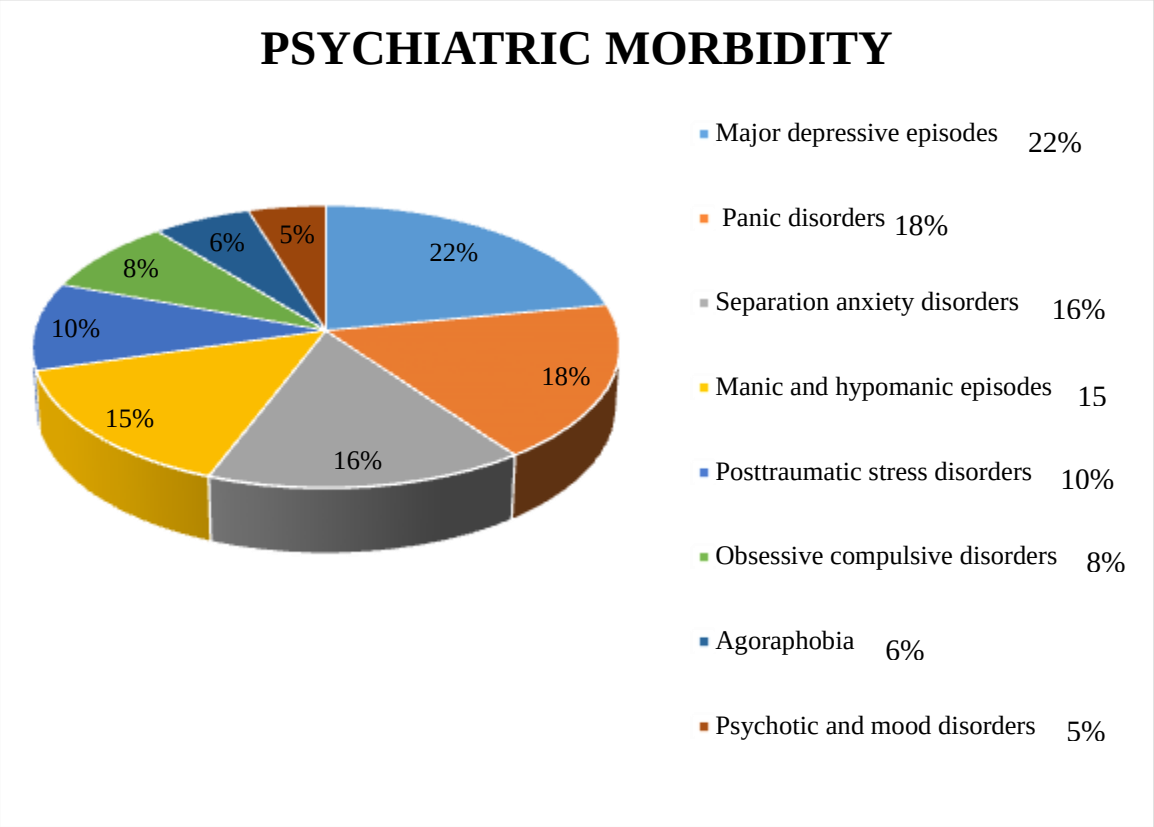

Figure 1: Prevalence of psychiatric morbidity in children and adolescents with sick cell disease

The first objective of the study was to determine the Prevalence of psychiatric morbidity among children with sickle cell disease at MTRH. The study findings show that there was a high prevalence rate among respondents who had Major Depressive episodes at 22% (138), followed by Panic Disorders 18% (113), Separation Anxiety Disorders 16% (99), Manic and Hypomanic episodes, 15% (92), Posttraumatic Stress

Disorders 10% (63), Obsessive Compulsive Disorders 8% (54) Agoraphobia 6% (38), and Psychotic and mood disorders 5% (30)

