EXPERIENCES OF LIVING WITH SICKLE CELL DISEASE AMONG ADULTS ATTENDING CLINIC AT MUHIMBILI NATIONAL HOSPITAL,DAR-ES-SALAAM,TANZANIA

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By

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A Dissertation submitted in (Partial) Fulfillment of the Requirement for the Degree of Masters of Nursing (Critical Care and Trauma) of

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CERTIFICATION

The undersigned certifies that they have read and hereby recommends for acceptance by Muhimbili University of Health and Allied Sciences, a dissertation entitled. "***Experiences of Living With Sickle Cell Disease Among Adults Attending Clinic At Muhimbili National Hospital, Dar-Es-Salaam, Tanzania*,"** as requirement for (partial) fulfillment of the degree of Master of Science Nursing in critical care and trauma) of the Muhimbili University of Health and Allied Sciences.

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DECLARATION

I, **Rehema Nkingi**, declare that this **dissertation** is my own original work and that it has not been presented and will not be presented to any other University for a similar purpose or any other degree award.

Signature: ……. Date: ……

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DEDICATION

This dissertation is dedicated to my lovely husband; Dr. Douglas Chamshama who always supported, encouraged and prayed for me, in my academic carrier, and to my four children Charlotte, Elizabeth, Samwel and Victoria-Nicole.

ABSTRACT

Background: Sickle Cell Disease (SCD) is a potentially overwhelming condition that is caused by an autosomal recessive inherited hemoglobinopathy. Sickle Cell Disease affects all areas of the patient's life and results in different events or experiences (occurrences which leaves an impression on someone).**Aim: This study aimed at** understanding the perceptions of adults living with SCD on triggering, aggravating and alleviating factors for pain, describing the perceptions on pain management, and understanding perspective experiences of social implication on living with SCD. Methods: The method used in this study was phenomenological study that used descriptive qualitative method. Study population was of adults living with Sickle Cell Disease in Dar-es -Salaam Region, aged 18 years and above. Sample size was of 15 adults living with SCD. Sampling procedure used to select study participants was Purposive/judgmental. Adults aged 18 years and above screened at Muhimbili National Hospital SCD Cohort and confirmed to have SCD, who consented to be enrolled in the study were included. Adults with SCD who were not enrolled in the cohort were excluded. Data were collected at Muhimbili National Hospital from March 2017 to May 2017. Fifteen in-depth interviews with adults living with SCD aged eighteen years and above were conducted to collect primary data. Data were analyzed by using content analysis approach. Findings: Adults living with SCD mentioned different factors that perceived to trigger, aggravate and alleviate pain. Most participants reported to manage pain by home remedy together with self-medication, however all participants seek hospital care whenever the pain continues. Sickle Cell Disease was also found to have led to poor school attendance and hence poor academic performances, also it has been found to have caused difficulties in getting life partner and establishing family as well as failing to work and become independent eeconomically. Recommendations: Living with a sickle cell disease is a challenge. According to experiences reported by participants, health outcomes of adults living with SCD depend on good physical, social and psychological management. These can be influenced by the health care system, health personnel and

individuals. The government through the Ministry of Health, Community Development, Gender, Elderly and Children, should support on prevention of the disease, (cut off the chain of inheritance), and management of the disease.

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ADRs	Adverse drug reactions
ER	Emergency Room
G.I	Gastrointestinal
HCP	Health Care Personnel
HRQL	Health-related quality of life
MNH	Muhimbili National Hospital
NRS	Numeric Rating Scale
RBCs	Red Blood Cells
SCA	Sickle Cell Anemia
SCD	Sickle Cell Disease
U.S.A	United States of America
USD	United States Dollars
VOCs	Vaso-occlusive Crises
WHO	World Health Organization
NSAIDS	Non Steroid Anti-inflammatory Drugs
OTC	Over-the-counter (OTC)
MG	Milligram
MoHCDGE	Ministry of Health, Community Development, Gender, Elderly and Children

CHAPTER ONE

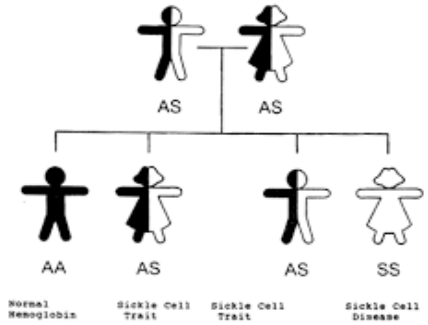
1.0 INTRODUCTION

1.1 BACKGROUND INFORMATION

Sickle Cell Disease is a potentially overwhelming condition that is caused by an autosomal recessive inherited gene for hemoglobinopathy. The genetic abnormality is due to a substitution of thiamine acid valine for glutamic acid at the sixth position on the beta globin chain. This was first described over one hundred years ago. Hemoglobin S (HbS) is produced as a result of this defect. It is a hemoglobin tetramer which is insoluble and polymerizes when deoxygenated. Patients with combination of two hemoglobinopathies in general, have the most severe forms of SCD (Neville& Panepinto, 2011).

SCD is an umbrella term representing several hemoglobin (major protein imparting the color to RBCs) disorders. Sickle hemoglobin (HbS) is a modification of normal hemoglobin (HbA), which arose many thousands of years ago. HbS is made differently from HbA, when oxygen is removed, the molecule tend to stick together forming long fibres which may distort the RBCs into the sickle shaped. It happens more rapidly in circulation and block flow in the vessels, poorly oxygenated blood supply to tissues, anemia, pain, and multi-system failure. The commonest type of SCD occurs when the HbS gene is inherited from both parents causing homozygous SCD or SS disease. Other types inherited which cause SCD are HbC (common in West Africa), beta thalassemia minor and beta thalassemia major. The HbSS and beta thalassemia major variants manifest as a more severe form of the disease, while HbSC and beta thalassemia minor as a less severe form. If both parents have the sickle-cell trait (AS), or one has sickle-cell trait and the other has another abnormal interacting hemoglobin trait, there is a 25% chance at each pregnancy that the child will have a form of Sickle Cell Disease. If one parent has AS, and the other has SS (or any form of SCD) the risk is 50% at each pregnancy (Adegbola et al. 2012).See figure 1: Inheritance sketch.

Figure 1: Inheritance sketch



EPIDEMIOLOGY

SCD disease is prevalent in Africa, the United States, Caribbean, Central America, South America, Saudi Arabia, India and the Mediterranean (Center for Disease Control and Prevention, 2011a). Approximately 90,000 to100,000 Americans are affected by SCD, making it the most common genetic disorder (Matthie, 2013). It is estimated that 16% of the population in Africa has a sickle hemoglobinopathy which is the highest proportion worldwide.

CLINICAL MANIFESTATION

Acute sickle-cell pain is typically sharp and/or throbbing in nature, and can beof a sudden or gradual onset. It may last from minutes to weeks in duration depending on how pain is managed. Acute sickle-cell pain is believed to be secondary to vaso-occlusion by sticky sickled red blood cells (RBCs) that adhere to vascular endothelium. Vascular occlusion causes ischemia, consequently damaging tissues of any organ supplied by the occluded vessel. Tissue damage, in turn, causes a state of inflammation with the release of several inflammatory mediators. The chemical energy caused by inflammation is changed into an electrical signal of pain transmitted along peripheral nerves, spinal cord and region of Central Nervous System (CNS).The impulse ascends along the contralateral spinothalamic tract to the thalamus which then interconnects reversibly with the limbic system and other regions of the central nervous system

(CNS).When the CNS tries to inhibit the transmission of the painful stimulus with endogenous serotonin and epinephrine. This modified electrochemical pain impulse is eventually sent to the cerebral cortex where it is perceived as pain (Samir K Ballas, 2011).

SCD is different from other diseases associated with chronic pain such as osteoarthritis, and rheumatoid arthritis, as sickle cell is acute pain manifests itself in infancy and recurs throughout the life span of the affected individual. With age, acute pain retains its unpredictable relapses and may result in chronic pain. Chronic pain may evolve into neuropathic pain. Acute pain, mostly, dominates the clinical picture and requires urgent treatment with parenteral opioids in the Emergency Room(ER) and/or hospital (Ballas,S.K,2011). The clinical presentation of SCD pain is complex. In the beginning, it may be largely episodic; however, tissue necrosis and the changes in the central nervous system and other factors, may be due to the cumulative impact of pain itself inducing an increasingly chronic component of SCD pain later in life (Hollins et al. 2012).

MORBIDITY AND MORTALITY

In the United States Platt et al, reported that many adults with Sickle Cell Disease died during acute sickle -cell related complications such as pain, acute chest syndrome, and stroke. Most common causes of death reported are pulmonary hypertension, sudden death of unknown etiology, renal failure, and infections.

During their life time, patients with Sickle Cell Disease are susceptible to various complications such as bone pain (dactilitis, avascular necrosis of flat/long bone), priapism, anemia (acute splenic sequestration, chronic hypersplenism), abdominal pain (abdominal pain crisis, cholecystitis), fever (septicemia, urinary tract infections, viral), deep jaundice (chronic hepatic congestion, viral hepatitis), leg ulcer, nervous system (ocular involvement, stroke) and acute chest syndrome. However, pain crisis is the most common symptoms reported by patients, and is considered the most common reason of referral to the emergency department and hospitals (Ahmadi et al. 2014).

People living with SCD face many types of morbidity and early mortality. Various characteristics causing morbidity and mortality are; increased susceptibility to infections, chronic hemolytic anemia, end organ damage, and intermittent episodes of vascular occlusion which result in acute and chronic pain (Wilkie et al. 2010).

In some African countries, nearly all babies born with SCD die in early childhood. In the United States (U.S.), newborn screening, prophylactic penicillin treatment in children and other aggressive treatments for pain and disease complications have increased the life expectancy for the 100,000 people with SCD to age 42 years for men and 48 for women. Recent advances in the treatment of SCD, such as hydroxyurea, prolong and improve the quality of life for many people, some living into their eighties. Unfortunately, people with SCD live with many threats to the quality of life. Palliative care offers the hope of reducing these threats (Wilkie et al . 2010).

CONSEQUENCES

Most often, chronic pain, affects all areas of the patient's life. Chronic pain is challenging for healthcare providers to manage, and can negatively change the patient's life into pathologies that include depression and coping difficulties (Adegbola, Maxine, 2015). In order to cope with the disease, SCD patients must adapt themselves to a set of behaviors that promote self-management and prevent complications associated with the disease (Ahmadi et al. 2014).

A comprehensive, dedicated SCD program that provides, follow-up care, family and patient education and counseling, and prevention and treatment of complications could have a significant impact in reducing morbidity and mortality and result in longer more productive lives(Makani et al. 2015).

1.2 PROBLEM STATEMENT

Living with the SCD has been a challenge to many adults with the disease. The effects of SCD are multi-dimensional, ranging from causing high morbidity, and reducing the quality of life, to imposing a high socio-economic burden on individuals, and families (Tluway & Makani, 2017).

Pain is one of the major problems of Sickle Cell Disease (SCD). SCD pain typically emerges in the second half of the first year of life, as red blood cells with the fetal form of hemoglobin wane, replaced by cells that are capable of sickling (deforming),preventing blood flow, and thus producing ischemia, hypoxia, and possible tissue damage. Pain is gradually in Sickle Cell Disease, affecting all aspects of life (Hollins et al. 2012;Adegbola et al. 2012;Akingbola et al. 2011;Ballas, 2011;Jenerete &Lauderdale,2008;Wilkie et al. 2010).

Management of SCD pain has to be holistic (take into account all aspects of patient's life without forgetting mental and social factors and not just the physical symptoms of the disease), but this has not been the case among health care providers in hospitals.

Poor painful crises management can lead to increase in frequencies of crises, and later to chronic pain that may result in recurrent hospital admissions, frustration, loss of precious time for adult's daily activities, and hence have direct consequences on economy and implicate social life.

Little is known about adults living with Sickle Cell Disease in Tanzania that show their experience or how the disease implicates normal life, and how they manage the pain. Therefore, this study is intended to fill this missing gap of information.

1.3 SIGNIFICANCE OF THE STUDY

The findings of this study will help understand what adults living with SCD know about self-care management and help fills in the gaps of knowledge; will help recognize nursing gaps in caring, guiding nursing action, and educating. Will also help to improve care in hospital to the adult patients with SCD. Understand these will help develop intervention plan like preparing education sessions on self-care management, prevention of/or reduction of crisis occurrences.

The finding will also help understand social implication on living with SCD. By understanding these, nurses will be able to know what to prepare in education, and also what are the problems needs counseling. Management of the adult living with SCD will then be improved.

These can be achieved by advocating them to right to places example in hospitals, and Ministry of Health, Community and Development, Gender, Elderly and Children.

1.4 DEFINITION OF TERMS

PAIN is an unpleasant feeling and emotional experience associated with actual or potential tissue damage. It is a subjective experience with both psychological and sensory components, and tissue damage does not need to be present for pain to be experienced (Nicholson, 2006).

ACUTE SPLENIC SEQUESTRATION-Is a sudden increase in spleen size associated with trapping of red blood cell (RBCs) (Rezende et al.2009).

