EFFECTIVENESS OF EXERCISE ON MUSCULOSKELETAL PAIN AMONG CHILDREN WITH SICKLE CELL DISEASE IN WESTERN REGION OF KENYA

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A Thesis Submitted in Partial Fulfillment of the Requirement for the Award of the Degree of Doctor of Philosophy in Nursing of Masinde Muliro University of Science and Technology

November, 2023

# DECLARATION

This thesis is my original work prepared with no other than the indicated sources and support and has not been presented elsewhere for a degree or any other award.

Signature ..... Date.....

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# CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance of Masinde Muliro University of Science and Technology a thesis entitled, "Effectiveness of Exercise on Musculoskeletal Pain among Children with Sickle Cell Disease in Western Region of Kenya."

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# DEDICATION

Special dedication to my family for the great support throughout the entire study period.

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#### ABSTRACT

Musculoskeletal pain is the most cardinal sign of sickle cell disease among children which occurs due to vaso-occlusion causing disability. Exercise has proven to be helpful in musculoskeletal pain and should be used like any other therapy. World Health Organization guidelines recommend all children to be active for 60 minutes daily for 3 months to achieve health benefits in health and illness. Therefore, the aim of this study was to analyze the effectiveness of exercise in musculoskeletal pain among children with sickle cell disease. Specifically, to determine the relationship between socio demographic characteristics and musculoskeletal pain among children with sickle cell disease, examine strategies used in management of musculoskeletal pain, analyze factors that influence management of musculoskeletal pain and assess the outcome of exercise on musculoskeletal pain. This study was guided by the theory of Bio-psychosocial theory of Health and Illness. The study adapted a quasi experimental pre and post design with two arms control and intervention groups. Intervention group was introduced to a 12 week exercise while the control group continued with their routine. Both groups were recruited live from sickle cell and hemophilic clinics. Quantitative data was collected using questionnaire and analyzed by chisquare test of independence and mixed model anova.Qualitative data was collected using key informant guides and indepth interviews and analysed by thematic content analysis. The study had a sample size of 176 children, 22 respondents participated in indepth interviews. The results found no statistically significant association between socio demographic characteristics and musculoskeletal pain among children with sickle cell disease. The majority of the respondents in intervention group reported mild musculoskeletal pain after the intervention (n=104, 59.1%). The results of the Chi-square test for hemoglobin levels ( $\gamma 2$  (2) = 23.99, p < .001), hospital visits ( $\chi 2$  (2) = 22.033 p < 0.01), exercise participation p < 0.01) and painful attacks p <0.01 were significant. There was a statistical significant difference in intervention group on baseline and post intervention pain levels as measured by Wong Baker Faces Pain Rating Scale self-reported pain p<0.01, unlike in control group, where there was no significance difference in baseline and post intervention results. Economic, sociocultural, individual factors influenced musculoskeletal pain management.Drugs were used as one of the strategies. A mixed model analysis of variance (ANOVA) with one within-subjects factor and one between-subjects factor was conducted to determine whether significant differences existed among pain- post and pain-pre between the levels of group. The main effect for group was significant, F (1, 174) = 135.02, p < .001, indicating that there were significant differences in painpost and pain-pre between the levels of group. The main effect for the within-subjects factor was significant, F (1, 174) = 278.76, p < .001, indicating that there were significant differences between the values of pain post and pain pre. For the intervention category of group, pain post was significantly less than pain pre, t (174) = -28.72, p < .001.Effectiveness of exercise was measured using partial eta squared $(np^2)$  where by above 0.14 indicates a large effect while 0.01 indicate a small effect. In conclusion, these results suggest that the intervention was effective in reducing musculoskeletal pain in this population with  $np^2$  of 0.44,0.62.0.60. The study recommends use of exercise to reduce musculoskeletal pain among children with sickle cell disease.

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# LIST OF ABBREVIATIONS AND ACRONYMS

BGM Bungoma BPT Bio psychosocial theory BUS Busia CHR **County Health Reports** HRQL Health Related Quality of Life KAK Kakamega KII Key informant interview MSK Musculoskeletal NGCMSCD National Guidelines For Control and Management Of Sickle Cell Disease In Kenya NSAIDS Non-Steroidal Anti-inflammatory Drugs PR Parent Respondent SCD Sickle Cell Disease **SDG** Sustainable Development Goals SSA Sub-Saharan Africa UNICEF United Nations Children's Education Fund VHG Vihiga **WBFPRS** Wong Baker Faces Pain Rating Scale WHO World Health Organization

## **OPERATIONAL DEFINITION OF TERMS**

Children: Any one aged 6 to 12 years

Effectiveness: The degree to which exercise is successful in reducing musculoskeletal pain

Exercise: A WHO program that is recommended in reducing musculoskeletal pain

Hyperalgesia: An increased feeling of pain

Musculoskeletal pain: pain that is experienced in muscles, ligaments, joints and bone

Musculoskeletal pain crisis:Uncontrollabe pain in muscles, ligaments, joints and bone

Musculoskeletal system: Bones ligaments, cartilage, tendons, connective tissues

Parent: Anyone taking care of the child

Physical activity: All movements done on daily basis

**Sickle Cell Disease-**A genetic disorder of red blood cells which occurs by sickling of RBCS leading to blockage of blood flow due to occlusion of blood vessels hence causing musculoskeletal pain.

Vaso-Occlusion: Blocking of blood vessels due to the sickled cells

Western Region of Kenya: The old western province with 4 counties: Kakamega, Bungoma, Busia and Vihiga.

### **CHAPTER ONE**

# **INTRODUCTION**

# 1.1 Overview

This chapter presents the background information, statement of the problem, justification, main and specific objectives of the study, research questions, hypothesis, limitations, theoretical and the conceptual framework.

### 1.2 Background of the study

## 1.2.1 Sickle Cell Disease

Sickle Cell Disease is an autosomal recessive disorder characterized by chronic painful episodes of vaso-occlusion. (Houwing *et al.*, 2019). It accounts for 5% of mortality in African children and presents with pain related to vaso-occlusive events. It is a global health issue with lack of awareness among the people in areas of high incidence (Mburu & Odame, 2019). The disease is most prevalent in malarial endemic areas in the tropics resulting in most children dying before reaching adulthood with a ratio of 3:1(children: adults) surviving (Wastnedge *et al.*, 2018). In Kenya,the prevalence varies in regions and occurrence is common in the malaria endemicity. In the western region it is estimated that 18% of children are born with a Sickle Cell Trait and 4.5% develop SCD . In the lake region, about 17% children are carriers of the trait with 0.6% having SCD while in the coastal region, using inpatient data, almost 1% of inpatient children had SCD and were almost 20 times likely to die compared to admissions of other morbidities. A study conducted in Kilifi county showed that morbidity and mortality was high in young children with Sickle Cell disease but was reduced with early diagnosis and supportive care(Uyoga *et al.*, 2019).

#### 1.2.2 Musculoskeletal pain in Sickle Cell Disease

Globally, musculoskeletal diseases are the major contributor to the burden of disease and disability affecting low and middle income countries. Affected children face increased morbidity, social isolation and economic hardships (Rebecca et al.,2022). Musculoskeletal manifestations are the commonest clinical presentations of both acute and chronic cases of vaso-occlusive crisis (Musowoya, 2019). The burden is in Africa, with increased child morbidity and mortality (Oron et al., 2020). The incidence in children is estimated to be between 300,000 and 400,000 neonates globally each year (Kato et al., 2018) with compromised quality of life (Simpson, 2019). Children experience musculoskeletal pain throughout their lives where they mostly use drugs (Wanjiku et al., 2019). Musculoskeletal pain crisis is the primary reason for hospitalization or visits to hospitals by children with SCD leading to high cost of medical care (Ballas et al., 2012). Despite assumptions that adverse events from exercise occur in SCD, the issues that frame our understanding of exerciserelated harms in both are distinct (Liem, 2018). In Western region, the prevalence of SCD is highest in Kakamega County (45.5%), followed by Bungoma (22.7%), then Busia (18.2% and Vihiga County (13.6). According to the hospital reports, western region has approximately a total of 528 cases admitted with sickle cell disease every year apart from 2020 and 2021 where the admissions dropped due to Covid 19 (CHR, 2020).

Musculoskeletal pain remains the cardinal sign of sickle cell disease and is not well treated. Recurrent painful episodes constitute the major morbidity in children with sickle cell disease (SCD). A significant number of children have chronic and severe forms of the disease, characterized by vaso-occlusive crises caused by the accumulation of sickle cells and the consequent obstruction of blood vessels, leading

to ischemia of the tissues (Sabino & Gradella, 2016). In Kenya, the most popular treatment used in musculoskeletal pain management in children with sickle cell disease is Opioid's. Non-steroidal Anti-inflammatory drugs (NSAIDS) remain the main treatment for vaso-occlusive events. However, research conducted indicate that opioids tolerance and opioids induced hyperalgesia are significant problems associated with long term use of opioids hence better strategies for chronic pain management are needed (Latika *et al.*,2018). Non -pharmacological approaches can also be used such as acupuncture, heat, ice, relaxation techniques, hypnosis and exercise. However, Studies document that Kenyan caregivers of children with SCD experience financial constraints, psychosocial, emotional and physical burden. The results can guide intervention development for caregivers of children with SCD in low-resource and global contexts (Kuerten *et al.*,2020).

Despite the respective government effort to improve health, provide needed medications, there is still a significant SCD fatality rate of about 31% with musculoskeletal pain being a cardinal sign (Watenga *et al.*, 2019). World Health Organization guidelines require that all children should be active for 60 minutes daily for 3 months to accrue required health benefits. Exercise has been shown to improve the development and functionality of cardiovascular system, muscular skeletal tissues and fitness, neuromuscular coordination and movement control, respiratory and metabolic health maintaining a healthy body weight. In western region, the most common cause of hospital admission for children with SCD is musculoskeletal pain related to vaso-occlusive events, unlike in adults where they experience abdominal pain, chest pain among many others (CHR, 2018).

There is evidence that musculoskeletal conditions are also a major contributor to disability in such children, with increasing rates of disability with age. Complications on the musculoskeletal system causes parts of the body not to get enough oxygen and begins to die off slowly, resulting in permanent tissue damage and death (Necrosis). Musculoskeletal pain can be acute or chronic and is unpredictable (Carroll, 2020). It presents with Hemoglobin S red blood cells being deformed and inflexible. Often breaking down in the circulation, they exhibit increased adhesive properties with the endothelium and activated neutrophils and platelets, increasing the risk of occlusion of the microcirculation. SCD is divided into two categories; hyperhemolytic, associated with priapism, leg ulcers, pulmonary hypertension, and stroke, and high hemoglobin viscosity, which may promote vaso-occlusion-associated pain, acute chest syndrome, and osteonecrosis (Ofori-Acquah, 2020). In case the vaso-occlusion is not managed well, it can lead to multisystem disorders which are characterized by progressive multi organ failure (Houwing *et al.*, 2019).

In children, the most common pain experienced is musculoskeletal pain and this affects the normal growth and development of these children (Uwaezuoke *et al.*, 2018). Limited resources in East African countries, reduces the survival of SCD children and most die before five years (Kawuki *et al.*, 2019). The pain affect the quality of life for children and the goal of management is to prevent and respond to acute vaso occlusive crises, as this is the most common reason for hospitalization in these children (Fiocchi *et al.*, 2020).

Exercise in children with SCD has been shown to decrease blood viscosity in sickle cell mice, which could be beneficial for adequate blood flow and tissue perfusion. A study that was conducted on Physical activity and exercise revealed that it can improve the development and functionality of cardiovascular system (heart, lungs),

muscular skeletal tissues and fitness (bones, muscles and joints), neuromuscular coordination and movement control, respiratory and metabolic health maintaining a healthy body weight. Acute intense exercise may increase blood viscosity in healthy individuals hence light exercises recommended in SCD patients (Nader *et al.*, 2019).

Low to moderate exercise and physical activities is recommended together with those that strengthen muscle and bone, at least 3 times per week (WHO, 2019). It is well established that endurance exercise training is an effective way to improve muscle oxygen supply in healthy subjects and also in pathophysiological conditions. The micro vascular benefits of regular physical activity have also been observed in sickle cell trait, with increased capillary network and tortuosity in active carriers compared with sedentary counterparts (Gellen *et al.*, 2018; Messonnier *et al.*, 2019). These children are commonly managed using pharmaceutical interventions like opioids, which with prolonged use, becomes resistant, expensive and with side effects. This creates negative impacts on the child's normal growth and developmental milestones with physical, psychological, emotional and social effects (Kosiyo *et al.*, 2020).

Global recommendations on physical health states that children and adolescents should accumulate at least 60 minutes of moderate- to vigorous-intensity physical activity daily. An amount of physical activity greater than 60 minutes provide additional health benefits hence it is recommended that most of the daily physical activity should be aerobic (CNN, 2020). Although acute high-intensity exercise is not recommended for SCD children because it may increase the risk of sickling, regular moderate-intensity physical activity could have beneficial effects on skeletal muscle and more generally on the well-being of children with SCD. Despite the importance of exercise and physical activity in children with SCD, there is a notion that exercises and physical activity is associated with worse pain outcomes which increase anxiety and fear related to severe pain among the children and caregivers. This makes caregivers and parents to restrict their children from participating in activities that may improve the circulation of blood to tissues, bones and cells leading to frequent occurrence of vasoocclusive events hence frequent hospitalization of the children. A study reported that exercise and physical activity were associated with worse pain outcomes which increased anxiety related to severe pain (Karlson et al., 2020). Therefore, there is need for a better understanding of the relationship between exercise and musculoskeletal pain which will guide multifactorial treatment interventions. Management of sickle cell musculoskeletal pain in children is inadequate, and the employment of proper management guidelines and practices are highly variable among different regions and populations (Abdo et al., 2019). There is also an urgent need to develop a strategy for musculoskeletal pain among children with SCD using exercise as a management option in Kenya, especially in Kakamega County.

### **1.3 Statement of the Problem**

Despite the fact that there is insufficient documented evidence in western region, anecdotal and empirical reports indicate that most hospital admissions of children with SCD are due to musculoskeletal pain (CHR, 2019). This is the most common clinical manifestation in children with SCD presenting with painful vaso-occlusive crisis. It causes pain in the joints, muscles and bones affecting extremities as opposed to headache, chest pain, abdominal and back pain in adults. The main treatment protocol for painful episodes has been Opioid's and NSAIDS (National Guidelines for Control and Management of sickle cell disease ,2020). Studies indicate that long

use of the opioids and NSAIDS can lead to opioid tolerance and opioid induced hyperalgesia (Latika *et al.*, 2018). Therefore, there is no clear alternative methods of managing musculoskeletal pain among children with SCD despite the well-documented benefits of regular exercise for children in healthy and disease states. Evidence from other studies in developed countries have shown that exercise is beneficial for health and it should be considered as a therapy just like any other therapeutic intervention (Vina *et al.*, 2012). This study was therefore conducted to assess the effectiveness of exercise in musculoskeletal pain management and see whether or not exercise would be beneficial to children with sickle cell disease. This study therefore aimed to try and fill the gap.

### **1.4 Objectives**

# 1.4.1 Main Objective

To determine the effectiveness of exercise on musculoskeletal pain among children with sickle cell disease in Western Region of Kenya.

# **1.4.2 Specific objectives**

- To determine the relationship between sociodemographic characteristics and musculoskeletal pain among children with sickle cell disease in Western Region of Kenya.
- 2. To examine the strategies used in management of musculoskeletal pain among children with sickle cell disease in Western Region of Kenya.
- To analyze the factors that influence effective management of musculoskeletal pain among children with Sickle Cell Disease in Western Region of Kenya.
- To assess the outcome of exercise on musculoskeletal pain among children with Sickle Cell Disease in Western Region of Kenya.

### **1.5 Hypothesis**

**HO**<sup>1</sup> There is no significant difference in musculoskeletal pain using exercise before and after the intervention among children aged 6-12 years with Sickle Cell Disease in the control and experimental group.

#### **1.6 Justification of the study**

Musculoskeletal pain is the most common pain experienced by children with SCD which affects the normal growth and development (Uwaezuoke *et al.*, 2018). Musculoskeletal pain is associated with an economic burden to society, although the availability of these data is limited (Yamato *et al.*, 2020). Statistics have shown that Kenya experiences a high burden of school drop outs and absenteeism in children and adolescents with SCD due to musculoskeletal pain. Data further reveals that prevalence of MSK pain quickly arises from childhood to adolescents and worsens in adulthood (Kamper *et al.*, 2016). The pain affects the quality of life for children and the goal of management is to prevent and respond to acute vaso-occlusive crises.

Musculoskeletal pain accounts to the most common reason for hospitalization in these children (Fiocchi *et al.*, 2020). The pain may be acute or chronic, varying in intensity, location and quality. Exercise can reduce the potential for various musculoskeletal disorders such as bone disorders, occlusion of blood vessels and pain among others. Exercise in children with SCD has been proven to decrease blood viscosity in sickle cell mice. This could be beneficial for adequate blood flow and tissue perfusion. Affordable healthcare is one of the 4 big Agendas to be achieved by 2022 by the Kenyan government. Regular exercise can decrease the risk of the inflammatory reaction related to MSK pain and increase the vasodilator reserve, decreasing the risk of vaso-occlusive crisis. WHO guidelines recommend all children to be active for 60 minutes daily for 3 months to attain required health benefits.

Exercise has been shown to improve the development and functionality of cardiovascular system, muscular skeletal tissues and fitness, neuromuscular coordination and movement control, respiratory and metabolic health maintaining a healthy body in both health and illnesses (WHO, 2019). Evidence suggests that exercise in all forms triggers epigenetic changes in several pathways that underlie the physiological benefits of exercise (Whitham *et al.*, 2018). Other measures are heat, distractors among others, and not necessarily medicines. Exercise is one of the cheapest interventions with lifelong benefits that helps in the improvement of circulation of blood to tissues, muscles and bones in children with sickle cell disease.

Exercise can be executed by parents, guardians and children themselves; it is simple and cost effective. Considering the increasing number of hospital admissions of children with sickle cell disease due to musculoskeletal pain in western region, life expectancy of these children is reduced. It is important to investigate children since exercise has been documented to reduce vaso-occlusive events which cause musculoskeletal pain. Motor development is enhanced after 5 years and so this category (5 years and below) cannot execute basic exercise skills hence exempted from participating in the study (WHO, 2019). The adolescents are not included in the study because the period of growth spurt is high which may not inform the effect of exercise program due to the rapid growth changes.

The objective of this study was to analyze the effects of exercise in musculoskeletal pain management in children aged 6 to 12 years with Sickle Cell Disease. Study population were children above aged 6 to 12 years because children below this age cannot execute basic exercise skills due to the under developed motor activity. The adolescents have a spurt growth due to the developmental changes which may affect the outcome of the intervention due to the hormonal changes. The findings of this study were to help the health sector to adopt the implementation of the exercise in children with sickle cell disease at all levels with support from parents, guardians, children and health care providers. The study will also form baseline information on the management of musculoskeletal pain in children with sickle cell disease using exercise.

### **1.7** Limitations of the Study

The design of this study was quasi experimental where by it is not possible to observe measures strictly between the control and experimental groups which may bring some biasness in allocation of groups. unlike in other research designs such as the randomized control trials where control and intervention groups are randomly assigned. This may bring differences in the two groups. However, every child who had sickle cell disease and met the inclusion had an opportunity to be assigned in either group. The researcher feels that the same study can be conducted in future using different designs and compare the outcome with the findings of this study. However, the findings of this study will form a basis of other related studies. Sample size included only one region in Kenya. This was mitigated by ensuring that all the four counties in this region were included in the study whereby referral hospitals were used in recruiting the participants. The participants were referrals from all over.

## **1.7 Theoretical Framework**

The study was anchored on the theory of Bio-psychosocial theory of Health and Illness as postulated by George L. Engel (1977).

### 1.7.1 Bio-psychosocial theory (BPT) of Health and Illness

Bio-Psychosocial theory was developed by George L. Engel (1977) which explains that behaviors, thoughts and feelings may influence physical state of an individual. BPT states that psychological and social factors influence biological functioning and play a key role in health and illness. Interactions between biological, psychological, and social factors determine the cause, presentation,wellness and disease. Health professionals can apply this theory to provide information on exercise in children with SCD in order to relieve musculoskeletal pain. Psychological factors such as selfesteem and perceived control increase health promoting behaviors like exercise in children with MSK in SCD (Derek Bolton& Grant Gillet, 2019). The biopsychosocial model argues that any one factor is not sufficient; it is the interplay between people's genetic makeup (biology), mental health and behavior (psychology), and social and cultural context that determine the course of their healthrelated outcomes.

The bio-psychosocial theory views health and illness behaviors as products of biological characteristics (such as genes), behavioral factors (such as lifestyle, stress, and health beliefs), and social conditions (such as cultural influences, family relationships, and social support). Health psychologists work with healthcare professionals and patients to help people deal with the psychological and emotional aspects of health and illness. This can include developing treatment protocols to increase adherence to medical treatments, exercise, weight loss programs etc. The theory often focuses on prevention and intervention programs designed to promote healthier lifestyles such as exercise in children with SCD.

### **1.7.2 Biological Influences on Health**

Biological influences on health include an individual's genetic makeup and history of physical trauma or infection. Many disorders have an inherited genetic vulnerability like the Sickle Cell Disease. It is clear that genetics have an important role in the development of sickle cell disease and musculoskeletal pain commonly occurs as a result of occlusion of blood vessels, but it is clear that there must be other factors at play. Bone pain, muscle pain, joint pain occur which impairs the child's normal body functioning and normal activities like playing and going to school. Non-biological factors like environment, lifestyle and support from friends and family influence the expression of the disorder in those children with a pre-existing genetic risk like sickle cell.

# **1.7.3 Psychological Influences on Health**

The psychological component of the bio-psychosocial theory sought to find a psychological foundation for a particular symptom. Children with a genetic vulnerability may be more likely to display negative symptoms that puts them at risk of stress. An example is when the children with SCD experience musculoskeletal pain, they are affected and stressed. Psychological factors may exacerbate a biological predisposition by putting a genetically vulnerable person at risk for other risk behaviors isolation and low esteem because of the pain these children go through. Increased risk-taking leads to an increased likelihood of disease in this case musculoskeletal pain.

# 1.7.4 Social cultural Influences on Health

Social factors include socioeconomic status, culture, technology, and religion. Musculoskeletal pain may predispose a child to developing depression, which may, in turn, contribute to physical health problems. The impact of social factors is widely recognized in chronic illness such as in musculoskeletal pain in SCD. Socialization and sharing with friends about the experiences that an individual undergoes is vital and promotes healing. Economic status of the parents is key in the management of these children with musculoskeletal pain. Social support from friends, peers and family is important. Culture can vary across a small geographic range, such as from lower-income to higher-income areas, and rates of disease and illness differ across these communities accordingly. Culture can even change biology, as research on epigenetics suggests that the environment can actually alter an individual's genetic makeup.

### **1.8 Conceptual Framework**

A conceptual framework is a model that identifies concepts under research and their relationships. It's a visual representation of the relationship between the variables being investigated. It shows the link between the independent and dependent variables and intervening variables (Mugenda & Mugenda, 2003).

The conceptual framework was informed by the Bio-psychosocial theory of health and illness which provides explanation of the three factors: Biological, psychological and social factors and how they inter relate in any intervention during health and illness. The theorist mentioned that these factors must be considered to achieve a beneficial patient outcome which is musculoskeletal pain relieve. The theory states that the workings of the body, mind, and environment all affect each other. According to this theory, none of these factors in isolation is sufficient to lead definitively to good health or illness. It is the deep interrelation of all three components that leads to a given outcome. Health promotion (exercise therapy) must address all three factors, as a growing body of empirical literatures suggests that it is the combination of health status, perceptions of health, and sociocultural barriers to accessing health care that influence the likelihood of a patient engaging in health-promoting behaviors, like taking medication and engaging in an exercise.

