CHAPTER ONE

INTRODUCTION

1.1Background to the Study

Abnormalities in individual genes cause genetic diseases. Some genetic disorders are inherited from the parents, while others are caused by changes or mutations in a pre-existing gene or gene group. The abnormality ranges from minor to major or from a discrete mutation to a gross chromosome abnormality (Stoppler, 2015). Genetic disorder often affects the physical, the psychological, the social, the spiritual, the life expectancy and academic performance of individual having the disease(Burke W, Fryer-Edwards K, and Pinsky L E., 2008).

Sickle cell disease (SCD) is a group of inherited red blood cell disorders (Centers for Diseases Control and Prevention, 2019) that was first described by Herrick in 1910 and it is the commonest genetic disease in most African countries (Paul S. Frenette and George F. Atweh, 2007). Globally, about 100 million people, predominantly blacks, are affected by the disease (Adegoke *et al.,* 2014).The frequency of carriers in Ghana and Nigeria ranges from 15% to 30%; while a broad variation of about 45 percent has been recorded in East African nations such as Tanzania and Uganda (Madu *et al.,* 2014). The prevalence of healthy carriers ranges from 10% to 40% across Equatorial Africa and 1% to 2% in Northern Africa, with less than 1% in Southern Africa (Anie *et al.,* 2010).

Adolescence is the period of transition between childhood and adulthood, and a time of great changes for young people. Adolescence is a phase of physical, social, psychological, emotional and intellectual growth (Sanders, 2013). Developmental attainment of adolescents cannot be overlooked, physical changes like development of secondary sexual characteristics, brain growth, seeking independence, peer relationship, self-exploration and others often occur between ages 13 and 19 years. The challenges of living with sickle cell disease among adolescents have been found to limit their normal developmental growth, giving them a slow-pace development, unlike their peers. (Bakri *et al.,* 2014).

Sickle cell disease affects persons across ages, and it places additional self-care need on individuals living with the disease. Theadditional self-care need often results in self-care deficit due to improper management. Adolescents with SCD often face a broad range of complications such as severe pain, chronic anaemia and jaundice, pulmonary complications, acute chest syndrome, stroke risk, short stature, delayed puberty and they aremore vulnerable to infections (Centers for Diseases Control and Prevention, 2019). These complications tend to compromise the health status and the quality of life of adolescents, which may interfere with the significant developmental process of adolescent transition to adulthood (Benenson, 2018).

Self-care ability is a concept which describes adolescents' capacitytowards activities that protect and promote individual's wellbeing in spite of living with SCD, knowing that sickle cell diseaseis a lifelong disorder that requires attention at each developmental stage. Adolescents living with SCD should be able to engage in self-care and perform activities that will promote well-being due to their chronological age.There has been a dearth of studies on the outcome of nursing intervention in form of self-care education on self-care ability and quality of life among adolescents living with SCD. Self-care education, however, has been used in some research among patients with chronic rheumatic illness (Lawson *et al.,* 2011), diabetes (Rambiharilal & Email, 2013), chronic back pain (Stenner, *et al.,* 2015), heart failure (Riegel *et al.,* 2011) and asthma (Pansera*et al.,* 2013) with reported results-based effectiveness.

Studies have shown that persons living with SCD do not understand fundamental facts about the disease (Treadwell *et al.,* 2011; Amoran et., al 2016).Similarly, Olakunle *et al.,* (2013) studied the understanding and attitude of high school students on SCD, report of the study showed that comprehensive understanding was slight despite good awareness among participants, hence the need for self-care training.Another research by Adewoyin, *et al.,* (2015) reported low SCD knowledge score among Corp employees despite their elevated awareness levels.The research identified the need for SCD control through public education and other preventive measures.

The hallmark of SCD is pain; therefore, proper understanding of pain is imperative among the clients. SCD pain is all encompassing as it can be acute or chronic with noticeable effect on clients' health status. Smith, *et al.,* (2008) said that SCD pain was a

daily feeling which was not only episodic but also acute. (Ballas, 2011) reported that SCD clients could simultaneously feel both acute and chronic pain.This is called mixed pain.Adegbola (2007)described SCD pain as biopsycho-spiritual, a disease-related difficulty which affects every dimension of client's life.

In addition, results from Adegbola *et al.,* (2012)disclosed discontent with pain management and medical care from health care providers. Participants were frequently denounced, disheartened and dismayed by providers who were unaware of their pain-related concerns (Adegbola *et al.,* 2012). Thus, self-care education is capable of equipping SCD adolescents with required knowledge which would enhance their self-care ability and pain coping ability on a daily basis in order to guarantee their optimum wellbeing.

Adequate understanding of SCD and appropriate ability to deal with SCD pain may have a positive impact on thequality of life of persons living with SCD. Several studies revealed either a low or a poor standard of living among SCD clients and the studies reiterated issues connected with low or poor quality of life such as low revenue, pain crises, increased susceptibility to infections, hospitalisation, fatigue and poor access to healthcare services. (A.D.A.M., 2001; Brown et al., 1993; Morse & Shine, 1998).

There is paucity of literature on nursing intervention in form of self-care education among adolescents with SCD, In the light of this, exposing adolescents to self-care education is essential in that adolescents would build up their own self-care ability in a way to curtail frequent hospital admissions, SCD crisis, absenteeism from school or work place, undue exposure to infection, anaemia, excessive anxiety, feeling inferior among peers and high cost of care. Self-care education is a nursing activity designed at increasing knowledge of the adolescents by building positive attitudes and improving their level of assertiveness and determination. The education is capable of making adolescents to be more courageous in the determinations to improve their own health status with utmost aim of being able to take care of self without the assistance of care givers. Adolescents with SCD are capable of caring for themselves with proper understanding of the disease process and its impact on their wellbeing and survival via self-care education Therefore, it is necessary to educate adolescents living with SCD on

how to cope with SCD challenges with an utmost view of improving their self-care ability and their quality of life.