CHRONIC HYPERSPLENISM-Is a chronic red cells sequestration (removing from circulation) associated with marked splenomegaly (Elmakki, 2012).

PRIAPISM

Stuttering priapism is a recurrent short-lived attack (usually 3-6 hours) of painful erection of the penis unassociated with sexual desire, while major priapism attack usually lasts two days. The patient complains of extremely tender and painful erection, and the pain is referred to the suprapubic and perineal region (Crane, & Bennett, 2010).

SELF-CARE MANAGEMENT (INDEPENDENT-DOING YOUR SELF)

This refers to all actions and coping strategies, carried out at home, and needed to take part in therapeutic behaviors targeted at preventing health complications, improving psychosocial conditions, and maintaining health (Jenerette & Murdaugh, 2008).

SOCIAL SUPPORT

This refers to all available helping, encouraging, whether positive words, financial/other aids from family or friends (Jenerette & Murdaugh, 2008).

1.5 OPERATIONAL DEFINITION

HYDRATION

In this study hydration means to supply plenty of fluid to a person to maintain a balance of fluid in the body, at least three to four liters of water/fluid per day (at least twelve to sixteen glasses) the water can be in the form of water, juice, tea, soup and other fluids. Alcoholic drinks should be avoided because alcohol exacerbates dehydration and can lead to other complications.

HEALTHY DIET

In this study a healthy diet means the diet that gives the body the nutrients it needs to function correctly. The food should be estimated in proportions e.g. One third of plate should be vegetable and fruits, another one third should be protein and the remaining one third should be carbohydrate. To get food rich in iron and calcium such as fish/sardine (small fish), liver, dark green leaves vegetables, beans and red meat are important. Also foods that have folic acid have to be included, such as fruits and Vegetables e.g. spinach, broccoli, avocado, peas, citrus fruits. They should also eat beans, cereals, rice, nuts, and fresh juice. People with Sickle Cell Disease have a greater risk of getting infections; it is important that food be handled with particular care, such as, maintaining strict hand hygiene, and proper food storage.

Figure 2: Healthy diet Plate and drinking water

1.6 OBJECTIVES

1.6.1 BROAD OBJECTIVE

To explore the experiences of living with sickle cell disease among adults.

1.6.2 SPECIFIC OBJECTIVES

1) To understand the perceptions of adults living with SCD on triggering, aggravating and alleviating factors for pain.
2) To describe the perception of adults living with SCD on pain management.
3) To understand participants' perspective experiences of social implication on living with SCD**.**

1.7 RESEARCH QUESTIONS

1) What are the perceptions of adult living with SCD on triggering, aggravating and alleviating factors for pain?
2) What are the perceptions of adult living with SCD on pain management?
3) What are the participants' perspective experiences of social implication on living with SCD?

1.8 CONCEPTUAL FRAME WORK

HEALTH OUTCOMES

In this study, health outcomes of adults living with Sickle Cell Disease are physical (number of painful crises, number of complications), social (availability of different supports (e.g. Family), availability of health care services, coping behavior) and psychological (such as frustration, low self-esteem, and depression). For populations with chronic disease, measurement of productive life gives a meaningful way to decide the impact of health care when cure is not possible. Physical, social and psychological outcomes are the results of interrelated factors which are; health personnel, health care system factors and individual factors that may have either positive and/or negative influence. In this study the bolded physical and social outcomes were addressed.

HEALTH PERSONNEL FACTORS

In this study, health personnel are nurses and doctors. Health personnel factors can influence the proper management (right treatment and management, right dosage, family and patient education, treatment of complications and counseling) of patients. Health personnel factors include knowledge, competence and attitudes. Health education to patients and family includes a lot of things such as adherence to treatment, self-care management, early recognition of problems, how to reduce number of crises, encouragement on follow-up clinics and others.

HEALTH SYSTEM FACTORS

In this study, health system factors are factors within health system (hospital, Ministry of Health, Community Development, Gender, Elderly and Children-MoHCDGEC) that can influence nurses or doctors in the management of patients. Health system factors in this case are availability of early screening clinics, follow up care system, treatment, diagnostic equipment availability, human resource, training and preventive measures. All these have an influence in the proper management of patients.

INDIVIDUAL FACTORS

Individual factors in this study (education, social support, employment, cultural and religion/Prayers, self-care management and action) can have either positive and/or negative influence on self-care management, as self-care management influences more productive life.

Despite having many influencing factors, according to limitation of time, this study focuses on education, social support, employment, cultural and religion/prayers, self-care management, physical outcome, and social outcome) that influences adults to have different life experiences. Other factors are beyond the scope of this study.

The figure 3 below shows the frame work.

*Variables were chosen based on the findings reported in the literature, after extensive reading.

FRAME WORK

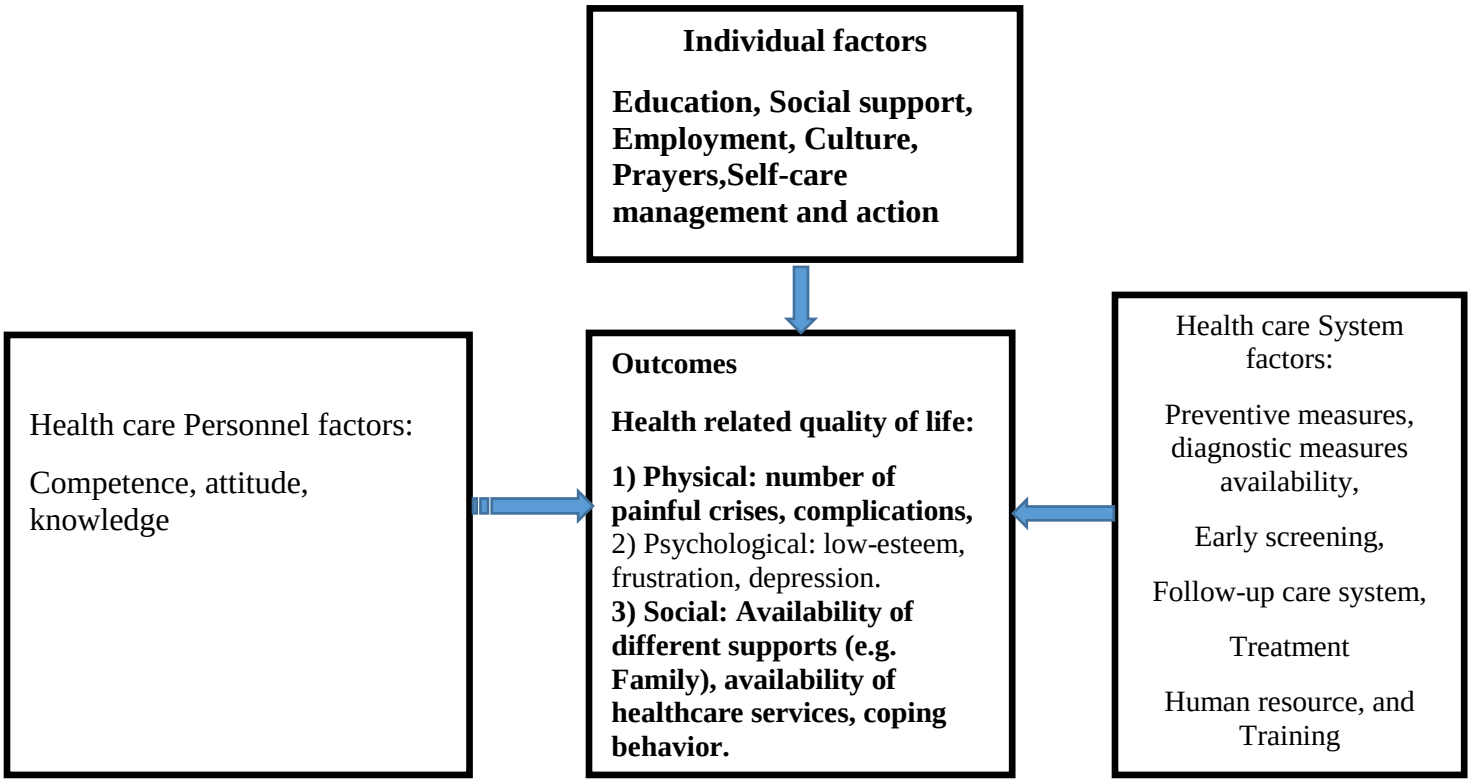


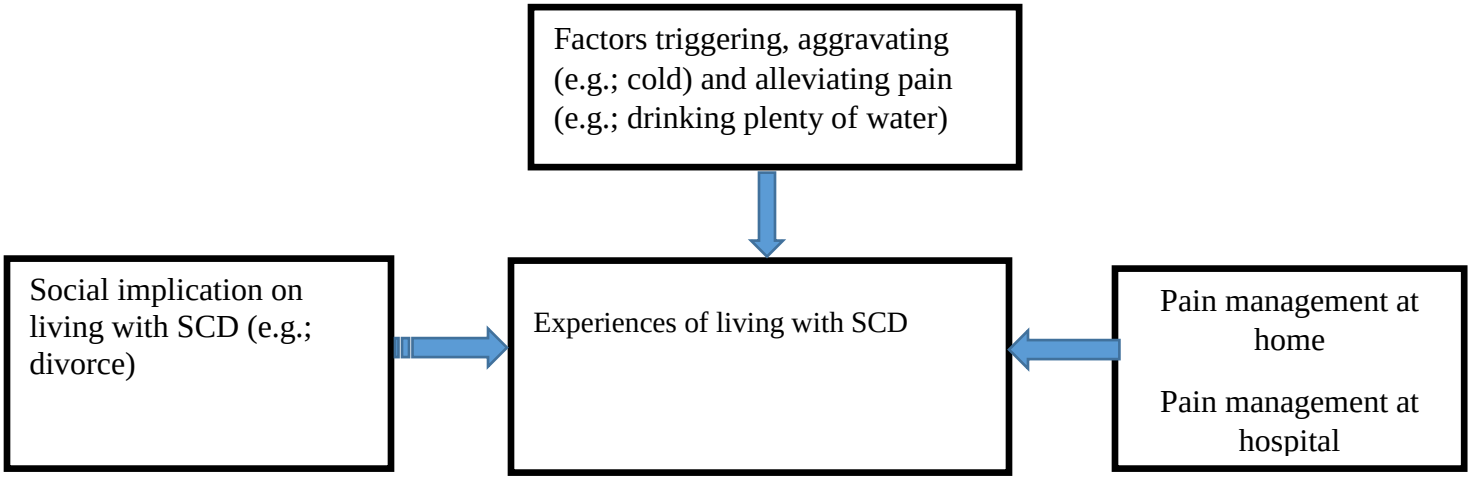
Figure 3: Frame Work.

This study is going to concentrate only on the bolded factors in the frame work above, other factors are beyond the scope of this study. These bolded factors are: individual factors, physical and social outcomes.

1.9 APPLICATION OF MODIFIED FRAME WORK IN THIS STUDY

Figure 4 below shows modified conceptual framework based on the original.

In this study Pain management at home/hospital, factors triggering, aggravating (eg; cold) and alleviating pain (e.g.; drinking plenty of water), together with social implications on living with SCD (e.g. divorce) are the experiences of living with SCD**.**



The above is application model which has been modified from the original framework. The health care system is replaced by pain management at home and at hospital. Pain is origin of experiences. Pain management starts at home, and can require also management at hospital. Management of pain can influence different experiences, either positively or negatively. Health care personnel is replaced by social implication of living with SCD.These are different experiences such as divorce, unemployment etc. which affects social life.Individual factors are factors triggering, aggravating and alleviating. These are personal experiences about pain.The outcomes are all experiences of living with SCD.

CHAPTER TWO

2.0 LITERATURE REVIEW

OVERVIEW

Sickle Cell Disease is a chronic illness that impacts patients physically and emotionally. Open and honest communication about advanced care planning, management of disease, relief of pain, other symptoms, bereavement and grief are all important for the patient, family, and health care providers. Given the multiple acute and chronic complications of Sickle Cell Disease, an approach to care which is holistic and comprehensive may help to improve a patient's biological function and the perceived wellbeing, functional status, and quality of life of the patient and family (Wilkie et al. 2010).

2.0.1 PERCEPTION ON TRIGGRING AND/OR GGRAVATING OF PAIN

A review of articles done by Tewari et al.(2015) concerning Environmental determinants of severity in sickle cell disease, extreme cold weather have been found to precipitate acute pains. Patients are routinely advised to avoid getting cold in all parts of the world. Edington reported that attacks of joint pain were linked to cold weather in ten out of 33 patients in the Gold Coast (Ghana), and speculated that cold coincided with the rainy season and that this was the main cause of increased pain. However in that study increased malarial infections, also mentioned to aggravate pain: Studies in New York conducted in the 1970s showed increased admissions to hospital with sickle pain in cold winter months even when episodes with overt infection were excluded, and speculated that this may be due to increased blood viscosity and cold diuresis.

The series of reports from the Unites State Food and Drug Administration (FDA), reported that, adult participants re-stated their sensitivity or intolerance to cold temperature or weather changes. Participants described a pain crisis that lasted for **two** days after being contacted/soaked with cold water, and explained that "when the cold gets into your bones, it's just like serious pain (FDA, 2014).