Evidence also suggests that there is not just a single route involved, in that exercise intervention for musculoskeletal pain management may result in either positive (relieve pain), or negative health outcomes by direct effects on organ systems like increase in musculoskeletal pain, muscle tension, motility. Indirect biological effects may also occur such as exacerbating or triggering a disease process in an already genetically vulnerable individual, or by increasing risk behaviors like sedentary lifestyle and inability to do exercise due to fear and anxiety that contribute to increase in musculoskeletal pain. If all the factors mentioned are considered, exercise may improve the functionality of the body reducing the occurrence of musculoskeletal pain among children with sickle cell Disease. Children with sickle cell experience frequent musculoskeletal pain following the occlusion of blood vessels. They require guidance and support from parents to enable them cope up with the disease. All the mentioned factors will enable them adhere to the treatment whether pharmacological or non -pharmacological. This will help in the improvement of thei quality of life of the children. Figure 1.1 shows the conceptual framework

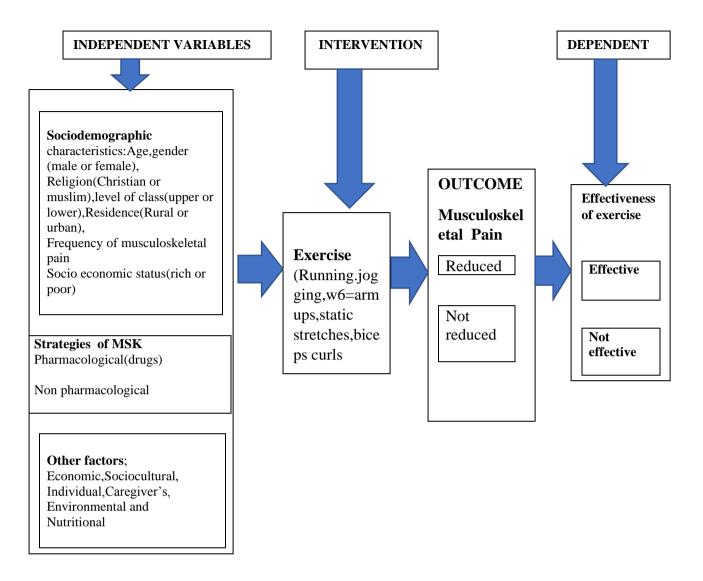


Figure 1.1 Conceptual Framework. Source:Adapted from George L. Engel (1977) BPT theoretical framework

### **CHAPTER TWO**

# LITERATURE REVIEW

#### 2.0 Overview

This chapter presents review of literature from journals, internet and previous research on epidemiology of musculoskeletal pain, relationship between socio demographic characteristics and musculoskeletal pain among children with sickle cell disease, strategies used in management of musculoskeletal pain among children with sickle cell disease, factors that influence management of musculoskeletal pain among children with sickle cell disease and outcome of exercise in management of musculoskeletal pain among children with sickle cell disease. It describes the selected demographic characteristics of children with sickle cell disease and the practice of parents on the management of musculoskeletal pain among children with sickle cell disease. It compares the incidences of pain before and after exercise intervention program among children with sickle cell disease. Other Studies conducted related to exercise in the management of musculoskeletal pain in children with sickle cell disease was reviewed and gaps identified in areas for further research.

## 2.1 Sickle Cell Disease risk factors, pathophysiology, clinical presentation,

#### complications, and management

Sickle cell disease (SCD) is a hereditary blood disorder that results from a single genetic mutation, primarily affecting individuals of African, Mediterranean, Middle Eastern, and South Asian descent. It is an autosomal recessive condition, meaning that both parents must carry the sickle hemoglobin (HbS) gene for a child to inherit the disease (Piel et al., 2017). Sickle cell disease (SCD) is a group of inherited disorders caused by mutations in HBB, which encodes haemoglobin subunit  $\beta$ . The

incidence is estimated to be between 300,000 and 400,000 neonates globally each year, the majority in sub-Saharan Africa. Haemoglobin molecules that include mutant sickle  $\beta$ -globin subunits can polymerize; erythrocytes that contain mostly haemoglobin polymers assume a sickled form and are prone to haemolysis(Kato et al.,2018). Other pathophysiological mechanisms that contribute to the SCD phenotype are vaso-occlusion and activation of the immune system. SCD is characterized by a remarkable phenotypic complexity. Early diagnosis is crucial to improve survival, and universal newborn screening programmes have been implemented in some countries but are challenging in low-income, high-burden settings.

#### 2.1.1 Causes and Risk Factors

The primary cause of SCD is a point mutation in the hemoglobin beta (HBB) gene, leading to the production of abnormal hemoglobin, HbS. The substitution of valine for glutamic acid at the sixth position of the beta-globin chain results in a hemoglobin variant with a tendency to polymerize in low-oxygen conditions. This polymerization causes red blood cells to become rigid and adopt the characteristic sickle shape (Piel et al., 2017). The risk of developing SCD is directly associated with parental genetics. Inheritance of one HbS gene from each parent leads to the homozygous condition (HbSS), which is the most common and severe form of SCD. Heterozygous inheritance (HbAS) is referred to as sickle cell trait, which generally doesn't cause the disease but can be passed on to the next generation (Piel et al., 2017).

#### 2.1.2 Pathophysiology

The pathophysiology of SCD revolves around the polymerization of HbS under conditions of low oxygen. When deoxygenated, HbS molecules aggregate, causing red blood cells to assume a sickle shape. These altered cells can adhere to the vessel walls, leading to vaso-occlusion, one of the hallmark features of SCD. Vaso-occlusion results in reduced blood flow, chronic inflammation, and infarctions that manifest as painful crises and tissue damage (Kato et al,2018).

### 2.1.3 Clinical Presentation of Sickle cell Disease

Individuals with SCD can experience a range of symptoms and complications. Pain crises, also known as vaso-occlusive crises, are common and involve severe pain due to the blockage of small blood vessels by sickled red blood cells. These crises can affect various body parts, including the bones, joints, and chest(Macklin *et al*,2020).

Chronic anemia is another characteristic of SCD. Hemolysis, the breakdown of sickled red blood cells, leads to a reduced number of red blood cells, causing fatigue, pallor, and jaundice. Additionally, organ damage may occur over time, with the spleen, liver, kidneys, lungs, and brain being common targets. However, the most common presentation is musculoskeletal pain due to vaso occlusion (Musowoya, 2019).

# 2.1.4 Complications of Sickle cell Disease

Several complications can arise from SCD, including acute chest syndrome, which is a life-threatening condition characterized by pulmonary infiltrates and can result from lung infarction and infection. Individuals with SCD are at an increased risk of stroke due to impaired blood flow and vessel damage in the brain. Furthermore, the spleen, an essential organ for immune function, can be compromised, leading to an increased susceptibility to infections (Fullen *et al.*,2023). Common acute complications are acute pain events, acute chest syndrome and stroke; chronic complications (including chronic kidney disease) can damage all organs. Hydroxycarbamide, blood transfusions and haematopoietic stem cell transplantation can reduce the severity of the disease.

Orthopedic complications of sickle cell disease (SCD) include vaso-occlusive bone pain, osteonecrosis, and infections such as osteomyelitis and septic arthritis. This has a lot of impacts on the children health physically, psychologically, emotionally and socially (Salah *et al.*,2021). Children with SCD have been reported to experience dyspnea when walking, climbing stairs or ramps, or performing vigorous physical activities, which indicates a loss of functional capacity in this population.

#### 2.1.5 Management of Sickle Cell Disease

The management of SCD is multifaceted. Symptomatic treatment primarily focuses on managing pain crises with analgesics and providing supportive care. Hydroxyurea, a medication that stimulates the production of fetal hemoglobin (HbF), has shown effectiveness in reducing the frequency and severity of vaso-occlusive crises (Kawuki *et al.*,2019). Blood transfusions can increase the number of healthy red blood cells and alleviate anemia. In more severe cases, bone marrow transplantation offers a curative option, although it is associated with significant risks.

#### 2.2 Musculoskeletal (MSK) pain among children with Sickle Cell Disease

Musculoskeletal pain (MSK) is acute or chronic pain that affects bones, muscles, ligaments, tendons and nerves (Salah *et al*,2021). MSK is common and debilitating symptom experienced by children with Sickle Cell Disease (SCD), unlike adults who experience chest pain, abdominal pain among others. MSK pain results from vessel

occlusion, leading to tissue ischemia, infarction and progressive end organ damage. However, in Kenya, limited studies on MSK pain have been conducted and may be underestimated in sickle cell disease (Musowoya, 2019). The most common reason for hospitalization of children with Sickle Cell Disease is acute vaso-occlusive crises (Fiocchi *et al.*, 2020). MSK pain in children with SCD is complicated and often has a lifelong and significant negative impact on the quality of life; therefore, improved pain management is considered a significant and unmet need. Neuropathic pain mechanisms are heterogeneous and difficulty in determining pain types contributing to poor treatment outcomes in this population (Orhurhu *et al.*, 2020). This could be managed through educating parents, guardians and children on the importance of exercise, and then initiating exercise in the communities hence this study. Managing MSK pain is a critical part of care, and research has been conducted to establish the factors that contribute to the strategies that are used to manage musculoskeletal pain in children with SCD.

A systematic review conducted on the prevalence,risks factors,prognosis and treatment of posed a burden to healthcare(Kamper *et al.*,2016). Pain in children and adolescents was reported not well managed because healthworkers had little understanding of MSK conditions with little evidence to relate to clinical practice. This can contribute to inappropriate interventions of the children when in pain. Many children with sickle cell disease (SCD) experience recurrent and chronic musculoskeletal pain, which has a negative impact on their health-related quality of life (HRQL). Astudy conducted on musculoskeletal complications in sickle cell patients in two Nigerian hospitals found the prevalence of musculoskeletal disorders to be 54.1% out of the cases that were admitted (Aliyu *et al.*,2015). The results also showed that the most common cause of hospital visitation was painful bone crisis

(35.5%). In the United States, a study reported that the prevalence of musculoskeletal pain among children with SCD was high, with an estimated prevalence of 80% (Kato et al., 2018) Similarly, in Brazil a study conducted by Salgado et al. (2021) also found that musculoskeletal pain was prevalent among children with SCD, and it was significantly associated with lower quality of life and worse functional status.In Nigeria, a study published in 2020 in the Journal of Pediatrics and Child Health reported that the incidence of musculoskeletal pain among children with SCD in Lagos, Nigeria, was high, with an estimated prevalence of 82%. The study also found that there was lack of access to appropriate management and treatment for this pain. A study conducted in Nigeria, evaluated the effectiveness of a 6-week home-based exercise program among children with SCD in managing musculoskeletal pain, the study found that the exercise program was effective in reducing pain and improving physical function (Oluyede et al. 2020). In Kenya, a study published in 2020 in the Journal of Hematology & Thromboembolic Diseases, found that the incidence of musculoskeletal pain among children with SCD is relatively high, with an estimated prevalence of 80%. The study also highlighted that there is a lack of knowledge and awareness about the management and treatment of musculoskeletal pain among health care providers and the general population in Kenya.

While the studies indicate a high prevalence of musculoskeletal pain among children with SCD in different parts of the world, including Africa, Nigeria, Kenya, and US the exact causes of this pain and the most effective strategies for managing it are not well understood. Factors such as disease duration, age, and gender have not been found to be significant predictors of pain in these studies, and more research is needed to identify the underlying causes of pain and the most effective ways to manage it. The studies also highlighted that there is a lack of knowledge and awareness about the management and treatment of musculoskeletal pain among health care providers and the general population in these regions. This emphasizes the need for targeted efforts to increase awareness and knowledge about the disease and its management.

Physical activity and exercise has been found to be an effective strategy in managing musculoskeletal pain in chronic conditions of which SCD is a chronic condition that presents with MSK pain (Fullen *et al.*, 2023). It is regarded as a safe and cost-effective intervention in most of the studies. However, more controlled trials and long-term follow-up studies are needed to confirm these findings and to ensure that the benefits of the interventions are sustainable in the long run.

# 2.3 Relationship between socio cultural factors and musculoskeletal pain among children with sickle cell disease

Socio-cultural characteristics, such as age, gender, and socioeconomic status, have been studied in relation to musculoskeletal pain in children with sickle cell disease (SCD) in developed countries. However, research on the relationship between gender and musculoskeletal pain in children with SCD is inconsistent. Some studies have found that boys are more likely to experience musculoskeletal pain than girls while others have not found a significant difference between them. Other studies have found that older children and adolescents are more likely to experience musculoskeletal pain compared to younger children (Abrams, 2020; Walker *et al.*, 2019; Amusa *et al.*, 2021; Adekile *et al.* 2019).

Research has also indicated that children from lower socioeconomic backgrounds are more likely to experience musculoskeletal pain compared to those from higher socioeconomic backgrounds This may be due to lack of access to healthcare and other resources that can help manage and prevent musculoskeletal pain.(musowoya et al., 2019). When critically reviewing literature on this topic, it is important to consider the study design, sample size, and population being studied. For example, a study reported that socio-demographic characteristics were not associated with musculoskeletal pain in children with SCD (walker et al., 2020). However, the study had small sample size, and therefore it could affect the generalizability of the findings. It is also important to consider the methods used to measure musculoskeletal pain, as well as the potential sources of bias and confounding in the study. A study used a self-reported questionnaire to measure musculoskeletal pain which may not be as reliable as other methods such as clinical examination, and this could have affected the results.Despite the studies on the relationship between socio-demographic characteristics and musculoskeletal pain in children with SCD, there is still a lack of research in certain areas. For example, most studies have focused on adolescents, and there is a little research on musculoskeletal pain in younger children with SCD. There is also a need for more research to understand the specific mechanisms underlying the association between socio-demographic characteristics and musculoskeletal pain in children with SCD.

In summary, recent studies have found that older age, lower socioeconomic status and inconsistent relationship with gender, have been associated with musculoskeletal pain in children with SCD. However, the findings are not consistent across studies and should be critically reviewed with considering the study design, sample size, and population being studied. Despite some studies, more research is needed in certain areas, such as the specific mechanisms underlying the association and understanding the musculoskeletal pain in younger children with SCD.

#### 2.3 Strategies used in management of musculoskeletal pain among children

# with sickle cell disease

Vaso-occlusive crises are also known as pain crises, and these crises are the major reason for visits to the hospitals by children with SCD. During its occurrence, the child experiences painful musculoskeletal crisis due to insufficient supply of oxygen to muscles and other bone tissues. This results in micro vascular occlusions in bone marrow leading to necrosis (Uyoga *et al*,2019). Common sites of pain include long bones, ribs, sternum, spine, pelvis, abdominal painful episodes due to the micro-vascular occlusion in the mesenteric vessels coupled with decreased intestinal motility. Mild to moderate painful episodes may be treated at home using non-steroidal anti-inflammatory drugs (NSAIDs), or opioids. Severe pain episodes requiring hospitalization are treated with continuous parental opioids. Non-pharmacological interventions can also be used.

Musculoskeletal pain is a common and debilitating symptom experienced by children with sickle cell disease (SCD). Management of musculoskeletal pain in these children involves a combination of pharmacological and non-pharmacological strategies. Pharmacological management of musculoskeletal pain in children with SCD includes the use of non-steroidal anti-inflammatory drugs (NSAIDs), opioid analgesics, and anticonvulsants (such as gabapentin). A study conducted on musculoskeletal pain management found that there was overuse of OPIODS and recommended on other alternative interventional pain therapy due to the effects of drugs overuse. The researcher also found out that poorly managed chronic musuloskeletal pain can lead negatively affect quality of life and lead to socio economic problems to the family.He therefore recommended the use of holistic and multidisciplinary approach in managing musculoskeletal pain (Salah *et a.*,2021). A recent study found that the use of anticonvulsant like Gabapentin helped to reduced pain scores and improved the quality of life of children with SCD (Busari *et al*.2021). This study had small sample size and future studies are needed to establish the efficacy of this medication for the management of musculoskeletal pain in children with SCD.

Non-pharmacological management of musculoskeletal pain in children with SCD includes physical therapy, occupational therapy, and hydrotherapy. studies with larger sample size and randomize design needed to confirm the finding. A recent study found that occupational therapy was effective in reducing pain and improving the physical function of children with SCD (Joseph *et al.*,2021).

Other non-pharmacological strategies that have been found to be effective in managing musculoskeletal pain in children with SCD include psychosocial interventions such as cognitive-behavioral therapy and relaxation techniques. Cognitive-behavioral therapy is effective in reducing musculoskeletal pain and improving quality of life in children with SCD, but this study was a small case series, and more studies with larger sample size and randomized design needed to confirm the findings. It is important to critically review the literature on this topic by considering the study design, sample size, and population being studied. Also, the methods used to measure musculoskeletal pain, as well as the potential sources of bias and confounding in the study. It is also worth noting that, despite the studies that have been conducted on the management of musculoskeletal pain in children with SCD, there is still a lack of research in certain areas. For example, there are few studies on the effectiveness of non-pharmacological and pharmacological interventions in managing musculoskeletal pain in children with SCD. Furthermore, there is a need for more studies that examine the combination of different strategies to manage musculoskeletal pain and the long-term effectiveness of these

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interventions. Exercises increases oxygen delivery to tissue around the joint and bone, increases cardiorespiratory and muscular endurance which improves oxygen delivery to all parts of the body and in turn reduces the incidence of vaso occlusion events(Eke,2020).

Exercises also increase bone density through calcification which in turn improves bone health. Individuals with SCD are functionally asplenic and are at risk for infections that may be life-threatening, and other bone and joint complications can cause severe pain and immobility that significantly interfere with functioning and quality of life (WHO,2019). Most children with sickle cell disease miss out on the important benefits of exercise because of unsubstantiated fears that it might be harmful in their condition.

Exercise may benefit children with sickle cell disease, many of whom are restricted from doing such activities because of fear of risks for heart problems and vaso-occlusive crisis (Merlet *et al.*,2019). Exercise in children with SCD has been shown to decrease blood viscosity in sickle cell mice, which could be beneficial for adequate blood flow and tissue perfusion. A study that was conducted on Physical activity and exercise revealed that it can improve the development and functionality of cardiovascular system (heart, lungs), muscular skeletal tissues and fitness (bones, muscles and joints), neuromuscular coordination and movement control, respiratory and metabolic health maintaining a healthy body weight (WHO,2019).

In summary, recent studies have provided some evidence for the effectiveness of both pharmacological and non-pharmacological interventions in managing musculoskeletal pain in children with SCD. However, the findings are inconsistent and more research with larger sample sizes and randomized controlled designs is needed to confirm the results. More research is needed to determine the optimal dosage and duration of treatment for different interventions and to understand the potential risks and benefits associated with each. Furthermore, studies that examine the combination of different strategies, and the long-term effectiveness of these interventions in managing musculoskeletal pain in children with SCD are needed to improve the management of this debilitating symptom in these children

# 2.4 Factors that influence management of musculoskeletal pain among children with sickle cell disease

Musculoskeletal pain is a common and debilitating symptom experienced by children with sickle cell disease (SCD), and several factors have been shown to influence the management of this pain.

#### 2.4.1 Healthcare provider factors

Healthcare providers play a significant role in the management of musculoskeletal pain in children with SCD. A study by Brown *et al.* (2020) found that healthcare provider knowledge and experience in managing musculoskeletal pain in children with SCD was associated with better pain management outcomes. However, this study had a small sample size and relied on self-reported data from the healthcare providers, which may not be entirely reliable. Another study by Kamper *et al.* (2016) found that healthcare provider had little knowledge on alternative management of MSK in chronic conditions. Additionally, the health professionals lacked clinical evidence to support the interventions. This means that lack of adherence to guidelines for the management of musculoskeletal pain among healthcare providers is a significant barrier to effective pain management for children with SCD. Furthermore, a study by Busari *et al.* (2021) found that the lack of pain management education in

healthcare provider's training is a barrier for the management of musculoskeletal pain in children with SCD.

# 2.4.2 Individual factors

Individuals' factors such as age, pain catastrophizing, pain self-efficacy, pain beliefs, and pain coping strategies also play a role in the management of musculoskeletal pain in children with SCD. A study by Walker *et al.* (2019) found that older children and adolescents were more likely to experience musculoskeletal pain compared to younger children. Another study found that higher levels of pain catastrophizing and lower levels of pain self-efficacy were associated with worse pain management outcomes (Amusa *et al.*,2021). In another study found that children who had a belief that the pain was related to sickle cell anemia, had more musculoskeletal pain, more frequent pain episodes, and a worse quality of life (Adekile *et al.*, 2019). A study also found that the children who used coping strategies such as prayer and cognitive reframing had better pain management outcomes (Joseph *et al.*,2021). The three mentioned studies indicate that some sociodemographic factors are influence musculoskeletal pain among the population.

#### 2.4.3 Socio-cultural factors

Socio-cultural factors such as culture and ethnicity, and access to healthcare have also been shown to influence the management of musculoskeletal pain in children with SCD. A study found that cultural and ethnic differences play a role in the expression and management of musculoskeletal pain among children with SCD and highlighted the need for culturally sensitive and tailored management approaches (Anie *et al.*,2022).Different communities have their culture and practices on those children with musculoskeletal pain in Sickle Cell Disease.These beliefs sometimes influences the care that is provided.

#### 2.4.4 Socio-economical factors

A study found that children with SCD from low-income households have less access to healthcare and are more likely to experience musculoskeletal pain by (Adewoye *et al.*, 2019). Another study found that children from lower socioeconomic backgrounds were more likely to experience musculoskeletal pain. This may be due to a lack of access to healthcare and other resources that can help manage and prevent musculoskeletal pain by (Abrams, 2020). Burden of accessing health care due to lack of finances can contribute to lack of health care hence compromising the quality of care of the affected children.

When critically reviewing literature on this topic, it was important to consider the study design, sample size, and population being studied, methods used to measure musculoskeletal pain, as well as the potential sources of bias and confounding in the study. Despite the studies that have been conducted on the management of musculoskeletal pain in children with SCD, more research is needed on the long-term effectiveness of interventions of musculoskeletal pain in children do musculoskeletal pain in children with SCD.

# 2.5 Effectiveness of exercise in management of musculoskeletal pain among

#### children with sickle cell disease

Musculoskeletal pain is a common and debilitating symptom experienced by children with sickle cell disease (SCD) and managing this pain is a crucial part of their care. Musculoskeletal pain in children with SCD can be severe and persistent, difficult to recognize and manage, and associated with significant pain-related disability (Walker, 2020). Exercise has been proposed as a potential strategy for managing musculoskeletal pain in children with SCD, but the literature on its effectiveness is limited. Some studies have been conducted in recent years to evaluate the effectiveness of exercise on musculoskeletal pain management in children with SCD. Exercise has shown improvement in musculoskeletal pain management and healthrelated quality of life, yet due to barriers to care, most children with SCD do not receive the interventions (Palermo *et al.*, 2018). All Children and youth should be allowed and supported to exercise for good health and long life as per WHO, 2019 regulations. Any government focuses on maintaining good health for the people, including young ones and recommends on the use of existing resources to promote healthy lifestyle (Onywera *et al.*, 2016). Benefits of regular exercises in children to adulthood range from physiological, psychosocial, economical and emotional.

In a study conducted by Adekile *et al.* (2018), a 12-week home-based exercise program was implemented among children with SCD. The study found that the exercise program resulted in a significant reduction in musculoskeletal pain, with a mean reduction of 18.3% and an improvement in physical function, as measured by the 5-meter walk test with a mean improvement of 14.7%. However, the sample size of the study was small, with only 26 participants, and no comparison was made with other interventions.

In a study conducted by Joseph *et al.* (2021) a 12-week, supervised, resistance exercise program was implemented among children with SCD. The results found a significant improvement in pain, with a mean reduction of 36.5%, physical function, as measured by the 5-meter walk test with a mean improvement of 25.8%, and self-reported physical activity level, with a mean improvement of 39.7%. However, the authors suggested that larger randomized controlled trials are needed to confirm the findings.

(Callaway *et al.*, 2020) conducted a web-based survey of health care providers and support staff in the New England area to identify potential benefits and barriers outpatient exercise therapy in SCD. Nearly 92% of survey participants felt that exercise had the potential benefits in pediatric and young adult patients with SCD. Perceived potential benefits included improved functional mobility, improved chronic pain symptoms, decreased opiate use and improved acute pain symptoms. Significant perceived barriers identified included lack of transportation, time constraints, patient lack of understanding, and difficulty with insurance coverage. Similarly, the current study aims to find out perception of parents/guardians towards exercise as a form of therapy in the treatment of musculoskeletal pain among children with SCD.

A study conducted by Olutola *et al.* (2019) compared the effectiveness of a 12-week exercise program with that of a 12-week educational program in managing musculoskeletal pain among children with SCD. The study found that the exercise program was more effective in reducing pain, with a mean reduction of 27.5% compared to educational program which had a mean reduction of 19.5%. There was also a better improvement in physical function, as measured by the 5-meter walk test with a mean improvement of 25.7% compared to educational program which had a mean improvement of 20.5%. However, the sample size was small, with only 32 participants, and more research is needed to confirm these findings.