1.2 Statement of the Problem

Adolescence is a transitional period from infancy to adulthood, a period of growth beginning with puberty and ending at the beginning of adulthood. This stage is a challenging period for all that attains puberty, most especially for individuals with a chronic disease. Adolescents living with SCD often depend on family and care givers for basic activities of daily living sequel to the illness while their peers who are not living with chronic illness are more independent. Typically, adolescents with sickle cell disease have delayed milestone by about two-and-a-half years reaching puberty, with delay in growth and development of sexual characteristics which subsequently result in significant psychological distress (Amr et al., 2011 and Drazen *et al.,* 2016).Also, adolescents or individuals with sickle cell disease suffer increased school absenteeism, poor school performance, increased hospital visits and increased hospitalisation with utmost effects on their quality of life. (Sufiyan MB, Tijani S, and Aminu L., 2018).

Amr et al., (2011) noted that adolescents with SCD experienced deterioration in quality of life across all domains, particularly in the physical domain; which could interfere with the important developmental process of adolescent transition to adult and with adult SCD medical care. Specifically, adolescents with SCD typically suffer from vasculo-occlusive crises and generally visit emergency rooms for pain therapy (Barriteau *et al.,* 2018), foranaemia and jaundice due to haemolysis (Rees et al., 2010), for stroke (Munube *et al.,* 2016), and for enuresis (Wolf *et al.,* 2014). There is a multifarious psychosocial impairment and perceived stigma among adolescents as a consequence of sickle cell disease (Adeyemo *et al.,* 2015).

Adolescents living with sickle cell disease also tend to have psychosocial challenges especially anxiety and depression which border on worries about crisis episodes, pain, frequent hospitalisation, medications and dying (Amr *et al.,* 2011; Brown & Davis, 2016). Priapism affects adolescent boys with SCD (Olujohungbe*et al.,*2011) and it typically occurs in the early hours during sleep and it is often painful and undesirable (Olujohungbe and Burnett, 2013).Priapism can result in impotency if left unrecognised and untreated (Broderick, 2012). Furthermore, frequent hospitalisation associated with

SCD in adolescents has consequences on school attendance and performance (Crosby *et al.,* 2015). Social impairment in adolescents as a result of SCD often results from restrictions on sporting activities and leisure that disrupt normal adolescent development and increase the feelings of isolation (Harris, *et al.,* 2012).

Previous studies showed that adolescents with SCD often experience painful crises and long-standing ulcers. They are prone to infection and they are afraid of premature death (Smith *et al.,*2008; Booth *et al.,* 2010). Prevention of crises is a key issue in the management of SCD because most times, crises reduce the life expectancy of the affected individual. Once a person has been diagnosed of SCD, it is anticipated that this individual would master the disease symptoms and management such that each person would have control on disease progression in order to ensure optimum wellbeing.

Generally, every adolescent desire independence as part of transition to adult life. Anecdotal report has shown that most timesadolescents make decisions outside parental consent, these decisions can be on their health, education, finance, religion and social engagement.Many times, such decisions bring good results, and occasionally, if made out of youthful exuberance, they bring sorrow. Adolescents living with SCD are not exempted from these feelings and demand for independence. However, the nature of SCD poses threats and challenges to adolescents living with this health condition, and this may bother the parents who may be worried about their children's state of health thus resultingin overprotection andconflict with the adolescents and consequent parental and care giver close monitoring.

The non-freedom to engage in transitional activities is oftentimes perceived as lack of independence and overprotection by adolescents living with SCD. They feel deprived of freedom like their peers, they think about their physical appearance and the stigma from peers and society and they are anxious about the outcome of the disease.

Self-care ability are actions that each adolescent executes when caring for self in totality. As part of developmental process, adolescents are expected to have an in-depth knowledge of how to care for self as a premise for successful transition to adult life. Literature and the foregoing predispose adolescents with SCD to have psychological distress, to feel isolated, to withdraw from peers, to develop nonconforming attitude and to entertain suicidal ideation.

Given all documented challenges associated with SCD (delayed milestone, painful crises, impaired school performance, frequent hospitalisation, recurrent vaso-occlusive crises, perceived stigmatisation, and anxiety about disease outcome) and the importance of self-care in the management of sickle cell disease, there is need for adequate knowledge of self-care so that adolescents with SCD will handle their health demand out of their own volition and maintain good quality of life. To this end, this study developed a self-care educational package (SCEP:GUIDED BY OREM'S THEORY OF SELF-CARE) to teach adolescents living with SCD on how to cope with SCD challenges

1.3 Objectives of the study

1.3.1 General objective

The broad objective of this study was to evaluate the outcome of nursing intervention of self-care education on self-care ability and quality of life of adolescents with SCD in Oyo and Ekiti States.

1.3.2 Specific Objectives

1. To assess the level of knowledge of SCD among adolescents in experimental and control groups at pre- and post -intervention.
2. To assess the knowledge of universal self-care requisites among adolescents living with SCD in experimental and control groups at pre and post intervention.
3. To determine the self-care ability of adolescents with SCD in experimental and control groups at pre and post intervention (developmental self-care requisite, health deviation self-care requisite, activity of daily living practices and pain-coping ability).
4. To assess the quality of life of adolescents living with SCD in experimental and control groups at pre and post intervention.