The study done by Adewoyin. (2015) in Nigeria, found that, pain episodes vary in intensity and tend to resolve within a few days. In about 57% of cases, no precipitating factor is identified. However, known precipitants include exposure to cold, dehydration, intercurrent infections such as malaria, physical exertion, tobacco smoke, alcohol use, high altitude, hypoxic conditions, physical pain, pregnancy, hot weather, emotional stress, or onset of menses.

Stress of any kind, traumatic, physical, psychological, physiologic, etc., may trigger the onset of a painful episode. Sickle pain may involve any part of the body, and the severity, location, and duration of the pain vary among patients (Ballas,S.K, 2007).

Health care providers are often questioned whether patients with SCD should participate in sports or strenuous physical activity. Exercise and physical activity may induce metabolic changes that can, if too large, potentially precipitate vaso-occluisve crisis Exercise and physical activity are known to induce marked metabolic changes, such as lactic acid production by active muscles. The presence of anemia is responsible for a faster transition from aerobic to anaerobic metabolism during exercise, which may stimulate the polymerization of HbS and lead RBCs to sickle and promote microvascular occlusions. An added consideration during exercise is the dehydration. It is often thought that prolonged endurance exercise is more stressful than short periods of exercise in patients with SCD, however greater efforts should also be paid to the effects of short intense exercise. For example, intense exercise, such as that which involves repeated jumping, may increase the risks for muscle and joint injuries. Contact sports, including American football, hockey, and similar events, should be avoided, particularly by patients with splenomegaly, given the high risk of splenic rupture. All these considerations stimulate fear from physicians about exercise recommendations in SCD patients. Clinicians should advise patients to start their exercise gradually, to avoid intense exercise and to stop exercising at the first sign of fatigue. SCD patients should not practice during illness. Prolonged exercise for more than 20 min without resting should be avoided: a resting period every 20 min of exercise is recommended to avoid

dehydration and lactic acid accumulation. In addition, to prevent dehydration, SCD patients should drink water during and after exercising. However, each patient should be able to independently manage his or her physical efforts (Connes et al. 2011).

In his study on Managing leg ulcer pain in SCD, Naoum found that,leg ulcers are common complications in adults with SCD (Naoum.F.A, 2010).Leg ulcers affect about 10% of adults with the disease in the US, 50-75% in Jamaica (Brousse et al. 2017). Leg ulcers occur in areas with less subcutaneous fat, thin skin, and with decreased blood flow. The commonest sites are the medial and lateral malleoli (ankles). Leg ulcers may be classified as acute or chronic according to their duration, however, there is no consensus as to a specific length of time to define chronicity. An acute ulcer usually should heal in less than a month. Six months duration seems to define the chronic ulcers. It is not uncommon for ulcers to last many years, often closing and re-opening repeatedly (Minniti et al. 2010).Sometimes these ulcers can be deep and large, provoking excruciating/unbearable pain and considerably disabling. Although both vaso-occlusion and chronic hemolysis are major determinants of leg ulceration, the exact mechanism of their formation is not totally understood and may involve other factors such as exposure of the leg to trauma or insect bites, local infection, edema and impaired circulatory dynamics (Naoum.F.A, 2010).

Acute pain is the most common manifestation of the disease in all age groups. Pain is thought to be caused by vaso-occlusion, which results in ischaemic tissue damage and subsequent inflammation and pain. It can affect any part of the body, although the limbs and back are most commonly involved. The US Cooperative Study of Sickle Cell Disease (CSSCD) commented that Initial assessment of pain should include estimate of pain severity, assessing precipitating factors such as severe dehydration, looking for evidence of infection and other, factors that would necessitate referral to hospital. General advice includes keeping warm; drinking plenty; and taking simple analgesia, such as paracetamol, ibuprofen, and weak opioids if pain is severe (Brousse et al. 2017).

Participants emphasized the importance of practicing holistic care in preventing or managing sickle cell disease symptoms. Specific therapies or practices mentioned included: Alternative therapies, including cupping, acupuncture, massage therapy, Transcutaneous Electrical Nerves Stimulations (TENS) units, heat pack therapy, aromatherapy, and topical oils to treat line incisions. Other practice mentioned were adequate hydration and diet, including eating a diet rich in natural organic ingredients and plenty of green vegetables and fruits, as well as eating a low sodium diet or avoiding iron-rich foods (FDA, 2014).

A study done in United Kingdom found different modalities that used to alleviate pains, include the use of heat or ice packs, relaxation, distraction, music, massage, vibration, prayer, therapeutic exercises, menthol cream rub, self-hypnosis, acupressure, acupuncture, transcutaneous electrical nerve stimulation (TENS), and biofeedback. There are no controlled clinical trials on the efficacy of any of these modalities in the management of sickle cell pain. Nevertheless, narrations from patients and providers attest that these approaches are effective in relieving pain and decreasing the amount of opioid consumption if the pain is severe. Ballas added that, rational and effective management of sickle cell pain is a function of thorough assessment and individualization of therapy coupled with the use of non pharmacologic and pharmacologic approaches to therapy (Ballas,S.K, 2007).

The interactions between SCD and environmental factors leads to a better understanding of the natural history of SCD and improved care of patients. Better understanding of environmental factors is also important for studies of pharmaceutical interventions in SCD, because any therapeutic effect may be lost or exaggerated by confounding climatic effects. For example, a particular trial drug used in summer may show far less effect than the same drug used in winter (Tewari et al. 2015).

2.0.2 PAIN MANAGEMENT

Pain management at home as self-care

The recommendations from the Centers for Diseases Control and Prevention (2010) are that these individuals should receive regular checkups at least annually, drink plenty fluids, eat a healthy diet, get enough rest, avoid cold and temperature extremes, and prevent infections. Other strategies for managing pain at home include medications, massage therapy, hot showers, distraction, and relaxation. Analgesic therapy, both opioids and non-opioids, is commonly used to treat acute pain in the home setting. Non-opioids most frequently include Non-Steroidal Anti-Inflammatory Drugs, like Ibuprofen, Acetaminophen, and an Acetaminophen-codeine mixture. Non-opioids used in Tanzania include Acetaminophen, Acetylsalicylic acid, Ibuprofen, and Diclofenac (Makani et al. 2014;The United Republic of Tanzania, 2013). Opioids used in the United States may include morphine, hydromorphone, oxycodone, Methadone, Codeine, or Tramadol (Matthie, 2013). In Tanzania Diclofenac, Morphine, Tramadol, Pethidine, or Methadone are used (The United Republic of Tanzania, 2013). Exchange transfusions and Hydroxyurea therapy are also used as preventive strategies in United State to reduce levels of Hb S and have been helpful in decreasing pain, but these do not completely prevent crises (Matthie, 2013). In Tanzania Hydroxyurea and blood transfusion is used. Other study done in University Hospital of the West Indies (UHWI) in Jamaica also indicates the analgesic used for pain relief treatments, that consisted of non-opioid based (NSAIDs, such as Diclofenac, Ibuprofen, Acetylsalicylic acid (Aspirin) and Acetaminophen (Boyd & Lee, 2014).

A study done in the United States to an African American, showed that, Nonpharmacological interventions are considered to have fewer side-effects and tend to be preferred by some participants. A range of non-pharmacologic therapies are used by individuals living with SCD for a variety of reasons. In a study that explored the use and perceived benefits of non- pharmacological therapies by persons with SCD, 91.6% (n =

208) of patients reported using at least one type of alternative therapy for pain management, and 23% (n = 48) reported benefits related to pain control by one of these approaches (Williams & Tanabe, 2016).

When assessing the safety profile of NSAIDs, it is important to distinguish between prescription and OTC use, especially since many adverse drug reactions (ADRs) are dose related. Prescription users typically use high-dose NSAIDs for prolonged periods and are monitored for ADRs on a regular basis by health care providers. In contrast, although risks are generally lower with occasional use of OTC NSAIDs, users of these products are not routinely monitored by a health care provider and may be at risk for unrecognized ADRs. In addition, although a majority of consumers use OTC NSAIDs as per labelled instructions, a small proportion may exceed recommended doses, likely resulting in the intake of prescription-level doses, the safety profile of which has also been well characterized. This review discusses some of the most clinically relevant DDIs reported with NSAIDs based on major sites of ADRs and classes of medication, with a focus on OTC ibuprofen, the most commonly used OTC NSAID. Fewer studies are available regarding ADRs and DDIs with other OTC NSAIDs, (eg, naproxen, ketoprofen, diclofenac); these data have been included where available. It is likely that the interactions described for ibuprofen apply to these other NSAIDs as well, since they share the same mechanism of action and many of the same pharmacologic properties. Concomitant medications also influence the risk of GI events among NSAID users. In addition to strength of dose, length of treatment also contributes to GI risk. Labelling for OTC NSAIDs currently states, “the risk of heart attack or stroke may increase if you use more than directed or for longer than directed (Moore et al. 2015).

It is advised that, adults living with SCD eating a daily balanced diet is an important part of managing symptoms and their overall health. This life-long condition gives them lower amounts of red blood cells, because the sickle cells die quickly. In only about 10 to 20 day, while healthy red blood cells live for 120 days. The bone marrow cannot keep

up with their body's demand and uses up certain nutrients quickly to make new red blood cells. The low red blood cell levels cause pain, severe infections and chronic anemia (Ndefo et al. 2008).

Jenerette & Murdaugh (2008) commented about Self-Care management that; self-care in the home contributes to individual pain management and thus pain crisis prevention. Self-care management includes, taking medications as prescribed, understanding (know why you are taking) medications, following the diet recommended by your nurse, knowing enough about your disease, drinking plenty of fluids, avoiding stress when possible, dress to stay warm. Self-care actions are important for enhancing health and well-being.

Patient's spirituality perspectives

In the study done in Nigeria, by Ola et al. (2013) to explored the stigmatizing attitudes towards SCD among secondary school students, the students completed questionnaires on attitude to SCD based on a modified Bogardus scale. A significant proportion of the students endorsed negative attitudes towards peers with SCD and showed poor knowledge of the condition. For example, only 41% thought most students would invite a peer with SCD to their birthday party; only 43% thought most students would like to study together with a peer with SCD; 30% believed spiritual and traditional healers can cure SCD; 11% believed that SCD is caused by evil spirits; 15% believed it can be caused by bad food; and 9% thought it is infectious. Regression analysis identified as significant predictors of negative attitudes these two factors: (a) having less personal contact with people affected by SCD, and (b) the belief that people with SCD cannot lead a normal life. Interventions to reduce negative attitudes towards victims of SCD among school children in Nigeria should include more exposure to people with SCD and positive information to challenge nihilistic beliefs about the condition.

Studies of spirituality and religion among African Americans have concluded that African Americans tend to be highly spiritual by nature or culture, and thus they may

benefit fromIn studies that have examined spirituality and spirituality/religiosity among persons with SCD, the authors concluded that spirituality and religiosity contribute to an individual's coping with SCD. Cooper-Effa et al. for example, conducted a cross-sectional study to examine the influence of spirituality on pain experience, and concluded that existential well- being is supportive and can help individuals with SCD cope more effectively with the pain of the disease. Harrison and colleagues, who examined the role that religiosity/spirituality plays in SCD patients' pain experience, concluded that individuals who attended church once or more a week reported less pain. Spirituality and spiritual health are essential ingredients in remaining motivated and acting on the desire to maintain quality health outcomes, thus balancing life with a chronic disease. Strickland and associates, summarizing the themes from their focus group, said that religion serves as a coping insulator. Participants in their study reported the use of religion, going to church, and frequent praying to cope with the pain, the stress of SCD, and the prospect of early death (Adegbola, 2011; Bediako & Beach, 2011)

In Africa, cultural factors are of prime importance to these problems because of beliefs and traditional practices. In Nigeria for instance, beliefs are usually influenced by cultural and religious values, which influence health behavior such as coping strategies For example, among the Igbo communities, SCD is believed to be the result of malevolent 'Ogbanje' (reincarnation) that is repeated cycles of birth, death and reincarnation. Other studies have shown that religious beliefs play a positive part in coping including prayer, faith in God and doctors, and a hopeful approach to health difficulties in Nigeria. Previous research also revealed that compared with people with SCD living in the UK, those in Nigeria commonly used praying and hoping as an affective coping strategy, which seems to be influenced by external factors such as religion, faith in God, superstition and stigma (Anie et al. 2010).

Studies have found that, those with SCD exhibit high levels of spirituality and religiosity, A study in Nigeria showed that religious beliefs including prayer, faith in God and health care personnel, and a hopeful approach to health difficulties play a positive part in coping (Anie et al. 2010). Spiritual well-being was correlated with life-control but not with pain severity. Patients cope with disease in different ways, such as, hypnosis, biofeedback, prayer, family support, drug use and abuse, behavior change, and psychological counseling. Spirituality is another coping method in wellness and illness (Cotton et al. 2009).