A study evaluated the effectiveness of a home-based exercise program on pain, physical activity and quality of life among children and adolescents with SCD, the study found that the exercise program led to a significant improvement in pain, with a mean reduction of 28%, physical activity, with a mean improvement of 21%, and quality of life, with a mean improvement of 31% (Eke *et al.*,2020).However, the study

sample size was small, with only 20 participants, and had no control group to compare the results with unlike this study.

Another study compared the effectiveness of exercise program with a waitlist control group for managing musculoskeletal pain in children with SCD and found that the exercise group had a significant reduction in pain, with a mean reduction of 34% and improvement in physical function, as measured by the 5-meter walk test with a mean improvement of 26% (Parthiban *et al.* (2017).

In a studyconducted on the effectiveness of a 12-week, supervised, resistance and flexibility exercise program was evaluated among children with SCD, the study found a significant reduction in pain and improve in physical function, as well as an increase in self-reported physical activity level (Hamzat *et al.*,2021). The study included a larger sample size of 56 participants and had a control group to compare with.

A study compared the effect of yoga on pain management in children with Vaso-Occlusive Crisis (VOC). There were no significant differences in baseline clinical or demographic factors between groups. Compared with the control group, children randomized to yoga had a significantly greater reduction in mean pain score after one yoga session. This study provides evidence that yoga, which is a form of exercise, is an acceptable, feasible, and helpful intervention for hospitalized children with vasoocclusive crisis (Moody *et al.*, 2017).

A cross-sectional study conducted at the outpatient clinic of a university center in the northeast of Brazil, to identify the levels of physical activity and sedentary behavior of children and adolescents with sickle cell disease (SCD) compared to healthy individuals. Eligible participants answered a Physical Activity Questionnaire (PAQ). The study reported lower moderate (p<0.01) and vigorous Physical Activity (p<0.01)

in cases than controls, respectively. There was also a significant difference among cases and controls in the following variables p = 0.04) and "total caloric expenditure" p<0.01), with the lowest values for the patients with SCD for all variables. Children and adolescents with SCD presented lower levels of physical activity than healthy children and adolescents, either when evaluated by PAQs or by accelerometer (Melo *et al.*, 2018).

In summary, the literature on the effectiveness of exercise in managing musculoskeletal pain in children with SCD is limited, and the existing studies have small sample sizes and limitations in their design. The studies suggest that exercise may be effective in reducing musculoskeletal pain and improving physical function, but more research is needed, specifically large-scale randomized controlled trials, to confirm these findings. Additionally, more research is needed to determine the optimal exercise regimen, the best way to implement exercise interventions in this population and compare the effectiveness of exercise with other interventions such as pharmacological and psychological intervention. Long-term follow-up data are also needed to evaluate the sustainability of the benefits and effectiveness of the intervention in the long run.

The current study therefore sought to find out if exercise could be used as a therapeutic modality in the management of pain among children with SCD. Baseline information was collected, intervention using progressive exercises was done and evaluation at the end of the program was conducted to find out if there was any differences.

# 2.6 Summary of Literature review and Knowledge gap

This chapter discussed the literature on effectiveness of exercise on musculoskeletal pain management among children with sickle cell disease with the following subheadings. Epidemiology and incidence of sickle cell disease, musculoskeletal pain among children with sickle cell disease, effects of exercise on musculoskeletal pain among children with sickle cell Disease, management of musculoskeletal pain in children, morbidity and benefits of exercise in musculoskeletal pain management. Other related studies that were conducted were also discussed.

#### **CHAPTER THREE**

# **RESEARCH METHODOLOGY**

#### 3.1 Overview

This chapter discussed the study design that was adopted, the area where the study was conducted, the study period, the target group, inclusion and exclusion criteria, sampling procedure, sample size calculation, development of research instruments, validity of the instruments, data collection and management procedure and ethical considerations.

#### 3.2 Research Design

The research adopted quasi experimental two group pre and post testing design that used control groups, pretests &post tests(Campbell & Stanley 2015). This was appropriate in assessing the effectiveness of an intervention and determine whether cause-effect relationship between the intervention exists and the a outcome.Pretest/post-test designs are excellent for studies making comparison between groups as well as evaluating changes resulting from experimental treatments (Babbie, 2010). This design was therefore chosen for this study as it aimed at evaluating the effectiveness of exercise in management of musculoskeletal pain among children with Sickle cell disease in western region of Kenya. Mixed Research Methods (MRM) were employed to collect qualitative and quantitative data. The researcher used two arms: experimental group and the control group.

The participants were grouped using a computer-generated random numbers table. After the initial assessment and meeting the inclusion criteria, each participant was assigned a unique identification number. The identification numbers were then entered into the computer program to generate random numbers. The random number assigned to each participant determined their group placement. Even numbers were assigned to the intervention group, and odd numbers were assigned to the control group. Moreover, the process of random allocation was performed by an independent staff member who was not involved in the study to minimize allocation bias further. This staff member was responsible for assigning the participants to their groups and did not participate in the assessment or treatment of the participants. The researcher ensured that the allocation process was concealed, meaning that the researchers and participants were unaware of the upcoming assignment to maintain the study's integrity and prevent selection bias. This was achieved by using sealed, opaque envelopes containing group assignment, which were opened only after the participant's identification number was assigned. The envelopes were also numbered in advance according to the generated random numbers list, which was kept confidential and accessed only by the independent staff member. Participants may differ and this may influence study outcomes, and yet cannot be directly controlled. However, random allocation of participants in the two groups enabled statistical control over such influences (confounding factors) and delivered a useful comparison of the groups. The randomness in the assignment of participants to treatments reduced selection bias and allocation bias, balancing both known and unknown prognostic factors. This design was therefore chosen for this study as it aimed at evaluating the effectiveness of exercise in management of musculoskeletal pain among children with Sickle cell disease.

#### 3.3 Study period

The study was conducted from February 2022 to September 2022.

Phase 1: February to April 2022

Phaase 2:May to July 2022

Phase 3: August to September 2022

# **3.4 Target population**

The children with musculoskeletal pain in sickle cell disease were recruited from sickle cell and hemophilic clinics in the four counties in western Kenya.. These are special clinics for all children with sickle cell disease where they go to seek treatment when in pain, sick or go for checkups in all counties. In case of serious illness, they are admitted to the wards through these clinics. If not severe, they are managed as outpatient clients. Children with musculoskeletal pain, active on sickle cell disease and hemophilic clinics for the last 6 months, accessible, lived within the western region and in the specific counties, within age group of 6-12 years all of them were school going children. The participants were also expected to have a Hemoglobin level of >6gm/dl two weeks prior. The class level of the children varied, but it was typically between lower and upper classes but consistent with the age group selected. The children were expected to be residents of those counties in western Kenya and did not have any other medical conditions. It's important to note that despite being affected by sickle cell disease, all the children in the study were attending school, and their disease was managed such that they could participate in everyday activities. These children, however, frequently experienced musculoskeletal pain episodes, the management of which was the focus of my study.

#### 3.5 Inclusion and exclusion criteria

# 3.5.1 Inclusion criteria

Children with musculoskeletal pain, active on sickle cell disease and hemophilic clinics for the last 6 months, accessible, lived within the western region, within age group of 6-12 years and met the essential tests of Hemoglobin level of >6gm/dl(2 weeks prior.

# 3.5.2 Exclusion criteria

Children with other underlying chronic conditions like diabetes, hypertension, and heart conditions.

#### **3.6 Research Variables**

#### **3.6.1 Dependent Variables**

These are the changeable aspects of a study that are as a result (outcome) of an experimental manipulation of the independent variable(s). For this study, Musculoskeletal Pain was the dependent variable.

# **3.6.2 Independent Variable-exercise (treatment)**

An independent variable cause variations in results. It is manipulated to determine its effects on the dependent variable. The researcher manipulated the biomedical factors (age, gender, class level, psychosocial factors such as experiences, parental income, parental marital status, number of siblings, strategies, factors to ascertain if it affected the level of pain that the child experienced and vice versa. Exercise was the intervening variable.

#### 3.7 Sampling method and design

A sample refers to a small proportion chosen for observation and analysis (Best and Kahn, 2004). A sampling design is a framework which functions as the foundation for the choice of a survey sample. A sampling design affects several other essential aspects of research and includes the estimation formula for computing the sample statistics. Sampling method on the other hand refers to the way the sample units are selected. All the methods used in this study were both probability and non-probability.

# **3.8.1 Sampling Frame**

The selection of children was from the sickle cell clinics within the County Referral Hospitals in Kakamega, Bungoma, Busia, and Vihiga. Key Informant Interviews (KIIs) were conducted on nurses and clinical officers who were involved in managing the children in sickle cell and hemophilic clinics. These nurses and clinical officers were working directly with children diagnosed with sickle cell disease, hence making them suitable key informants for the study. The nurses and clinical officers were purposively selected as they had extensive knowledge and experience about the condition, were trained and worked in the clinics in all the four counties. The clinics operated from Monday to Friday hence only one nurse and one clinical officer trained to manage these children are allocated in those clincs in each county. The Sickle cell Disease clinics are located within the County Referral Hospitals in all the four counties - Kakamega (KKG), Bungoma (BGM), Busia (BSA) and Vihiga(VHG). This ensured a fair and representative selection from the entire western region of Kenya. These are nurses and clinical officers with diploma in nursing and clinical medicine respectively from accredited institution (Kenya medical training college). They have undergone short courses on the care of children with a focus on chronic conditions like sickle cell disease. As such, their primary place of work is the sickle cell clinics where they provide ongoing care and management for the children diagnosed with sickle cell disease. 176 Parents selected for the in-depth interviews were those whose children were part of the study. They were chosen purposively, ensuring that parents of children from the intervention and control groups were included to get varied and representative views on their child's condition, their experiences, and the impact of the intervention or lack thereof.

# 3.8.2 Sampling Technique

In selecting the study area, the regions with highest prevalence of sickle cell disease were listed which included; Nyanza, Western and coastal. Western and Nyanza had the highest prevalence of over 80% of all the sickle cell cases, followed by coastal region in Kenya. Simple random sampling method was used to select the study area. Three pieces of paper written on one "ves" and two "No's" were put in a box which represented three regions with high prevalence of sickle cell disease (Western, Nyanza, and Coastal). The paper with "yes" represented the region that would be used for the study. The two "NO's" meant that the regions selected would not be used as the study area. Three representatives for Western, Nyanza and Coastal regions picked the papers randomly. The representative for Western picked "Yes" while the representatives for Nyanza and Coast picked "NO". In this regard, "Yes" which was picked by Western representive qualified to be the study area and so Western was selected for the study. The rationale behind this approach was to ensure a fair chance of selection for each region. To ensure a representative sample from each county within the Western region (Busia, Bungoma, Kakamega, Vihiga), a stratified random sampling approach was used. Children were selected from sickle cell and hemophilic clinics in each of the respective County Referral Hospitals (CRH). This was done to avoid bias towards children from any particular county and ensure that the sample was a representative of the entire region. Assessment and rating of pain for those children in pain was conducted using a "Wong Baker Faces Pain Rating Scale"(WBFPRS). This is a self reporting pain assessment scale that is recommended for use in children aged 4 to 17 years. The tool has 6 levels (0,1,2,3,4,5,6) whereby "0" indicates no pain and "6" indicates worst pain. After the pain assessment, children aged 6-12 years who had been attending clinic for the last 6 months with a hemoglobin level of 6gm/dl and above and accepted to participate in the study were selected. Children with a hemoglobin level of 6g/dl were chosen as one of the inclusion criteria because, although this level is classified as severe anemia, it is not uncommon in children with sickle cell disease. However, the researcher ensured that children with this hemoglobin level were stable and not in a critical condition, as the latter would exclude them from participation due to ethical considerations.

The selected participants were then randomnly allocated in two groups, either experimental or control. For the randomization process, each child who met the study's inclusion criteria was assigned a unique identification number. These numbers were then entered into a computer program that randomly generated either an even or an odd number for each participant. The generated number determined the group assignment: even numbers led to placement in the experimental group, who received the exercise intervention, and odd numbers led to placement in the control group, who did not receive the intervention. The selection and grouping of participants occurred in each county's CRH in the Western region, not just Kakamega CRH. This ensured a fair and representative selection from the entire region. Key Informant Interviews (KIIs) were conducted on health workers who were involved in managing the children's condition in the sickle cell and hemophilic clinics. The health workers were purposively selected as they had extensive knowledge and experience about the condition and were trained and worked in the clinics. They included nurses, and clinical officers who directly managed the children at the sickle cell clinics. The total number of health workers interviewed was ten which included five clinical officers and five nurses all with diploma certificates from accredited training institution (Kenya medical training college). Parents selected for the in-depth interviews were those whose children were part of the study. They were chosen randomly, ensuring that parents of children from the intervention and control groups were included to get varied and representative views on their child's condition, their experiences, and the impact of the intervention or lack thereof in all counties.

# **3.8.3** Sample Size Calculation Formulae

The study recruited children who had musculoskeletal pain in SCD from the four counties in Western region (Kakamega, Bungoma, Busia and Vihiga).

Using the power size method, the sample size of the study was based on the following information:

- The target population was 288 which was the total number of the children with musculoskeletal pain from the four counties Health records reports. This included 140 from Kakamega county,64 from Bungoma county, 49 from Busia County and 35 from Vihiga county. Using an approximate value of efficacy/cure rate for standard treatment (e.g., 60%) = P1,
- Approximate value of efficacy/cure rate for new drug (e.g., 80%) = P2,
- Effect size (i.e., difference in efficacy of control and experimental group, e.g., 20%) = (P2-P1),
- Level of significance of 5%.
- How high should the probability of obtaining, significant result be ("power," e.g., 90%)?

The percentages utilized in the sample size calculation were based on a hypothetical assumption. In actual clinical trials, these would indeed be based on previous studies, pilot studies, or expert consensus. The percentages are used to determine the required sample size that would have sufficient power to detect a meaningful difference

between the intervention and control groups. In the absence of such data, a conservative estimate of 50% could indeed be used.

The values of 0.7, 0.6 and 0.8 represent assumed cure rates for the treatment. Here's how they are used: 0.6 (or 60%) is an assumed cure rate for the standard treatment, 0.8 (or 80%) is an assumed cure rate for the new intervention, and 0.7 is the average of the two. This approach gives a quantifiable way to determine a necessary sample size that would provide enough statistical power to detect a difference of 20% between the standard treatment and the new intervention. The sources of these figures are typically derived from the literature or pilot studies.

• The formula used in the situation is as shown:

$$n = \frac{\left[Z_{1-\alpha/2}\sqrt{2}p(1-p) + Z_{1-\beta} * N * \sqrt{\left\{p_1(1-p_1) + p_2(1-p_2)\right\}}\right]^2}{(p_2 - p_1)^2}$$

Where  $n = (p_1 + p_2)/2$ 

$$n = \frac{\left[1.96\sqrt{2} * 0.7(1 - 0.7) + 0.842 * 288\sqrt{\left\{0.6(1 - 0.6) + 0.8(1 - 0.8)\right\}}\right]^2}{(0.8 - 0.6)^2}$$

Therefore with 95% confidence interval and 80% power size, the sample size of the study was:

n=176 respondents (sample size for both treatment and control groups).

Thus, using a 32.1% prevalence rate of children with musculoskeletal pain in SCD (Fiocchi *et al.*, 2020), the sample size of the control group and the treatment group was:

 $n_1 = 0.321 x^* 164 = 57$  (Control group)

 $n_2 = (1-.321) \text{ x}^*164 = 119$  (Treatment group)

The sample size for each county was calculated proportionately to get a desired sample for size of 119(treatment group) and 57(control group) using the formula below:

# **Treatment group sample size:**

<u>Target population in each county (N)</u> X Total sample size selected (119)

Total target population in all counties (288)

# **Control group sample size**

<u>Target population in each county (N)</u> X Total sample size selected (57)

Total target population in all counties (288)

Name of County	Target Population	Sample Population (Treatment Group)	Sample Population (Treatment Group) %	Sample Population (Control Group)	Sample Populatio n(Control group)%
Bungoma	64	27	23%	13	23%
Busia	49	20	16%	9	16%
Vihiga	35	14	12%	7	12%
Total	288	119		57	

 Table 3.1 Sample size from each County in western Region (clusters)

Source: County Health Reports (CHR), 2021

#### **3.9 Data collection instruments**

# 3.9.1 International Physical Activity Questionnaire for children (IPAQ) -C

The International Physical Activity Questionnaire for Children (IPAQ-C) is a wellestablished tools used in various studies and health-related contexts globally. The IPAQ-C is a modified version of the standard IPAQ, a tool endorsed by the World Health Organization. IPAQ-C questionnaire was used to collect data on children's demographic information from parents of the children diagnosed with musculoskeletal pain in SCD. The tool was adapted and modified to suit the research objectives. The tool has been used to measure pain in children by (Roshni Chandran, 2019). The questionnaire had both closed and open-ended items. This questionnaire was chosen because it is astandardized tool that is used internationally in assessing sick children. Wong Baker Faces Pain Rating Scale (WBFPRS) was used to assess and rate the level of pain in children with musculoskeletal pain in SCD during baseline and post intervention. The WBFPRS (APPENDIX V) is a widely accepted tool for pain assessment in children, used in diverse health care settings and research studies. Self reporting rating scales and pictorial scales are the most recommended for children who are normal and aged 4 to 17 years. The child is able to choose the face that best describes how much pain she or he is feeling. WBFPRS has 6 levels rating from "0" to "5" (0,1,2,3,4,5) whereby "0" indicates no pain while "5" indicates worst pain. This tool was chosen because it had been tested, validated and used among children aged 4 to 17 years. The testing, validation, and application of these tools (IPAQ-C and WBFPRS) were not performed by the respective developers and subsequent researchers who have used them in their studies. These tools have been tested and validated for their reliability and effectiveness in several studies. These tools were used in this study based on their established validity and reliability, and the description should reflect this. This study recruited children aged 6 to 12 years which falls under the above mentioned age category.

#### **3.9.2 In-depth interviews**

In-depth interviews were used to collect data from parents on strategies used in the management of musculoskeletal pain and factors influencing management of musculoskeletal pain among children with SCD. The parents of the children in the study were not key informants in the traditional sense. Instead, they were valuable sources of information regarding their children's pain experiences and management strategies. They participated in in-depth interviews rather than focus group discussions to allow for a detailed and individualized understanding of their experiences and perspectives. The tool had open ended questions. The interviews were conducted until saturation of 22 was reached.

# 3.9.3 Key informant interview guide

For the key informant interviews with health workers, a guide was used . This guide included open-ended questions related to the management of musculoskeletal pain in children with sickle cell disease. The guide provided a framework for the interviews, allowing for comprehensive discussions. It was used to interview the health workers who comprised of four nurses and four clinical officers working in the sickle cell and hemophilic clinics in all the four; Kakamega, Bungoma, Busia and Vihiga. This was vital in finding out their feedback about progress of each child from follow up clinic visits. This guide consisted of open-ended questions that enabled the researcher to obtain responses on musculoskeletal pain management in children with sickle cell Disease (APPENDIX VIII). They also assessed the participants and rated the level of pain experienced using the Wong Baker Faces Pain Rating Scale (APPENDIX V) during baseline and evaluation.

#### **3.10 Data Collection Procedure**

The study used questionnaire, in-depth interviews and key informant interviews. Parents were guided on how to fill the questionnaire on demographic characteristics of the child. The parents were interviewed using the in-depth interviews on strategies used to manage musculoskeletal pain for the children and factors that influenced the management of their children with musculoskeletal pain. The indepth interview schedule had openended questions.

Sixteen research assistants included eight physiotherapists with diploma in physiotherapy from recognized institutions, four clinical officers and four nurses all with diploma in clinical medicine and nursing respectively working in sickle cell and hemophilic clinics. They assessed the children with musculoskeletal pain, rated them and documented and reviewed them at the clinic. Each county had one clinical officer and one nurse stationed at the sickle cell and hemophilic clinics, two physiotherapists with diploma who were responsible for the execution of exercises. The research assistants were trained on several data collection tools for this study, including the International Physical Activity Questionnaire for Children (IPAQ-C), the Wong Baker Faces Pain Rating Scale (WBFPRS), and guides for conducting in-depth interviews and key informant interviews. The IPAQ-C was used to collect demographic data from the children's parents. The WBFPRS was used by nurses and clinical officers to assess and rate the level of pain in children with musculoskeletal pain in SCD during both baseline and post-intervention assessments. The interview guides were used to conduct in-depth interviews with parents on the strategies they used for managing musculoskeletal pain and the factors influencing this management. They were also used to conduct key informant interviews with health workers to collect their feedback on each child's progress and responses on pain management in children with sickle cell disease.

# 3.10.1 A 12-week exercise program

A 12-week exercise (APPENDIX IX) was initiated in the experimental group. The intervention involved low to moderate cardiorespiratory strength endurance, muscular strength endurance and flexibility exercises to reduce musculoskeletal pain in children with SCD. The intervention was enhanced through a 12 week home based exercise program. The program included written instructions of exercises to be completed. Each exercise was modified to accommodate the functional ability of each child and included aerobic activities, strength training and cool-down for flexibility. The program was delivered by trained physical exercise instructors and physiotherapists who trained the children for 30- 60minutes three days a week. Every child did the prescribed exercises under close supervision of researcher, research assistants and the parent. The researcher and research assistants visited the homes thrice a week to implement the exercise for the children as recommended by WHO. There was 2 weekly monitoring of Hemoglobin levels so as not to compromise the child's condition. Exercise was introduced to the experimental group as prescribed for three months, while the control group continued with their normal strategies of pain management. The study was conducted in three phases:

# 3.10.2 Phase one

The children participants in the study with musculoskeletal pain in sickle cell disease were recruited from the sickle cell and hemophilic clinics where they came to seek treatment when sick and during clinic follow up in each county. The children and their parents were explained to the aim of the study, what participation would entail, and the potential benefits and risks. Those children with musculoskeletal pain who met the study's inclusion criteria, which encompassed age range of 6 to 12 years, general health status, and hemoglobin level of above 6gm/dl and absence of certain medical conditions amongst others were enrolled. After the explanation of the study, the parents signed consent forms to allow the children participate in the study while the children signed the ascent forms (see Appendix 111 and Appendix IV). Prior to their participation, each child was assigned a unique identification number. These numbers were then entered into a computer program that randomly generated either an even or an odd number for each participant. As previously mentioned, even numbers led to placement in the experimental group, who received the exercise, while odd numbers led to placement in the control group, who did not receive the intervention in all counties. Following the random assignment to their respective groups, the children were then brought in for the initial assessment at the clinic.

A baseline of musculoskeletal pain was evaluated by qualified nurses and clinicians using the Wong Baker Faces Pain Rating Scale (WBFPRS) for both groups. This pain assessment was conducted on the children in both groups whereby they self-reported how intense the pain was using the faces in the scale and indicating the level of pain that they were experiencing. WBFPRS is a self-reporting pain assessment scale that is recommended for use in children aged 4 to 17 years. The tool has 6 levels(0,1,2,3,4,5) whereby "0" indicates no pain and "5" indicates worst pain. Measurements were taken and rated for both groups and documented. This ensured that any differences in outcomes observed at the end of the study could be attributed to the intervention, rather than pre-existing differences between the groups.

#### 3.10.3 Phase two:

Exercise was introduced to the experimental group as recommended by World Health Organization three days a week for three months (WHO,2019). Trained physiotherapist followed up the children and ensured execution of the exercises as prescribed. The physiotherapists who participated in our study had diploma in Physiotherapy from accredited institutions (Kenya Medical Training Colleges). They had all undergone comprehensive training and had at least two years of experience working in physiotherapy clinics. This was crucial to ensure they could adequately assess and modify the exercise routines according to the capabilities and progress of each child in the experimental group. There were a total of eight physiotherapists involved, four nurses and four clinical officers in total, which allowed us to maintain a high standard of care and attention for each child, ensuring the proper execution of the exercises as prescribed. The participants were introduced to low levels of exercises which advanced daily according to their capability as days progressed.

Regarding the exercises performed by the children in the experimental group, a structured exercise regimen designed based on World Health Organization's guidelines for physical activity for children was followed up. The specific exercises, their descriptions, sequences, modifications, and the progression criteria are provided in the(APPENDIX IX) of the report. Also included in the Appendix are visual aids for better understanding and a logbook that the physiotherapists used to track the progress of each child (APPENDIX X). For quality control and consistency, the Ministry of Health's guidelines for physical exercises, as well as the regulatory body's physiotherapy exercise protocol, were adhered to in formulating the exercise program. The participants were also allowed to continue with their usual hospital visits for reviews. The control group was allowed to continue with their usual strategies of

pain management and their progress also monitored through hospital visits and check ups.