1.4 Research Questions

1. What is theknowledge of participantsin experimental and control groups about SCD?
2. What is the knowledge of universal self-care requisite among adolescents living with SCD in experimental and control groups?
3. What is the self- care ability of adolescents living with SCD in experimental and control groups?
4. What is the quality of life of adolescents living with SCD in experimental and control groups?

1.5 Significance of the study

Sickle cell disease is a hereditary blood disorder prevalent among Africans, with a substantial high rate in Nigeria. In middle income nation where there is no cure for SCD, clients live in continuous pain, they often experience chronic anaemia, and they pay high cost of hospital admission, medication and blood transfusion. The researcher believes that the study would increase the cohort of adolescents' knowledge of SCD, improve their self-care capacity in order to ensure optimum standard of living (helping them to adjust their way of life) so that the disease would not overwhelm their physical health, psychological feelings, and social relationships. Increase in knowledge would enhance adolescents' skill in SCD management, especially in the area of non-pharmacological self-management of pain.

- Findings of this study haveempowered the participants skills in self-care practice.Hence, findings would assist care givers in teaching adolescent's necessary self-care skillsfor daily activities to help them engage in independent self-care.
- Adoption of healthy living tips would help adolescents develop skills towards SCD management such that frequency and severity of crisis, duration of hospital admission / length of stay and associated complications will becurtailed as observed in the experimental group.

- The findings of the study would be helpful in developing clinical guidelines for intervention strategies for adolescents with SCD.
- The results of this study would assist policymakers in formulating appropriate policies that would improve the overall well-being of adolescents with sickle cell disease. Consequently, findings from this research would help care providers in addressing problems by integrating suitable self-care strategies into the care plan of SCD clients.

1.6 Delimitation

The study was restricted to SCD adolescents within the ages of 10 and 19 years, who willingly consented to participate in the study in selected health institutions in south western Nigeria.

1.7 Operational Definitionsof Terms

Adolescent: A person between ages 10 and 19 years who has been diagnosed of SCD and has been living with SCD.

Self-Care Ability: This refers to independentactions that each adolescent executes while engaging in developmental self-care, health deviation self-care, activities of daily living and pain coping to maintain optimum wellbeing.

Quality of Life: Extent to which SCD affects the physical, social, psychological, and intellectual well-being of adolescents and their own philosophy of SCD. It also describes individual life expectancy and standard of living.

Activity of daily living practices: These are basic/daily life requirements of an adolescent living with SCD which promotes healthy living like sufficient intake of water, food, intake of required atmospheric air, staying in aesthetic environment, avoid sleeping in over crowded room and seeking medical attention as at when due.

Pain-coping ability: Adolescents ability to take voluntary actions to reduce pain which is associated with SCD.

Self-care education: Training of adolescents who are living with SCD using Self-Care Educational Package (SCEP) to improve the understanding and skills of the adolescents.

Supportive Supervision: Home visit for SCD client to ensure client commitment to educational tips: regular intake of food, avoidance of strenuous exercise, adequate rest, eating balance diet, taking their drugs and preventing exposure to infection.

CHAPTER TWO

LITERATURE REVIEW

This chapter presents literature review of various concepts related to the study. The review includes epidemiology of sickle cell disease,knowledge of participants about sickle cell disease, self-care requisites of adolescents with sickle cell disease, self-care practices and the quality of life of adolescents with SCD. The conceptual framework and hypotheses for the study were also discussed.

2.1 Epidemiology of Sickle Cell Disease (SCD)

Sickle cell disease is a hereditary autosomal recessive genetic disorder that affects 1 in 500 Blacks(Centre for Disease Control and Prevention, 2019). Nigeria is the country with the highest burden of sickle cell disorder in the world.Over 150,000 babies are born each year with sickle cell in the country.Also, over 40 million Nigerians are carriers of the sickle cell gene,it is characterised by inheritance of sickle haemoglobin (HbS) from both parents (Ebuka Onyeji, 2018). The presence of haemoglobin S often causes red blood cell to change from usual biconcave disc shape to a crescent or sickle shape during deoxygenation. Repeated crises potentiate haemolysis and erythrocyte damage which is responsible for anaemia, which is a major public health problem

among the black race. About 25% of Nigeria adults have the sickle cell genes, while the haemoglobin C traits is about 6%, and it is mainly limited to Yoruba individuals in south-western Nigeria. With the greatest prevalence, SCD continues to be the cause of elevated morbidity and premature death among the clients(Abioye-Kuteyiet al.,2009).

Sickle cell disease is a long-term chronic disease with variable life expectancy. Probable causes of death among children with sickle cell disease include bacterial infections, splenic sequestration crisis, and acute chest syndrome (Center for Children with Special Health Needs, 2006). Acute and chronic tissue injury may occur when the abnormally shaped red cells obstruct blood flow through the vessels. Complications of SCD include unbearable pain episodes involving soft tissues and bones, acute chest syndrome, priapism, cerebrovascular accidents, splenic and renal dysfunction. (Samir K. Ballaset al., 2012).

Sickle cell disease is one of the prevalent hematological hereditary diseases in the world (Center for Disease Control, 2017). It is a global problem and one of the most commonly known hereditary blood disorders.

Globally, up to 100 million individuals worldwide, mainly Black people are affected by SCD in Africa, Europe and the American. (McKew & Pilon 2013).The prevalence of healthy carriers (sickle cell traits) commonly ranges between 10% and 40% across equatorial Africa, decreasing to 1 to 2% on the North African coast and less than 1% in Southern Africa.SCD affects more than 70,000 Americans, primarily those of African descent. It is estimated that 8% of African American population is predicted to have the sickle cell disease, and that one African American child in every 375 persons suffers from sickle cell disease. Also, SCD has been identified as one of the prevalent genetic diseases in the United State, while the life expectancy of sickle cell clients is reduced by

about 30 years, resulting in poor quality of life even in the best medical practice (Brousseau *et al.,*2010).