Pain management in health facilities

Adewoyin. (2015) made a treatment guidelines for bone pain crisis, at home and hospital, some were; adequate analgesia, hydration, warmth, prophylactic or therapeutic antibiotics if pyrexia after necessary culture samples are taken, as well as oxygenation if hypoxic (SpO2<90%).Explained more that oral hydration must be adequate with at least 60–70mL/kg of water per day in adults. Patients should be encouraged to keep a stock of simple analgesics at home in event of a painful episode. However, mild to moderate pain that does not respond to home-based oral analgesia and hydration within 2 days it then requires hospitalization.

The Numeric Rating Scale (NRS) is often used in pain management in hospitals. The NRS assesses pain intensity using a 0–10 ranking scale with 0 representing "no pain" and 10 "unbearable pain". The study done in Netherlands, by Boonstra et al. (2016) showed that NRS less or equal to five, correspond to mild pains, six to seven correspond to moderate and scores equal or more than eight correspond to severe pains, in terms of pain related interference with functioning.

Approximately 90% of the hospitalizations in patients with Sickle Cell Disease occur due to the most common complication, which are pain crises. Prevention of painful crises requires the patient to have an active role in his or her disease management. Management of this disorder primarily occurs at home and the focus is on these crises as

they most often lead to Emergency Department visits and hospitalizations (Matthie, 2013).

A study done in the United States to an African American, shows that SCD patients need twenty four hour access to medical facility that can provide urgent evaluation and treatment of any acute illness. Pharmacological and nonpharmacological interventions have been found to be effective in managing pain (Williams & Tanabe, 2016).

Summary

There are no standard treatments to cure Sickle Cell Disease. However, there are treatments that help people manage and live with the disease. Sickle Cell Disease generally can be managed by simple ways including: hydration, pain medication, antibiotics for treating infections, healthy diet, folic acid supplementation, Blood Transfusion (BT) and exchange blood transfusion, some other management of specific conditions, and availability of follow up clinic system (Makani et al. 2014)**.**

2.0.3 EXPERIENCES OF ADULTS LIVING WITH SCD

Research done at Chicago revealed that, because of physical disabilities, frequent acute and chronic pain episodes or other complications that lead to hospitalization; SCD patients risk being fired for excessive job absences, and may have difficulty in securing employment (Pereira et al. 2013). Also, patients experience difficulties with community relationship (Wilkie et al. 2010).

According to a the series of reports from the Unites State Food and Drug Administration (FDA), study found that, adults living with SCD showed difficulties in Managing their work and careers, due to unpredictable and lengthy absences in working places. Participants struggled to keep up at work, or not being able to work at all. For example, some described the difficulties in attending “all the doctor’s appointments, and work a full-time job at the same time, another shared devastating news after being “told that could not be a chef anymore” (FDA, 2014).

Anxieties that young people with SCD experience may result in the development of a negative image of themselves. Mood is an important consequence of SCD. People with SCD commonly report low self-esteem and feelings of hopelessness as a result of frequent pain, hospitalizations, and loss of schooling (in children) and employment (in adults). These accounts could indicate depressive symptoms (Anie et al.2010).

Frequent school absence in children with SCA in Brazil has been reported as an important predictor of academic attainment as children who are frequently or consistently absent from school tend to perform poorly (Vilela et al .2012;Ezenwosu et al. 2013). The low educational level of many chronic disease patients does not enable them to obtain or hold well-paid jobs, which might give rise to the employment and financial difficulties they endure. This precarious financial situation becomes one of the main triggers of depressive symptoms in adults with SCD (Vilela et al .2012).

Frequent school absence in children with SCA in Brazil has been reported as an important predictor of academic attainment as children who are frequently or consistently absent from school tend to perform poorly (Vilela et al .2012;Ezenwosu et al. 2013).

Roby agreed with this and was able to document a statistically significant relationship between students' attendance and school achievement. This finding was supported by Day and Chismark in the USA who noted poor school performance in children with SCA following frequent school absences due to sickle cell complications. However, despite the significantly high absence rates reported in SCA children by Ogunfowora et al. no significant correlation was found between school absence and academic under-achievement. They argued that SCA may have a more direct impact on the intellectual abilities of some of the affected children through some undetermined mechanism (Ezenwosu et al .2013).

A study done by Gallo et al., (2010) in Chicago, shows that when participants asked about sharing Sickle Cell Status, they responded as follow; To facilitate partner choice, participants stressed the importance of talking about and sharing their sickle cell status with partners when their relationship got "serious" and/or "intimate," and when they wanted to begin a family but before pregnancy. They emphasized that sharing was a two-way process and that asking partners about their sickle cell status was quite appropriate. As one woman with Sickle Cell Trait (SCT) said, "You need to ask them if they have the trait because they are susceptible to having the trait or the disease." Most participants believed that even though they may have been reticent to share their sickle cell status early in the relationship it avoided surprises that might frighten their partners, such as frequent, unexpected sickle cell pain episodes.

With all the multitude of challenges facing patients living with SCD, many adults can lead successful careers and fulfilling family responsibilities. Such patients' optimism has been clearly described by the late Linda Collins, a respected Chicago sickle-cell activist, University of Illinois at Chicago, patient and the founder of the *Have a Heart for Sickle Cell Foundation* (Wilkie et al. 2010).

CHAPTER THREE

3.0 METHODOLOGY

3.1 DESIGN

In this study, the design was phenomenological study that used descriptive qualitative method.

3.2 SITE

The study was conducted at Muhimbili National Hospital, in Dar-es-Salaam, Tanzania. The study was conducted among SCD adults attending General Hematology Clinics (which is under the Department of Hematology and Blood Transfusion), who were enrolled in SCD cohort. This is because the researcher was making a follow up of SCD adults patients who were enrolled in Muhimbili National Hospital Sickle Cell Disease Cohort.

This study emerged from a large SCD cohort program, probably the largest documented single-Centre cohort in the world. The Welcome Trust funded the SCD research at Muhimbili National Hospital (MNH) and Muhimbili University of Health and Allied Sciences (MUHAS) in Dar-es-Salaam since 2004.The new enrolment started in 2004, since then a cohort of over 6000 individuals with SCD were recruited. The study ended in 2016.Although enrolments ended, some patients are still being attended at Muhimbili National Hospital while others are being attended at different district hospitals.

Muhimbili National Hospital is a tertiary, referral and teaching hospital, it serves the whole country. Dar-es-Salaam where Muhimbili National Hospital is located is Tanzania's largest city, which is divided into four districts namely Ilala, Kinondoni, Temeke and Kigamboni.

3.3 STUDY POPULATION

The group of people of this study were are adults living with Sickle Cell Disease, living in Dar-es -Salaam Region, aged 18 years and above.

3.4 SAMPLE SIZE

The number of SCD adults enrolled in the study were fifteen (15).This number of participants was determined by data saturation as a guiding principle in a qualitative study sampling. That is, sampling was conducted to the point at which no new information was obtained (Polit,&Beck, 2004;Polit,&Beck, 2012).

3.5 SAMPLING PROCEDURE

Purposive/judgmental sampling procedure was used to select participants attending general hematology clinic living in Dar es Salaam. Purposive sampling is a non-probability sampling technique, where researcher's knowledge about the population can be used to pick sample members. The researcher may decide purposely to select participants who are judged to be typical of the population or particularly knowledgeable or experts about the issue of study (Polit &Beck, 2004;Polit&Beck, 2012). The researcher requested the nurse running the clinic to help identifying participants who met inclusion criteria and recruited them purposefully. Fifteen participants were interviewed until data were saturated.

3.6 CRITERIA FOR SELECTING STUDY PARTICIPANTS

3.6.1 INCLUSION CRITERIA

Adults aged 18 years and above confirmed to have SCD screened at Muhimbili National Hospital SCD Cohort who consented to be enrolled in the study.

3.6.2 EXCLUSION CRITERIA

Adults with SCD who were not enrolled in the cohort.

3.7 DATA COLLECTION

Data were collected at Muhimbili National Hospital from March 2017 to May 2017.Fifteenin-depth interviews with adults living with SCD aged eighteen years and above were conducted to collect primary data. The interviews were guided by guiding questions with open- ended questions. The guiding questions (Appendix A) were constructed in English and translated to Swahili (Appendix B).The guiding questions were pre-tested, to test the drafted questions. The purpose was to find out if the

questions would answer the research questions and to ensure all relevant issues were included. (See Appendix B).

All interviews were conducted in a convenient room to avoid interruption during interview sessions. All interviews were conducted in Swahili language to capture in depth information from participants as Swahili is well understood, and is more comfortable to participants than English. The interviewee's function was to let participants talk freely on all the topics on the list, and to tell stories in their own words. This technique ensured that the researcher obtained all the information required, and made respondents offer information required voluntarily in their own words, gave as much information as they wished, and offered illustrations and explanations. The researcher used tape recorder with permission from study participants to increase the accuracy/reliability of data collection and to make sure all information was captured. Field notes also were taken. Interviews were conducted until saturation was reached(Polit, & Beck, 2004;Polit, & Beck, 2012).

3.8 DATA ANALYSIS

Data analysis was guided by Graneheim and Lundman concept. Researcher analyzed the interviews using qualitative content analysis. Audio recorded interview were first transcribed verbatim. Qualitative content analysis offers development of categories from the text data induction, the inductive derivation of categories is important in capturing the experiences from the participants' .The full transcript and the field notes were first read and re-read by researcher in order to become familiar with the data and the context. Condensed meaning unit were then formed through data reduction. The condensed meaning unit was red and re-red in order to extract the codes. Initial codes were discussed with supervisors and agreed, and then revised and final codes developed. Similar codes were grouped together and through comparison, they were abstracted into categories. Using comparison and the checking and rechecking of similarities and differences between the categories, the categories were sorted to form themes that reflected the manifest content of the interviews.The emerged themes were interpreted to answer research questions (Graneheim & Lundman, 2004).Then, the used quotes were

translated from Swahili to English.Thorough double-check of the translated quotes against the original was done to ensure quality of the translation. Table 1 below shows the examples of data analysis process.

Table 1: The examples of data analysis process.

MEANING UNIT	CONDENSED MEANING UNIT	CODES	CATEGORIES	THEMES
-Yes, my husband knew, but after the marriage the problems started again, I was in Muhimbili on daily basis, sometimes admitted, sometimes this, till when I had my first child. After the delivery, the frequency of sickness declined, but he knew this would happen again and so I was divorced and went back home.	-My husband knew about my SCD status before marriage. The problems were severe prior to my first delivery and then declined. However, I was divorced because he knew this will happen again.	-Illness and frequent admission affects family life.	Difficulty in getting life partner and establish family.	Social and psychological implication of living with SCD.
-I was surprised, heh! Still frequent sickness continued! Just like that, I got married. When a man gets married, He would like to have a baby. So I was pregnant but I had miscarriage. Never got pregnant again. The husband got tired of waiting for the baby and I was divorced. I went back home and started life all alone.	-I got married and conceived; unfortunately I had miscarriage and never conceived again. My husband got tired of waiting for a baby and I was divorced.	-Divorced due to no children.		
-No, I never wanted to stay single, I do get fiancée but when I tell them I have Sickle Cell Disease they abandon me. Three so far have abandoned me that's why I am still single. "Nurse, is there a problem if I get married to a fellow	-I never wanted to stay single, only that when fiancées know about my SCD status they abandon me. Are there any problems if	-Still single after being abandoned by three fiancées.		

Sickle Cell Disease patient?" "Which is the better way of telling them about the disease which will not let them quit?	SCD patients get married?			
-Oooh! To be honest, When you tell a fiancée that you have this condition (SCD), most won't be ready to be with you, they will leave and you will not see them again, even when you call, they won't pick the call, they pretend to be busy .	-Most men are afraid to marry somebody with SCD.	-Sickle cell disease hinders marriage.		
-Ah! When I was still sick, I was employed by a certain woman in her salon but soon I lost the job because of the illness. -I was employed by a woman selling hardware, I stopped working when I fell sick, after my recovery my employer told me she will call me back but never called back, I decided to call and told her that I have recovered but she said; just relax and watch over yourself, I will call you, but never called back again till now. -Aaah! I was told to stop working by my boss because of these ulcers.	-Employers fear having employee with Chronic illnesses.	-Lost job because of chronic illness and ulcers. Frequent illness makes one fail to work to expectations of employer.	Failing to maintain employment.	

3.9 TRUSTWORTHNESS OF THE STUDY

Trustworthiness is the degree of confidence qualitative researchers have in their data.Trustworthness is assessed using the credibility, transferability, confirmability, and dependability (Polit, D.F & Beck, 2012). Credibility is the criterion for evaluating integrity and quality in qualitative studies, referring to confidence in the truth of data and interpret; analogous to internal validity in quantitative research. (Elo et al. 2014;Polit, D.F & Beck, 2004). Throughout the research process, supervisor and co-supervisor worked closely with researcher, discussed every stage together and reach consensus, in guiding the research process.Transferability is the extent to which findings can be transferred to other setting or groups or how the qualitative researcher demonstrates that the research study's findings can be transferred to other settings or groups. "How can the reader evaluate the transferability of the results?" (Elo et al. 2014;Polit, D.F & Beck, 2012;Anney, 2014).The emerging of this study from a large SCD cohort program, can enhance transferability. Confirmability is the degree of neutrality in the research study's findings. In other words, this means that the findings are based on participants' responses and not the researcher's biases, motivations, or perspectives (Elo et al. 2014;Polit, D.F & Beck, 2012).Quotes from the participants are provided to ensure confirmability of the study. Dependability refers to the stability of data over time and under different conditions. The extent that the study could be repeated by other researchers and that the findings would be consistent. The main question is then, "Would the findings of an inquiry be repeated if it were replicated with the same or similar participants in the same context (Polit, D.F & Beck, 2012;Anney, 2014).I think for now stability of data could be there, but after few years, may be five years to come will be not present, because there is a lot of raising awareness, so I expect to see changes.