4.4 Factors associated with psychiatric morbidity among children and adolescents with sickle cell disease

Table 3: Association

Variable	Psychiatric morbidity(depression/panic) Present	Absent	P-value Depression	Panic
Age (years)				
6-8	6 (6.0%)	94 (94.0%)	.350**	.052
9-11	6 (11.5%)	46 (88.5%)		
12-14	11 (12.4%)	78 (87.6%)		
15-17	12 (21.1%)	45 (78.9%)		
Sex				
Male	12 (8.2%)	135 (91.8%)	-.007	.015
Female	23 (15.2%)	128 (84.8%)		
Net monthly family income				
0-2999	12 (11.3%)	94 (88.7%)	.179	.259**
3000-5999	12 (11.0%)	97 (89.0%)		
6000-8999	1 (20.0%)	4 (80.0%)		
More than 9000	10 (12.8%)	68 (87.2%)		
Live with				
Both parents	22(11.9%)	163 (88.1%)	-.126	.005
One parent	9 (10.8%)	74 (89.2%)		
Foster parents	2 (28.6%)	5(71.4%)		
Other relatives	2 (9.1%)	20 (90.9%)		
Number of hospital admissions in the last year				
Never	1 (16.7%)	5(83.3%	.015	.033
1-5	18 (14.2%)	109 (85.8%)		
6-10	3 (6.5%)	43 (93.5%)		
More than 10	13 (10.9%)	106(89.1%)		
When diagnosed with sickle cell disease				
Less than 1 year	3 (27.3%)	8 (72.7%)	.163	.106
1-5 years	14 (9.9%)	127 (90.1%)		
6-10years	5 (7.0%)	66 (93.0%)		
More than 10years	13 (17.3%)	62 (82.7%)		
Mental expert encounter				
Yes	25(8%)	83(28.0%)	.071	-.202**
NO	10(3%)	180(61.0%)		

n=298

The final objective of the study was to examine whether an association existed between socio-demographic characteristics of the respondents and mental disorders. Bivariate analyses for mental disorders versus age, sex, who the respondents lived with, the number of hospital admissions, when respondents were diagnosed with sickle cell disease and mental expert encounter were done**.** There was a statistically significant association between depression and the number of hospital admissions at p=0.015. Furthermore, Panic disorders significantly associated with age, sex, who the respondents lived with and the number of hospital admissions at (p=0.052, p=0.015, at p=0.005, p=0.033) respectively. There was a higher proportion with panic disorder among the older participants compared to the younger (21.1% vs 6.0%).This could be due to the fact that that as children grow older, they become self-aware and the likelihood of a mental illness emerging increases as they approach teenage. In terms of gender there was a higher proportion with panic disorder among females compared to males (15.2% vs 8.2%). Also, there was a higher proportion of panic disorder among those respondents who lived with foster parent's verses those who lived with other relatives (28.6% vs 9.1%).This could be because biological parents are more likely to give better parental support compared to foster parent. A higher proportion of those respondents who had never been admitted reported panic disorder compared to those with 6-10 hospital admissions (16.7% vs 6.5%). This could be explained by the fact that children and adolescents seen in the sickle cell clinic are less likely to encounter a mental health practitioner unlike their admitted counterparts who are likely to be seen by a mental health practitioner such as a psychologist.

CHAPTER FIVE

DISCUSSION

5.0 Introduction

The discussion will compare study findings with the other studies reviewed in the literature. Each objective will then be reviewed and findings will be linked to previous research on psychiatric morbidity among children and adolescents with sickle cell disease. The section will finish with recommendations and suggestions for future research.

This thesis is by far the only study conducted so far in Kenya that sought to investigate the prevalence of psychiatric morbidity among children and adolescents with sickle cell disease and explore the factors associated with psychiatric morbidity among children and adolescents with sickle cell disease.