In Nigeria, carrier prevalence of SCD is about 20 to 30%, which affects about 2 to 3% of the Nigerian population of more than 160 million (Ademola Samson Adewoyin, 2015).Patients living with sickle cell disease seek care due to inadequate psychosocial support, poor coping skills and unsuitable therapeutic expectations that subsequentlyaffect their quality of life.The incidence of SCD at birth is determined by prevalence of carriers in the population. SCD contributes up to 5% equivalent to under five death in Africa, having up to 16% in West Africa. The level of knowledge about SCD is low in Nigeria despite the large number of people affected with sickle cell disease. (Ugwu, 2016)

2.2 Knowledge of Sickle Cell Disease

It is pertinent to establish the knowledge of clients who are living with SCD about the disease. This is germane to the care providers in fixing the strength, weakness and misconceptions of clients and adolescents who have been diagnosed of sickle cell. Earlier Studies about knowledge of SCD showed that patients have low to moderate knowledge about SCD; Jaffer *et al.,* (2009) revealed that patients mostly lack knowledge of their illness situation with 58% mean score understanding while Gamit *et al.,*(2014) reported that 16.0% had correct knowledge about sickle cell. Also, Olakunle *et al.,* (2013)reported that 54.0% of participants were of the knowledge that SCD could only be diagnosed through blood test; Omolase *et al.,*(2010) asserted that respondentsin their study were aware of SCD; while Al Arrayed and Al Hajeri, (2010) revealed that 84.0% of their respondents knew that SCD was an inherited disease.

Ugwu (2016) conducted a study on sickle cell disease awareness, knowledge and attitude among undergraduate students of a Nigerian tertiary educational institution result showed that all students were aware of the existence SCD but do not have comprehensive knowledge about SCD. Majority (70.6%) of the young adults involved in the study do not have knowledge about the features commonly associated with SCD while 29.4% only know the features of SCD. Also, some of the participantsshowed misconceptions about SCD in terms of disease aetiology they said SCD is caused by witchcraft, evil spirit, enemies, punishment from God and 10.3% believed SCD is contagious.

Study of Oludare and Ogili (2013) reported low knowledge of sickle cell anaemia (SCA) and negative attitudes towards SCA among participants while assessingknowledge, attitude and practice of pre-marital counselling for SCD among youths in Lagos. Similarly, Chandnani et al., 2013 revealed that a significant proportion of adolescents are unaware of their sickle cell genotype despite the availability of universal new born screening for genotype in USA. Adequate knowledge of SCD is a means of helping adolescents acquire the necessary self-care skills for successful transition to adulthood, thus the gap in knowledge as established from all these researchers is a good entry point for self-care education among adolescents living with SCD.

Jaffer, *et al.,* (2009) recommended that self-education, participating actively in SCD association, effective utilisation of available resources and adherence to crises preventive measures among SCD clients would go a long way in reduction of crises among the sufferers.Ezenwosu *et al.,* (2015) also investigated knowledge and awareness

among parents of children with sickle cell disease of personal sickle cell genotype.The results of this study suggested that after the birth of a child with sickle cell anemia, most parents became conscious of their own genotype. Participants reported radio as a system of public enlightenment, and as the most effective means of increasing adolescents' understanding about sickle cell disease.

Gomes *et al.,* (2011) evaluated the understanding of sickle cell disease by family health professionals in Brazil, the result showed that all the observed scores were less than 75%, indicating a level of knowledge that was below the desired levels. According to the researcher, the quality of care that doctors and nurses provided for patients under their care was below what was expected as clients' level of knowledge is a reflection of the quality of care that was given. England Report of the National Confidential Enquiry highlighted a lack of knowledge of physicians and nurses in the management of patients with SCD in the hospital environment (Lucas*et al.,* 2008).

Another study reported poor knowledge of sickle cell disease among participants, in which 95% showed favourable attitude towards pre-marital counseling, 70% of respondents who had favorable attitudes were aware of their partners genotype in line with sickle cell status while a quarter of respondents who were married and those who were engaged did not understand their partners' SCD status. (Abioye-Kuteyi *et al.,*2009).Sobota *et al.,* (2014) conducted a self-reported transition readiness study to evaluate knowledge and skills among young adults with sickle cell disease. Most participants indicated excellent understanding of SCD but were concerned that SCD would stop them from doing career-related jobs in their lives despite the excellent social support available in their neighbourhood. These study findings necessitate educational programmes among adolescents who are undergoing transition to adulthood.

Jenerette and Brewer, 2010 reported that young adults who had SCD were mainly vulnerable to pain due to inadequate transition from paediatric care to adult care and not having adequate skills to navigate the health-care system. Thus, adolescents with SCD should make effort to manage pain at home because self-care is an important part of living with chronic diseases that should be taught and reinforced during adolescence stage before transition to adult care. Also,Tanabe, Porter and Creary, 2010 statedthat usingnumerous means to increase knowledgeof SCDwill allow patientshave better control of their illness.

Tavares, Natália & Nascimento, Nayara & Neto, Raimundo & Júnior, Jucier & Christofolini, Denise (2017) assessed self-care practice in people with sickle cell anemia. It was reported that participants lack accurate knowledge about the disease aetiology and clinical features, thus indicates a disadvantaging position to the primary foundation for self-care. Also. It was documented that some of the participants said they do not have precise information regarding their pathological condition and this affects their care conditions. In addition, findings from Tavares et.al, (2017) showed that educational actions provided by the multidisciplinary health team provide a unique opportunity for persons living with sickle cell anaemia and their care givers to make an informed choice by means of self-care activities and actions.