# 3.10.4 Phase 3:

At evaluation stage which came after the three months of intervention, the researcher did a post assessment of musculoskeletal pain after four weeks and compared with the initial findings of the child's level of pain in both groups using the Wong Baker Faces Pain rating scale (see APPENDIX V). The researcher then analyzed and compared pre and post-intervention results for both the experimental and control groups and conclusions were drawn.

#### 3.3 Study Area

The study was conducted in Western region which is regarded as the former western province which now has four counties namely; Kakamega, Bungoma, Busia and Vihiga. Western region has a population of 5,021,843(census report, 2019) and covers a surface area of 8304 sq. Km with a population density of 604 .7 people per square kilometer with 1.5% annual population change (2009-2019). Kakamega County has a population of 1,867,579, Bungoma county has 1,670,570, Busia County has 893,681 while Vihiga county has 590,013(Kenya National Bureau of Statistics). The population of children from age 0-19 years is 2,781,936 and above 20 years is 2,239,907. Western region borders Uganda and is in west of the Eastern Rift Valley. It is inhabited mainly by the luhya people. Kenya's second highest mountain, Mount Elgon is located in Bungoma County. Western region has diverse physical features, from the hills of northern Bungoma County to the plains bordering Lake Victoria in Busia County. The Kakamega Forest rainforest is part of the area. It is an agricultural region and the major economic activities are maize and sugarcane farming. Rainfall

is uniformly distributed throughout the year with March and July receiving highest rains while December to February the least. The climate is mainly tropical, with variations due to altitude. Kakamega County is mainly hot and wet most of the year, while Bungoma County is colder but just as wet. Busia County is the warmest, while the hilly Vihiga County is the coldest. The entire western region experiences very heavy rainfall all year round, with the long rains in the earlier months of the year. Farming is the main economic activity in the region.

Bungoma County is a major sugarcane growing area and has the largest sugar factories, as well as numerous small-holder sugar mills. Maize is also grown for subsistence, alongside pearl millet and sorghum. Dairy farming is widely practiced, as well as the raising of poultry. There is a small but important tourist circuit, centering on the biennial circumcision ceremonies. Kakamega County has a mixture of both subsistence and cash crop farming, with sugar cane being the preferred medium to large scale crop. The County has three sugar factories. There is also a significant tourism industry centering on Kakamega Forest. Busia County experiences perennial floods from the Nzoia River, and the dominant economic activity is fishing on Lake Victoria. Limited commercial farming is also practiced, mainly of sugar cane. Subsistence farming of cassava is widely practiced. Vihiga County has large tea plantations, and is the most densely populated rural area in Kenya. Quarrying for construction materials is a significant activity in the hilly County. Dairy farming is also widely practiced in Vihiga. Western region has many large factories, including sugar processing plants (4 factories). The largest of these is Mumias Sugar, based at Mumias, to the west of Kakamega. This factory produces the dominant sugar brand in Kenya and is an economic success story. Despite this, living standards are generally low and poverty index is high. Western region is the second leading with cases of sickle cell disease after Nyanza.

# **Baseline information**

Children with sickle cell have special clinics in hospitals called sickle cell and hemophilic clinics. The children visit the clinics when they are sick, in pain or for their reviews. Incase of severe clinical presentation, they are admitted through these clinics to the wards. For this study, children who came to the clinic with musculoskeletal pain and met the inclusion criteria were recruited. Socio demographic information was collected using the International Physical Activity Questionnaire for the children (IPAQ-C). The pain was assessed and measured using "Wong Baker Faces pain rating scale(WBFPRS)" which has 6 levels. WBFPRS is the most recommended and commonly used in Paediatric and Child pain assessment. Rating of this scale is from "0,1,2,3,4,5" where "0" indicates no pain while "5" indicates worst pain. The tool was chosen because it is recommended in children from ages 4 years to 17 years to communicate how much pain they are feeling. The tool has also been validated for use in age category of 4 years to 17 years. This study was conducted on children aged 6 years to 12 years which falls under the age category of use of Wong Baker Faces pain rating scale. WBFPRS involves pictorial and self reporting scales which is most recommended in children aged 4years to 17 years (HockenBerry et al., 2005). The pain was assessed and rated by clinical officers and nurses working in the Sickle Cell and hemophilic clinics using WBFPRS and results documented for each child. The children were then randomly assigned to either experimental or control group. Randomization of participants was done using a computer-generated random numbers table, which is a widely recognized method for achieving true randomization in clinical trials. After the initial assessment and meeting the inclusion criteria, each participant was assigned a unique identification number. The identification numbers were then entered into the computer program to generate random numbers. The random number assigned to each participant determined their group placement. Even numbers were assigned to the intervention group, and odd numbers were assigned to the control group. This process ensured an unbiased allocation, as the assignment of participants to either the intervention or control group was determined purely by the computer-generated random numbers, which the investigators had no influence over. Moreover, the process of random allocation was performed by an independent staff member who was not involved in the study to minimize allocation bias further. This staff member was responsible for assigning the participants to their groups and did not participate in the assessment or treatment of the participants. The researcher ensured that the randomization process was concealed, meaning that the researchers and participants were unaware of the upcoming assignment to maintain the study's integrity and prevent selection bias. This was achieved by using sealed, opaque envelopes containing group assignment, which were opened only after the participant's identification number was assigned. The envelopes were also numbered in advance according to the generated random numbers list, which was kept confidential and accessed only by the independent staff member.For the control group, they were allowed to continue with their usual pain management strategies but still were followed up and attended their usual clinics. For those in the intervention group, in addition to their usual pain management strategies, exercise was initiated by physiotherapists three days in a week for three months(WHO,2019). Both groups were followed up and maintained their clinic visits for check ups as prescribed. During baseline pain assessment using the Wong Baker Faces pain rating scale.

#### **3.10.2 Post-test Phase**

The primary objective of this phase was to assess the outcome of exercise on musculoskeletal pain. After the three months of intervention and follow up,post assessment was done using Wong Baker Faces pain rating scale(WBFPRS) to measure the intensity of pain for both groups ;control and experimental groups and results documented. This was done four weeks after the interventions. The scores for the participants in the experimental and those in the control groups were computed and compared to the initial scores to determine which intervention between and within the groups had significant differences. Musculoskeletal pain assessment was continuously assessed by the clinical officers and nurses at the clininics during follow ups. On every visit, the children were assessed and pain rated using the Wong Baker Faces pain rating scale (WBFPRS). After the three months exercise, a comprehensive report was compiled about the progress of each child whether in experimental or control.Children were encouraged to continue with the exercise after the three months. After four weeks, a follow up was conducted to assess the musculoskeletal pain among the children through the clinics as they came for reviews. This was done by nurses and clinical officers at the clinic. Apart from assessing the level of pain experienced, they also assessed how frequent musculoskeletal pain occurred to these children during follow ups and at the end of the exercise.

### 3.10.3 Selection and Training of the Research Assistants (RAs)

Sixteen research assistants were selected to help in data collection in the selected Counties. The selected were eight holders of diploma in physiotherapy from accredited institution, four nurses and four clinical officers from accredited institutions with practicing licenses. In each team, we had one nurse, one clinical officer, two physiotherapists. The research assistants were taken through a three day's training on the aim of the study, the objectives of the study, data collection methods and tools together with the ethical considerations. The trainers included two experts in physiotherapists with higher diploma,two nurses with higher diploma in paediatric nursing and two clinical officers with higher diploma in paediatrics and child health from county governments. Emphasis was put on consent, ascent, honesty, integrity and confidentiality. Matters of informed consent were also highlighted in the training for consideration during fieldwork. The research assistants signed a commitment form to keep data private and be confidential.Each research assistant supported the participants to execute the exercises as prescribed.This was done according to the childs capability.Continuos monitoring was done so that incase of any deviations,an action would be taken.The exercise advanced as days moved by as assessment continued (Appendix IX).This exercise was conducted three days a week for 30-60 minutes and for a period of three months.

# 3.10.4 Reliability

Reliability in a study denotes the trustworthiness or consistency of the research tool used (Everett & Skrondal, 2010). Split-half method was employed in assessment of reliability of the questionnaires. The reliability was confirmed by computing Cronbach's coefficient alpha, conceding high reliability estimates, with dependability being reasoned as good or satisfactory if the reliability coefficient was 0.80 or above. A test-retest correlation of +.80 or greater was considered to indicate good reliability. The correlation that was more than >0.7 meant that the tool was considered highly reliable.

Cronbach's alpha	Internal consistency
$\alpha \ge 0.9$	Excellent
$0.9 > \alpha \ge 0.8$	Good
$0.8 > \alpha \ge 0.7$	Acceptable
$0.7 > \alpha \ge 0.6$	Questionable
$0.6 > \alpha \ge 0.5$	Poor
<u>0.5&gt;α</u>	Unacceptable

Table 3.2: Level of Internal consistency based on Cronbach's alpha

Source: George & Mallery (2003)

#### 3.10.5 Validity

To determine the validity of the questionnaires, construct validity was used, so that the correlation coefficient of the scores of study subjects was assessed. Construct validity pertains to the degree to which a test takes into consideration a specific theoretical construct or feature. To accomplish construct validity in this study, the researcher guaranteed that musculoskeletal pain measurements were cautiously developed depending on existing knowledge. More so, survey design was employed in the pre-test study. Mixed method approach was used to provide an opportunity to triangulate and cross-check the results to ensure validity and credibility to the research (Namenya, 2018). The items which failed to meet the anticipated data in the Sociodemographic questionnaire and the key informant interviews were discarded. The questionnaire had only significant questions with the aim of measuring known markers of musculoskeletal pain.

# 3.11 Pretest

Pretesting of the tools was conducted at Jaramogi Oginga Odinga Teaching and Referral hospital in Kisumu County Hospital. This location was chosen as it has a significant population of children with SCD but is not part of the main study sites in the Western region, therefore avoiding potential biases in the main study. It involved administering the International Physical Activity Questionnaire for Children (IPAQ-C) and the Wong Baker Faces Pain Rating Scale (WBFPRS) was used to assess and rate children with musculoskeletal pain. A sample of 18 children with SCD, or 10% of 176 projected sample size which was 18 (Cornell, 2008) was used. The 10-20% of the sample population to be used was supported by O'Neill, 2022.Pretesting assisted the researcher to test the instruments by checking the clarity of the questions and also taking comments from respondents who helped in the improvement of the instruments before the actual field work (Burns *et al.*, 2008). Parents participated in in-depth interviews. The aim was to test the clarity and comprehensibility of these tools, as well as the feasibility of the study procedures. The results showed that some questions in the IPAQ-C and in the in-depth interview guides were not well understood by the participants. These issues were identified and the instruments were subsequently revised and corrected with the help of experts.

#### **3.12 Data Management**

Data was secured under key and lock, cleaned confirmed for completeness of entries. All data instruments were checked for quality and completeness.

#### 3.13 Data Processing. Analysis and Presentation

Data analysis was done on both qualitative and quantitative data by descriptive and inferential statistics. Data was entered into Statistical Package for Social Sciences. All the analyses were computed by SPSS version 26.0 software and *p*-values were computed for the purposes of measuring the statistical significance and effect size.Quantitative data was coded, entered in excel sheet and computed using Statistical Package of Social Sciences (SPSS) version 26. Raw data was collected and analyzed by assigning numerical values to each response and entered into a coding table. Thereafter the numerical numbers representing responses from the

questionnaires were transferred to a code sheet so as to obtain quantitative results from the closed ended questionnaires. Quantitative data was presented as frequencies, percentages, standard deviation, means as well as inferential statistics.

Qualitative data from the key informant and indepth interviews were analyzed thematically using NVivo, translation and transcription of the data was done, then themes were developed and presented. Any mistakes in grammar were checked from the emerging themes. A chi square was used to test any significant associations between and within subjects and musculoskeletal pain. A t-test is a type of inferential statistics used to determine if there was a significant difference between the means of two groups, which might be related in certain features. Analysis of variance (ANOVA) was used. It is a statistical technique that is used to check if the means of two or more groups are significantly different from each other. ANOVA checks the impact of one or more factors by comparing the means of different samples. Both two tailed T-test and one-way (ANOVA) was used to determine whether there were any statistically significant differences between exercise and musculoskeletal pain management in children with SCD. A paired t-test was used to compare the group mean over time or after an intervention. Therefore, paired t-test was used to analyze the pre and post results of the exercise in the management of musculoskeletal pain in children with SCD.

The Table 3.3 shows the summary of this section:

Sociodemographic	International	Age,gender,class	Frequencies,
characteristics	Physical Activity	level,parental	Percentages, means and
	Questionnaire-	marital status.	standard Deviation
	Children (IPAQ-C)		Regression, Odds ratio
Factors for		psycho-socio-	Categorization of
musculoskeletal	Indepth Interviews	cultural ,economic,	themes for the
pain management		psychological,	qualitative data
		nutritional ,hospital	
		factors	
Strategies for	key informant	Medication, resting,	Categorization of
musculoskeletal	Indepth interview	a lot of fluids.	themes for the
pain management	schedule	exercise	qualitative data
			-
Outcomes of			
exercise on	Wong Baker Faces		
musculosleletal	pain rating	Pain	Means and standard
pain management	scale(WBFPRS)		deviations, effect of size
			tests, and t- tests

Table 3.3	Data	analysis	methods	per ob	iective

Source: Researcher, 2022

#### 3.14 Ethical Considerations

The researcher sought approval to carry out the study from Masinde Muliro University Directorate of Post Graduate Studies as guided by the institutional policy on research. This was to ensure that all the protocols were observed during research period. Therefore, ethical clearance from the Research Ethics Committee of Masinde Muliro University was sought to ensure ethical principles were adhered to. This enabled acquisition of permit from National Commission of Science Technology and Innovation (NACOSTI). Other approvals were also obtained from areas where the research was to be conducted: Kakamega, Bungoma, Busia and Vihiga Counties research and ethical review committees, County Director of Health services, County Director of Education, County Commissioner, and County research and ethical committee prior to commencement of the study.

#### 3.14.1 Autonomy

Autonomy ensures that subjects are free to make their own decisions without being coerced in any manner while the study is ongoing. The researcher respected the decision that was made by the subjects. The researcher provided information to subjects prior to them signing informed consent and ascent. For the purpose of this study, the subjects fell in a category where they could not consentconsent and due to reduced autonomy, the researcher protected their right by gaining parental consent.

#### 3.14.2 Informed Consent and ascent

The parents of the participants in this study were given information concerning the study and made informed decision after critically analysing the information. An acesnt was also used by the children whereby the parents witnessed and signed. In cases where children refused to participate, the parents accepted and did not force the children to participate. The researcher respected the decision of the child either to participate in the study or not. The participants who voluntarily showed their willingness to participate in this study signed both ascent and consent. A written consent form was provided for the parents, key informants and ascent for children. Anonimity was used to ensure that no name was written on the form. Any benefits or risks associated with the study were discussed in the process of consenting and the participants were allowed to withdraw from the study at any point without suffering. The participants.

#### 3.14.3 Confidentiality

Participants information was kept confidential throughout the entire research period so that they were not hurt in anyway. Participants were protected from any disadvantages that could arise because of participating in the study and willingly providing their information. The questionnaires and key informants were coded with a unique code. Examples of the codes that were used were KII ,PR for purposes of anonymity.

#### **3.14.4** Non-maleficence

The subjects were not subjected to any harm during the process of research. However, in an event that possibility of harm was anticipated, the researcher had a plan on how the study would mitigate the harm that was likely to occur. Harm could result in fear leading to anxiety or emotional trauma, physical injury, psychological or social trauma among the respondents .

#### 3.15.5 Justice

All subjects were treated equally so that incase of any benefits, it is equally distributed. This was achieved by the researcher randomly sampling the partipants that were involved in the study then randomly assigning the participants in the treatment and control groups. By doing this, the participants had an equal chance of being involved or not involved in the study and thus an equal distribution of any benefit or harm that was likely to occur.

#### **CHAPTER FOUR**

#### RESULTS

#### 4.1 Overview

In this chapter, we provide a comprehensive description of the results obtained from the data analysis survey. The study encompasses both qualitative and quantitative findings, organized thematically to explore the effectiveness of exercise in managing musculoskeletal pain among children with sickle cell disease. This thematic exploration includes an examination of sociodemographic characteristics and their relation to musculoskeletal pain, the strategies employed in managing musculoskeletal pain among children with sickle cell disease, factors influencing the management of such pain, and the outcomes associated with exercise as a management approach for musculoskeletal pain.

#### 4.1 Response Rate

This study targeted a sample size of 176 respondents out of which 176 filled in and returned the questionnaires, making a total response rate of 100%. This was considered adequate. Response rate for pre intervention and post intervention was 100%. Aresponse rate of 75% is considered acceptable according to Bowling ,2004,

# 4.2 Socio demographic characteristics of children in control and intervention groups

Table 4.1 shows the sociodemographic characteristics of children in control and intervention groups. Atotal of 176 children participated in the study whereby 119 were in intervention group and 57 were in control group. During the 3 months follow up, all the participants were followed up both for the intervention and control groups. Most of the participants were aged 9 years and above (control=17.6%, intervention=37.5%). Most of the participants were females(control=

18.2%, intervention=37.5%). participants Most of the were in upper class(control=25.6%),intervention=39.2%). Most of the participants were Christians(control=25.0%,intervention=55.7%). Majority of the participants resided in rural area (control=23.9%, intervention=51.7%). Majority of the participants had both parents (control=23.3%, intervention=45.5%). On parental marital status, most of the parents were married(control=22.2%,intervention=42.6%). On parental socio economic status, most of the families were rich(control=29.0%, intervention=52.3%). In conclusion, chi square analysis of data collected at baseline, showed no significant difference in the socio-demographic characteristics between intervention and control groups as per the results shown in the table 4.1 below. However, the number of family members in both groups showed that in control group, there was (24.4%) with 5 or more members while intervention group had(34.7%) with 4 or less members with a p<0.01. Table 4.1 summarises socio demographic characteristics of children in control and intervention groups.

Characteristics		Grou	лр
		Control	Intervention
		n, frequency	n,
		(%)	frequency(%)
Age groups(years)	8years andbelow	26(14.8%)	53(30.1%)
	9years and above	31(17.6%)	66(37.5%)
Gender	Female	32(18.2%)	66(37.5%)
	Male	25(14.2%)	53(30.1%)
Class	Lower	12(6.8%)	42(23.9%)
	Upper	45(25.6%)	69(39.2%)
Religion	Christian	44(25.0%)	98(55.7%)
e	Muslim	13(7.4%3)	21(11.9%)
Residence	Rural	42(23.9%)	91(51.7%)
	Urban	15(8.5%)	28(15.9%)
Parents	Both parents	41(23.3%)	80(45.5%)
	Single parent	16(9.1%)	39(22.1%)
Parental marital	Divorced	7(4.0%)	9(5.1%)
status	Married	39(22.2%)	75(42.6%)
	Single	11(6.2%)	35(19.9%)
Parental	Rich	51(29.0%)	92(52.3%)
socioeconomic status	Poor	6(3.4%)	27(15.3%)
Family members	4 or less	14(8.0%)	61(34.7%)
	5 or more	43(24.4%)	58(33.0%)

 
 Table 4.1 Socio demographic characteristics of children in control and intervention groups

### 4.3 Baseline association between Socio-demographics and self reported MSK

#### pain among the respondents in both control and experimental groups

The results showed that 46 (26.1%) respondents reported mild MSK pain and 33 (18.8%) reported moderate MSK pain. The analysis of the relationship between MSK pain and age groups showed no statistically significant difference between the two age groups (p=0.834). There was also no statistically significant difference in MSK pain prevalence between males and females (p=0.736). Similarly, there was no significant difference in MSK pain between respondents of different classes, religions, or residences. Regarding parental socioeconomic status, the results showed no statistically significant difference between respondents with moderate or poor

status (p=0.286). Furthermore, the number of family members was not found to be associated with MSK pain (p=0.602). In terms of marital status, divorced respondents reported slightly higher MSK pain prevalence than others, but this difference was not statistically significant (p=0.560).

In summary, the results suggested that socio-demographic characteristics may not be strong predictors of MSK pain prevalence among the general population of children with sickle cell disease..

Table 4.2 summarises the baseline association between Socio-demographics and self reported MSK pain among all respondents in both control and experimental groups.

Characteristics			Group			X <sup>2</sup> <sup>p</sup> -
	-	Cont	rol(n)	Interv	vention(n)	value
	_	Mild	Moderate	Mild	Moderate	
						0.044, 0.834
Age groups(years)	8years andbelow	13	13	46	7	
	9years andabove	10	21	58	8	
Gender	Female	14	18	59	7	0.11,
	Male	9	16	45	8	0.736
Class	Lower	5	7	36	14	1.132,
	Upper	18	27	68	1	0.008
Religion	Christian	18	26	83	15	
8	Muslim	5	8	21	2	0.125, 0.724
Residence	Rural	18	24	76	15	
	Urban	5	10	28	1	0.855, 0.355
Parents	Both parents	16	25	71	9	2.234,
	Single	11	9	33	6	0.525
Parental marital	Divorced	4	3	6	1	2.988,
status	Married	14	25	68	7	0.560
	Single	5	6	28	7	
Parental	Rich	19	32	88	4	
socioeconomic status	Poor	4	2	16	11	2.506, 0.286
Family	4 or less	8	6	46	15	
members	5 or more	15	28	58	1	0.272, 0.602

 Table 4.2: Baseline association between Socio-demographics and self reported

 MSK pain among the respondents

#### 4.4 Logistic regression analysis for significant socio-demographic characteristics

The logistic regression analysis aimed to examine the relationship between the group and two predictor variables: class and family members. The results indicated that both variables had an impact on predicting the group. Starting with the intercept, the coefficient was found to be 0.84, with a standard error of 0.36. This coefficient was statistically significant ( $\chi 2 = 5.42$ , p = .020), suggesting that when all other variables are held constant, there is a positive effect on the likelihood of being in the group.

About the class variable, it was observed that the coefficient was -0.72, with a standard error of 0.39. Although this coefficient did not reach statistical significance at the conventional level ( $\chi 2 = 3.44$ , p = .064), there was a notable trend indicating a negative relationship between class and the likelihood of being in the group. The odds ratio (OR) associated with this coefficient was 0.49, implying that individuals from higher social classes were less likely to be part of the group. The 95.00% confidence interval for the odds ratio ranged from 0.23 to 1.04. Regarding the family members variable, the coefficient was 0.96, with a standard error of 0.37. This coefficient was statistically significant ( $\chi 2 = 6.88$ , p = .009), indicating that the number of family members had a positive effect on predicting the group. The odds ratio associated with this coefficient was 2.61, meaning that individuals with four or fewer family members were more than two and a half times more likely to be in the group compared to those with more than four family members. The 95.00% confidence interval for the odds ratio ranged from 1.27 to 5.36.

Overall, the logistic regression model demonstrated a statistically significant relationship between the predictor variables (class and family members) and the group ( $\chi 2(3) = 18.83$ , p < .001). The model accounted for approximately 8% of the variance in the group, as indicated by the McFadden pseudo R-squared value of 0.08.

It is important to note that these results are based on the specific dataset and analysis conducted for this study, and caution should be exercised when generalizing the findings to other populations or contexts.

Odds ratio for significant socio-demographic characteristics is summarized in table 4.3 :

group							
Variable	В	Se	X <sup>2</sup>	Р	OR	95.00% ci	
(intercept)	0.84	0.36	5.42	.020	-	-	
Class upper	-0.72	0.39	3.44	.064	0.49	[0.23, 1.04]	
				.009	2.61	[1.27, 5.36]	
<i>Note.</i> $X^2(3) = 18.83, p < .001$ , McFadden $r^2 = 0.08$ .							

 Table 4.3 Logistic Regression Results with class and Family members predicting group

# 4.5 Baseline test of independence between control and intervention groups on other factors

Table 4.5 shows the number and percentage of participants in each group for each factor, as well as the chi-square value and p-value for the test of independence. On the Hemoglobin levels, 32.4% of the control group and 55.2% of the intervention group had hemoglobin levels of 6-11gm/dl. The test of independence found a significant difference between the two groups ( $\chi 2 = 23.99$ , p < 0.001). The second factor was hospital visits, with 26.7% of the control group and 51.7% of the intervention group having monthly hospital visits. The test of independence found a significant difference between the two groups ( $\chi 2 = 22.033$ , p < 0.001).