5.1 Discussion

Demographic characteristics

Age

From our findings, majority of the respondents 100(33.6%) were between ages 6-8 years. The least were between the ages of 9-11yrs accounting for 52 (17.4%) of the respondents. The mean age among our participants was 10.53. A case control study (Amir Tawfiq et al 2010) in King Fahad Hospital Saudi Arabia consisted of 110 adolesents with sickle cell disease and a convenient sample of 202 adolescents without sickle cell disease as controls. The mean age among participants was 16.8±3.6. This is higher compared to our study. This is attributable to the fact that our inclusion criterion was children and adolescents between the age of 6-17 years, a lower age range than previous researchers who had 8-18 yrs. This age range was

adopted because the tool used in our study (MINI-KID) is designed to screen for mental illnesses only in this age bracket (Sheehan et al 2009).

In another case control study in a western European country (Hijmans,Grootenhuis et al 2009) that looked at behavioral and emotional problems in children with sickle cell disease, the mean age of participants was 12.3%. Just like the Saudi Arabian study this mean age is higher than that in our study. This is still attributable to the higher age ranges (8-18years) chosen by these researchers.

A Nigerian case control study (Iloeje, 1991) that looked at the prevalence rate of mental illnesses in children with sickle cell disease had a mean age of participants lower at 9.63. This is due to the researcher having used a lower age range of 6-13yrs in his study.

Gender (sex)

This study suggests that a higher proportion of children and adolescents with sickle cell disease attending the sickle cell clinic at Moi teaching and Referral Hospital are female 151 (50.0%) of the respondents. The study results are contrary to a Saudi Arabian study (Amir ,Tawfiq et al., 2010) with 110 participants with sickle cell disease, the males were dominant accounting for 90(81%) of the respondents while girls accounted for 20 (18.2%).

Another case control study (Bakri, Ismail et al., 2014) looking at behavioral impact of sickle cell disease in young children with repeated hospitalizations had 35 children recruited to the study. The male accounted for 18(51.4%) while the female accounted for 17(48.6%).

The global male to female ratio of sickle cell disease is 1:1. There is no sex predilection since sickle cell anemia is not an X linked disease (Maakron, Medscape 2021).

These differences in proportions between male and female could be because these were hospital studies and not community studies. Bias is likely to arise because studies were conducted on children and adolescents with sickle cell disease already on follow up in various clinics. These differences in gender distribution are therefore not a reflection of the actual findings in the population.

Family income

Majority of the respondents had a net monthly income of between Ksh 3000-5999. This accounted for 109(36.6%) of the respondents. This translates to between 26USDs and 53USDs at current exchange rates of 1USD =Ksh112.30. This means that a great proportion of our respondents spend more than a dollar a day and therefore don't live below the poverty line. This is in line with the World Bank publication in 2018 that showed the proportion of Kenyans living below the poverty line (Less than 1.19 USDs a day) to be 35.6%having reduced from 43.6 %in 2005/06.

In a case control study in Saudi Arabia (Amir, Tawfiq et al., 2010) majority of the respondent with sickle cell disease had a net family monthly income of between 2500-6000 Saudi Riyals translating to 666.7 -1600USDs monthly. This difference between our study and the earlier study could be attributed to the fact that Saudi Arabia is a high-income country with GDP per Capita of 20110.32 USDs while Kenya is a low-income country with GDP per capita of 1838.28 USDs (World Bank 2020)

Number of Hospital Admissions

Most of our respondents had 1-5 admissions in the last one-year accounting for 120(41.2%). A retrospective cohort design study in the US (Matthew, Myrvik et al., 2012) using the Pediatric Health Information System (PHIS) found the mean hospital admission rate to be 1.9 admissions per patient per year. This is comparable to our study that had majority of our respondents having had 1-5 admissions in the last 1 year. It contrasts with our study in that this earlier study only documented admissions as a result of vaso- occlusive events. In the current study, we did not explore the reasons for admission but rather focused on whether or not a participant had been admitted for sickle cell disease.