2.3 Self-Care Requisite of Adolescentswith Chronic Diseases

Jenerette, Brewer and Leak (2011) documented that self-care interventions were essential for people that were diagnosed of chronic disease because:Self-care operations were crucial for reducing health care costs, and for enhancing the standard of living of

individuals who had chronic diseases. In studies evaluating self-reported health demands and the use of main health care services by adolescents enrolled in post-obligatory universities or vocational training in Switzerland; participants revealed that they had suffered frequently or very commonly from distinct physical complaints or pain over the last 12 months, including: headache (boys 15.9%, girls 37.4%); back pain (boys 24.3%, girls 34.7%) stomach ache (boys 9.7%, girls 30.0%); joint pain (boys 24.7%, girls 29.5%); gynaecological problems (girls 25.3%); sleep problems (boys 16.6%, girls 24.4%) and acne (boys 20.5%, girls 23.4%) (Jeannin*et al.,*2005).

Brown, Falusi and Jaudes (2013) emphasise importance of engaging children and adolescents in personal care to aid successful transition of childhood to adulthood, due to the fact that transition to adulthood seems difficult for adolescents living with SCD. Panthumus*et al.,* (2012) conducted a study on self-care behaviours among Thai primi gravid teenagers; the result showed that the overall score of self-care behaviour in second trimester was lesser than scores reported in first and third trimesters. Also, factors like family type, gestational age at the first antenatal clinic visit of the present pregnancy and nurturing of babies were not associated with self-care. The first visit of teenagers to antenatal clinic was after the first trimester (above 12 weeks) due to low understanding of the advantages of antenatal services.

The study also found that respondents had low knowledge of how to care for themselves when they were pregnant. The perceived self-efficacy (SEF), perceived family support (SSF), knowledge of self-care during pregnancy (KN), and schedule for baby rearing and accessibility to health services (AHS), self-esteem (SE) and age were also linked with self-care behaviors among Thai primigravid adolescents. Shrivastava, Shrivastava

and Ramasamy (2013) reviewed the functions of self-care in diabetes mellitus management.The study showed that the day-to-day self-care activities in the form of healthy eating, being physically active, monitoring blood sugar, compliance with regimen and healthy coping skills are self-care behaviors that have a positive correlation with good glycemic control, complication reduction and improved quality of life when clients adopt self-care behaviour.

The study further emphasised the role of clinicians in promoting self-care as essential to the survival of clients. Expert Panel Report 2 (1997) emphasised the need to produce guidelines for management of asthma through improved patients' education and self-management as a means of reducing asthma morbidity, patient's utilisation of emergency department and hospitalisation. Sharifirad *et al.,*(2009) reported that education programmes has improved knowledge and self-management skills and better health outcomes in chronic diseases. In their research, Griffey *et al.,* (2014) disclosed that insufficient literacy is likely a marker for worldwide problems with poorer health status, emergency conditions, and health results among clients with chronic disease.

Dennison *et al.,*(2011) in their study on inadequate literacy as a barrier to association with heart failure knowledge found out that low-literacy patient has poorer heart failure knowledge and self-management skills than those with adequate knowledge. The outcome showed high prevalence of inadequate and marginal health literacy and that literacy is an important prerequisite for promoting knowledge of heart failure and boosting self-care behaviours, particularly among older adults and those with less formal education. Self-care demands depicts proper understanding of SCD in respect of daily needs which includes grooming, adequate intake of food, avoidance of stress,

adequate sleep and rest, and seeking medical assistance when necessary (Jenerette *et al.,* 2011).

In SCD, theories of self-care management indicated that the health outcomes in the transition phase of adolescents could be enhanced if self-management resources were improved (Jenerette & Valrie, 2010). A main construct in self-care management is self-efficacy, which is the belief in one's ability to initiate health behavior change, to completehealth-related tasks, and reach health goals (Molter & Abrahamson, 2014). In addition, self-care requisite are actions directed towards self-management to promote healthy lifestyles among adolescent living with SCD. However, there are limited documentation for adolescents and young adults with SCD on self-care management (Lori *et al.,*2016*)*. According toa study conducted by Lori *et al.,*in 2016 on pilot of chronic disease self-management programme for adolescent and young adults with SCD. It was revealed that the intervention self-management programme was acceptable and has the ability to improve self-practices.

Self-Care Requisite of adolescents is a good method to promote self-care practices and self -care abilities of persons living with SCD towards attainment of independent action. Adequate understanding of the universal, developmental and health deviation requisites promotesadolescents'independent actions towards attainment of optimal living and good quality of life. This is in support of findings from a self-care management programme that revealed that self-care requisites are essential to improve the quality of lifeand status of sickle cell patients. It further documented that to achieve acceptable level of quality of life, they need to learn how to managed control the disease (Jenerette & Murdaugh, 2008).

2.4 Self-Care Practices of Adolescents Living with Sickle Cell Disease

Activity of daily living practices, inform of self-care, is germane to ensuring overall health of adolescents living with SCD; therefore, good self-care practices would help adolescent live an independent life with positive health outcome. There is a dearth of literature on knowledge of self-care practice among adolescents living with SCD; however, some researchers have examined self-care of other clients living with SCD and other chronic diseases. In a research on daily coping exercise and therapy among children with sickle cell disease, Gil et al., (2001) reported that children who were instructed, or who received intervention training (coping strategies)had fewer health care contacts, fewer school absences, and less interference with household activities than on days when they did not practise.