3.10 ETHICAL CLEARANCE

Ethical clearance **(See Appendix C)** was obtained from MUHAS Directorate of Research and Publications. The permission to conduct the study at MNH was requested from Muhimbili National Hospital **(See Appendix** E**).**

3.11 ETHICAL CONSIDERATIONS

Before recruiting the participants, researcher explained everything on the consent form **(See Appendix F).** The participants were informed about the aim of the study and procedures. Participants were informed that participation was voluntary and that the participants could withdraw from the study at any time. All information which would be obtained from participants would remain confidential. No names would be used. The participants were given an opportunity to ask any preliminary questions before the actual interview. Willing participants signed the written consent form. The informed written consent was constructed in English then translated into Swahili. Permission was obtained from participants to record the interviews.

3.12 SUBMISSION AND DISSEMINATION

The findings of this study generated important information, which will be disseminated to School of Nursing, Muhimbili University of Health and Allied Sciences (MUHAS), Ministry of Health Community and Development, Gender, Elderly and Children, Academic forum MUHAS Scientific Conference, Nursing Conferences, Sickle-cell group patients, and the study will be published in an academic journal.

CHAPTER FOUR

4.0 RESULTS

This chapter presents findings from the data analyzed in this study. The first part presents demographic characteristics of the study participants and then followed by the findings from analyzed transcripts of participants describing their experience of living with SCD

4.1 Participant's demographic characteristics

This study included fifteen study participants. These participants were adults living with Sickle Cell Disease. Their ages ranged from 18 to 45 years. Nine were females and six were males. Thirteen participants were single and two were divorced. Their levels of education were; seven had primary school education, four secondary school education and four had college education .Their employment status were as follows; eight were unemployed, five were self-employed and two were employed in private sectors.

4.2 Participants' experiences of living with SCD

This part presents findings from analyzed transcripts. During analysis of the data, eight categories emerged that described the experiences of participants on living with SCD. The categories were supported by number of codes that describe the manifest content of participants experiences on triggering, aggravating and alleviating factors for pain; Living with disease and dealing with arising pain and social and psychological implications of living with SCD. The categories and related codes are presented in Table two below.

Table two: Categories and themes emerging from the study

Codes describing manifest content	Categories describing latent content	Themes
-Energy demanding work -Excessive exercises -Having wounds -Getting cold due to wet -Stress -Pain can start by itself. -Dehydration	Pain Triggering or aggravating factors	Triggering, aggravating and alleviating factors for pain.
-Drinking plenty of water -Pain killer such as Diclofenac and Ibuprofen -Resting (sitting or sleeping) -Distraction-concentrating with normal activities. -Pain relief gives hope -Praying daily	Pain relief or alleviating factors	
-Prayers. -Faith in God -God gives strength and hope -God heal the disease	Prayers and faith in God as a coping strategy.	Living with disease and dealing arising pain
-Drinking plenty of water -Oral pain killers -Eating healthy diet -Sough for tradition healers	Home and self-care remedies for the disease.	
-Relief is sought at the hospital -Tramadol injection and IVFs in hospital are preferred for treating pain. -Need for health checkup.	Need for hospital care for pain management.	
-Frequent illnesses -Frequent admission	Poor school attendance and academic performance	Social and psychological implication of living with SCD.
-Illness and frequent admission affects family life -Divorced due to no children	Difficulty in getting life partner and establishing family	

-Still single after being abandoned by three fiancée -Sickle cell disease hinders marriage		
-Frequent illness makes one fail to work to expectations of employer -Lost job because of chronic illness -Stigma	Failing to maintain employment	

4.2.1 Experiences on triggering, aggravating and alleviating factors for pain.

This theme described two related categories that SCD adults experienced as; "factors perceived to trigger or aggravate pains" and "factors perceived to alleviate pains.

Perceived pain triggering or aggravating factors

`In this study, participants shared their experiences on what they perceive as factors that trigger or aggravate pains. Some participants reported that when they drink little amount of water and hence gets dehydrated, it triggers or aggravates pain. Others mentioned that, when it rains, they get wet, catch cold and then starts to feel pains immediately. Some of them reported that, when involved in energy demanding physical activities such as running (which requires much effort) they experience pain. Some reported excessive exercises and wound/leg ulcer as factors that can triggers pain as attested by one of the participant below.

"May be if I do excessive *exercises, but if I just do normal exercises there are no problem, I don't feel pain. Another thing is that I may not eat due to financial problems, and then I fail to drink water. Although I know that water is a medicine, I can't drink water without having eaten and even if I drink it I can't finish even one liter. So I get pain". (P 15)*

Perceived pain alleviating factors

SCD adults who had participated in interview reported the different modalities of alleviating pain. Some of participants stated that when sleeping or sitting without doing anything (resting) the pain disappear or get reduced. Other participants stated that, God granted relief from pain while others reported that praying relieves pain. Some reported that drinking plenty of water or fluids can alleviate or prevent pains crisis to occur. Adults' living with Sickle Cell Disease also expresses that wearing lots of clothes to keep themselves warm helps in alleviating pains. Others prefer massage or hot water bottle application to alleviate pain. However, some participants tried to distract pains by continuing with their normal activities. Furthermore they reported self-treatment by using analgesics (tablets) as a way of alleviating pains, as stated below.

"I take Diclofenac and rest whenever I feel pain". Another method I use is for instance if I start feeling the pain, or I feel unwell, I don't think too much that about being sick, I just try to continue with normal activities, and then feel the pain reduces". (P 8)

"Faith helps, when I feel pain, I was taught to pray, I hold the paining area and utter the words we were taught and i get a relief". (P10)

"I think to some extent this gives a relief, like, when you are sick you utter: Oh! The Almighty God, help me, praying helps me to some extent, even the Almighty God hears". (P 9)

"I drink a lot of water every day! I finish four liters. I always measure the water in bottles of one liter volume that we buy in the shop. So I always drink four of them. I do boil tap water, cool it and put it in bottles. I only buy water few times when I'm far from home. I see that it really helps me not to feel pain frequently and if I feel pain it's not very severe". (P 4)

4.2.2 Experience on living with the disease and dealing with arising pain

This section reports participants' experiences in living with SCD and how they dealt with pain. The section carries three related categories; prayers and faith in God as a coping strategy, home and self-care remedies for the disease and need for hospital care for pain management.

Prayers and faith in God as a coping strategy

Among the ways adults living with SCD reported to use for managing their health and pain was prayers and faith. Some participants expresses that they believe that God grants relief in pain. They mentioned that they pray every day for relief from SCD, ulcers and pain. Others had the opinion that prayers help them cope with the disease and reduces painful crisis. Some who initially had given-up, and lost hope, later felt that prayers had strengthened them. Furthermore they mentioned that, they have a hope that, there will come a time when God will bless them and they will forget all bad experiences. Participants elaborated that, they believe that God heals the disease as attested by two participants below**.**

"*Religion has a big role to play. I think I am in this stage because of religious belief. When you attend the religious congregation you ask God for His help, and life goes on. When you look at some other Sickle Cell Disease patients you feel pity for them though I am among them but when I look at others you say". Ehh, is it!" (P 11)*

"We pray every day. I daily pray for a relief from SCD and leg ulcers because I know even ulcers are a result of SCD.I daily pray, I believe, I believe in God and He will heal me".(P 1)

Home and self-care remedies for the disease

Apart from believing in God and use of other spiritual and traditional medicines, participants also mentioned some measures which they usually use to take care of their disease while at home. Some participants mentioned that, when they become ill and feel pain, they drink plenty of water to get relief from pain. Though participants are normally advised to drink about three liters per day, some participants reported to have been drinking more or less than what is recommended. However, other participants reported to get difficulty to achieve the required amount of water per day and mentioned that, achieving that goal need some extra effort as mentioned by one participant below . .

"I drink that amount because I don't like water. I try my best to drink but I cannot finish two liters in a day. I don't like water like others do, so, drinking that amount needs some effort". (P 6)

Table 3. Number of litres of drinking water consumed daily by participants

Participants ID numbers	15	6	7	12	8	2	5	10	1	13	9	3	11	4	14
Litres of water taken per day	1	1	1	2	3	3	2	1.5	1.5	2	1.5	3	2	4	4
Severity of the most recent pain experience.On a scale of 1-10	10	10	10	10	10	10	9	9	8	6	5	5	5	4	4
Pain experienced in the last six months	Every day	3x/week	3x/week	5	3	2	6	5	3x/week	6	5	0	4	2	0

The table above describes number of litres consumed daily by the 15 participants, by intensity and frequencies of pain and the relationship with severity of pain and number of pain experience in the last six months. (The pain severity is in the scale of 1-10)

Participants also reported of eating different types of foods and that the foods eaten seem to be balanced. Participants reported to eat rice, ugali, or potatoes; together with vegetable, fish/sardine, liver, beans, red meat and milk. Some participants revealed that they are not used to dona (Ugali made with unrefined corn flour), instead they ate sembe (Ugali made with highly refined corn meal).

Furthermore, some participants reported to use analgesic medications such as Acetaminophen which are not prescribed, as self-care and most were non opioids. Participants who use analgesics medication, mentioned using pain killers such as Non-Steroids Anti Inflammatory Drugs (NSAIDS), like Diclofenac, Ibuprofen, Meloxicam, Diclopar (combination of Diclofenac 50mg and Acetaminophen 500mg), they also use Acetaminophen and Folic Acid. However few participants said that, they sometimes forget taking Folic Acid. More than half of the participants used Diclofenac for treatment at home. However, some combined two or more drugs; for example one participant reported to take Ibuprofen and Diclofenac simultaneously. One participant attested as follows;

"When I start feeling pain, with my experience on sickle cell, I know the way the pain starts, I take some drugs. The drugs I take are two tablets of Diclofenac and two or three tablets of Ibuprofen if the pain is intense. Some other days I take two tablets of Diclofenac or two tablets of Meloxicam. Sometimes the pain doesn't respond to the drugs, even when you take ten tablets once. I used the experience of buying the drugs from my late mother, who used to buy for me before she died." (P 1)

However some of them reported to have been taken by family members to tradition healers, as family members believed that other symptoms of the disease are due to witchcraft.

"Religion has helped me accept my situation. But in reality, at the beginning I did not accept "What is this that has happened to me?" "I didn't understand. I didn't

understand at all; my mother and other relatives started taking me to traditional healers. I didn't know what it was, only to know that they thought of witchcraft. 'Aah!' later I rejected all of them". (P 15)

Need for hospital care for pain management

Participant stated that, although they use self-care management and treatment such as analgesics, but when the pain is severe or persistent they go to hospital. Almost all participants in this study reported going to hospital when the pain persists or whenever it is severe. Some mentioned when the pain persisted for three days, in spite of using other home remedies they seek hospital treatment. Participants reported to go for health checkup one to four times a year, when they are not feeling sick. However few of them never go for a checkup until they fall sick. When asked about the treatment used when attending hospitals, most participants mentioned that they were treated by injectable Diclofenac or Tramadol and IV fluids. Two stated as below.

"*When I take tablets and I do not get relief, I rush to the nearby hospital. I introduce myself and because they are familiar with me I get the right treatment. I get injections, drips (IVF) and after a while I get a relief and go back home. The injection that they give me is Diclofenac". (P 1)*

"When at home and very sick in severe pain I will be taken to the hospital. I will be given Tramadol injection and drips (IVF), or when in moderate pain I will only take oral pain killers". (P 6)

4.2.3 Social and psychological implication of living with SCD

This category describes the social and psychological experiences of adults living with SCD in all aspects of life. The three categories are; poor school attendance and academic performance, difficulty in getting life partner and establishing family, failing to work and become independent economically.

Poor school attendance and academic performance

When participants were asked about their experiences during school time, primary and secondary school, almost all participants…reported to have missed classes in schools. Some of them mentioned that, they felt sick frequently. However others reported that, the decline of sickness occurred in secondary schools. There were also those who declared that they missed the national examinations, and this resulted in repeating an academic year. Unfortunately few dropped out of school completely due to sickness.

"In reality, when I was in primary school I frequently fell sick. I missed some classes frequently in a month. However, I completed my studies". (P 3)

"I started secondary school. There were times when I was very sick and even during form four national examinations I was sick. I could not sit for the examinations and hence I had to do the examinations in another year". (P 1)

Some dropped out of school due to sickness.