On exercise participation, 26.4% of the control group and 47.2% of the intervention group participated in exercise. The test of independence found a significant difference between the two groups ( $\chi 2 = 76.664$ , p < 0.001). Family support had 32.4% of the control group and 67.6% of the intervention group having family support.

On play/socialization, 6.0% of the control group and 62.5% of the intervention group reported of having engaged in play/socialization. The test of independence did not find a significant difference between the two groups ( $\chi 2 = 2.541$ , p = 0.281).On Painful attacks, 20.5% of the control group and 55.6% of the intervention group experienced less common painful attacks. The test of independence found a significant difference between the two groups ( $\chi 2 = 12.96$ , p = 0.002).

Missing school had 11.9% of the control group and 51.1% of the intervention group missing school mostly. The test of independence did not find a significant difference between the two groups ( $\chi 2 = 4.093$ , p = 0.129).

Effect of pain on performance had 27.0% of the control group and 57.7% of the intervention group reporting pain affecting their performance. The test of independence did not find a significant difference between the two groups ( $\chi 2 = 0.001$ , p = 0.972).

Table 4.4 presents a summary of baseline test of independence between control and intervention groups on other factors:

Factors	in other fac		Gr	oup		<b>X</b> <sup>2</sup>	p-value
		Cont	rol	Inter	vention	value	-
		n	%	n	%	_	
Hemoglobin	6-	56	32.4%	97	55.2%	23.99	0.001
levels	11gm/dl						
	Above	1	0.1%	22	12.5%		
	11gm/dl						
Hospital visit	Monthly	47	26.7%	91	51.7%	22.033	0.001
Ĩ	Rarely	10	5.6%	28	13.1%		
Exercise	No	46	26.4%	33	18.8%	76.664	0.001
participation	Yes	11	6.0%	83	47.2%		
Play/socializatio	No	10	6.0%	7	4.0%	2.541	0.281
n	Yes	47	26.4%	110	62.5%		
Painful attacks	Less	36	20.5%	92	55.6%	12.96	0.002
	common						
	Very	21	11.9%	27	15.3%		
	common						
Missing school	Mostly	21	11.9%	29	51.1%	4.093	P=0.12
-	Rarely	36	20.5%	90	49.4%		9
Effect of pain on	Yes	47	27.0%	100	57.7%	0.001	P=0.97
performance	No	10	6.0%	20	11.0%		2

#### Table 4.4. Baseline test of independence between control and intervention groups on other factors

## 4.6 Logistic regression results with hemoglobin levels, hospital visit, exercise

#### participation, and painful attacks predicting group

Table 4.5 shows the results of a logistic regression analysis with group (control verses intervention) as the dependent variable and hemoglobin levels, hospital visits, exercise participation, and painful attacks as the independent variables. The table presents the estimated coefficients (B), standard errors (Se), Wald chi-square test statistics ( $X^2$ ), p-values, odds ratios (OR), and 95% confidence intervals (CI) for each independent variable. The intercept in this model is -0.89, indicating that the log odds of being in the intervention group were lower than the control group when all other variables were held constant. The variable "Hemoglobin levels above 11gm/dl" had a coefficient of 18.90, indicating that individuals with hemoglobin levels above

11gm/dl had much higher odds of being in the intervention group than those with lower hemoglobin levels. However, the p-value for this variable was not significant, indicating that this result may be due to chance. Similarly, the variable "Hospital visits weekly" had a coefficient of 18.76, indicating that individuals who visitited the hospital weekly had much higher odds of being in the intervention group than those who visit less frequently. However, the p-value for this variable was also not significant, indicating that this result may be due to chance.

The variable "Exercise participation 'yes" had a coefficient of 4.60, indicating that individuals who participated in exercise had much higher odds of being in the intervention group than those who did not. The result was statistically significant with a p-value < .001 and an odds ratio of 99.68, indicating that individuals who participated in exercise were almost 100 times more likely to be in the intervention group than those who did not. "Painful attacks being very common" had a coefficient of 0.73, indicating that individuals who experienced very common painful attacks had higher odds of being in the intervention group than those who experienced very common painful attacks had higher odds of being in the intervention group than those who experienced less common painful attacks. However, this result was not statistically significant with a p=0.157.

In summary, the model was significant with a chi-square test statistic of 114.96 and a p-value < .001. The McFadden R-squared value is 0.52, indicating that the model explains about 52% of the variance in the dependent variable.

Table 4.5 Logistic regression results with hemoglobin levels, hospital visit,

Variable	B	Se	<b>X</b> <sup>2</sup>	Р	Or	95.00% ci
(intercept)	-0.89	0.32	7.81	.005	-	-
Hemoglobin levels above 11gm/dl	18.90	3,067.72	0.00	.995	$1.62 \times 10^{8}$	[<0.01]
Hospital visits rarely	-0.90	1.52	0.35	.553	0.40	[0.02, 8.00]
Exercise participation yes	4.60	1.13	16.63	< .001	99.68	[10.91, 910.50]
Painful attacks very common	0.73	0.52	2.01	.157	2.08	[0.76, 5.73]

exercise participation, and painful attacks predicting group

*Note.*  $X^2(9) = 114.96$ , p < .001, McFadden  $r^2 = 0.52$ . control group is the reference.

#### 4.7 Comparison of Wong Baker Faces Pain Rating Scale self reported results

#### for Baseline and post intervention in control and experimental groups.

The baseline findings for the control group showed that; (39%,n=22) had worst hurtful pain , 26%, n=15 had hurtful whole lot pain,19%,n=11 had hurtful even more pain,9%,n=5 had hurts little more pain,7%,n=4 had hurts little bit pain while no one had no hurt pain. The baseline findings for the intervention group, results indicated that; (n=42,35%) had worst hurtful pain, 24%, n=28 had hurtful whole lot pain,16%,n=19 had hurtful even more pain,15%, n=18 had hurts little more pain,10%,n=12 had hurts little bit pain while no one had no hurt pain. The post intervention results for the control group indicate that; (n=21,37%) had worst hurtful whole lot pain,7%,n=4 had hurts little more pain,7%,n=12 had hurtful whole lot pain,21%,n=12 had hurts little more pain,7%,n=4 had hurts little more pain,9%,n=5 had hurts little bit pain while no one had no hurt pain. For the intervention group, report (n=3,2.5%) had worst hurtful pain,1%, n=1 had hurtful whole lot pain,1.7%,n=2 had hurts little more pain,14%,n=17 had hurts little bit pain while 94%,n=79 had no hurt pain.

Comparing pain levels before and after the intervention, the intervention did not show statistically significant improvements in pain levels for the control group. There were no significant changes in the likelihood of experiencing different pain levels between the baseline and post-intervention periods. These findings suggest that the intervention had limited impact on pain reduction in the control group. The results indicate significant changes in pain experiences across different categories. Prior to the intervention, the experimental group reported no participants experiencing no hurt. However, after the intervention, a significant improvement was observed in the experimental group, with 79% of participants (94 out of 119) reporting no hurt. For the category of "Hurts little more," 10% of participants (12 out of 119) reported experiencing slightly more pain before the intervention. Following the intervention, 14% of participants (17 out of 119) reported similar experiences. Although not statistically significant, there was a trend suggesting a higher likelihood of experiencing slightly more pain in control group after the intervention.

In contrast, the intervention showed significant improvements in the categories of "Hurts little bit," "Hurts even more," "Hurts whole lot," and "Hurts worst." Before the intervention, 15% of participants (18 out of 119) reported feeling a slight amount of pain. However, post-intervention, only 1.7% of participants (2 out of 119) reported experiencing the same level of pain.

Similar patterns were observed for the categories of "Hurts even more," "Hurts whole lot," and "Hurts worst," where the likelihood of experiencing these higher levels of pain significantly decreased after the intervention. The odds ratios calculated for each category further support these findings. For "Hurts little bit," "Hurts even more," "Hurts whole lot," and "Hurts worst," the odds ratios were significantly below 1, indicating a reduced likelihood of experiencing higher levels of pain after the intervention. The 95% confidence intervals for these odds ratios also provided support for the statistical significance of the findings. In summary, the experimental group experienced significant improvements in pain levels following the intervention with a p<0.01. The likelihood of experiencing different levels of pain, ranging from slight discomfort to the worst level of pain, significantly decreased after the intervention. These findings provide evidence for the effectiveness of the intervention in reducing pain and support its statistical significance.

Table 4.6 has a summary of comparison of Wong Baker Faces Pain Rating Scale self reported results for baseline and post intervention in control and experimental groups.

Pain levels	Control	Expe	rimental	
<u> </u>	OR (95%		OR	
	CI)	p-value	(95%CI)	<b>p-</b> value
No hurt	Re	ef.	Ref.	
Hurts little more	1.12 (0.47 2.67)	, 0.12	1.75 (0.82, 3.74)	<0.01
Hurts little bit	0.89 (0.31, 2.58)	0.24	0.10 (0.02, 0.45)	<0.01
Hurts even more Hurts whole lot	1.09 (0.53, 2.23) 1.00 (0.50, 2.00)	0.127 0.675	0.09 (0.02, 0.40) 0.03 (0.01, 0.23)	<0.01 <0.01
Hurts worst	0.91(0.47, 1.77)	0.455	0.06 (0.02, 0.18)	< 0.01

 Table 4.6 Comparison of Wong Baker Faces Pain Rating Scale self reported results for Baseline and post intervention in control and experimental

groups

#### 4.8 Strategies used in management of musculoskeletal pain among children

#### with sickle cell disease in western Kenya

Results from the interviews indicated that majority of children presented with pain in

the joints and in all extremities, cried a lot, became restless and others could verbalize

that they were feeling pain.

The most reported used strategy for pain management by the respondents was the use

of drugs which meant all children were on medications. These drugs included DF 118,

morphine, brufen, tramadol diclofenac and hydroxyurea.

One of the respondents stated;-

"My daughter is normally given DF 118 when we go to the hospital. Hydroxyurea is another good drug that she uses but very expensive. 'But sometimes I buy brufen when she is in pain and i have less money". PR 11

Another respondents stated;-

"At home, i buy drugs from the counter most of the time because they are commonly used in the management of musculoskeletal pain. DF118 and hydroxyurea are good but very expensive and are normally given at the hospital, and so most of us cannot afford to buy, but get at the hospital. We go to the hospital when the pain has complicated. Sometimes when you rush to the hospital, you get frustrated with the system and without money, the situation even worsens and your child suffers more pain".PR18

The findings were supported by a key informant who said this;-

"All these children are put on medication whether admitted or not. This is a strategy that we have put in place to control and manage the pain. However, although some do not comply because of various reasons, the most common being lack of finances to buy the drugs. We give them at hospital when they are available but most times they are out of stock. The most commonly dispensed drug from the hospital is DF118 and Hydroxyurea".KII 04

To monitor the progress of children and ensure compliance, follow up clinics were

initiated monthly where children go for checkups.

In another interview, one of the key informants stated;-

"We have the sickle cell and hemophilic clinics that run daily in our hospitals where children are booked on monthly basis or two weekly according to the severity of the condition. Sometimes we go for outreach programs when we have funds but once in three months. These clinics have proved to be beneficial in monitoring the child's progress. Any child who is admitted in the hospital with sickle cell is normally discharged through these clinics". KII 7

Some of the respondents reported that they allowed their children to rest so that their

condition does not worsen. They felt that it was important to allow the child to rest

because it enhanced relaxation of the body hence reducing the severity of the pain.

They therefore absent from school until they recover.

A respondent when asked on the strategies used to manage musculoskeletal pain

among children with SCD stated:-

"Restricting children from going to school and playing with other children is a strategy that is used in managing this pain. The children are confined in the house and kept warm. This is because when they play, the pain becomes too much and unbearable. When they are in the house, we try and give warm fluids and let them relax and even encourage them to sleep. Even when the pain subsides, we discourage them from socializing and playing with others." PR16

The above was supported by a key informant who reported:-

"Allowing children to rest is very important strategy. This is because the body gets time to repair and rebuild the worn out tissues. During clinic reviews, we encourage parents to allow their children rest when they are in pain, avoid school and other strenuous activities until the condition improves".KII 2

From the qualitative results, use of warm fluids was reported as a strategy that was

used to reduce pain during cold weather variations. It was however reported that warm

fluids help in the improvement of circulation. Another strategy that was reported for

managing the pain was by keeping their children warm.

This was supported by the following statement from a key informant who said:-

"Sometimes weather in this region is very cold. We advise parents to ensure that their children are kept warm by using warm clothings, shoes and socks while at home or at school. This will help improve tissue temperature, blood flow and reduce muscle spasm. During cold weather, the blood flow to tissues is reduced due to vaso-occlusion". KII 5

Another strategy that was mentioned in managing musculoskeletal pain was coming up with support groups for the children with sickle cell. Respondents n=22 had impressed this and they felt that it was very helpful. They were able to share experiences from each other and this helped to prevent occurrence of painful events. This also reduced stigma in both parents and children.

The last strategy that was reported was use of exercise which was rarely used. Exercise was least reported as most parents had fears due to misconceptions about it. One of the respondents stated;

## "Children should not be enrolled into exercise because they are still weak and sick looking, the condition will worsen".PR 14

Most of the parents had little knowledge on the use of exercise in musculoskeletal pain management among the children with SCD. Others from control group commented that their children had remained the same with swollen and painful joints and limbs. However, they felt that their children would benefit from exercise. For the intervention group, a marked improvement was reported which was supported by the a parent of one of the children from the experimental group.

One of the respondents from the experimental group commented:-

"Previously, I never allowed my child to do any form of exercise or even playing with other children. I thought that it would worsen her condition. When I enrolled her in this program, my child has really benefited and her general health is very good. Hospital admissions have reduced and I feel all children who experience this pain should be initiated on such programs".PR 3

Another respondent said the following from control group:-

"My child does not do exercise, but the pain remains the same. If I know that exercise will help him, I can allow my child to do it immediately".PR20

A key informant echoed the importance of exercise in these children:-

"Exercise is really helpful as it improves blood flow preventing vaso occlusion for children with sickle cell which helps in pain reduction. We still do not have a structure in hospitals on how to implement this but it is sustainable and can be afforded by our clients. This helps in reduction of musculoskeletal pain among this category of children, is economical and we should embrace it".KII 7

Other key informants commented that most of the children had visited the clinic looking weak and sick with painful swollen joints. Those in intervention group had marked improvement after the exercise, while most of those in the control group had minimal improvements. Exercise was recommended as one of the strategies in management of musculoskeletal pain among children with SCD. Another informant noted that exercise was important in managing MSK pain as it helped to ensure the body tissues had adequate blood supply hence preventing the child from going into musculoskeletal pain. It was appreciated that exercise was important in managing the pain as it enhanced activeness and mobility of the child without much difficulties. One of the informant commented that it is due to the lack of awareness that make people not impress exercise as one of the strategies used in musculoskeletal pain management.

About drugs,the most common used drugs for musculoskeletal pain management among children with sickle cell disease were hydroxyurea represented by 58%,followed by Brufen (43%) and DF 118(38%). The least used drugs included Morphine(9%), tramadol(14%) and diclofenac(20%). Most of the participants mentioned atleast use of more than one drug. This was influenced by several factors including availability of the drugs, availability of funds and severity of the condition. among others. However, prolonged use of some drugs have long term effects on renal and cardiovascular systems. Therefore , alternative methods are recommended in management of Musculoskeletal pain among children with sickle cell disease.

In summary, the qualitative results suggests that the most common strategy used in management of musculoskeletal pain among children with sickle cell disease is use of drugs. It is a complex issue that requires a multifaceted approach and should include not only medical management, but also other therapies like exercise which has many benefits including cost effectiveness and minimal effects.

### 4.9 Factors that influence management of musculoskeletal pain among children with sickle cell disease in western Kenya

Indepth interviews were used and a total of 22 Caregivers for children with musculoskeletal pain in SCD were interviewed. This was done until the thresh hold was reached whereby the same answers were being repeated. The interviews lasted approximately 25 minutes with the indepth interviews. The interviewer took notes and completed a field note following each interview. Each interview was transcribed and subsequently coded by two authors. A thematic approach to analysis was used. A code book was created based on findings from literature review and expanded with re-occurring themes encountered during review of themes. Examples of codes included economic factors, hospital factors, psychological factors, environmental factors, nutritional factors and psychological factors. Any discrepancies were reviewed and it was agreed that the interviews had reached theoretical saturation. Thematic analyses of the interview transcripts revealed seven broad themes regarding

factors that influenced management of musculoskeletal pain among children with sickle cell disease.

#### 4.9.1 Psychological factors: caregiver's burden and stress

Caring for a child with a chronic condition like sickle cell disease with frequent musculoskeletal pain. When discussing the factors, majority of caregivers caring for their children reported of feeling overwhelmed with the ongoing care. Caregivers reported the unpredictable nature of the disease and its complications made them feel hopelessness during painful crisis. Children experience in great pain and this increased the stress levels among most of the caregivers. Most of the times the caregiver's mental status was altered because of what the children were going through. Some felt that they were the cause of the suffering of their children. These really affected the care of the children as some caregivers felt withdrawn and overwhelmed.This was supported by the following statement;

"I feel so sad because I know that my son is experiencing all this pain because of the father and I, and that he will live with it the rest of his life. I didn't know that I had the trait, and I didn't know that his father had the trait, so I kind of felt responsible...like it was my fault that my son has this disease. Managing him when he has the painful attacks make me sick too, and caring for him becomes a big problem".PR 22

#### **4.9.2 Economic Factors**

Economic factors was among the most common factor mentioned by the caregivers which affected the care in managing children with musculoskeletal pain. Common themes included financial strain, cost of drugs, hospital bills and missed days of work. Among the caregivers cited at least one of these areas as a barrier. Abscentism from school occurred due to lack of finances to manage the children in time leading to poor performance. When a child was admitted in severe pain, the hospital requested one to buy everything including gloves and brannulars which became a challenge due to limited resources. One of the respondents stated:-

"Lack of enough finances to manage children with sickle cell disease more so when they experience the painful attacks is a very big problem to many of us. My son had a very bad experience and I felt going to the hospital was a waste of time unless one had money. The painful events started abruptly and I was very low financially. I rushed to the nearby county hospital and the system could not allow him unless we paid registration fee of five hundred shillings and a deposit of two thousand shillings. My son kept suffering until we rushed to a private facility where they admitted him and offered the emergency care and the bill was paid later. We had to sell a cow to pay the bill but his condition was stabilize with no more pain. This made me believe that my son would have complicated just because of lack of money".PR 17

#### **4.9.3 Socio cultural Factors**

It was reported by caregivers that some communities believe that the mothers are the cause of these illness and this was associated with a' curse" from ancestors and this really influenced the kind of care accorded to the child. The mothers carried the responsibility of taking care of the child. Some families had even broken because the fathers avoided being associated with such children. Rejection by other family members was also a problem and the children isolated from other extended family members. Some female parents had to explain to their children reason for their separation and these really affected the care of the child. These caused a lot of psychological trauma to the family more so the mother and other siblings. The entire community did not accept these children and had an attitude towards parents. This contributed to a lot of stigma from both family and community.

One of the parent's child stated:-

"I experienced tough moments when my husband abandoned me because of our sickling child. This happened when we really needed his support as a family. When I probed to find why he did that, he said he had to leave because there was no history of SCD in their family and he didn't want to be associated as it was regarded as a curse".PR 21

#### 4.9.4 Individual factors:

Some of the children were exposed to many infections which was a contributing factor to musculoskeletal pain among these children with SCD. The most common infections included malaria, diarrheal and upper respiratory Tract Infections. If infections are not treated well, then the child would have frequent musculoskeletal pain attacks. The general body immune status of the child also influenced musculoskeletal pain as it was reported by caregivers . If the immune status was low or more compromised, the child would experience more attacks. If the immune status was strong, frequency of musculoskeletal pain would be reduced. Hemoglobin level of the child was vital when managing musculoskeletal pain. Low Hemoglobin levels caused a problem unlike when high. So these factors really affected the care of children with musculoskeletal pain, more so when the immune status was compromised.

#### 4.9.5 Nutritional factors:

It reported through the interviews conducted that malnutrition was a factor that affected the management of musculoskeletal pain among children with SCD. This contributed to frequent musculoskeletal pain experiences due to less oxygen being supplied to tissues, cells, bones and other organs. Many children were reported to lose appetite most times more so when they experienced the pain. Children become irritable and cry a lot, refusing to feed which affected their nutritional health. Due to pain, the children feared taking food and just became irritable. Getting the required nutritious diet is also hard due to financial implications. This affected the general care that children received. A key informant stated the following regarding nutrition:-

"These children with musculoskeletal pain in SCD need a nutritious diet. However, with the hard economic times, most parents are not able to afford and so it becomes difficult for them to provide a nutritious diet. They need a lot of fruits to boost their immune status and a balanced diet. This makes the child's body system to be weakened and so managing the child becomes more complicated".KII 7

#### 4.9.6 Environmental factors

Change of weather from hot to cold seasons had an implication on the care of children with Musculoskeletal pain in SCD. Caregivers reported of having experienced many difficulties during cold seasons unlike dry seasons. This provoked frequent attacks of musculoskeletal pain among these children with frequent absenteeism from school. The child also added that he missed school most times during rainy seasons.

One of the participants stated:-

"I normally get worried when rainy season approach because my child is frequently admitted during this seasons due to musculoskeletal painful attacks. He becomes dull, always sick looking and complains of feeling pain all over the body most times. She remains at home most of the time and this has actually affected her academic performance. .During dry season, her health becomes better and she looks healthy and active." PR19

#### 4.9.7 Hospital factors

The care givers reported that the care provided to the children during previous admissions in hospitals was a concern because of the bad experiences This contributed greatly to buying counter medication for their children instead of seeking medical care. Health care systems delivery were not friendly and patient oriented, but money oriented. Instead they are mostly money oriented. Care givers reported facility related factors like lack of resources and health workers associated factors (attitude).Some of the children were also not comfortable because of the hospital environment which was unpleasant. The admission made them miss school and so it made them not happy at all. They preferred being managed at home than being in the hospital environment. These affected the care of these children with musculoskeletal pain and their outcome.

# Table 4.7: Themes and associated caregivers quotes on Factors that influencemanagement of musculoskeletal pain among children with sickle cell

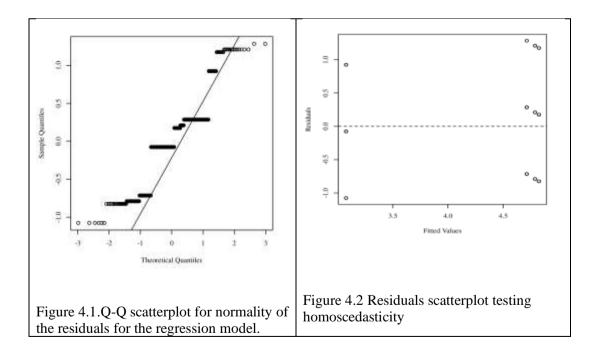
Codes/Themes	Quotes
Caregivers factors ; Psychological factor	"I feel so affected when my child is experiencing musculoskeletal pain, I try all means to ensure that my child copes, but I really feel for him. Sometimes I cry before him, it is really traumatizing and overwhelming ".PR12
Economic factors	"Financial burden is a key factor when managing children with musculoskeletal pain. Drugs, good nutrition and other basic needs are required. All these requires money. Without money, it is true that your child will suffer. No one supports us".PR 9
Sociocultural factors: Community and family support	"My husband's community believe that this disease occur as a result of generational curse from the side of the child's mother. So, we have very little support from the family. He supports us although with a lot of pressure from the elders. Otherwise he was advised to divorce me, if not the child will die". Whenever the child experiences musculoskeletal pain, we are isolated and as a family, it really affects the care". PR2
Individual factors : Immune status of the child	"My daughter becomes sick most of the times due to other illnesses like malaria and pneumonia. She becomes sick almost every month. This is because of the low immunity she must be sick. We used to be stressed as a family, but nowadays. We have learnt how to

disease

	Hemoglobin level	cope by taking measures to prevent such infections".PR 15
Nutritional factors;	Nutritional status of the child	"I try to ensure that my child's hemoglobin levels do not go down below 6g/dl. This is because whenever her hemoglobin level goes low, she becomes sick and she commonly presents with musculoskeletal pain. I ensure that her diet is prioritized with a lot of vitamins and iron". PR17
		"I provide the required diet for my son, but sometimes challenges occur whereby I have no finances to provide all that is required. Good nutrition is good for him because it boosts the body immunity. With poor
Environmental factors;	cold seasons/hot Seasons	nutrition, he becomes sickling because of the weakened immunity". PR3 "The cold weather is always unfavorable for my daughter. She is always in and out of the hospital because of pain. I just don't like the seasons. I prefer the dry season. In the wards, we are normally many with the same problem. So when it starts raining, I take a lot of precautions in ensuring he is always warm. But when he goes to school, it becomes a challenge. She gets frequent pain all over the body. I really spent a lot of time and money to manage her".PR20

### 4.10 Outcome of exercise in management of musculoskeletal pain among children with sickle cell disease in western Kenya

A mixed model analysis of variance (ANOVA) with one within-subjects factor and one between-subjects factor was conducted to determine whether significant differences exist among pain- post and pain-pre between the levels of group. The assumption for mixed model ANOVA were conducted. The assumption of normality was assessed by plotting the quantiles of the model residuals against the quantiles of a Chi-square distribution, also called a Q-Q scatterplot (DeCarlo, 1997). For the assumption of normality to be met, the quantiles of the residuals must not strongly deviate from the theoretical quantiles. Strong deviations could indicate that the parameter estimates are unreliable. Figure 4.1 presents a Q-Q scatterplot of model residuals. Homoscedasticity was evaluated by plotting the residuals against the predicted values (Bates *et al.*, 2014; Field, 2017; Osborne & Walters, 2002). The assumption of homoscedasticity is met if the points appear randomly distributed with a mean of zero and no apparent curvature. Figure 4.2 presents a scatter plot of predicted values and model residuals. The usual sphericity assumption does not apply when there are only two repeated measurements. To identify influential points in the residuals, Mahalanobis distances were calculated and compared to a  $\chi^2$  distribution (Newton & Rudestam, 2012). An outlier was defined as any Mahalanobis distance that exceeds 13.82, the 0.999 quantile of a  $\chi^2$  distribution with 2 degrees of freedom (Kline, 2015). There were no outliers detected in the model.