This denotes skill acquisition measures that improve the health outcomes of people who consistently practice it. In addition, Coretta and Carolyn (2007) investigated factors that predict health outcomes in people with SCD within the SCD self-care management theory. Results showed that combinations of self-care, self-efficacy, assertiveness, and social support are resources that often assist people with SCD to handle the daily operations required to deal with life-long disease.

Study that assessed the effectiveness of family psycho-educational intervention in paediatric sickle cell disease reported that patients receiving family therapy had improved knowledge of sickle cell disease post treatment (after 6 months follow-up)

compared to patients in the control group who interacted with the same employees but did not receive organised intervention. Furthermore, children and adolescents within age range (10–20 years) who were living with sickle cell disease, who obtained sessions of biofeedback involving thermal & electromyography and received the training showed decrease in anxiety; self-reported pain and medication use from pre to post training (Chen *et al.,* 2004). Also, Sheena (2015) reported that individuals with sickle cell disease who received Cognitive Behavioral Therapy (CBT) had improved adherence conduct (rest, fluid intake) after therapy compared to pre-treatment.

Harrison *et al.,* (2005) investigated the role of religion and spirituality in pain experiences among sickle cell patients; their findings showed that individuals who attended church once or more in a week reported less pain. Harrison *et al.*(2005) assessed the effect of spirituality on pain experience among sickle cell clients, and the results revealed that existential well-being is a supportive measure of coping effectively with sickle cell pain. Adegbola (2007), investigated spirituality, self-efficacy and quality of life among adults (18 years and above) with sickle cell disease who were invited to participate in the study through a mail out and electronic survey. Findings of his study showed that there was positive relationship between self-efficacy and QoL, and between self-efficacy and spirituality. Therefore, the research emphasized powerful relationships between spirituality, self-efficacy, and quality of life in individuals with SCD. This impliesrepeated self-care practice speed the clients ' self-efficacy.

Physiological self-care recommendations refer to steps that have been identified in studies regarding the care of the physical body of adolescents while psychological self-care recommendation refers to knowledge and understanding of the disease, aiding self-

care practices. A research finding reported that self-awareness and body awareness among the respondents were the most reported self-care management, also nutrition and knowledge of disease also emerged as themes in their study (Tanabe et al., 2010). In a study by Jenerette *et al.,*(2011) on steps taken for the body care, the suggestions from the study include staying warm, eating good food, getting enough rest and staying hydrated. The study also revealed that psychological self-care recommendations needed by SCD patients include learning the way individual body reacts to the pain and listening to the body, talking to God with words of prayers and having social support (having someone or a group of people to talk to). Study of Druye, (2017) among SCD patients in Ghana upheld the findings of Jenerette*et al.,* (2011) wherein hydration and taking good diet were reported as the prominent physiological self-care habits that must be practised by SCD patients. The study established that good diet should contain eggs, fish, green leaves, fruits and lots of meat.

Self-care practices is an important aspect of self-management in sickle cell disease. Self-care practices in SCD entails the ability to understand and interpret the cardinal signs of deviation from healthy status. It contributes to individual pain management and thus pain crisis prevention. A better understanding of self-care can help health care providers equip patients with the resources and skills necessary to participate in their disease management. A study conducted on role of self-care in sickle cell disease in South-eastern part of the United State in 2015 indicated that an individual with SCD may benefit from self-care interventions that enhance social support, SCD self-efficacy, and access to education. It was further proposed that to inform intervention development, further investigation is needed regarding daily self-care behaviour used by young adults with SCD (Matthie, Jenerette, & McMillan, 2015).

Conversely, barriers experienced in self-care practices by young people with sickle cell disease have been categorized under five themes: (1) feelings: anger, sadness, and fear; (2) bullying and stigmatization: challenges regarding walking, speaking, or behaving, as well as patient labels; (3) cognitive factors: doubts related to medication, hydration, heredity and maternity; (4) medication compliance: fear of the side effects suffered and anger triggered by the obligation to use the medication; (5) family issues: complaints of not earning the mothers' trust to live independently. These barriers were identified in an interview to investigate the barriers to self-care practice and the feelings associated with sickle cell disease in Brazil which indicated difficulties related to emotional, behavioural, and environmental aspects. In addition, understanding these factors will favour a better adaptation of youths to the context of sickle cell disease (Sumaya et al., 2018).

2.5 Quality of Life of Clients Living with Sickle Cell Disease

Quality of life depicts how an individual perceives his/her position in life, in relation to set objectives and aspirations.Sequel to medical advancements and subsequent access in disease morbidity, quality of life (QoL) views individual'sassessment in terms of his/her satisfaction with the physical, mental, spiritual, and social elements of life. Edwards *et al.,* (2005) revealed a unique interaction between patient psychosocial adjustment and SCD pathophysiology.

Considering the rise in medical discoveries and the ensuing reduction in disease morbidity and mortality, more attention has been given to the quality of life (QoL),which is the evaluation of an individual's satisfaction with distinct elements of

life: physical, mental, social, spiritual, and intellectual. Quality of life is a general concept, so health-related quality of life is often used to evaluate aspects of individual's subjective experiences that are directly and indirectly connected with health, disability, and impairment. Duncan *et al.,* (2014) affirmed this through their submission that health-related quality of life illustrates the impact of illness on the subjective wellbeing of an individual.