Psychiatric morbidity

From our findings, 129(43.3%) of our respondents met criteria for one or more psychiatric diagnoses while 169(56.7 %) did not meet criteria for any psychiatric diagnosis. A cross sectional case control study in Nigeria (Iloeje, 1991) with 84 participants with sickle cell disease and 84 controls without sickle cell disease found the prevalence of psychiatric morbidity to be 26.6% on the parents' scale and 22.6% on the teacher scale. This Study used the Rutter scale to screen for psychiatric conditions among children and adolescents with sickle cell disease. These rates are lower than ours and this could be attributable to the methodological differences and variations in screening tools used by the researchers. The current study used MINI-Kid while the earlier study used the Rutter Scale

On the other hand, 16% of the participants had anxiety disorder. This result is comparable to others recorded in Nigeria and Jamaica. The Nigerian study indicated that anxiety was almost absent among a group of adults with sickle cell disease but

not depression [Ehigie , 2003]. A study by (Thomas, Hambleton, Serjeant,2001) found that Jamaican patients ($n = 50$) with homozygous sickle cell disease had less general anxiety, a lower emotional response to pain, and lower levels of perceived pain compared to their London counterparts ($n = 50$) who believed the disease had a more marked effect on their psychological health.

In a cross sectional study at the Comprehensive Sickle Centre at the Children's Hospital of Philadelphia (Benton, Boyd, Ifeagwu , Fieldmose, Smith –White 2011) found the frequency of Psychiatric diagnosis to be 50%. 40 children aged 12-19 years attending the sickle cell disease clinic were evaluated for a psychiatric diagnosis using the Children's interview for Psychiatric Syndrome, Child (ChIPS) and parent (P-ChIPS). 20(50%) of the respondents met criteria for a DSM-IV psychiatric diagnosis. Attention –deficit/ hyperactivity (n=16, 40%) was the most frequent diagnosis followed by oppositional defiant disorder (n=9, 22.5%) and conduct disorder (n=7, 17.5%). There were however few individuals with internalizing disorders (Major depressive Disorder (n=5, 12.5%)). 3 individuals (7.5%) met criteria for generalized anxiety disorder. In my study 43.3% of the respondents met criteria for one or more mental illnesses with the most frequent diagnoses being major depressive disorder (22%) and panic disorders (18%). In comparison, there were higher rates of depression in my study unlike in this earlier study. These differences could have arisen due to differences in methodology and the screening tools used. My study used the MINI-KID for screening of mental illnesses while the earlier researcher used children's Interview for Psychiatric Syndrome, Child (ChIPS) and parent(P-ChIPS). In addition to that, this earlier study had a smaller sample size of 40 participants while my study had a larger sample size of 298 participants.

The finding that Major depressive episodes and panic disorders were the most prevalent psychiatric diagnoses 22% and 18% respectively among respondents is not surprising given that other studies on psychiatric morbidity; (Lallinger et al., 2015) found out that the prevalence of depression in children with sickle cell disease was 13% the highest of the screened mental illnesses. In another study done by (Jerrell et al., 2015) showed that the prevalence of depression in children and adolescents with SCD was 10%. Like in the current study, depression is the leading cause of psychiatric morbidity among children and adolescents living with sickle cell disease.

Compared to this study, a study in Nepal (Sharma et al., 2021) using the diagnostic interview schedule for children IV (DISC IV), found the most common diagnosis to be conversion disorder (29, 20.7%) followed by depressive disorder (25, 17.5%) and anxiety disorder (14,10%). A similar study (Engoba et al., 2021) using the DSM V manual found the prevalence of anxiety to be at 29.9% and depression at 5.5%. Just like in the current study, these were the highest of the screened mental illnesses. Contrary to earlier studies and our study, according to (Noll et al.,2007), on depression in a group of children aged 8–15 with SCD using the Children's Depression Inventory reported that no differences were found between children with SCD and healthy children (the control group).A study (Bakri et al., 2014) found out that the rate of depression and anxiety among children with SCD was higher than among the control group (65.2 ± 14.2 vs. 55.1 ± 4.6) which goes along with the study of(Anie et al., 2012) who conceptualized that children with SCD reported high rate of depression and anxiety. The study findings are as well in agreement with (Amr et al., 2010) who stated that older children with SCD displayed high rate of depression and anxiety compared to their healthy peers. (Levenson et al 2008) explained that depression and anxiety in children with SCD may result from living with a chronic

stigmatizing disease. These studies are in agreement with my study findings that depression and anxiety disorders are the commonest psychiatric morbidities among children and adolescents with sickle cell disease. The variations in the rates of different psychiatric morbidities could be explained by the different psychiatric screening tools employed by different researchers.