"I studied until form two because before sitting for the form two examination I was sick and admitted for two weeks and missed the examinations. So, after I was discharged, I lost hope and I quit school until to date". (P 6)

Difficulty in getting life partner and establishing family

Marriage to many adults living with SCD has become a challenge. Some said that when they disclose the disease to fiancé/fiancée most won't be ready to marry them. Some participants stated that; during courtship, the fiancés were informed about the Sickle Cell Disease, and asked if they would accept living with Sickle Cell Disease patients. They replied that, they would, so long as the disease is not infectious. But even though the husbands were initially aware of the disease and agreed to get married but later lost patience. Also the parents' in-law convinced their sons to divorce their wives. Other participants expresses that, due to frequent illnesses and crisis, or miscarriages, even parents' in-law become intolerant and convince their sons to divorce. Again some reported that, when a man gets married, would like to have kids. Furthermore, one participant was eager to have information instantly if there is a problem for sickle cell

patients getting married. Females who were divorced due to frequent sickness and miscarriages stated as followed.

"Yes, my husband knew, but after the marriage the problems started again, I was in Muhimbili on daily basis, sometimes admitted, sometimes this, till when I had my first child. After the delivery, the frequency of sickness declined, but he knew this would happen again and so I was divorced and went back home". (P 7)

"I told him about the disease and asked him if he is ready to live with me, then no problem. I accepted the marriage. After twelve years of marriage, relatives, especially the father and mother in-law started telling him; for how long will you live with her with the infertility? Sickle Cell Disease patients are not fertile, they were saying these in secrecy but later revealed to me. He initially neglected them, was patient and was telling them; this is my wife that I chose, later he lost patience and was overwhelmed by his parents and divorced me". (P 8)

One participant wanted to know if there is any problem getting married to a fellow Sickle Cell Disease patient.

"No, I never wanted to stay single, I do get fiancée but when I tell them I have Sickle Cell Disease they abandon me. Three so far have abandoned me that is why I am still single. "Nurse, is there any problem if I get married to a fellow Sickle Cell Disease patient?" "Which is the better way of telling them about the disease which will not let them quit?" (P 3)

Failing to work and become independent economically

When participants explain about employment, some mentioned that they lost their jobs because of SCD illnesses. Few reported to be stopped working by their employers. One reported that could not be employed because he had only a primary education. Another one reported stigma as also a problem, when SCD patient disclose the disease before they are employed, they risk being rejected and also once employed, disclosure of the disease risks being fired.

"In my working place if I tell them I have sickle cell disease it will be a problem, because it will be again stigmatization. This may result in not being accepted for a job or stop your employment if already employed. There are those who will understand that I am just like anybody and there are those who will say, "This person will not manage doing anything," He should just wait for the death". (P 14)

"Aaah! I was told to stop working by my boss because of these ulcers". (P 15)

"I was employed by a woman selling hardware, I stopped working when I fell sick, after my recovery my employer told me she will call me back but never called back, I decided to call and told her that I have recovered but she said; just relax and watch over yourself, I will call you, but never called back again till now". ***(****P 6)*

Summary

In this study, participants shared their experiences on what they perceived as factors that triggers and or aggravates pain as; cold, dehydration, excessive exercises, energy demanding physical activities and leg ulcers. Factors which were mentioned as alleviating pain were; drinking plenty of water, simple analgesics, resting, covering the body with clothing, distraction and praying. Ways of dealing with pain practiced were home remedy and hospital management. In social and psychological implications of living with SCD, participants mentioned having difficulties in school attendances and academic performance as well as difficulties in getting life partners and establishing families and failing to work hence become dependent economically.

CHAPTER FIVE

5.0 DISCUSSION

This part present discussion of research findings that is based on the experiences of living with sickle cell disease among adults. Individuals living with SCD can get different experiences despite of having similar disease.

Factors triggering and/or aggravating pain

***Pain triggering or aggravating factors*;**

This study revealed that, triggering or an aggravating factor for pain which has been mentioned by most participants was cold. Similarly the reviewing of articles done by Tewari et al.(2015) showed that, Extreme cold weather have been found to precipitate pains. Patients are routinely advised to avoid getting cold in all parts of the world.Tewari explained more that Edington reported that; attacks of joint pain were linked to cold weather in ten of thirty three patients in the Gold Coast (Ghana), and speculated that cold coincided with the rainy season and that this was the main cause of increased pain. However, Tewari mentioned that, in Edington study increased malarial infections, also was mentioned to aggravate pain. Other study mentioned by Tewari is a study in New York conducted in the 1970s which showed increased admissions to hospital with sickle pain in cold winter months even when episodes with overt infection were excluded, and speculated that this may be due to increased blood viscosity and cold diuresis.

According to a series of reports from the United State Food and Drug Administration (FDA), few participants described similar factors that trigger crisis as cold weather and stress.Adult participants re-stated their sensitivity or intolerance to cold weather. Participants described a pain crisis that lasted for two days after being soaked with cold water, and explained that “when the cold gets into your bones, it's just like serious pain ‘’ (FDA,2014).Stress of any kind, traumatic, physical, psychologic, physiologic, etc., may trigger the onset of a painful episode. Sickle pain may involve any part of the body,

and the severity, location, and duration of the pain vary among patients (Ballas,S.K, 2007). Nurses should help adults living with SCD to minimize stress by counseling.

Other participants mentioned hard physical activities (which required much effort) for example running, excessive exercises and dehydration as triggering or aggravating factors. One participant mentioned that when stressed gets pain.A study done in Nigeria by Adewoyin. (2015) also reported similar findings. In this study it is found that conditions which were known could trigger or precipitate pain were exposure to cold, dehydration, physical exertion, and emotional stress. However, Adewoyin study added other factors which are not mentioned in this study, such as, tobacco smoke, alcohol use, and intercurrent infections such as malaria, high altitude, hypoxic conditions, pregnancy, hot weather, or onset of menses.

Additionally this study supported by study done by Connes et al. (2011) ,found that, exercise and physical activity may induce metabolic changes that can, if too large, potentially precipitate vaso-occluisve crisis. An added consideration during exercise is the dehydration. For example, intense exercise, such as that which involves repeated jumping, may increase the risks for muscle and joint injuries. Contact sports, including American football, hockey, and similar events, should be avoided, particularly by patients with splenomegaly, given the high risk of splenic rupture.

Clinicians should advise patients to start their exercise gradually, to avoid intense exercise and to stop exercising at the first sign of fatigue. SCD patients should not practice during illness. Prolonged exercise for more than 20 min without resting should be avoided: a resting period every 20 min of exercise is recommended to avoid dehydration and lactic acid accumulation. In addition, to prevent dehydration, SCD patients should drink water during and after exercising. However, each patient should be able to independently manage his or her physical efforts (Connes et al. 2011).

In addition the US Cooperative Study of Sickle Cell Disease (CSSCD) commented that Initial assessment of pain should include estimate of pain severity, assessing

precipitating factors such as severe dehydration, looking for evidence of infection and other, factors that would necessitate referral to hospital. (Brousse et al. 2017).

Leg ulcers are common complications in adults with SCD (Naoum.F.A,2010).It occur in areas with less subcutaneous fat, thin skin, and with decreased blood flow The commonest sites that ulcer occurs are the medial and lateral malleoli (ankles).Leg ulcers may be classified as acute or chronic according to their duration, however, there is no consensus as to a specific length of time to define chronicity. An acute ulcer usually should heal in less than a month. Six months duration seems to define the chronic ulcers.However,It is not uncommon for ulcers to last many years, often closing and re-opening repeatedly times (Minniti et al. 2010).In this study wounds (Leg ulcers) have been also reported as factor triggering or aggravating pain. This study concurs with a study done by Naoum which showed that Leg ulcers sometimes can be deep and large, provoking or trigger unbearable pain and considerably disabling (Naoum.F.A,2010).

The interactions between SCD and environmental factors Leading to a better understanding of the natural history of SCD and improved care of patients (Tewari et al.2015).It is important for the nurses to know factors triggering or aggravating pain to help educating patients. Adults living with SCD are also to be aware of these factors so that they can help prevent or reduce pain frequencies.

Pain relief or alleviating factors

The study also found a number of factors that can be used to alleviate or relieve pain and that these factors can be non pharmacological or pharmacological interventions. In this study found nonpharmacological interventions such as taking plenty of water, and covering with a lot of clothes. Similarly, the US Cooperative Study of Sickle Cell Disease (CSSCD) mentioned general advice used to alleviate pain, which includes keeping warm; drinking plenty; and taking simple analgesia, such as Acetaminophen or Ibuprofen (Brousse et al. 2017).

Other remedy that found to alleviate pain in this study is massage, and hot water bottle application. A series of reports from the Unites State Food and Drug Administration (FDA), found many alternative therapies, used to relief pain, among those similar therapies was massage, and heat pack therapy. Other therapy which are not mentioned in this study include; cupping, acupuncture, Transcutaneous electric Nerves Stimulation (TENS), aromatherapy, and topical oils to treat line incisions (FDA, 2014).

Resting and distraction by continuing with activities also reported as interventions that can be used by patient to relieve themselves from pain. Ballas,S.K.(2007) found distraction as a way of relieving pain. Other ways found to relieve pain include relaxation, massage use of heat or ice packs, music, vibration, prayer, therapeutic exercises, menthol cream rub, self-hypnosis, acupressure, acupuncture, transcutaneous electrical nerve stimulation (TENS), and biofeedback. Furthermore the study commented that for rational and effective management of sickle cell pain is a function of thorough assessment and individualization of therapy coupled with the use of non pharmacologic and pharmacologic approaches.

Non pharmacological interventions are considered to have fewer side-effects and tend to be preferred by some participants in North Carolina of USA (Williams & Tanabe, 2016).

Some participants knew factors that triggers, aggravates and alleviates pain, but yet made wrong decisions. For example, they know that drinking plenty of water alleviates pain but still drinks little amount of water. So, more health education is needed. Two third of participants revealed that they do not drink enough water, they drink less than 3 liters a day. Taking plenty of water, which advised to be more than three liters daily (Adewoyin,2015) including other fluids (such as water, juice, tea, and soup) is one way of preventing/reducing crisis and managing pain . Without taking fluids, crisis will recur.

The study found the use of medications particularly pain killers as a pharmacological interventions used to alleviate pain. The study found the most used pain killers is Diclofenac and other non steroids medications. This is similarly to study done in

Jamaica by Boyd & Lee. (2014) which indicate the use of non-steroid medications, such as Diclofenac, Ibuprofen, Acetylsalicylic acid (Aspirin) and Acetaminophen as a commonly used medication for pain relief among patient living with SCD.

Living with the disease and dealing with arising pain

The role of prayers and faith in God as a coping strategy

The study found the role of prayers and belief in supernatural power as resourceful mechanism to strengthen people with SCD to cope better with the diseases. Previous research findings regarding prayers and faith revealed that; comparing people with SCD living in the UK and those in Nigeria, those living in Nigeria commonly used praying and hoping as an affective coping strategy, which seems to be influenced by external factors such as religion and faith in God (Anie et al. 2010).This current study agrees with the findings of the study in United Kingdom, it revealed that, prayers and faith are among ways used by adults for manage their health and pains. Prayers help some cope with the disease. Some, who had initially dismissed prayers, found that prayers gave them strength. Despite of all difficulties that make them lose hope, they reported that they gained hope again.

Similarly, other studies found that, those with SCD exhibit high levels of , for example, a study in Nigeria showed that religious beliefs including prayers, faith in God and health care personnel, and a hopeful approach to health difficulties play a positive part in coping (Anie et al. 2010). However there is no study that reported about God's power of healing the disease, as some participants reported.

Other similar studies of spirituality and religion among African Americans have concluded that African Americans tend to be highly spiritual by nature or culture, and thus they may benefit from.In studies that have examined spirituality and spirituality/religiosity among persons with SCD, the authors concluded that spirituality and religiosity contribute to an individual's coping with SCD. Cooper-Effa et al. for example, conducted a cross-sectional study to examine the influence of spirituality on

pain experience, and concluded that existential well- being is supportive and can help individuals with SCD cope more effectively with the pain of the disease. Harrison and colleagues, who examined the role that religiosity/spirituality plays in SCD patients' pain experience, concluded that individuals who attended church once or more a week reported less pain. Spirituality and spiritual health are essential ingredients in remaining motivated and acting on the desire to maintain quality health outcomes, thus balancing life with a chronic disease. Strickland, summarizing the themes from their focus group, said that religion serves as a coping strategy. Participants in their study reported the use of religion, going to church, and frequent praying to cope with the pain, the stress of SCD (Adegbola, 2011; Bediako & Beach, 2011;Cotton et al. 2009)**.**

Home and self-care remedies for the disease

Self-care management refers to all actions and coping strategies carried out at home and needed to take part in therapeutic behaviors, targeted at preventing health complications, improving psychosocial conditions, and maintaining good health (Jenerette & Murdaugh, 2008).