Sickle cell is a disease which has effects on clients' Quality of life (QOL) and on their family members (Hurst, 2014). Brandow *et al.,* (2010) examined health related quality of life(HRQoL) in children with SCD, specifically in relation to painful occurrences at presentation in the emergency room and seven days after discharge; outcome showed that painful events diminished all domains of HRQoL and that these domains often increase after the pain resolves. McClish *et al.,* (2005) noted that the health-related QoL of individuals with SCD is worse than that of the general population. The decreased QoL may be correlated with disease chronicity coupled with frequent pain, hospitalisations, or other problems which may lead to impairment of psychosocial functioning (Edwards *et al.,* 2005).Similarly, Sufiyan, Tijaniand Aminu(2018) reported role limitations in areas of physical and emotional health which leads to poor quality of life among SCD patients.

Chronic diseases such as SCD have been discovered to frequently leave the client with feelings of helplessness and reduced self-esteem, this may lead to failure to use usual coping resources such as physical strength, psychological stamina, and enhance favourable self-esteem. Sickle cell disease carries an enormous psychosocial burden, affecting physical, psychological, social and occupational well-being of clients and their independence levels within the family (Ware*et al.,* 2010).

Sufiyan, Tijani and Aminu (2018) affirmed paucity of information as regards quality of life of individuals living with SCD in Nigeria. Also, anecdotal report discovered that adolescent boys with SCD have more adjustment problems than adolescent girls with SCD and also noted that girls who are chronically ill are more likely to have emotional problems than their healthy peers. Psychological complications in patients with sickle cell disease usually result from the impact of pain on their daily lives and attitudes towards them in society (Barakat *et al.,* 2008). Previous studies have recorded increase in psychological morbidity such as depression, ineffective coping and low quality of life among clients and caregivers (Morgan *et al.,* 2014 and Forrester *et al.,* 2015).

The well-being of adolescents with chronic disease is mostly determined by the severity of the disease. It also relies on the psychological and social complications that may accompany this disease (Engelmann *et al.,* 2015). Barakat *et al.,* (2010) discovered major adverse effects on puberty and reduced seriousness of HRQoL among paediatric and adolescent patients, which strongly affect the physical function of children living with sickle cell disease. Furthermore, all HRQoL domains were negatively correlated with growing age of adolescents with SCD, particularly in energy, emotional well-being, social functioning, and general health (Amr *et al.,* 2011).

Amanda et al.,(2018) found thatchildren and adolescents with sickle cell anemia have socioeconomic limitations when compared to reference populations. Jenerette and Brewer (2010), affirmed that socio-demographic variables such as race, gender, age, socio-economic status and educationaffect psychosocial adjustment in children and adolescents with SCD. Mam Amret al., (2010) reported that female adolescents with SCD preferred having their treatment in private facilities for confidentiality and for fear of disclosure to people around in a bid to avoid stigmatisation.

Any chronic condition potentially affects developmental process of adolescents in both physiological and psychosocial domains. Adolescents who have delayed puberty as a consequence of chronic illness may be regarded as less mature by adults and peers; this may affect employment consideration (Suris *et al.,*2004). The ill adolescent is more likely to develop psychiatry and behavioural disorders (Simonoff*et al.,*2008) and is more susceptible to depression or low self-esteem (Luyckx *et al.,* 2008). Chronic diseases as diabetes and SCD are known to have long-term neuropsychological impacts on adolescents as a consequence of the disease progression;hypoglycaemia in diabetes (Perantie et al., 2008) and SCD stroke (Hulbert *et al.,* 2011).

Population-based surveys have shown that adolescents with chronic disease are more displeased with their bodies than those without chronic illness (Suris *et al.,* 2004).Suris *et al.,* (2008) also stated that adolescents with chronic disease had higher rates of coitus and unsafe sexual practices than healthy people. There is also evidence that chronic disease affects identity, self-image, and ego growth in a generic manner (Verschuren *et al.,* 2010), such that chronic disease can impair the body image and development of sexual sense.

Field *et al.,* (2014) reported increasing depressive symptoms among adolescent with SCD especially when they are from less cohesive families.Mostafa*et al.,* (2011) found that adolescents with SCD had a considerable delay in their education due to their frequent hospitalisation, emergency admissions, and medical check-up. Similarly, Brousseau et al., (2010) said it is important to understand how young adults with SCD seek care because young adults with SCD between age 18-30 years have highest rates of emergency admissions and highest rates of re-hospitalisation for pain.

To achieve acceptable quality of life or deal with sickle cell disease, patient needs to learn how to manage their health at home. Ahmadi et al., (2015) assessed effectiveness of self-management programme on quality of life in patient with sickle cell disease. Report of their study showed that persons living with sickle cell disease suffer from many psychological and social problems which invariably affects their quality of life, thus they need to learn skills and behaviour that will help them manage their disease and prevent complications which might be associated with the disease. Also, Akinyanju, Otaigbe, &Ibidapo(2005) reported that having a well-organised holistic care will substantially reduce illness and death and thereby improving the QoL of persons living with HbSS in Nigeria. The importance of health education program was emphasized for all parents of children living with SCD, it was reported that parental socio-economic status or educational backgrounds may be critical for mitigating the complications of sickle cell anaemia in their children. (Noronha, Sadreameli, and Strouse, 2016).

In the same vein, Orem self-care model have established to be effective in intervention programmes to promote quality of life of chronic disease conditions (Hashemi et al., 2014; Aghakhani et al., 2017). According to Hashemi et al., (2014), it was reported that theeffect of Orem self-care program on quality of life of burns patients showed that patients who used self -care model for at least two months had increased quality of life in the time interval compared with non-significant changes in quality of life of patients in the control group (Hashemi et al., 2014). It was further stated that measures like educational interventions, support and empowerment programmes should be put in place to help patients overcome problems and complications associated with their disease conditions. This can be applicable to adolescents and young adults living with SCD could benefit from the implementation of the self -care model in health promotion

of quality life styles. Ahmadi et.al., (2015) reported significant improvement in quality of life of persons living with SCD after utilization of self-management programs which was designed for patients based on each person need.