Factors associated with Psychiatric Morbidity

In our study, there was no statistically significant association between family income and psychiatric morbidity among children and adolescents with sickle cell disease. In contrast with our study, a cross sectional study done on Saudi Arabian children and adolescents with 110 subjects with sickle cell and 202 subjects without sickle cell disease revealed that male gender and high family income were independent protective factors while frequent pain episodes served as an independent risk factor for the development of psychiatric morbidity. (Amr, Tawfik, Hatem, & Hablas, 2010) The same study (Amir, et al., 2010) is in agreement with my study whereby it concluded that frequent pain episodes, comparable to multiple admissions in our study served as independent risk factors for development of psychiatric morbidity.

In a study (Mohammed Bakri et al, 2014) children who have sickle cell disease had statistically significant behavioral changes on child behavior checklist compared to the control group: Anxiety/depression (65.2 vs. 55.1; $P < 0.001$), somatic complaint (66.7 vs. 54.4; $P < 0.001$) withdrawn (63.4 vs. 53.2; $P < 0.001$), aggressive behavior (60.4 vs. 56; $P=0.04$), and internalizing symptoms (64.7 vs. 51.5; $P < 0.001$), respectively. The study concluded that children with SCD who had history of repeated hospitalization are at an increased risk of developing behavioral problems. These findings are similar to my study in which there was statistically significant association between depression and number of hospital admissions ($P=0.015$). Like in my study

(Kwoba et al. 2017) found that number of complaints and hospitalizations were significantly associated with psychological disorders.

Panic disorders significantly associated with sex (P=0.015). In line with this study, (Amr et al 2010) observed that male gender was an independent protective factor against psychiatric disorder in adolescents' population.

This study demonstrated that panic disorder is associated with who the respondents lived with (p=0.005). Like in this study, (Mohammed Bakri et al 2014) showed that a higher level of parent support was significantly associated with decreased depressive symptoms, demonstrated by lower Child Depression Inventory (CDI) scores. Better quality of life was shown by the associated higher total mean of PedQL 4.0 self-scores of children with sickle cell disease (B = −1.79, P = 0.01 and B = 1.89, P = 0.02 respectively). This is comparable to this study that found a statistically significant association between who the child lives with (single parent, foster parent, both parents) and psychiatric morbidity (panic disorder) in our case.

Vast majority of children and adolescents with sickle cell disease attending the Moi Teaching and Referral hospital have never had an encounter with a mental health expert. These further highlights the emphasis put on the treatment of physical symptoms with little regard to the psychological needs that come with a diagnosis of sickle cell disease.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATION

6.1 Conclusions

1. Psychiatric morbidity remains a matter of concern among children and adolescents with sickle cell disease. There is a high burden of mental illnesses in children and adolescents attending the Moi Teaching and Referral Hospital Sickle cell clinic.
2. Depression and anxiety disorders are the leading cause of psychiatric morbidity among children and adolescents with sickle cell disease attending the Moi Teaching and Referral Hospital sickle cell clinic.
3. There is statistically significant association between number of hospital admissions, who the child lives with and gender with psychiatric morbidity.

6.2 Recommendations

1) Knowing that depressive and panic disorders associated with sex, who the respondents lived with, and the number of hospital admissions routine mental examination for psychiatric disorders among those with sickle cell disease could enhance diagnosis and hence management of psychiatric disorders among children and adolescents with sickle cell disease. In the past, more focus has been directed towards the physical symptoms with little attention to the psychological problems that come with sickle cell disease.