Management of SCD primarily occurs at home and the focus is on the crises as they most often lead to Emergency Department visits and hospitalizations. Pharmacological and non-pharmacological interventions have been found to be effective in managing pain (Williams & Tanabe, 2016).The findings of this study revealed that, few adults living with SCD do practice self-care at home. The ideal self-care action are medication, taking plenty of fluid, checkup, diet, stress avoidance, staying warm, resting, distracting pain by other activities, and beliefs in God. However other studies, example study done in United State to African Americans, by Williams & Tanabe (2016),showed different modalities which are non-pharmacological therapies, used in other places, which have not been reported in this current study; which include cognitive behavioral therapy, biofeedback, prayer, relaxation techniques, acupuncture, hypnosis, herbal therapies, and megavitamins.

Prevention of painful crises requires the patient to have an active role in his or her disease management (Matthie,2013). The findings of this study revealed that, almost two-thirds of the participants drink less than three liters of water a day. The study done in Nigeria by Adewoyin. (2015) suggested that, Oral hydration must be adequate with at least 60–70 mL/kg of water per day in adults. The study explained that, dehydrated erythrocytes have an increased tendency to polymerize and sickle and results in pain crisis. Fluids especially water can be seen as an easily implemented management tool, however one participant said it needs effort to drink more than three liters per day. Participants reported measuring drinking water using a one liter water bottle obtained from the shops. Participant reported to use a cup of tea, others a glass of juice which researcher regards as fluids.

It is advised that, adults living with SCD eating a daily balanced diet is an important part of managing symptoms and their overall health. This life-long condition gives them lower amounts of red blood cells, because the sickle cells die quickly. In only about 10 to 20 day, while healthy red blood cells live for 120 days. The bone marrow cannot keep up with their body's demand and uses up certain nutrients quickly to make new red blood cells. The low red blood cell levels cause pain, severe infections and chronic anemia (Ndefo et al. 2008). The same practice mentioned in a series of reports from the Unites State Food and Drug Administration (FDA, 2014).

The findings of this study are also supported by the guidelines for management of Sickle Cell Disease in Tanzania which insists on patient to taking recommended diet, plenty of water, folic acid supplementation, (Makani et al. 2014).

Analgesic therapy, both opioids and non-opioids are commonly used to treat acute pain in the home setting. In this study, the findings showed that participants' base on analgesic drugs, together with other modalities of pain management in managing pain. Analgesics in the form of tablets used at home frequently were reported to be Diclofenac, Diclopar (combination of Diclofenac 50mg and Acetaminophen 500mg),

Meloxicam, Ibuprofen, and Acetaminophen. Most participants used the drugs as advised. However some mix two drugs at a time. Mixing Acetaminophen and Ibuprofen in adults is allowed for reducing pain and fever, but there are those who mix Diclofenac and Ibuprofen which is not recommended because both are Non Steroid Anti-inflammatory Drugs (NSAIDS). So in mixing these two drugs, the anticipated side effects may be multiplied (Moore et al. 2015). This findings are similarly to Previous studies done in Tanzania showed that; Non-opioids used in Tanzania includes Acetaminophen, Acetylsalicylic acid, Ibuprofen, and Diclofenac (Makani et al. 2014; The United Republic of Tanzania, 2013).However, contrary of mixing two drugs at a time is a lack of knowledge to the users.

Furthermore in this study some adults taken by family members to tradition healers, as family members believed that some disease symptoms such as priapism and leg ulcers were due to superstition and they sought healing in among traditional healers. However, literatures from other study to support this are limited. As the family members believes, is similar in the study done in Nigeria, by Ola et al. (2013) secondary school students believed that spiritual and traditional healers can cure SCD.

Education is important to adults living with SCD to know the symptoms related to SCD, as will make them to seek hospital management in steady of traditional healers. Participants involved in the study, reported they do not go to traditional healers after knowing that their problems were due to SCD.

It has been observed that all participants did not have prescriptions from the doctors; they used experience from previous prescriptions to buy drugs. However, Diclofenac and Ibuprofen are an Over-The Counter drugs (OTC) but adults living with sickle cell should be carefully on using them, since many adverse drug reactions (ADRs) are dose and periods related. Occasionally home users of these products, OTC NSAIDs may be at risk for unrecognized ADRs as are not routinely monitored by a health care provider In addition, although a majority of consumers use OTC NSAIDs as per labeled instructions, a small proportion may exceed recommended doses. (Moore et al. 2015).

Nurses should reinforce knowledge about self-care management, especially drinking plenty of water and self-medication. Some participants seem to have low knowledge about self-care management, for example; there are patients who drink water because they like it and not because they know that water is important in preventing or minimizing crisis. They did not have a reason as to why they don't drink plenty of water.

Need for hospital care for pain management

The findings showed that, whenever the pain persisted or become severe, all participants were seeking hospital care. Perhaps because I met them at the hospital, May be others do not go. Management of pain in the hospital has been reported to be mostly with injectable like Diclofenac and Tramadol as well as IV fluids. Generally this is consistent with the Tanzanian regimes, Diclofenac, Morphine, Tramadol, Pethidine, or Methadone are used (United Republic of Tanzania, 2013).However, Opioids used in the United States may include morphine, hydromorphone, oxycodone, Methadone, Codeine, or Tramadol (Matthie, 2013).

Other managements in other countries includes; exchange transfusions and hydroxyurea therapy are also used as preventive strategies in United State to reduce levels of Hgb S and have been helpful in decreasing pain, but these do not completely prevent crises (Matthie, 2013).In Tanzania hydroxyurea and blood transfusion are rarely used (Makani et al. 2014).

Social and Psychological Implication of Living with SCD

Findings in this study also indicated that, living with SCD accompanied by number of social and psychological Challenges. The study show that frequent illnesses and admissions to hospitals caused some to miss classes, perform poorly in subjects, and miss examinations. Hence some repeated years of examinations and others lost hope and dropped out of school. Similarly, frequent school absence in children with SCA in Brazil has been reported as an important predictor of academic attainment as children who are

frequently or consistently absent from school tend to perform poorly (Vilela et al .2012;Ezenwosu et al. 2013).

The study also show that having SCD affect school performance and that others dropped from school due to stigmatizations. This finding concurs with the findings from study done in Lagos State, Nigeria among secondary school students by Ola et al. (2013). This revealed a significant proportion of the students had negative attitudes towards peers with SCD and showed poor knowledge of the condition. They had having less personal contact with people affected by SCD and a peer believes that people with SCD cannot lead a normal life.

Additionally, doing poorly in school led to low education level which consequently in adult life caused difficulties in securing employment. The low educational level of many chronic disease patients does not enable them to obtain or hold well-paid jobs, which might give rise to the employment and financial difficulties they endure.

Those who managed to advance in school still faced difficulties in securing employment due to stigmatization, a result of living with Sickle Cell Disease. Those who were employed risked losing jobs if they disclose that they lived with Sickle Cell Disease. Some lost their jobs after being recognized to have Sickle Cell Disease by their employers. Research done in Chicago U.S.A. also revealed that, because of physical disabilities, frequent acute and chronic pain episodes or other complications that led to hospitalization, SCD patients risked being fired for excessive job absences, and may have difficulty in securing employment. (Wilkie et al. 2010;Anie et al. 2010).

Furthermore another study concerning quality of life, done in Brazil by Pereira et al. (2013) also concluded that within the sickle cell group, the social profile was that of low income and unemployment with sickle cell disease considered to be a significant impediment to finding a job. According to a the series of reports from the Unites State Food and Drug Administration (FDA), study found the similar results; adults living with SCD showed difficulties in Managing their work and careers, due to unpredictable and lengthy absences in working places. Participants struggled to keep up at work, or not

being able to work at all. For example, some described the difficulties in attending “all the doctor’s appointments, and work a full-time job at the same time, another shared devastating news after being “told that could not be a chef anymore” (FDA, 2014).

Furthermore study shows that, living with Sickle Cell Disease result in getting difficult getting married and failing to establish family life. The study also showed unstable courtship; break up of relationship and living single life among patients with SCD. These findings are also supported by the study done by Gallo et al. (2010) in Chicago, who found that when participants were asked about sharing Sickle Cell Status, they stressed on the importance of talking about and sharing their sickle cell status with partners when their relationship got “serious” and/or “intimate,” and when they wanted to begin a family but before pregnancy, to avoid abandonment.

Some participants were divorced as a result of frequent illnesses and miscarriages. Similarly, research done at Chicago revealed that, because of physical disabilities, frequent acute and chronic pain episodes or other complications that lead to hospitalization, SCD patients experience marital dysfunctions or difficulties with interpersonal relationship (Wilkie et al. 2010).

Choosing a partner in adults living with SCD should take into consideration of the possibility of perpetuation of the disease in among the off springs. Strategies should be made to prevent the disease or to cut off the chain of inheritance, such as advices and education to SCD patients on marrying non SCD, genetic counseling is very important to adult with SCD before marriage.

5.1 STUDY LIMITATIONS AND MITIGATION

This study has several limitations; first, transferability of the results is limited, because the study was carried out only in Dar-es-Salaam with a known SCD cohort. The second concern is the method for selection of the study participants, which were purposeful, selected, in order to answer the research question. However, this study aimed at providing insight of what people living with SCD experiences.

5.2 IMPLICATION OF FINDINGS

This study will help in education, because the insight gained will be used for preparing materials for teaching patients and other health care personnel who caring SCD patients. It will guide a change to health care personnel practices in hospitals as they will see the important and needs of holistic care to adults living with SCD (take into account all aspects of patient's life).

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATION

6.1 CONCLUSION

The study findings indicate that, living with SCD has been a challenge to many adults. The most difficult experiences of Sickle Cell Disease are due to the frequent painful crises, and complications, which contributed to personal suffering.

The study also explored how adults with Sickle Cell Disease care for themselves during painful crisis. Some are able to use different modalities of pain management at home. Some participants reported ways to cope with the disease such as prayers. Hospital management is also crucial especially when it comes to persisting pain or severe pain or other specific problems due to SCD.

Many studies described the burden of Sickle Cell Disease (SCD) in Africa. In Tanzania, the current study also shows the burden of SCD as experienced by adult living with the disease. Although for now, SCD cannot be cured, health care workers, especially nurses can help make SCD adult patients manage and live the productive lives. These findings give a basis of formulating recommendations concerning precaution measures that have to be taken in order to live well with the disease, or to cut off the chain of inheritance of SCD, as illustrated below**.**

6.2 RECOMMENDATIONS

According to experiences reported by participants, health outcomes of adults living with Sickle Cell Disease depend on good physical, social and psychological management. These can be influenced by the health care system, health personnel and individuals factors.

PRACTICE

- SCD adults living with the disease should get holistic care.
- In case of pain, as is subjective, health care personnel should treat/care every adults living with SCD as an individual, pain self-report and patient's view on treatment should be respected.
- Number of nurses/doctors should be increased, so that they should care for patients and follow them closely.

EDUCATION

- All service providers for Sickle Cell Disease patients should have knowledge on SCD, through training/more education.
- Nurses should be trained on Sickle Cell Disease management, so that they can help patients living with SCD.
- Genetic counselors for SCD in all aspects (disease and life experiences) should be trained.
- Nurses should teach adults living with SCD about diet proportional, drinking plenty of water (a little bit of water but frequently) and should be active themselves in other self-care management and actions (remedies at home),so as to prevent or minimize crises.
- SCD living with the disease should get Counseling about genetic disease, marriage difficulties, employment difficulties and any other problems accordingly.

POLICY

- Strategies should be made by the government through the Ministry of Health, Community Development, Gender, Elderly and Children, to prevent the disease or to cut off the chain of inheritance.
- Awareness should be increased to Tanzanian community, to understand the disease and its management.
- Primary hospitals should be equipped and prepared to receive and care for SCD patients.

RESEARCH

There is a need for further research to be conducted to include peripheral regions and remote areas. There is a big difference between Dar-es-Salaam region with many hospital and dispensaries as compared to the peripheral regions and remote areas. There might also be a difference in knowledge and financial/economic status between people living in Dar es Salaam and in the periphery. So further research should be done on important areas such as type of food consumed by such patients, water, availability &accessibility of health services and knowledge about the disease management.

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APPENDICES A-G

APPENDIX A-GUIDE QUESTIONS (ENGLISH VERSION)

GUIDE QUESTIONS FOR IN-DEPTH INTERVIEW FOR ADULTS LIVING WITH SICKLE CELL (AGED 18 YRS AND ABOVE)

INTERVIEWEE NO: ……..

DATE OF INTERVIEW ……

PART ONE: DEMOGRAPHIC

A. Year of birth …….
B. Sex (m/f) ……
C. Education level (none/primary/secondary/university) …….
D. Marital status (single/married/cohabiting/separated/divorced/widow)……
E. Do you have children? How many……
F. Are there other people in your family with Sickle Cell Disease?.....
G. Employment status (unemployed, Peasant, Government employee, Private sector employee, Self-employed)…….
H. Do you have any health insurance to be used for your treatment?.....
I. Did you experience pain in the last six months? How many times (estimation)?
J. When was the last time you were hospitalized for pain or other SCD problem?

K. How severe was your most recent SCD pain experience? On a scale of 1-10 (1 means little pain, increasing to10 being the worst), which number best represents the level of your pain you experience some times?