The table 4.8 presents the results of a mixed model ANOVA that was conducted to evaluate the effectiveness of exercise in musculoskeletal pain management. The analysis involves both between-subjects and within-subjects factors. The betweensubjects factor is the Group (exercise vs. non-exercise) while the within-subjects factor is the Within Factor (pre-treatment vs. post-treatment).

The results show that the Group factor was significant, with a large effect size (F =135.02, p < .001,  $\eta p = 0.44$ ), indicating that the exercise group had significantly better outcomes than the non-exercise group. The Within Factor was also significant with a large effect size (F = 278.76, p < .001, np2 = 0.62), indicating that both groups showed significant improvements from pre-treatment to post-treatment. Additionally, the Group: Within Factor interaction was significant, with a large effect size (F =255.87, p < .001,  $\eta p = 0.60$ ), indicating that the exercise group showed significantly greater improvements from pre-treatment to post-treatment than the control group.

In summary, the mixed model ANOVA results suggest that exercise is effective in musculoskeletal pain management, as it led to significant outcomes than control in experimental group when compared to control group...

Source	df	SS	MS	F	р	<b>η</b> թ2
Between-Subjects						
Group	1	64.12	64.12	135.02	<.001	0.44
Residuals	174	82.63	0.47			
Within-Subjects						
Within Factor	1	53.98	53.98	278.76	<.001	0.62
Group: Within. Factor	1	49.55	49.55	255.87	<.001	0.60
Residuals	174	33.70	0.19			

**Effectiveness of exercise in Musculoskeletal Pain Management** 

Table 4.8 Mixed Model ANOVA Results

Table 4.9 below displays the results of the Marginal Means Contrasts for each combination of Within-Subject Variables for the Mixed Model ANOVA. The table 88

shows two contrasts: the difference between pain-post and pain-pre for the group control and the group intervention. For the group control, the difference between pain-post and pain-pre was -0.04, with a standard error (SE) of 0.08. The degrees of freedom (df) were 174, and the t-value was -0.43, with a p-value of .671, indicating no significant difference between pain-post and pain-pre in the control group. For the group intervention, the difference between pain-post and pain-pre was -1.64, with an SE of 0.06. The df were 174, and the t-value was -28.72, with a p-value of less than .001, indicating a significant difference between pain-post and pain-post and pain-pre in the intervention group. Tukey Comparisons were used to test the differences in estimated marginal means.

Table 4.9. The Marginal Means Contrasts for each Combination of Within-Subject Variables for the Mixed Model ANOVA

Contrast	Difference	SE	Df	t	р
group control					
Pain-post – pain-pre	-0.04	0.08	174	-0.43	.671
group intervention					
Pain-post - pain_pre	-1.64	0.06	174	-28.72	< .001
Note. Tukey Compariso	ns were used t	o test th	e diffe	rences in	estimated

*Note.* Tukey Comparisons were used to test the differences in estimated marginal means.

#### 4.10.1 Differences in post-intervention pain score between Counties

An analysis of variance (ANOVA) was conducted to determine whether there were significant differences in post intervention pain scores by County. ANOVA was examined based on an alpha value of .05. The results of ANOVA were significant, F (3, 172) = 7.81, p < .001, indicating there were significant differences in post intervention pain scores among the levels of County. The eta squared was 0.12 indicating County explains approximately 12% of the variance in post intervention pain scores. The results from the Analysis of Variance (ANOVA) show that there

were significant differences in post-intervention pain scores among the four counties. The F statistic of 7.81, with an associated p-value less than 0.001, strongly suggests that the means of post-intervention pain scores are not the same across the counties. The eta squared value of 0.12 signifies that approximately 12% of the variance in post-intervention pain scores can be explained by the variable "County". This suggests that the county where the child lives may influence their post-intervention pain score to some extent. However, as the eta-squared value is relatively small (12%), the majority of the variation in pain scores (88%) is explained by factors other than the county.

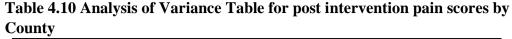
Genetic, environmental, or cultural factors could be playing a role in these differences." For instance, differences in healthcare infrastructure, access to medications, or lifestyle factors across counties could contribute to differences in pain management and hence in post-intervention pain scores. These are, however, hypotheses that would need to be further investigated as the study did not directly provide these insights. Moreover, the significant result does not indicate which counties differ from each other in terms of post-intervention pain scores. This can be explored using post-hoc tests such as the Tukey's HSD test. To provide a more comprehensive interpretation, the specific mean pain scores for each county and their respective standard deviations would be valuable. This would allow for an understanding of the specific differences in pain scores across counties. This information can also guide targeted interventions in the counties where the post-intervention pain scores are particularly high. The means and standard deviations are presented in Table 4.10;

90

 Term
 SS
 df
 F
 p
  $\eta_p 2$  

 COUNTY
 20.74
 3
 7.81
 <.001</td>
 0.12

 Residuals
 152.26
 172



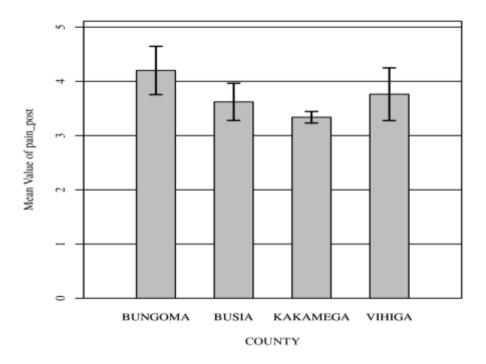


Figure 4.3: Means of post intervention pain scores by COUNTY with 95.00% CI Error Bars

The figure 4.3 above shows the mean, standard deviation, and sample size for postintervention pain scores by county. In Bungoma, the mean post-intervention pain score is 4.20, with a standard deviation of 1.44 and a sample size of 40. In Busia, the mean score is 3.62, with a standard deviation of 0.94 and a sample size of 29. In Kakamega, the mean score is 3.34, with a standard deviation of 0.50 and a sample size of 86. Finally, in Vihiga, the mean score is 3.76, with a standard deviation of 1.14 and a sample size of 21. The highest mean pain score is observed in Bungoma County (4.20) and the lowest mean pain score is in Kakamega County (3.34). This suggests that the children from Bungoma County reported the highest levels of pain after the intervention, while the children from Kakamega County reported the lowest levels of pain.

The standard deviation provides an indication of the variability or spread of the pain scores within each county. In this context, Bungoma County has the highest standard deviation (1.44), indicating a wider spread of pain scores among the children in that county, while Kakamega County has the smallest standard deviation (0.50), indicating a tighter spread of pain scores. The sample sizes differ across the counties, with Kakamega County having the largest sample (n=86) and Vihiga County having the smallest (n=21). It's important to consider sample size when interpreting these results, as larger sample sizes generally provide a more accurate representation of the population. For instance, genetic differences could lead to varying severity of SCD and thus differences in pain experience. Environmental factors such as access to healthcare, quality of healthcare, lifestyle, and diet could also play a role. Additionally, cultural factors, such as perceptions of pain and coping strategies, could potentially influence self-reported pain scores.

pain scores for intervention group by County			
М	SD	п	
4.20	1.44	40	
3.62	0.94	29	
3.34	0.50	86	
	M           4.20           3.62		$ \begin{array}{c ccccccccccccccccccccccccccccccccccc$

3.76

1.14

21

Vihiga

 Table 4.11 Mean, Standard Deviation, and Sample Size for post intervention

 pain scores for intervention group by County

A *t*-test was calculated between each group combination to further examine the differences among the variables based on an alpha of .05. The Tukey HSD p-value adjustment was used to correct for the effect of multiple comparisons on the family-wise error rate. For the main effect of County, the mean of post intervention pain scores for Bungoma (M = 4.20, SD = 1.44) was significantly larger than for Kakamega (M = 3.34, SD = 0.50), p < .001. No other significant effects were found.

#### **CHAPTER FIVE**

# DISCUSSION

#### **5.1 Introduction**

This chapter discusses the results of the study as they relate to the literature. Additionally, the chapter provides a comparison between this study's findings and those studies reviewed in chapter two of this manuscript.

# 5.2 Association between socio-demographic and musculoskeletal pain among children with sickle cell disease

The discussion chapter of this research report focused on the results from the chisquare statistics that showed various results on the association between sociodemographic characteristics and musculoskeletal pain among children with sickle cell disease. In order to contextualize these findings, a review of relevant literature from studies conducted was done and compared with this studies results.

A study that was conducted at Webuye County hospital on factors associated with SCD severity among patients with sickle cell Disease found that there was no association between sociodemographic characteristics and painful attacks in SCD (Benard Oduor,2018). Similarly,the results of this study found no statistical association between socio-demographic characteristics and MSK pain among the general population of children with sickle cell disease.Some of the characteristics included age,gender,socio economic status of the family and number of family members among others were found not to be predictors of MSK in children with sicklecell disease. Just as the results of the study mentioned above,MSK is a presentation that occur as a result of severity of Sickle Cell Disease. Asystematic review was conducted and published in Brazillian journal on physical therapy on musculoskeletal pain in children and adolescents.The results showed that, physical

and psychosocial factors were associated with MSK report, but the strength and direction of these relationship was not clear. Therefore recommendations for further studies on the same was done (Kamper *et al.*,2016). This remains contrary to the findings of this study where no significant was found between sociodemographic characteristics and musculoskeletal pain in children with sickle cell disease.

A cross sectional case control study conducted in Iceland on Musculoskeletal pain and its effect on daily activity and behaviour in Icelandic children and youths with juvenile idiopathic arthritis reveaved that, children with juvenile idiopathic arthritis had more pain with many painful attacks compared with peers in control group who were the healthy peers (Svanhildur *et al.*,2022).This could be an indication that painful attacks could be exacercabated in children with other medical conditions unlike those without any other medical condition.However,this study included all participants with MSK in sickle cell Disese hence did not have the children with other medical conditions which was one of the exclusion criteria,or healthy peers.

A study published in the Journal of Pain Research found that children with sickle cell disease had a higher incidence of musculoskeletal pain compared to healthy controls, but did not investigate potential associations with sociodemographic characteristics (Fakoya *et al.*,2019). This discrepancy may be due to the different study populations and methods used. This study findings are consistent with this study in that we also observed a higher incidence of musculoskeletal pain in children with sickle cell disease, but our results indicate that this pain is not associated with sociodemographic factors. For example, this study had a larger sample size and a more diverse population.

A study published in the Journal of Child Neurology found that children with sickle cell disease who had a higher level of fatigue had a higher incidence of musculoskeletal pain (Adeyemo *et al.*,2019). This study did not investigate the association between fatigue and musculoskeletal pain in children with sickle cell disease, but these findings suggest that addressing fatigue in this population may be important in managing musculoskeletal pain.

A study published in the Journal of Pediatric Hematology/Oncology found that children with sickle cell disease who had a higher level of physical activity had a lower incidence of musculoskeletal pain (Adewoye *et al.*,2021). This study did not investigate the association between physical activity and musculoskeletal pain in children with sickle cell disease, but these findings suggest that promoting physical activity in this population may be an effective strategy for reducing musculoskeletal pain. This may be in agreement with this study where exercise was found to be significant in management of musculoskeletal pain among children with sickle cell disease.

Overall, this study's findings add to the growing body of literature on musculoskeletal pain in children with sickle cell disease by indicating that there is no statistically significant association between sociodemographic characteristics and musculoskeletal pain in this population. However, other studies have found associations between other factors such as history of pain crises, BMI, physical activity, fatigue, and psychological distress and musculoskeletal pain. Therefore, more research is needed to understand the underlying causes of musculoskeletal pain in children with sickle cell disease. In conclusion, the study findings suggest that musculoskeletal pain in children with sickle cell disease is not associated with sociodemographic characteristics. Our results are similar to some studies published as described above. However, there are some studies that have reported associations between other factors such as history of pain crises, BMI, physical activity, fatigue, and psychological distress and musculoskeletal pain. This highlights the complex and multifactorial nature of musculoskeletal pain in children with sickle cell disease. Further research is needed to investigate these factors and their potential interactions in order to develop effective interventions for managing musculoskeletal pain in this population.

# 5.3 Strategies used in management of musculoskeletal pain among children

# with sickle cell disease

The discussion chapter of this research report focused on interpreting the results of the study and comparing them to other relevant studies. The study aimed to investigate the strategies used in the management of musculoskeletal pain among children with sickle cell disease (SCD). This is discussed and compared with other studies that have been conducted in other related studies below;

Astudy conducted in Nigeria on barriers to the use of hydroxurea inmanagement of sickle cell disease found out adverse effects on the prolonged use of this drug (Adeyemo *et al.*,2019).The researchers recommended on alternative options and investigations for these patients.This study concurs with the results of this study where hydroxyurea was the most drug used by these children.Having looked at the effects of the prolonged use of this drug,the research supports the use of alternative therapies instead of long term use of drugs which includes hydroxyurea.

A qualitative study conducted in in USA on chronic pain and self-management in adults with sickle cell disease reported exercise as one of the effective strategies used in chronic pain management in SCD (Nadine *et al.*,2018). It also revealed that pharmacological interventions were the most commonly used although recommended that reseach should be conducted on the best drug to be used as most people were using more than one drug at a time. These findings concur with the findings of this study which found out that drugs were most commonly used in management of MSK pain among children with SCD whereby some were using more than two drugs.

The results of the study showed that the most commonly used strategy in the management of musculoskeletal pain among children with SCD was the use of pain management drugs such as DF 118, Hydroxyurea and Brufen among others. This results concur with a randomized Controlled Trial study that was conducted on Intravenous Acetaminophen verses Intravenous Diclofenac Sodium in Management of Skeletal Vaso-occlusive Crisis Among Children with Homozygous Sickle Cell Disease in India which found that there was reduction in pain score in both groups for acetaminophen and diclophrenac(Prakash *et al.*,2021). However, prolonged use of the drugs has also been noted to have adverse effects for on renal system, liver and cardiovascular system. This has led to many studies recommending on use of alternative non pharmacological methods to manage musculoskeletal pain among these children with Sickle cell disease.

Another study conducted on effectiveness of a home-based therapeutic exercise program on lower back pain and functionality in Sickle Cell Disease (SCD) patients (Camila *et al.*,2019) showed that, daily home-based exercises for a three-month period alleviate pain and improve disability related to lower back pain and muscle strength. It also found out that exercise was effective strategy although not commonly

used in management of MSKpain in this category. The results concur with the results of this study which showed that a three month exercise alleviated the level of pain in the intervention group when compared to the control group who did not do the exercises. This concludes that exercise is an effective strategy in management of MSK Pain among the children with sickle cell disease.

Overall, these studies demonstrate that the use of pain management drugs, regular clinic follow-ups, health education, and adequate intake of fluids are commonly used strategies in the management of musculoskeletal pain among children with SCD. Regular exercise also appears to be an effective strategy in reducing pain among children with SCD although it was less used. These findings support the importance of using a multi-faceted approach to manage musculoskeletal pain in children with SCD, including the use of pain management drugs, regular clinic follow-ups, adequate intake of fluids, and regular exercise.

It is worth noting that there may be some variations in the specific strategies used and the results reported in these studies, which could be due to differences in study populations, methods, and interventions used. For example, some studies focused on specific pain management drugs or exercise, while others may have included broader categories. Additionally, the study by Adeyemo *et al.*(2019) found a positive association between regular exercise and reduced pain, while the other studies did not specifically investigate exercise as a pain management strategy. Despite these variations, the overall consistency of the findings across studies suggest that a multifaceted approach is generally effective in managing musculoskeletal pain in children with SCD. In conclusion, the results of this study, along with the findings of previous research, demonstrate the importance of using a multi-faceted approach to manage musculoskeletal pain in children with SCD. The use of pain management drugs should be minimized because of the effects on body organs. Regular exercise is one of the important strategies that should be considered in the management of MSK pain in this population. These findings have important implications for healthcare providers, caregivers and policy makers as it highlights the importance of providing appropriate pain management and care for children with SCD.

# 5.4 Factors that influence management of musculoskeletal pain among children with sickle cell disease

The themes that emerged from the caregivers interviews in this study were consistent with factors identified in previous researches. However, these interviews revealed economic factors as a major theme which was attributed to high cost of health care and drugs as significant factor affecting the management of children with musculoskeletal pain in sickle cell disease. Caregivers expressed their fears towards the costs of managing this children. It is important for hospitals to be equipped with drugs and other resources, unfortunately there are no drugs .Parents spend a lot of money buying drugs for their children. Other alternative options for management of children with musculoskeletal pain would be appropriate. The themes that emerged also included: socio cultural, individual, nutritional, and environmental and hospital factors which aligned with the majority of previous research on the subject.

A systematic review and meta-analysis was carried out on Health related quality of life(HRQL) in children with sickle cell disease. The results showed that children with SCD had high chances of experiencing worse poor quality of life as compared to healthy children. This was related to effect of several biological, psychological and

social factors. Future research was recommended to examine how sociocultural factors affect the population and their overall quality of life (Stokoe *et al.*,2022). The results concur with the findings of this study whereby Biolological,economical and social factors were found to influence the management of musculoskeletal pain among children with sickle cell disease. This means that these factors determine the type of quality of life these children have.For example, from this study,many children reported to have missed school because of musculoskeletal pain as they could not cope.If they are not able to perform their normal activities like going to school when in pain,this already indicates that their quality of life is already compromised.

A systematic review was conducted on physical impairement and function in children and adolescents with sickle cell disease in Maryland (Marchese *et al.*,2022). The study found that children and adolescents experience a lot of physical function limitations due to trauma of pain. This study did not lookat health condition as a factor that could aggreviate the condition in children. However, the researcher agrees with the study findings because when these children and adolescents are in pain, their normal body functionality is compromised. Hence this study of use of exercise in management ofmusculoskeletal pain among children to improve their body functionality.

A study investigated the socio-economic determinants of musculoskeletal pain in children with SCD in Nigeria, which found that socio-economic factors such as poverty and lack of family support played a significant role in the management of musculoskeletal pain in children with SCD (Adewoye *et al.*,2019). This is consistent with this study's findings on the impact of lack of finances and lack of family support on the management of musculoskeletal pain among children with SCD.

However, there are also studies that had inconsistent results. For example, a study found that children with SCD had a higher prevalence of musculoskeletal pain and that it was associated with poor physical function, but they did not find a significant association between musculoskeletal pain and cold weather which this study found as significant factor (Brown *et al.*,2020). This could be attributed to the smaller sample size of 28 that was used unlike the larger sample size of 176 that was used in this study. The smaller sample size may not give a clear picture hence larger sample size may be used for generalization.

A systematic review was conducted on the effect of home-based exercise on pain, physical function, and quality of life in children with SCD and found that there is insufficient evidence to support the effectiveness of home-based exercise in improving musculoskeletal pain among children with SCD(Eke *et al.*2020). This is inconsistent with the findings of this study where exercise was found to be effective.

Overall, the literature suggests that musculoskeletal pain is a common complication among children with SCD, with various risk factors and socio-economic factors influencing its expression and management. The study findings are consistent with the majority of previous research, but there are also inconsistent results from some studies. Further research is needed to further understand the complexity of musculoskeletal pain in children with SCD and to identify effective interventions for managing this pain. These studies that had inconsistent results with our study, highlights the need for more studies to be conducted in different population with different settings, as well as to consider other factors that may influence the outcome of musculoskeletal pain among children with SCD, such as genetic and environmental factors. Additionally, more research is needed to examine the effectiveness of different interventions in managing musculoskeletal pain in children with SCD in order to develop more effective treatment strategies for this population.

# 5.5 Outcomes of exercise in management of musculoskeletal pain among children with sickle cell disease

The discussion chapter of this research report focused on interpreting the results of the study and comparing them to other relevant studies. The study aimed to evaluate the outcomes of exercise in the management of musculoskeletal pain among children with sickle cell disease. The results showed that there was a significant differences in post-intervention musculoskeletal pain and pre-intervention musculoskeletal pain between the control and intervention groups. The main effect for group was significant and the main effect for the within-subjects factor was also significant. For the intervention group, post-intervention musculoskeletal pain was significantly less musculoskeletal In than pre-intervention pain. contrast, post-intervention musculoskeletal pain was not significantly different from pre-intervention musculoskeletal pain in the control group.

A study was conducted on musculoskeletal pain current and future directions on physical exercise. The results showed that physical activity and exercise was proven effective in management of musculoskeletal pain in chronic conditions (Fullen *et al.*, 2023). Sickle cell disease is a chronic condition where musculoskeletal pain presents due to vaso occlusion. The findings concurs with the results of this study where exercise was found to have a significant difference in pre- pain and post- pain assessment among participants in the intervention group. This means that the participants reported of reduced pain after the exercise. Therefore, the researcher supports the use of exercise in MSK pain management among children with ssickle cell disease. Another study was conducted on cardiovascular benefits of a home based

exercise program in patients with sickle cell disease in Brazil in both control and experimental groups. The results showed that the exercise group had significant improvement in cardiovascular function unlike control group who were not enrolled in exercise.Conclusion was made that exercise was beneficial in sickle cell disease patients(De Araujo *et al.*,2021). This concurs with the results of this study where by exercise was effective in management of muscusculoskeletal pain with many benefits in many systems including integumentary,respiratory,cardiovascular among many others.

Musculoskeletal pain negatively affects the quality of life in children with SCD (Adekunle *et al.*,2019). A study on the effects of home-based exercise on musculoskeletal pain and physical function in children with SCD (Asghar *et al.*,2021). This is consistent with this study's findings on the benefits of exercise on musculoskeletal pain. Another study found that a combined exercise program of aerobic and strength training improved cardiovascular fitness and decreased pain levels in children with sickle cell disease by Brown *et al.*,2020). The study supports the outcome of this study whereby through exercise, pain was reduced.

A study on 'light to moderate exercise may bring benefits for sickle cell disease' published in the journal of African society of hematology found that an 8-week exercise regimen had a significant effect on improving blood vessels and physical ability in sickle cell disease. The study had 40 patients and assigned them in two groups whereby half followed their normal routine while the other half participated in the regimen three times a week. After 8 weeks, the researcher found positive effects on the muscle function and overall physical ability(American society of hematology, 2019). Although previous studies had disputed such results that exercise increased the effects on sickle cell disease patients. It is possible that the exercise used

in this study may have been more effective than the programs used in the studies that did not find significant reductions in pain. Additionally, it is also possible that other factors, such as the specific population of children with sickle cell disease or the duration of the exercise program, may have influenced the results.