2) Frequent hospital admissions are associated with psychiatric morbidities among children and adolescents with sickle cell disease. We should therefore improve outpatient care of these children through proper hydration, medications and vaccinations to minimize their admission in hospitals.

3) Improve on modifiable sociodemographic characteristics such as the living status of SCD patients that are associated with psychiatric morbidities through government policies and programs.

4) Further research to determine causal relationships where associations were significant. Special focus will be on depressive disorders and anxiety disorders as these came out as the most frequent psychiatric diagnosis in children and adolescents with sickle cell disease.

6.3 Limitations

Non reporting bias for some positive symptoms was possible due to fear of being labeled mentally ill. This was mitigated by assuring respondents of confidentiality and de-identification of data.

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APPENDICES

Appendix I: Informed Consent Form

Study Title: Psychiatric morbidity among children and adolescents with sickle cell disease attending the moi teaching and referral hospital sickle cell clinic.

Name of Principal Investigator: Isaac Babu Kisiang'ani

Name of Organization: Moi University and Moi Teaching and Referral Hospital

Name of Sponsor: Self

This Informed Consent Form consists of two parts:

1. Information Sheet (to share information about the study with you)
2. Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the signed Informed Consent Form.

Part I: Information Sheet

Introduction:

You are being requested to take part in a research study. This information is provided to tell you about the study. Please read this form carefully. You will be given a chance to ask questions. If you decide to be in the study, you will be given a copy of this consent form for your records.

Taking part in this research study is voluntary. You may choose not to take part in the study. Saying no will not affect your rights as a patient at Moi Teaching and Referral Hospital. You are also free to withdraw from this study at any time. If after data collection you choose to quit, you can request that the information provided by you be destroyed under supervision- and thus not used in the research study. You will be notified if new information becomes available about the risks or benefits of this research. Then you can decide if you want to stay in the study.

Purpose of the study:

The purpose of this study is to assess psychiatric morbidity among children and adolescents with sickle cell disease attending the moi teaching and referral hospital sickle cell clinic.

Type of Research Project/Intervention:

The study will involve a questionnaire in order to answer the study questions.

Commonly asked questions

- **Why have I been identified to Participate in this study?**

298 patients attending the sickle cell clinic at MTRH have been selected to participate in the study

- **How long will I be involved in the study?**

You will be involved in the study only during the interview which is one day.

- **What will happen to me during the study?**

  We are asking you to participate in the study to help us understand psychiatric morbidity among patients with sickle cell disease and factors associated with these psychiatric morbidities.

- **What side effects or risks I can expect from being in the study?**

We shall not be applying any interventions or giving any medication, therefore we don't anticipate any risks nor side effects from the study.

- **Are there benefits to taking part in the study?**

This knowledge will help improve the care given to children and adolescents with sickle cell disease by giving a more holistic approach to their management. We anticipate that there will be better understanding of mental health problems associated with sickle cell disease and therefore timely interventions to improve outcomes.

- **Reimbursements:**

There shall be no reimbursements to those who volunteer to participate in the study

- **Who do I call if I have questions about the study?**

For questions about the study, call Isaac Babu Kisiang'ani on Tel No: 0743901770

For questions about your rights as a research subject: You may contact Institutional Review Ethics Committee (IREC) 053 33471 Ext.3008. (IREC is a group of people that reviews studies for safety and to protect the rights of study subjects).

- **Will the information I provide be kept private?**

All reasonable efforts will be made to keep your protected information (private and confidential. Protected Information is information that is, or has been, collected or maintained and can be linked back to you. Using or sharing ("disclosure") of such information will follow National privacy guidelines. By signing the consent document

for this study, you are giving permission ("authorization") for the uses and disclosures of your personal information.

As part of the study, Isaac Babu Kisisang'ani may share the results of your [age, residence, level of education health status e.t.c]. These may be study or non-study related. They may also share with the groups named below:

- The Institutional Review and Ethics Committee,
- MTRH and Moi University

National privacy regulations may not apply to these groups; however, they have their own policies and guidelines to assure that all reasonable efforts will be made to keep your personal information private and confidential.