0_____1_____2_____3_____4_____5_____6_____7_____8____9____10

Little pain *severe pain*

1. How do you manage your SCD pain?
2. What alleviates or aggravates the pain.
3. (PROBE) fluid intake per day, medication, Follow up clinics, adherence to Folic Acid, Healthy diet,
4. Tell me about your life, living with SCD.(PROBE)family/marriage/friends relationship,support,employment.1
5. Do you believe in God? What does that belief influence your life?
6. What are your cultural beliefs in relation to Sickle Cell Disease?
7. Tell me about what you think health care professionals (Nurses, Doctors) need to do to best take care of SCD patients.
8. Do you have any thing that you wanted to discuss about the topic that we have not covered?

APPENDIX B-DODOSO LA MAHOJIANO

DODOSO LA MAHOJIANO KUHUSU UGONJWA WA SELI MUNDU

SEHEMU YA KWANZA: MAELEZO YANAYOMHUSU MTU (DEMOGRAPHIC)

NAMBA YA UTAMBULISHO: ……..

TAREHE YA MAHOJIANO ……

a) Mwaka wa kuzaliwa…….
b) Jinsia (Mke/Mume) ……
c) Elimu yako (Sijasoma/Msingi/Secondari/Chuo /Elimu ya juu) ……
d) Hali ya ndoa (Sijaoa/olewa,Nimeoa/olewa,Tumetengana,Ninaishi na mke/mume, Nimeachika,Mjane)…….
e) Je umejaliwa kuwa na watoto? Wangapi…….
f) Kuna watu wengine kwenye familia wenye ugonjwa wa seli mundu?
g) Hali ya ajira (sijaajiriwa/mkulima/serikali/binafsi/nimejiajiri)……
h) Kipato cha familia (kutoka chanzo chochote) kwa mwezi (cha chini/kati/juu)…….
i) Una kadi ya bima ya afya yoyote unayotumia kwenye matibabu yako?
j) Uliwahi kupata maumivu miezi sita iliopita? Mara ngapi(kadiria)?
k) Mara ya mwisho ulilazwa lini kwa ajili ya maumivu au tatizo lolote la seli mundu?
l) Maumivu uliyopata mara ya mwisho ya Seli mundu yalikuwa ya ukali gani katika kipimo cha 0-10 (0 maana yake maumivu kidogo na kuongezeka mpaka 10 kwa ukali) namba gani ingewakilisha ukali wa maumivu uliyopata?

0____1____2____3____4____5____6_____7____8_____9____10

Maumivu madogo *Maumivu makali*

1) Unajitibu vipi mara unapopata maumivu ya seli mundu?
2) Nini huzidisha au hupunguza maumivu?
3) (DODOSA kuhusu) unywaji wa maji, dawa, kumeza foliki acid kila siku, kuhudhuria kliniki, chakula bora
4) Nieleze kuhusu maisha yako ukiwa unaishi na ugonjwa wa seli mundu.(DODOSA) mahusiano ya familia, ndoa, jamii na marafiki,ajira,Msaada,marafiki na familia wanakusaidia vipi(kimawazo/kifedha).
5) Unaamini Mungu? Je, Imani ya dini ina nafasi gani katika maisha yako?
6) Mila zenu zinasemaje kuhusu ugonjwa wa seli mundu?
7) Unafikiri ni nini wahudumu wa afya (Wauguzi/madaktari) wafanye ili kuwahudumia vizuri zaidi wagonjwa wa ugonjwa wa seli mundu?
8) Je, kuna lolote ambalo unapenda tulijadili kuhusu ugonjwa wa seli mundu ambalo hatujalijadili?

APPENDIX C-ETHICAL APPROVAL LETTER

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

P.O. Box 65001
DAR ES SALAAM
TANZANIA
Web: www.muhas.ac.tz

Tel G/Line: +255-22-2150302/6 Ext. 1015
Direct Line: 255-22-2151378
Telefax: +255-22-2150465
E-mail: dpgs@muhas.ac.tz

Ref. No. MU/ PGS/SAEC/Vol. XVI/

7th March, 2017

Ms. Rehema Nkingi
MSc. Critical Care and Trauma
MUHAS.

RE: APPROVAL OF ETHICAL CLEARANCE FOR A STUDY TITLED; "EXPERIENCES OF ADULTS LIVING WITH SICKLE-CELL DISEASE WITH A FOCUS ON PAIN MANAGEMENT"

Reference is made to the above heading.

I am pleased to inform you that, the Chairman has, on behalf of the Senate, approved ethical clearance for the above-mentioned study. Hence you may proceed with the planned study.

The ethical clearance is valid for one year only, from 6th March, 2017 to 5th March, 2018. In case you do not complete data analysis and dissertation report writing by 5th March, 2018, you will have to apply for renewal of ethical clearance prior to the expiry date.

Prof. Andrea B. Pembe
DIRECTOR OF POSTGRADUATE STUDIES

cc: Director of Research and Publications
cc: Dean, School of Public Health and Social Sciences

APPENDIX D- INTRODUCTION LETTER

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR OF POSTGRADUATE STUDIES

P.O. Box 65001
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Web: www.muhas.ac.tz

Tel G/Line: +255-22-2150302/6 Ext. 1015
Direct Line: +255-22-2151378
Telefax: +255-22-2150465
E-mail: dpgs@muhas.ac.tz

Ref. No. HD/MUHAS/T. 303/2015

9th March, 2017

Executive Director
Muhimbili National Hospital
P.O. Box 65000
DAR ES SALAAM.

Re: INTRODUCTION LETTER

The bearer of this letter Ms. Rehema Nkingi is a student at Muhimbili University of Health and Allied Sciences (MUHAS) pursuing MSc. Critical Care and Trauma.

As part of his studies has intends to do a study titled:*"Experiences of dults living with sickle-cell disease with a focus on pain management".*

The research has been approved by the Chairman of University Senate.

Kindly provide her the necessary assistance to facilitate the conduct of her research.

We thank you for your cooperation.

Ms. A. Ndyeikiga
For: DIRECTOR, POSTGRADUATE STUDIES

cc: Dean, School of Nursing
cc: Ms. Rehema Nkingi

APPENDIX E-PERMISSION LETTER

MUHIMBILI NATIONAL HOSPITAL

Cables: "MUHIMBILI"
Telephones: +255 22-2151367-9
FAX: +255-22-2150534
Web: www.mnh.or.tz

Postal Address:
P.O. Box 65000
DAR ES SALAAM
Tanzania

In reply please quote:
Ref: MNH/TRC/ Research/ 2017/ 021

Date. 14th March, 2017

Ms. Rehema Nkingi
MUHAS.

RE: PERMISSION TO COLLECT DATA AT MNH NO: 2017/ 021
(HEMATOLOGY CLINIC)

Name	Ms. Rehema Nkingi
Title	Experiences of dults living with sickle-cell disease with a focus on pain management.
Institution	MUHAS
Supervisor	Dr. Amendulwater Dr. Dickson mkoka
Period	14th March, 2017 – 11th August, 2017 6months

You have been permitted to collect data in respect to the undertaking of the above mentioned study.

Please ensure that you abide to the ethical principle and other conditions of yours approval.

Sincerely,

Dr. Faraja Chiwanga (MD,M.Med, Msc)
Hend, Teaching, Research and Consultancy Coordination Unit

APPENDIX F-CONCENT FORM (ENGLISH VERSION)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES (MUHAS)

DIRECTORATE OF RESEARCH AND PUBLICATIONS

MUHAS INFORMED CONSERT.

ID NO……..

Consent to participate in a research study

Greetings!

My name is Rehema Nkingi. I am a student at Muhimbili University. Currently I am conducting a research on **EXPERIENCES OF ADULTS LIVING WITH SICKLE CELL DISEASE WITH A FOCUS ON PAIN MANAGEMENT.**

Purpose of the study

The study is conducted in partial fulfillment of requirement for the degree of masters of Critical Care and Trauma. The study aims to Understand Sickle Cell Disease adults' experiences of living with the disease, and pain management of the disease.

You're being asked to participate in this study because the investigator wants to know your views.

If you agree to join the study, you will be interviewed in order to answer a series of questions in the questionnaire prepared for the study.

Confidentiality

I assure you that all the information collected from you will be kept confidential. Your name will not be written on any questionnaire or any report / document that might let someone identify you. Your name will not be linked with research information in any way. All information collected on forms will be entered into the computers with only the study identification numbers. Confidentiality will be observed and unauthorized person will have no access to the data collected.

Risks

We do not expect that any harm will happen to you because of participating in this study. Some questions could potentially make you feel uncomfortable. You may refuse to answer any particular question and stop the interview any time.

Right to withdraw and alternatives

Taking part in this study is completely voluntary. You can stop participating in this study at any time, even if you have already given your consent. Refusal to participate or withdraw from the study will not involve penalty.

Benefits

The information gathered from you will ascertain the quality and outcomes of the health services provided to the sickle-cell patients. The study will also provide information to MNH and Ministry of Health Community and Development, Gender, Elderly and Children about aspects that can improve health services.

Compensation

You will be given compensation for bus fare.

If you ever have questions about this study you should contact, principal investigator Rehema Nkingi of Muhimbili University of Health and Allied Sciences, P.O. Box 65004, Dar es Salaam. Tel: +255784371485.

Your rights as a participant, you can also contact the Director of Research and Publications, Prof. S. Aboud, P.O. Box 65001, Dar es Salaam. Tel: +255 222152489.

Do you agree?

Participant agrees……Participant does not agree…….

I, _____ have read the content in this form. My questions have been answered. I agree to participate in this study

Signature of participant_____

Signature of principal investigator_____

Date of signed consent_____

APPENDIX G- FOMU YA RIDHAA KUSHIRIKI KATIKA UTAFITI

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

KURUGENZI YA TAFITI NA UCHAPISHAJI.

FOMU YA RIDHAA KUFANYA UTAFITI

Namba ya utambulisho: …….

Salamu!

Naitwa Rehema Nkingi,ni mwanafunzi chuo kikuu cha afya na sayansi shirikishi muhimbili. Ninafanya utafiti kuhusu watu wazima wenye ugonjwa wa selimundu wanavyoishi na ugonjwa huu,wanavyojihudumia wakipata maumivu na shida wanazopata kwa sababu ya ugonjwa huu. Utafiti unafanyikia Hospitali ya Taifa Muhimbili. Mkoa wa Dar Es Salaam.

Lengo la utafiti.

Utafiti huu unafanyika katika kutimiza Sehemu ya matakwa ya shahada ya uzamili ya wagonjwa mahututi (wasiojiweza) na waliopata majeraha ya Chuo Kikuu kishiriki cha Afya na Sayansi Muhimbili.

Lengo la utafiti ni kuelewa jinsi watu wazima wenye ugonjwa wa selimundu wanavyoishi,wanavyojihudumia wakipata maumivu na shida wanazopata kwa sababu ya ugonjwa huu.

Unaombwa kushiriki kwenye utafiti huu.

Ukikubali kushiriki katika utafiti huu, utasailiwa ili kuweza kujibu Maswali toka kwenye dodoso lililoandaliwa kwa ajili ya utafiti huu.

Usiri

Taarifa zote zitakazokusanywa zitakuwa ni za siri na zitaingizwa kwenye ngamizi kwa kutumia namba za utambulisho. Hakuna mtu yeyote asiyehusika atakayepata Taarifa zilizokusanywa.

Athari na kutokea kwa madhara.

Hatutegemei kupata/kutokea madhara yeyote unapo shiriki katika utafiti huu. Baadhi ya Maswali yanaweza yasikupendeze, unaweza kukataa kujibu swali lolote la aina hiyo na unaweza kuamua kuacha udahili wakati wowote.

Uhuru wa kujitoa.

Kushiriki kwenye utafiti huu ni hiari. Unaweza kujitoa kwenye utafiti huu wakati wowote hata kama umeshajaza fomu ya ridhaa ya kushiriki katika utafiti huu. Kukataa kushiriki au kujitoa kwenye utafiti huu hakutaambatana na masharti yeyote.

Faida

Utafiti huu utatoa taarifa kwa hospitali, wizara ya afya na maendeleo ya jamii,jinsia,wazee na watoto kuhusu mambo yatakayoboresha huduma za afya.

Fidia

Mtafiti atakurudishia pesa ya nauli ya basi.

Nani wakuwasiliana naye.

Kama una Maswali yoyote kuhusu utafiti huu, unaweza kuwasiliana na mtafiti mkuu Rehema Nkingi wa chuo kikuu cha afya na sayansi shirikishi muhimbili.S.L.P 65004, Dar es Salaam. Mkurugenzi wa Kitengo Cha Utafitina Uchapishaji, Profesa Said Aboud S.L.P 65001 Dar es Salaam. Tel +255 222152489

Je unakubali?

Mshiriki kakubali……Mshiriki hajakubali…….

Mimi, _____ nimesoma na nimeelewa maelezo ya fomu hii. Maswali yangu yote yamejibiwa na nakubali kushiriki katika utafitihuu.

Sahihi ya mshiriki _____

Sahihi ya mtafiti_____ Tarehe _____