It is also important to note that some studies may have used different measurements for pain, which can make comparisons difficult. Furthermore, other studies may have used a different population of children with sickle cell disease which can also affect the results.Overall, the results of this study, along with the findings of the previously mentioned studies, provide strong evidence for the effectiveness of exercise in managing musculoskeletal pain among children with sickle cell disease. The studies that have found consistent results, including this study, have used a variety of exercise interventions, such as a combination of aerobic and resistance training, and have found significant reductions in musculoskeletal pain among children with sickle cell disease. However, it is important to also consider the inconsistent findings from other studies when interpreting the results of this study, and further research is needed to better understand the effectiveness of exercise in managing musculoskeletal pain among children with sickle cell disease.

#### **CHAPTER SIX**

#### SUMMARY, CONCLUSION AND RECOMMENDATIONS

#### **6.1 Introduction**

This chapter focused on the summary of findings analyzed in chapter four. The summary of findings was based on the study's research objectives. Consistent with this study's findings, recommendations were offered for how these findings would be used to inform different parts of the field, particularly regarding policy, practice and possible future research endeavors.

#### 6.2 Relationship between socio demographic characteristics and

#### musculoskeletal pain among children with sickle cell disease

The first research question in the study was to determine the relationship between socio demographic characteristics and musculoskeletal pain among children with sickle cell disease. Results from chi-square statistics showed that there was no statistically significant association between socio demographic characteristics and musculoskeletal pain among children with sickle cell disease.

# 6.3. Strategies used in management of musculoskeletal pain among children with sickle cell disease in western Kenya

The second research question was to find out the strategies that are used in management of musculoskeletal pain among children with sickle cell disease. Overall, the resuts of the study showed that the management of musculoskeletal pain among children with sickle cell disease primarily involved the use of pain management drugs which possed a problem due to stock outs at the hospital, economic burden of buying the drugs and the adverse effects of the prolonged use of most of the drugs.

# 6.4 Factors that influence management of musculoskeletal pain among children with sickle cell disease in western Kenya

The third research question was to find the factors that influence management of musculoskeletal pain among children with sickle cell disease. The results of the qualitative data suggested that economic factors was the common factor that influenced their management of musculoskeletal pain among children with sickle cell disease. These factors were categorized into themes such as economic, sociocultural, Individual, psychological, nutritional and environmental factors.

#### 6.5 Outcomes of exercise in management of musculoskeletal pain among

#### children with sickle cell disease in western Kenya

The fourth research question was to assess the effectiveness of exercise in management of musculoskeletal pain among children with sickle cell disease in westernregion of Kenya. The results of this mixed model ANOVA indicated that there was significant differences in in intervention group in pain post and pain pre between the levels of group. The main effect for intervention group was significant, indicating that there were significant differences in repported pain pre and pain post between the levels of group using wong baker faces pain reporting scale. The main effect for the within-subjects factor was also significant, indicating that there were significant differences of pain post and pain pre. The interaction effect between the within-subjects factor and group was significant, suggesting that the relationship between pain post and pain pre differs significantly between the levels of group. Specifically, for the intervention category of group, pain post was found to be significantly less than pain pre, suggesting that the intervention may have been

effective in reducing pain. These results suggested that the intervention had potential to be effective in reducing pain in this population.

Therefore, we reject the hypothesis, "There is no significant difference in musculoskeletal pain among children with Sickle cell disease in the control and experimental group".

## 6.6 Conclusions

- The study found no statistically significant association between socio demographic characteristics and musculoskeletal pain among children with sickle cell disease.
- 2. The most commonly used strategy in musculoskeletal pain management among children with sickle was the use of drugs despite the adverse effects of the prolonged use of most drugs and the economic burden.
- 3. The most common factor that affected the management of musculoskeletal pain was the economic factors which was a burden to most of the participants in accessing care, as well as as sociocultural factors which hindered people from seeking medical attention.
- 4. The results suggested that the exercise was effective in reducing musculoskeletal pain in this population.

## 6.7 Recommendations

# 6.7.1 Relationship between sociodemographic characteristics and musculoskeletal pain among children with sickle cell disease in Western Region of Kenya

The study recommends that healthcare professionals and researchers in the field of sickle cell disease in the Western Region of Kenya conduct further studies to identify

specific sociodemographic factors that significantly contribute to musculoskeletal pain in children with sickle cell disease. This will allow for targeted interventions and personalized care for affected individuals.

# 6.7.2 Strategies used in the management of musculoskeletal pain among children with sickle cell disease in Western Region of Kenya

The study recommends recommends that, in addition to the use of drugs exercise should be used in reducing musculoskeletal pain among children with Sickle Cell Disease.

# 6.7.3 Factors that influence effective management of musculoskeletal pain among children with Sickle Cell Disease in Western Region of Kenya

The study recommends that health institutions should provide activities that empower people economically to be able to access medical care. In addition, health professionals should provide health education to the people on socio cultural factors that hinder access to medical care.

# 6.7.4 Outcomes of exercise on musculoskeletal pain among children with Sickle Cell Disease in Western Region of Kenya

Although exercise is effective in reduction of musculoskeletal pain, there is need for further studies to verify other interventions in reduction of musculoskeletal pain like heat and cold therapies.

### 6.8 Suggestion for Further researches

• The study recommends similar study to be conducted for a longer period to ascertain the best and safe exercise for Musculoskeletal pain management among children with sickle cell disease.

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## **APPENDIX I: Introduction Consent**

My name is Roselyne Asiko Abwalaba, having a Master of Science in Advanced Nursing Practice (Paediatrics), and a researcher currently studying Doctor of Philosophy in Nursing at Masinde Muliro University of Science and Technology. I invite you to participate in the study" Effectiveness of exercise on musculoskeletal pain among children with sickle cell disease in western Kenya". It is voluntary for you to participate in the study and you can opt out in case you are not comfortable.

# **Purpose of the study**

The purpose of the study is to determine the effectiveness of exercise in musculoskeletal pain among children with sickle cell disease in western Kenya.

## Procedure

Questionnaire, in depth interview and key informant guide will be used to obtain information from participants by answering questions, and researcher will be noting. An exercise intervention will be initiated and monitored three days in a week for a period of three months.

#### Benefits of the study

Participating in this study will help increase understanding of the effectiveness of exercise in musculoskeletal pain management among children with sickle cell disease. We hope that the results of this study will reveal any gaps and effectiveness on the child's outcome.

# **Risks of the study:**

Invasive procedures will not be conducted hence no much risk.

# Confidentiality

The information about of what i observe or what you provide during the study will be kept confidential and will not be shared by anyone without your permission. Only the principal investigator and the interviewers will have access to information .The information will be kept under key and lock by the principal investigator during the course of the study. No identity of child's name will be used during the process.

### **APPENDIX II: Children Participant Information And Consent Form**

### **Parental Consent/Ascent**

## **Title of Study:**

EFFECTIVENESS OF EXERCISE ON MUSCULOSKELETAL PAIN AMONG CHILDREN WITH SICKLE CELL DISEASE IN WESTERN KENYA

Principal Investigator: Roselyne Asiko Abwalaba

**Institutional affiliation:** Masinde Muliro University of Science and Technology, School of Nursing, Midwifery and Paramedical Sciences

#### **Co-Investigators and institutional affiliation:**

1. Prof. John Okoth

Professor of Nursing, Masinde Muliro University of Science and Technology

2. Prof. Fabian Esamai

Professor of Child Health and Paediatrics, Moi University

## Introduction:

I would like to tell you about a study being conducted by the above listed researchers. The purpose of this consent form is to give you the information you will need to help you decide whether or not your child should participate in the study. Feel free to ask any questions about the purpose of the research, what happens if your child participates in the study, the possible risks and benefits, the rights of your child as a volunteer, and anything else about the research or this form that is not clear. When we have answered all your questions to your satisfaction, you may decide if you want your child to be in the study or not. This process is called

'informed consent'. Once you understand and agree for your child to be in the study, I will request you to sign your name on this form.

You should understand the general principles which apply to all participants in a medical research:

- i) Your child decision to participate is entirely voluntary.
- ii) You child may withdraw from the study at any time without necessarily giving a reason for his/her withdrawal.
- iii) Refusal to participate in the research will not affect the services your child is entitled to in any facility.

#### May I continue? YES / NO

For children below 18 years of age we give information about the study to parents or guardians. We will go over this information with you and you need to give permission in order for your child to participate in this study. We will give you a copy of this form for your records.

If your child is at an age that he/she can appreciate what is being done the he/she will also be required to agree to participate in the study after being fully informed.

## WHAT IS THE PURPOSE OF THE STUDY?

The researchers listed above are interviewing individuals' who have had musculoskeletal pain in sickle cell disease. The purpose of the interview is to determine the effectiveness of exercise in musculoskeletal pain among children with sickle cell disease in western Kenya. Participants in this research study will be asked questions about how frequent they experience musculoskeletal pain and what is done to relieve the pain both pharmacological and none Pharmacological. Participants will also have the choice to undergo an exercise sessions for 3 months.

There will be approximately 176 participants in this study randomly chosen. We are asking for your consent to consider your child to participate in this study.

# WHAT WILL HAPPEN IF YOU DECIDE YOU WANT YOUR CHILD TO BE IN THIS RESEARCH STUDY?

If you agree for your child to participate in this study, the following things will happen:

You will be interviewed by a trained interviewer in a private area where you feel comfortable answering questions. The interview will last approximately 30 minutes. The interview will cover topics such as age, sex, occupation, marital status, siblings (demographic data of your child) frequency of musculoskeletal pain and management, hospital admissions, drugs used and any other techniques used.

After the interview, a baseline assessment will be done, exercise program will be initiated if you accept us for 3 months. You will be informed about the results as we proceed.

We will ask for a telephone number where we can contact you if necessary. If you agree to provide your contact information, it will be used only by people working for this study and will never be shared with others. The reasons why we may need to contact you is to find out more about your child's progress and pain management.

# ARE THERE ANY RISKS, HARMS, DISCOMFORTS ASSOCIATED WITH THIS STUDY

Medical research has the potential to introduce psychological, social, emotional and physical risks. Effort should always be put in place to minimize the risks. One potential risk of being in the study is loss of privacy. We will keep everything you tell us as confidential as possible. We will use a code number to identify your child in a password-protected computer database and will keep all of our paper records in a locked file cabinet. However, no system of protecting confidentiality can be absolutely secure so it is still possible that someone could find out your child was in this study and could find out information about your child.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview or any questions asked during the interview.

It may be embarrassing for you to have your child do some of the exercises .We will do everything we can to ensure that this is done in private. Furthermore, all study staff and interviewers are professionals with special training in these examinations/interviews. Also, helping the child to do the required exercise may be stressful.

Your child may feel some discomfort when doing the exercise and may have a small bruise or swelling in on the body. In case of an injury, illness or complications related to this study, contact the study staff right away at the number provided at the end of this document. The study staff will treat your child for minor conditions or refer the child for treatment for conditions that require more extensive care.

#### ARE THERE ANY BENEFITS BEING IN THIS STUDY?

Your child may benefit by receiving free training on exercises that may reduce the frequency of musculoskeletal pain and improve the general health. You may be counseled on the type of exercises to be conducted and its benefits. We will refer your child to a hospital for care and support if necessary. Also the information you provide will help us better understand the management of painful events of your child. This information is a major contribution to science and research.

#### WILL BEING IN THIS STUDY COST YOU ANYTHING?

It may cost your time because you will need to be available during the exercise training of your child.

## IS THERE REIMBURSEMENT FOR PARTICIPATING IN THIS STUDY?

There is no payment for you to participate in the study. However, there will be transport reimbursement and lunches where there is need.

## WHAT IF YOU HAVE QUESTIONS IN FUTURE?

If you have further questions or concerns about your child participating in this study, please call or send a text message to the study staff at the number provided at the bottom of this page.

For more information about your child's rights as a research participant you may contact the Secretary/Chairperson, Masinde Muliro University Ethics and Review Committee Telephone No. 056-31375, Email ierc@mmust.ac.ke.

The study staff will pay you back for your charges to these numbers if the call is for study-related communication.

# WHAT ARE YOUR OTHER CHOICES?

Your decision to have your child participate in this research is voluntary. You are free to decline or withdraw participation of your child in the study at any time without injustice or loss of benefits. Just inform the study staff and the participation of your child in the study will be stopped. You do not have to give reasons for withdrawing your child if you do not wish to do so. Withdrawal of your child from the study will not affect the services your child is otherwise entitled anywhere.

For more information contact Roselyne Asiko Abwalaba at

0722345997 from 8. 00am to 5.00 pm.

# **APPENDIX III: Children Assent Form**

**Title:** Effectiveness of Exercise on Musculoskeletal Pain among Children with Sickle Cell Disease in Western Kenya.

My name is Roselyne Asiko Abwalaba. I am a student of Doctor of Philosophy in Nursing at the Masinde Muliro University of Science and Technology. I am carrying out a study on Effectiveness of Exercise on Musculoskeletal Pain among Children with Sickle Cell Disease in Western Kenya. Permission has been granted to undertake this study by the Masinde Muliro University of Science and Technology. At least 176 children ,176 mothers and 8 clinicians and nurses will be participating in this research study.

If you decide that you want to be part of this study, you will be asked to sign in the blank space provided below, be required to IPAQ-C questionnaire with your parent. Filling the questionnaires will take you one 30 to 45 minutes. The researcher will be with you to ask questions for that period. Some information asked of you may be sensitive but will be kept confidential by the researcher. In case you accept to participate in the study, a 12 week exercise program will be implemented on you.

When we finish this study we will write a report about the findings. This report will not include your name or that you were in the study.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too. Your parents will always be with you.

If you decide you want to be in this study, please sign your thumb.

I,	,	want t	o be	e in	this
research study.					

research study.

(Signature/Thumb stamp)

(Date)

# **APPENDIX IV: Consent Form (Statement Of Consent For Parents/Guardian)**

The person being considered for this study is unable to consent for him/herself because he or she is a minor (a person less than 18 years of age). You are being asked to give your permission to include your child in this study.

Parent/guardian statement

I have read this consent form or had the information read to me. I have had the chance to discuss this research study with a study counselor. I have had my questions answered by him or her in a language that I understand. The risks and benefits have been explained to me. I understand that I will be given a copy of this consent form after signing it. I understand that my participation and that of my child in this study is voluntary and that I may choose to withdraw it any time.

I understand that all efforts will be made to keep information regarding me and my child's personal identity confidential.

By signing this consent form, I have not given up my child's legal rights as a participant in this research study.

I voluntarily agree to my child's participation in this research study:

Researcher's statement

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

Printed Name: \_\_\_\_\_ Date: \_\_\_\_\_

Signature:

Role in the study: collection of data, implementation and post evaluation

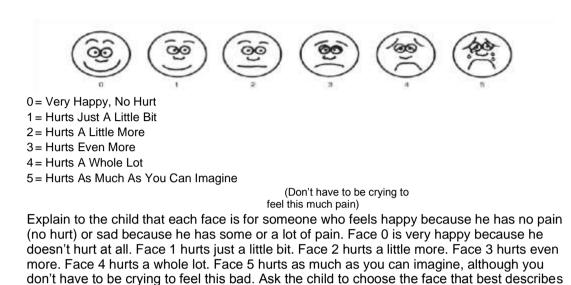
Witness Printed Name (If witness is necessary)

Signature: Date;

## **APPENDIX V: Wong Baker Faces Pain Rating Scale(WBFPRS)**

It has 6 levels and it was developed for young children to communicate how much pain they are feeling(0,1,2,3,4,5).

#### Wong-Baker FACES Pain Rating Scale



#### **Pain Assessment Questions**

#### Quality

How does your pain feel?

how he is feeling.

aching	sharp	tingling	burning	dull
numb	throbbing	pricking	pressing	pulling

#### Intensity

Using an assessment scale above: What number/picture best describes your pain? **Location** 

Where on your body is your pain?

#### Duration

Is pain always there? Does it come and go (breakthrough pain)?

#### Triggers

What positions, activities, or situations: Make the pain worse? Make the pain better? **Effects** 

How has the pain affected important parts of your life?

relationships eating energy work sleep recreation moods Do you have any symptoms in addition to pain?

Do you have any symptoms in addition to pair?

nausea/vomitingweaknessconstipationsleepiness/confusionitchingproblemswith urinationKnowledgeWhat do you understand about your pain and its causes?

Have you ever seen educational materials about pain? Have you taken any medicine for pain? Have your tried any non-drug therapies for pain?

## APPENDIX VI: International Physical Activity Questionnaire for Children

## (Ipaq-C) Adopted And Modified

## Please fill in the blanks and tick ( ) in the bracket of answers where necessary

Pseudo-Name ....../Date:...../...../.....

Name of county.....

- 1. Age in years :( )2. Gender:Male ( ) Female ( )3. Class:Lower ( ) upper ( )4. Religion:Christian ( ) Muslim ( )
  - 5. Residence: Urban () Rural ()
  - 6. Do you have Parents? Both Parents () Single parent ()
  - 7. Parental marital status: Married () Single ()
  - 8. Parental socio-economic status: poor() Rich()
  - 9. Number of family members : ( )
  - 10. Hemoglobin levels 6-11gm/dl ( ) >11gm/dl ( )
  - 11. How frequent do you visit the hospital because of painful crisis? Weekly ( ) Rarely ( )
  - 12. Do you participate in any exercise ? Yes ( ) No ( )
  - 13. Would you say you experience family support? Yes ( ) No ( )
  - 14. Do you play and socialize with friends? Yes ( ) No ( )
  - 15. How frequent are the painful attacks? Less common() very common()
  - 16. How frequent do you miss school because of the pain? Rarely () Mostly)

17. Are you on any medication? Yes() No()

18. Do the painful crisis affect your performance in school? Yes () No ()

## **APPENDIX VII: In-Depth Interview Guide For Parents**

## Introduction

Thank you for accepting to speak with me today about your child who experiences pain due to sickle cell disease. The interview should take 30 minutes to complete. Everything you share with me shall be kept confidential. None of the information about your child will be shared to anyone outside this study. If there is something you do not understand please let me know. I may video record the conversation, and so I request for your permission. Is this okay? Do you have any questions before we start the interview?

# Strategies and factors for musculoskeletal pain management in children with Sickle Cell Disease

- 1. Are there any beliefs and cultures you consider when managing your child during painful crisis? If yes, please tell me more about them.
- 2. What medication does your child take for pain management?
- 3. Do you use any other alternative therapies to treat your child during painful event? If yes, tell me more about it.
- 4. What are your experiences in managing a child with musculoskeletal pain in sickle cell?
- 5. Does your child do any exercise? If yes, which ones?
- 6. What do you think about use of exercise in managing children with painful crisis in sickle cell Disease?

Explain further.

7. What are some of the factors that affect management of your child during musculoskeletal pain events

## THANK YOU, THIS IS THE END OF OUR INTERVIEW.

## APPENDIX VIII: Key Informant Guide For Clnical Officers and Nurses Working In Scd Clinics

- 1. Would you please explain the current state of the condition of the child?
- 2. Explain the progress of the child from your follow up evaluations?
- 3. Which measures have been put in place to manage musculoskeletal pain among children with SCD?
- 4. What would you recommend about the exercise program in management of musculoskeletal pain among children with SCD?
- 5. What other measures do you think should be put in place to manage musculoskeletal pain among children?

## THANK YOU FOR YOUR RESPONSES

## APPENDIX IX: 12 Week Exercise Program for Children with Musculoskeletal

PHASE 1	PHASE 2	PHASE 3
WORKING AT 50% OF MAX	WORKING AT 60% OF MAX	
WEEK 1 (4 Reps 2	WEEK 5 (9 Reps 2 sets )	WEEK 9 (8 Reps 3 sets )
<ul> <li>sets )</li> <li>MON-Warm up 5 mins, sitted leg raised, biceps curls, overhead daps, static stretches 10 mins</li> <li>WED- Warm up 5 mins, bicycle kicks, abdominal curls, posterior ball lift, static stretches 10 mins</li> <li>FRI- Warm up 5 mins, sitted leg raised, biceps curls, overhead ball lift, static stretches for 10 mins</li> </ul>	<ul> <li>MON-Warm up 10 mins, sitted leg raised, biceps curls, overhead claps, static stretches 10 mins</li> <li>WED- Warm up 5 mins, sitted leg raised, bicycle kicks, abdominal curls, posterior ball lift, static stretches: 10 mins</li> <li>FRI- Warm up 10 mins, sitted leg raised, biceps curls, pull back, fly it, sit and stand overhead claps, static stretches: 10 mins</li> </ul>	MON-Warm up 10 mins, sitted leg raises, biceps curls, sit and stand, overhead claps, overhead arms push, static stretches: 10 mins WED- Warm up 10 mins, sitted leg raises, biceps curls, sit and stand, overhead claps, overhead arms push, static stretches: 10 mins FRI- Warm up 10 mins, sitted leg raise, sitted crunch it, sit and stand, overhead claps, power punch ,static stretches:10 mins
WEEK 2 (with 5 Reps 2 sets )	WEEK 6 (9 Reps 2 sets )	WORKING AT 80%OF MAX
MON-Warm up 5 mins, sitted leg raised, biceps curls, overhead claps, static stretches: 10 mins WED- Warm up 5 mins, bicycle kicks, abdominal curls, posterior ball lift, static stretches 10 mins FRI- Warm up 5 mins, sitted leg raised, biceps curls, overhead ball lift,	<ul> <li>MON-Warm up 10 mins, sitted leg raised, biceps curls, sit and stand, overhead claps, static stretches:10 mins</li> <li>WED- Warm up 5 mins, sitted leg raised ,bicycle kicks, abdominal curls ,posterior ball lift, static stretches :10 mins</li> <li>FRI- Warm up 10 mins, sitted leg raised, biceps curls, pull back, fly it, sit</li> </ul>	WEEK 10 (10 Reps 3 sets ) MON-Warm up 10 mins, sitted/lying leg raises, weighted biceps curls, sit and stand overhead claps, lateral arms push, static stretches 10 mins WED- Warm up 10 mins, sitted/lying leg raises , weighted biceps curls, sit and stand, sitted/lying bicycle kicks, overhead

## Pain In Sickle Cell Disease as Per WHO,2019

static stretches for 10 mins	and stand, overhead claps, static stretches: 10 mins	hand claps, lateral arm push, overhead ball push, static stretches: 10 mins <b>FRI-</b> Warm up 10 mins, sitted/lying leg raises , weighted biceps curls, sit and stand, overhead hand claps, lateral arm push, overhead arms push, static stretches: 10 mins	
WEEK 3 (7Reps 2 sets )	WORKING AT 70% OF MAX	WEEK 11( 12 Reps 3sets )	
MON-Warm up 5 mins, sitted leg raises, biceps curls, overhead daps, static stretches: 10 mins WED- Warm up 5 mins, sitted leg raises ,bicycle kicks, abdominal curls, posterior ball lift, static stretches; 10 mins FRI- Warm up 5 mins, sitted leg raises, biceps curls, overhead ball lift, static stretches: 10 mins	WEEK 7 (8 Reps 2 sets ) MON-Warm up 10mins, sitted leg raised, biceps curls, sit and stand, overhead arms push, static stretches 10 mins WED- Warm up 10sitted leg raises, biceps curls, hamstring curls, sit and stand, overhead claps, overhead arms push, static stretches 10 mins FRI- Warm up 10 mins, sitted leg raises, pull back, sitted crunch it, sit and stand, overhead claps, power punch, static stretches for 10mins	MON-Warm up 10 mins, sitted/lying leg raises, weighted biceps curls, sit and stand, overhead claps, lateral arm push, overhead arms push, static stretches 10 mins WED- Warm up 10 mins, sitted/lying leg raises, weighted biceps curls, sit and stand, sitted/lying bicycle kicks, overhead hand claps, lateral arm push, overhead arms push, static stretches 10 mins FRI- Warm up 10 mins, sitted/lying leg raises, weighted biceps curls, sit and stand, overhead claps, lateral arm push, overhead arms push, static stretches 10 mins	
WORKING AT 60% OF MAX WEEK 4 (8 Reps 2 sets ) MON-Warm up 10 mins, sitted leg raises, biceps curls, sit and stand, overhead daps, static stretches :10 mins	WEEK 8 ( 8 Reps 3 sets ) MON-Warm up 10 mins, sitted leg raised, biceps curls, sit and stand, overhead daps, overhead arms push ,static stretches; 10 mins	WEEK 12 (14 Reps 3 sets) MON- Warm up 10 mins, sitted/lying leg raises, weighted biceps curls, sit and stand, overhead claps, lateral arm push,	

WED- Warm up 5	WED- Warm up 10 mins,	overhead arms push,
mins, bicycle kicks,	sitted leg raises, biceps	static stretches 10 mins
abdominal curls,	curls, sit and stand,	WED- Warm up 10 mins,
posterior ball lift, static	overhead claps, overhead	sitted/lying leg raises,
stretches: 10 mins	arm push, static stretches	weighted biceps curls, sit
<b>FRI</b> - Warm up 10 mins,	10 mins	and stand, overhead hand
sitted leg raises, biceps	<b>FRI-</b> Warm up 10 mins,	claps, lateral arm push,
curls, sit and stand,	sitted leg raises, pull back,	overhead ball push, static
overhead claps, static	sitted crunch it, sit and	stretches; 10 mins
stretches:10 mins	stand, overhead claps,	<b>FRI-</b> Warm up 10 mins,
	power punch, static	sitted/lying leg raises,
	stretches:10 mins	weighted biceps curls, sit
		and stand, overhead
		claps, lateral arm push,
		overhead arms push,
		static stretches: 10 mins

## **APPENDIX X: Logbook That The Physiotherapists used to Track the Progress**

## of Each Child

Logbook Entry Date	Child's ID	Session Number	Exercises Performed	Child's Pain Score (Before Session)	Child's Pain Score (After Session)	Observations/Comments

## **APPENDIX XI: Approval From Directorate Of Postgraduate Studies**



#### MASINDE MULIRO UNIVERSITY OF SCIENCE AND TECHNOLOGY (MMUST)

Tel: 056-30870 Fax: 056-30153 E-mail: <u>directordps@mmust.ac.ke</u> Website: <u>www.mmust.ac.ke</u> Directorate of Postgraduate Studies P.O Box 190 Kakamega – 50100 Kenya

Ref: MMU/COR: 509099

12th October 2021

Roselyne Asiko Abwalaba, HNR/H/01-53166/2018, P.O. Box 190-50100, KAKAMEGA.