The study results will be retained in your research record for at least 7 years after the study is completed. At that time, the research information not already in your medical record will be stored in a secure location, only accessible to the researcher. Research information will be kept for a period of 7 years and will then be destroyed permanently.

Part II: Consent of Subject:

I have read (or have had read to me) the description of the research study. The investigator or his representative has explained the study to me and has answered all of the questions I have at this time. I have been told of the potential risks, discomforts and side effects as well as the possible benefits (if any) of the study. I freely volunteer to take part in this study.

_____ _____ _____

Name of Participant Signature of subject/thumbprint Date

_____ _____ _____

Printed name of Investigator Signature of Investigator Date

Appendix II: Questionnaire

1) Age…….

2) Sex

Male ❑

Female ❑

3) What is your caretakers/parents net income (total if both present)?

0-2999 ❑

3000-5999 ❑

6000-8999 ❑

More than 9000 ❑

4) Who do you live with?

Both parents (father and mother) ❑

One parent (mother only/father only) ❑

Foster parents ❑

Other relatives ❑

4) How long ago were you diagnosed with sickle cell disease?

Less than 1 year ❑

1-5 years ❑

6-10years ❑

More than 10years ❑

5) How many times have you been admitted because of sickle cell disease or its complications?

Never ❑

1-5 ❑

6-10 ❑

More than 10 ❑

7) Have you ever encountered a mental health expert in the course of your treatment for sickle cell disease?

Yes ❑

No ❑

Appendix III: Budget

ITEM	**COST**
Stationery……	20,000
Laptop …….	60, 000
Printer ……	20,000
Toner ……	15,000
Data analysis ……	50, 000
Lunch for assistants ……	20,000
Contingency ……	40,000
**Total…… **	**225,000/=**

Appendix IV: Time schedule

Activity timeline

1.	Writing and submission proposal from May 2019	November 2018-
2.	Present proposal to IREC for approval	May 2019
3.	IREC approval	August 2019
4.	End of proposal writing	September 2019
5.	Data collection October 2020	October 2019-
6.	Data cleaning, coding and entry Feb 2021	November 2010-
7.	Data analysis 2021	March 2021- June
8.	Submission of the draft of thesis for scrutiny	July 2021
9.	Correction of thesis and submission for final scrutiny November 2021	September-
10.	Correction binding and submission of thesis	December 2021

Appendix V: IREC Approval

MTRH/MU-INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL
P.O. BOX 3
ELDORET
Tel: 33471//2/3

MOI UNIVERSITY
COLLEGE OF HEALTH SCIENCES
P.O. BOX 4606
ELDORET

Reference: IREC/2019/133
Approval Number: 0003430

29th August, 2020

Dr. Isaac Babu Kising'ani,
Moi University,
School of Medicine,
P.O. Box 4606-30100,
ELDORET-KENYA.

Dear Dr. Kising'ani,

RE: CONTINUING APPROVAL

The Institutional Research and Ethics Committee has reviewed your request for continuing approval to your study titled:-

"Psychiatric Morbidity among Children and Adolescents with Sickle Cell Disease at Moi Teaching and Referral Hospital Sickle Cell Clinic".

Your proposal has been granted a Continuing Approval with effect from 29th August, 2020. You are therefore permitted to continue with your study.

Note that this approval is for 1 year; it will thus expire on 28th August, 2021. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to the expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

INSTITUTIONAL RESEARCH & ETHICS COMMITTEE
29 AUG 2020
APPROVED
P. O. Box 4606-30100 ELDORET

Sincerely,

PROF. E. WERE
CHAIRMAN
INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

cc CEO - MTRH Dean - SOP Dean - SOM
Principal - CHS Dean - SON Dean - SOD

Appendix V: Mini-Kid Tool

M.I.N.I. KID

MINI INTERNATIONAL NEUROPSYCHIATRIC INTERVIEW

For Children and Adolescents

English Version 7.0.1

For

DSM-5

DISCLAIMER

Our aim is to assist in the assessment and tracking of patients with greater efficiency and accuracy. Before action is taken on any data collected and processed by this program, it should be reviewed and interpreted by a licensed clinician.