Dear Ms. Asiko,

#### RE: APPROVAL OF PROPOSAL

I am pleased to inform you that the Directorate of Postgraduate Studies has considered and approved your Ph.D. Proposal entitled; "Effectiveness of Exercise on Musculoskeletal Pain Management Among Children with Sickle Cell Diseases in Western Kenya" and appointed the following as supervisors:

- Prof. John Okoth SONMAPS, MMUST
- 2. Prof. Fabian Esamai Pro
- Professor of Child Health and Paediatrics, Moi University

You are required to submit through your supervisor(s) progress reports every three months to the Director of Postgraduate Studies. Such reports should be copied to the following: Chairman, School of Nursing & Midwifery Graduate Studies Committee and Chairman, Department of Nursing Research, Education & Management and Graduate Studies Committee. Kindly adhere to research ethics consideration in conducting research.

It is the policy and regulations of the University that you observe a deadline of three years from the date of registration to complete your Ph.D. thesis. Do not hesitate to consult this office in case of any problem encountered in the course of your work.

We wish you the best in your research and hope the study will make original contribution to knowledge.

Yours Sincerely, mm

ProvSlephen Odebero, Ph.D., FIEEP BIRECTOR, DIRECTORATE OF POSTGRADUATE STUDIES

## **APPENDIX XII: Approval Letter from Institutional Ethics and Review**

## Committee



REF: MMU/COR: 403012 Vol 5 (01)

Date: December 16th, 2021

To: Roseline Asiko Abwalaba

Dear Madam.

#### RE: EFFECTIVENESS OF EXERCISE ON MUSCULOSKELETAL PAIN MANAGEMENT AMONG CHILDREN WITH SICKLE CELL DISEASE IN WESTERN KENYA

This is to inform you that Masinde Mullro University of Science and Technology Institutional Ethics and Review Committee (MMUST-IERC) has reviewed and approved your above research proposal. Your application approval number is MMUST/IERC/040/2021. The approval period is December 16<sup>th</sup>, 2021-December 16<sup>th</sup>, 2022.

This approval is subject to compliance with the following requirements;

- i. Only approved documents including informed consents, study instruments, MTA will be used.
- All changes including (amendments, deviations, and violations) are submitted for review and approval by MMUST-IERC.
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to MMUST-IERC within 72 hours of notification
- Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to MMUST-IERC within 72 hours
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to MMUST-IERC.

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <u>https://research-portal.nacosti.go.ke</u> and also obtain other clearances needed.

Yours Sincerely,

Prof. Gordon Nguka

Chairperson, Institutional Ethics and Review Committee

Copy to:

- The Secretary, National Bio-Ethics Committee
- Vice Chancellor
- DVC (PR&I)

## **APPENDIX XIII: Research Licence**



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## **APPENDIX XIV: Research Authorization from County Commissioner**

## **Kakamega** County

#### **REPUBLIC OF KENYA**



#### OFFICE OF THE PRESIDENT MINISTRY OF INTERIOR AND CO-ORDINATION OF NATIONAL GOVERNMENT

Telephone: 056 -31131

Email: <u>cckakamegal2/dyahoo.com</u> When replying please quote:

Ref: ED.12/1/VOL.VI/20

Roseline Asiko Abwalaba Masinde Muliro University of Science and Technology (MMUST) P.O Box 190-50100 KAKAMEGA County Commissioner Kakamega County P O BOX 43 - 50100 KAKAMEGA

Date: 31st January, 2022

#### RESEARCH AUTHORIZATION

Following your authorization vide letter Ref: No. NACOSTI/P/22/15052 dated 20<sup>th</sup> January, 2022 by NACOSTI to undertake research on "Effectiveness of Exercise on Musculoskeletal Pain Management among Children with Sickle Cell Disease in Western Kenya" for the period ending 20<sup>th</sup> January, 2023. I am pleased to inform you that you have been authorized to carry out the research on the same in this county.

COUNTY COMMISSIONER KAKAMEGA COUNTY

EREDI C.M FOR: COUNTY COMMISSIONER KAKAMEGA COUNTY

## **APPENDIX XV: Research Authorization from County Director Education**

## **Kakamega County**

## REPUBLIC OF KENYA



MINISTRY OF EDUCATION STATE DEPARTMENT OF EARLY LEARING AND BASIC EDUCATION

Telephone: 056 -30411 Fax: 056 - 31307 E-mail: roeducation2016@gmail.com When replying please quote our Ref. County Director of Education Kakamega County P. O. BOX 137 - 50100 KAKAMEGA

#### REF: KAKA/GA/29/17/VOL VI/04

31st January, 2022

Ms. Roselyne Asiko Abwalaba Masinde Muliro University of Science & Technology KAKAMEGA

#### **RE: RESEARCH AUTHORIZATION**

The above has been granted permission by National Council for Science & Technology vide letter Ref. NACOSTI/P/22/15052 dated 20<sup>th</sup> January, 2022 to carry out research on "Effectiveness of Exercise on Musculoskeletal Pain Management among Children with Sickle Cell Disease - Kakamega" for the period ending 20<sup>th</sup> January, 2023.

Please accord him/her any necessary assistance he may require.

Interes

COUNTY DIRECTOR OF EDUCATIO

DICKSON O. OGONYA COUNTY DIRECTOR OF EDUCATION KAKAMEGA COUNTY

CC The Regional Director of Education WESTERN REGION

## **APPENDIX XVI: Approval to Conduct Study in Kakamega County**



#### COUNTY GOVERNMENT OF KAKAMEGA MINISTRY OF HEALTH SERVICES

Telephone: 056-31850/1852/31853 Email: health@kakamega.go.ke Website: www.kakamega.go.ke The County Director of Health P.O. Box 36-50100 KAKAMEGA

Ref: No. CGK/MOH/ME/VOL.1/10

Date: 31st January, 2022

Roselyne Asiko P.O.BOX 190-50100 Kakamega

Email: rabwalaba@mmust.ac.ke

Dear Abwalaba,

#### RE: APPROVAL TO CONDUCT STUDY IN KAKAMEGA COUNTY

Pursuant to your request to carry out a study protocol entitled:

#### "Effectiveness of Exercise on Musculoskeletal Pain Management among Children with Sickle Cell Disease in Western Kenya".

This is to notify you that we have reviewed your study and ascertained that due procedures have been followed prior to the commencement of data collection. You have provided the study protocol, approval of Proposal from MMUST, Institutional Ethics and Review Committee (IERC) approval from Masinde Muliro University of Science and Technology, and research license from the National Commission for Science and Technology (NACOSTI); and we have established beyond reasonable doubts that the study will not disenfranchise the vulnerable in the County.

Your approval to conduct a research has been granted; you shall work closely with the County medical team during the data collection period.

Yours,

Dr. John Otieno. Ag. Director, Health Services,

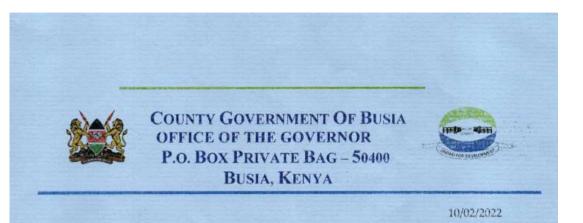
Copy To: CHMT, SCMOHs

## APPENDIX XV1I: Approval From Department of Health and Sanitation Busia

## County

	COUNTY GOVERNMENT OF BUSIA OFFICE OF THE CHIEF OFFICER Department Health & Sanitation	唯一
THE REAL PROPERTY OF	P.O. BOX 1040 - 50400 BUSIA, KENYA	LOPMEN
CG/BSA/PRT/5/12/V	OL.I (22) DATE: 9 <sup>TH</sup> FEBRUARY	202
TO WHOM IT M	AY CONCERN	
Dear Sir/ Madam,		
RESEARCH AUTHO	DRIZATION	
& innovation (NACOS	ch authorization vide Director General National Commission for Science-Techy STI) letter dated: 20 <sup>th</sup> January 2022 Ref No: 128920 which authorized research Management among children with Sickle Cell disease for the Period ending 20	
This is to let you know Busia County.	that Ms. Roselyne Asiko Abwalaba has been authorized to carry out research	n
Please accord her the n	necessary support.	
Thank you in advance.		
Yours faithfully.	TRIMENT OF BUSIA MEALTH & SANITATION	
DR. ISAAC OMERI	EB 2022 IEDICAL SERVICES	
DEPARTMENT OF	HEALTH AND SANITATION	
CC CECM- HEALTH AN	ND SANITATION	

## **APPENDIX XVIII: Approval From County Government of Busia**



#### TO WHOM IT MAY CONCERN

#### **RE: ROSELYNE ASIKO ABWALABA**

The above named person has sought permission from the office of the governor to allow her carry out research on the topic: Effectiveness of Exercise on Musculoskeletal Pain Management among Children with Sickle Cell Disease in Western Kenya, as a requirement to complete her course at Masinde Muliro University of Science and Technology. License Number NACOSTI/P/22/15052.

Among the counties she is researching on, is Busia County.

This letter is therefore to notify you that, she has permission from the county government of Busia to carry out her research without hindrance of any case whatsoever, from the date of this letter to close of business on 20<sup>th</sup> January 2023.

Any support accorded to him is highly appreciated.

Regards,

Ezekiel Otieno Okwach Chief Officer Office of the Governor For: H.E the Governor

## **APPENDIX XIX: Approval From Department of Education and Vocational**

## training, Busia County

	REPUBLIC OF KENYA COUNTY GOVERNMENT OF I DEPARTMENT OF EDUCATION AN TRAINING P.O. BOX PRIVATE BAG BUSIA, KENYA	NE VOCATIONAL
REF: CG/B	SA/ED/63/VOL IV/18	10 <sup>TH</sup> February, 202
TO, WHOM IT	MAY CONCERN	
Dear Sir/Ma	idam	
RE: PERMI	SSION TO CONDUCT RESEARCH	
Education a carry out re Pain Mana Kenya, as	Asiko Abwalaba has sought permission and Vocational Training, County Gov esearch on the topic: Effectiveness of agement among Children with Sickl a requirement to complete her course and Technology. License Number N	ernment of Busia, to allow her Exercise on Musculoskeletal e Cell Disease in Western at Masinde Muliro University
Among the	counties she is researching on, is Bus	sia County.
Departmen Busia to ca	is therefore to notify you that, she has t of Education and Vocational Trainir rry out her research without hindrance this letter to close of business on 20 <sup>th</sup>	ng, County Government of e of any case whatsoever, from
Any suppo	rt accorded to her is highly appreciate	d.
Regards,		
LEONARD	OPOLLO	
FOR. COUNTY C Copy to:	THIEF OFFICER: EDUCATION & VOC	ATIONAL TRAINING
	ity Secretary ity Commissioner Busia	

## **APPENDIX XX: Research Authorization From County Commissioner, Busia**

County

#### REPUBLIC OF KENYA



#### OFFICE OF THE PRESIDENT MINISTRY OF INTERIOR AND CO-ORDINATION OF NATIONAL GOVERNMENT

ccbusia@gmail.com When replying please quote

Ref No. ADM 15/27/112

and Date

BUSIA (K) 10<sup>th</sup> february, 2022

COUNTY COMMISSIONER'S OFFICE

BUSIA COUNTY

P.O. BOX 14

Deputy County Commissioners, BUSIA COUNTY

#### **RE: RESEACH AUTHORIZATION**

Following research authorization vide Director General National Commission for Science Technology & Innovation (NACOSTI) letter, Ref.No.128920 dated 20<sup>th</sup> January, 2022 authorizing research **on Musculoskeletal Pain Management among Children with Sickle Cell Disease** for the period ending 20<sup>th</sup> January, 2023.

This is to inform you that Ms. Roselyn Asiko Abwalaba has been authorized to carry out research in Busia County. Please accord her the necessary action.

COMMISSIONER BI 0 FEB 2022 enu all:cchusia@gmail.co 14.50.00 P. K.Kemei

For: County Commissioner BUSIA COUNTY.

## **APPENDIX XXI:** Authorization from County Commissioner, Vihiga County

#### REPUBLIC OF KENYA



## THE PRESIDENCY MINISTRY OF INTERIOR AND COORDINATION OF NATIONAL GOVERNMENT

Email: vihigacc1992@gmail.com Telephone: Vihiga0771866800 When replying please quote COUNTY COMMISSIONER, VIHIGA COUNTY, P.O. BOX 75-50300, <u>MARAGOLI.</u>

REF: VC/ED.12/1 VOL.III/177

1st February, 2022

All Deputy County Commissioners Vihiga County.

#### RE: RESEARCH AUTHORIZATION - ROSELYNE ASIKO ABWALABA.

This is to introduce to you Roselyne Asiko Abwalaba of Masinde Muliro University of Science and Technology to carry out research on "*Effectiveness of exercise on Musculoskeletal Pain Management among children with sickle cell disease*," in Vihiga County, Western Kenya for a period ending 20<sup>th</sup> January, 2023.

Kindly accord her the necessary assistance.

From

KonchelaU. Naula FOR:COUNTY COMMISSIONER VIHIGA COUNTY.

cc.

Roselyne Asiko Abwalaba

## **APPENDIX XXII:** Authorization from County Director of Education Vihiga

## County



#### MINISTRY OF EDUCATION STATE DEPARTMENT OF EARLY LEARNING AND BASIC EDUCATION

Telegrams: ..... Telephone: (056) 51450 Email:vieducounty@gmail.com When replying please quote COUNTY EDUCATION OFFICE, VIHIGA COUNTY, P.O. BOX 640 - 50300 MARAGOLI.

REF: MOE/VC/ADM/100/VOL.3/71

Date: 01/02/2022

#### TO WHOM IT MAY CONCERN

#### RE: AUTHORITY TO CONDUCT RESEARCH Ms. Roselyne Asiko Abwalaba

Reference is made to your letter Ref No. NACOSTI/P/22/15052 dated 20th Jauary,2022

Permission is hereby granted to the above named student from Masinde Muliro University to conduct research on "Effectiveness of exercise on Musculosketal pain management among children with sickle cell disease" this will to enable her to conduct research as required by her institution.

Kindly note, in order for the office to be informed a copy of the same be shared with the County Education office for intervention purposes upon completion of the research.

HELLEN NYANG'AU COUNTY DIRECTOR OF EDUCATION VIHIGA COUNTY

Cc County Commissioner VIHIGA





## **APPENDIX XXIII: Acceptance Letter to Conduct Study in Vihiga County**

#### COUNTY GOVERNMENT OF VIHIGA

When Replying please quote...

Ref. No: VCHS/CDH/ME/2022/007

Email: cdhvihiga@gmail.com; vihigamande@gmail.com



County Director of Health P.O. BOX 344-50300, <u>Maragoli</u> Date: 11/02/2022

To:

Roselyne Asiko,

rabwalaba@mmust.ac.ke

Tel: 0722345997

#### Re: Acceptance of your proposal to conduct a study in Vihiga county.

We are in receipt of your proposal to conduct a study titled "Effectiveness of Exercise on Musculoskeletal Pain Management Among Children with Sickle Cell Disease in Western Kenya."

We are glad to inform you that your proposal is accepted under the following conditions:

- You furnish this office with key information of the study by filling in the attached template and deliver it back in soft or hard copy before commencement of the study.
- You commit to submit regular reports to the county department of health through this office on the progress of the study.
- 3. You share the findings of the study in form of final informative products such as reports, journal articles or abstracts.

Thank you very much for considering Villiga County as we look forward to engaging more.

COUNTY DIRECTOR OF HEALTH SERVICES COUNTY GOV Yours sincerely, 11 FEB 2022 P. O. Box 344-50300, MARAGOLI Dr. Eric Sikuku CDH, Vihiga County Copied:

Professor Justus Inonda, CECM Health Services

Dr. Mary Anyiendah, Chief Officer, Health Services

Collins Mudogo-Head Division of health information, M&E and Research Development

## **APPENDIX XXIV: Authorization Letter From County Commissioner Bungoma**

## County

## REPUBLIC OF KENYA



#### THE PRESIDENCY MINISTRY OF INTERIOR AND COORDINATION OF NATIONAL GOVERNMENT

Telephone: 055-30326. Fax: 055-30326. E-mail: <u>ccbungoma@yahoo.com</u> When replying please quote Office of the County Commissioner P.O. Box 550-50200 BUNGOMA.

REF:ADM.15/13/VOL.III/160

1<sup>st</sup> March, 2022

## TO WHOM IT MAY CONCERN

### RE: RESEARCH AUTHORIZATION - MS. ROSELYNE ASIKO ABWALABA

Reference is hereby made on the research license letter Ref: 128920 dated 20<sup>th</sup> January, 2022 License No. NACOSTI/P/22/15052 signed by Director General, National Commission for Science, Technology and innovation.

The above named has requested for authority to conduct research on the topic "Effectiveness of Exercise on Musculoskeletal Pain Management Among Children with Sickle Cell Disease" within Bungoma County for a period ending 20<sup>th</sup> January, 2023.

Authority is hereby granted for the specific period and any assistance accorded to her in this pursuit would be highly appreciated by this office.

COUNTY COMMISSIONER BUNGOMA

Christine W. Chacha For: County Commissioner BUNGOMA COUNTY

## **APPENDIX XXV: Autorizatio Letter From County Secretary & Head of Public**

**Service Bungoma County** 

## COUNTY GOVERNMENT OF BUNGOMA



OFFICE OF THE COUNTY SECRETARY AND HEAD OF PUBLIC SERVICE

Telephone: 0725 39 39 39 E-mail: countysecretary@bungoma.go.ke Municipal Building P.O Box 437- 50200 BUNGOMA

Our Ref: CG/BGM/CS/GEN/VOL. V (36)

Date: 1<sup>st</sup> March, 2022

## TO WHOM IT MAY CONCERN!!!

### **RE: RESEARCH AUTHORIZATION – ROSELYNE ASIKO ABWALABA**

Your letter Ref: No. NACOSTI/P/22/15052 on the above subject refers.

We acknowledge the request and subsequent approval from the National Commission for Science, Technology and Innovation to conduct research in Bungoma County.

This is to grant approval for three months to carry out the research in Bungoma as stipulated in the license subject to relevant approvals from **County Commissioner** and **County Director – Education Bungoma County**.

Kindly accord her the necessary assistance required.

Wambati J. W COUNTY SECRETARY & HEAD OF PUBLIC SERVICE

Vision: A hub of Diversity for Social Economic Development

## **APPENDIX XXVI: Letter from County Director of Health Bungoma County**

## REPUBLIC OF KENYA

COUNTY GOVERNMENT OF BUNGOMA MINISTRY OF HEALTH OFFICE OF THE COUNTY DIRECTOR HEALTH



Telegrams: "MEDICAL", BUNGOMA Telephone: (055) 30230 Fax: (055) 30650 E-mail: docakatu@yahoo.com When replaying please quote

COUNTY DIRECTOR OF HEALTH BUNGOMA COUNTY P. O. BOX 18 - 50200 BUNGOMA

OUR REF: CG/BGM/CDH/RESRC/VOL.1

DATE: 1st March, 2022

MS. ROSELYNE ASIKO P.O BOX 190-50100 KAKAMEGA

Dear Madam,

#### RE: PERMISSION TO CONDUCT RESEARCH IN BUNGOMA COUNTY.

Following your application for authority to carry out research on "Effectiveness of Exercise on Musculoskeletal Pain Management among Children with Sickle Cell Disease in Bungoma County", I am pleased to inform you that you have been authorized to carry out research for a period ending 20th January, 2023.

Kindly note that, as an applicant who has been licensed under the Science, Technology and Innovation Act, 2013 to conduct research in Kenya, you shall deposit a copy of the final research report to the County Director of Health. The soft copy of the same should be submitted through the online Research Information system.

GOMA

OUN

Thank you.

Box 18-50200 BUNGOMA DR. MATHIAS LUKORITO FOR: COUNTY DIRECTOR OF HEALTH

**BUNGOMA COUNTY** 

## APPENDIX XXVII: Letter to Carry Out Reaserch from County Director of

## **Education Bungoma County**



REPUBLIC OF KENYA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY State Department of Basic Education and Early childhood – Bungoma County

When Replying please quote e-mail: <u>bungomacde@gmail.com</u> County Director of Education P.O. Box 1620-50200 BUNGOMA

Ref No: BCE/DE/19/VOL.II1/206

Date: 1st March 2022

#### TO WHOM IT MAY CONCERN

#### RE: AUTHORITY TO CARRY OUT RESEARCH - MS ROSELYNE ASIKO ABWALABA NACOSTI/P/22/15022

The bearer of this letter Ms. Roselyne Asiko Abwalaba of Masinde Muliro University of Science and Technology has been authorized to carry out research on "*Effectiveness of Exercise on Musculoskeletal Pain Management among Children with Sickle Cell in Bungoma*" for the period ending 20<sup>th</sup> January 2023.

Kindly accord him the necessary assistance.

FOR COUNTY DIRECTOR OF EDUCATION

Centert CALLEB OMONDI

BUNGOMA COUNTY

COUNTY DIRECTOR OF EDUCATION & U N G O M A P. O. Box 1620, BUNGOMA - 50200



### **APPENDIX XXVIII: Authorization Letter from County Commissioner**

## **Bungoma County**

### REPUBLIC OF KENYA



#### THE PRESIDENCY MINISTRY OF INTERIOR AND COORDINATION OF NATIONAL GOVERNMENT

Telephone: 055-30326. Fax: 055-30326. E-mail: <u>ccbungoma@yahoo.com</u> When replying please quote Office of the County Commissioner P.O. Box 550-50200 BUNGOMA.

REF:ADM.15/13/VOL.III/160

1<sup>st</sup> March, 2022

### TO WHOM IT MAY CONCERN

#### RE: RESEARCH AUTHORIZATION - MS. ROSELYNE ASIKO ABWALABA

Reference is hereby made on the research license letter Ref: 128920 dated 20<sup>th</sup> January, 2022 License No. NACOSTI/P/22/15052 signed by Director General, National Commission for Science, Technology and innovation.

The above named has requested for authority to conduct research on the topic "Effectiveness of **Exercise on Musculoskeletal Pain Management Among Children with Sickle Cell Disease**" within Bungoma County for a period ending 20<sup>th</sup> January, 2023.

Authority is hereby granted for the specific period and any assistance accorded to her in this pursuit would be highly appreciated by this office.

COUNTY COMMISSIONER
BUNGOMA

Christine W. Chacha For: County Commissioner BUNGOMA COUNTY

## APPENDIX XXVIX: Western Region Map