This program is not designed or intended to be used in the place of a full medical and psychiatric evaluation by a qualified licensed physician – psychiatrist. It is intended only as a tool to facilitate accurate data collection and processing of symptoms elicited by trained personnel. It is not a diagnostic test.

Patient Name:		***Patient Number:***	
Date of Birth:		***Time Interview Began:***	
Interviewer's Name:		***Time Interview Ended:***	
Date of Interview:		***Total Time:***	

	MODULES	TIME FRAME	MEETS CRITERIA	ICD-9-CM	ICD-10-CM	
A	MAJOR DEPRESSIVE EPISODE	Current (Past 2 weeks)	☐			
		Past	☐			
		Recurrent	☐			
	MAJOR DEPRESSIVE DISORDER	Current (Past 2 weeks)	☐	296.20-296.26 Single	F32.x	☐
		Past	☐	296.20-296.26 Single	F33.x	☐
		Recurrent	☐	296.30-296.36 Recurrent	F33.x	☐
B	SUICIDALITY	Current (Past Month)	☐			☐
		Lifetime attempt	☐	☐ Low ☐ Moderate ☐ High		☐
	SUICIDE BEHAVIOR DISORDER	Current	☐	(In Past Year)		☐
		In early remission	☐	(1 - 2 Years Ago)		☐
C	MANIC EPISODE	Current	☐			
		Past	☐			
	HYPOMANIC EPISODE	Current	☐			
		Past	☐	☐ Not Explored		
	BIPOLAR I DISORDER	Current	☐	296.41-296.56	F31.0 - F31.76	☐
		Past	☐	296.41-296.56	F31.0 - F31.76	☐
	BIPOLAR II DISORDER	Current	☐	296.89	F31.81	☐
		Past	☐	296.89	F31.81	☐
	BIPOLAR DISORDER UNSPECIFIED	Current	☐	296.40/296.50	F31.9	☐
		Past	☐	296.40/296.50	F31.9	☐
	BIPOLAR I DISORDER WITH PSYCHOTIC FEATURES	Current	☐	296.44/296.54	F31.2/31.5	☐
		Past	☐	296.44/296.54	F31.2/31.5	☐
D	PANIC DISORDER	Current (Past Month)	☐	300.01	F41.0	☐
		Lifetime	☐	300.01	F40.0	☐
E	AGORAPHOBIA	Current	☐	300.22	F40.00	☐
F	SEPARATION ANXIETY DISORDER	Current (Past Month)	☐	309.21	F93.0	☐
G	SOCIAL ANXIETY DISORDER (Social Phobia)	Current (Past Month)	☐	300.23	F40.10	☐
H	SPECIFIC PHOBIA	Current (Past Month)	☐	300.29	F40.218-40.298	☐
I	OBSESSIVE-COMPULSIVE DISORDER	Current (Past Month)	☐	300.3	F42	☐
J	POSTTRAUMATIC STRESS DISORDER	Current (Past Month)	☐	309.81	F43.10	☐
K	ALCOHOL USE DISORDER	Past 12 Months	☐	303.9	F10.10/F10.20	☐
L	SUBSTANCE USE DISORDER (Non-alcohol)	Past 12 Months	☐	304.00-.90/305.20-.90	F11.10/F11.20 - F19.20	☐
M	TOURETTE'S DISORDER	Current	☐	307.23	F95.2	☐
	PERSISTENT (CHRONIC) MOTOR TIC DISORDER	Current	☐	307.22	F95.1	☐
	PERSISTENT (CHRONIC) VOCAL TIC DISORDER	Current	☐	307.22	F95.1	☐
	PROVISIONAL TIC DISORDER	Current	☐	307.21	F95.0	☐