2.6 Summary of Literature Review

The literature reviewedthe epidemiology of SCD, knowledge of SCD among clients, quality of life of SCD clients, self-care requirements of adolescents with chronic disease, and self-care practice of adolescents with SCD. Also, the quality of life of persons living with SCD were equally discussed.

The literatureestablished SCD as a public health problem and the most common hereditary disease in Nigeria. Also, studies have shown that individuals with SCD suffer school absenteeism, poor school performance, increased hospital visits and hospitalization with subsequent effect their quality of life. Further reviewposited low and poor knowledge of SCD among individuals living with SCD despite the general awareness among patients thus, recommending educational programs to improve SCD knowledge among patients.

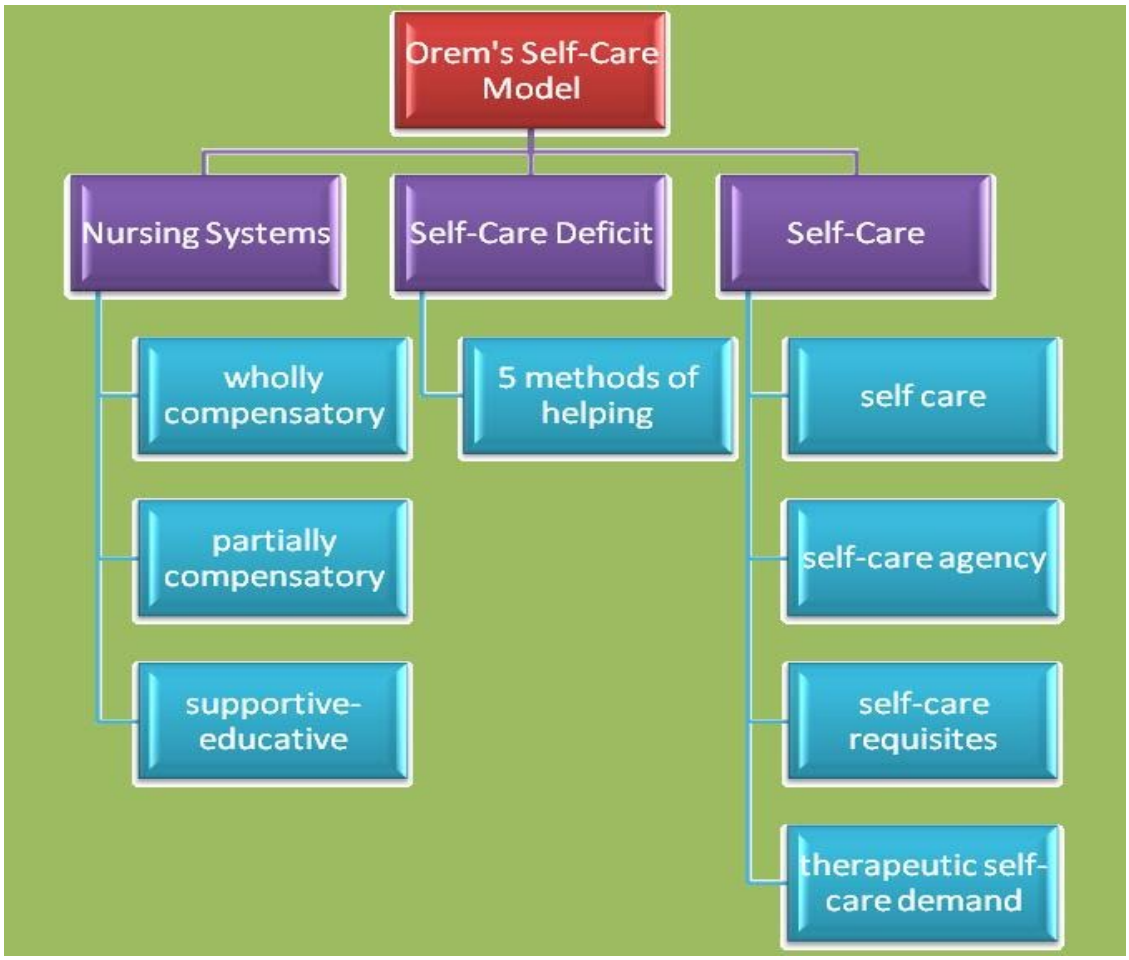
This review established paucity of information with respect to quality of life of persons living with SCD. In addition, participants were found to haverole limitations in areas of physical and emotional health which usually results in poor quality of life. Thus, researchers suggest putting in place intervention programs that would improve physical and emotional health of patients living with SCD,

Therefore, self-care education will go a long way in building the self-care abilities of adolescents towards independent care,so that they will be able to participate actively in

SCD clubs and associations, make use of available resources effectively and adhere to crisis preventive measures to ensure optimum life expectancy.

2.7 Theoretical Framework: Dorothea Orem's Theory of Self-Care Deficit Nursing

Dorothea Orem's Theory of Self-care Deficit Nursing is considered the most appropriate for this study. She is well known as a respected nurse theorist, born in Baltimore, Maryland 1914 died in 2007 at the age of 92 years. The model is a popular model and most American nursing schools base their curriculum entirely on this theory. The theory focuses on the concept of "caring for self" and her objective was to improve the quality of nursing care in general hospital throughout her state.



Shrooti Shah(2015): Dorothea Orem's Theory of Self-Care Model

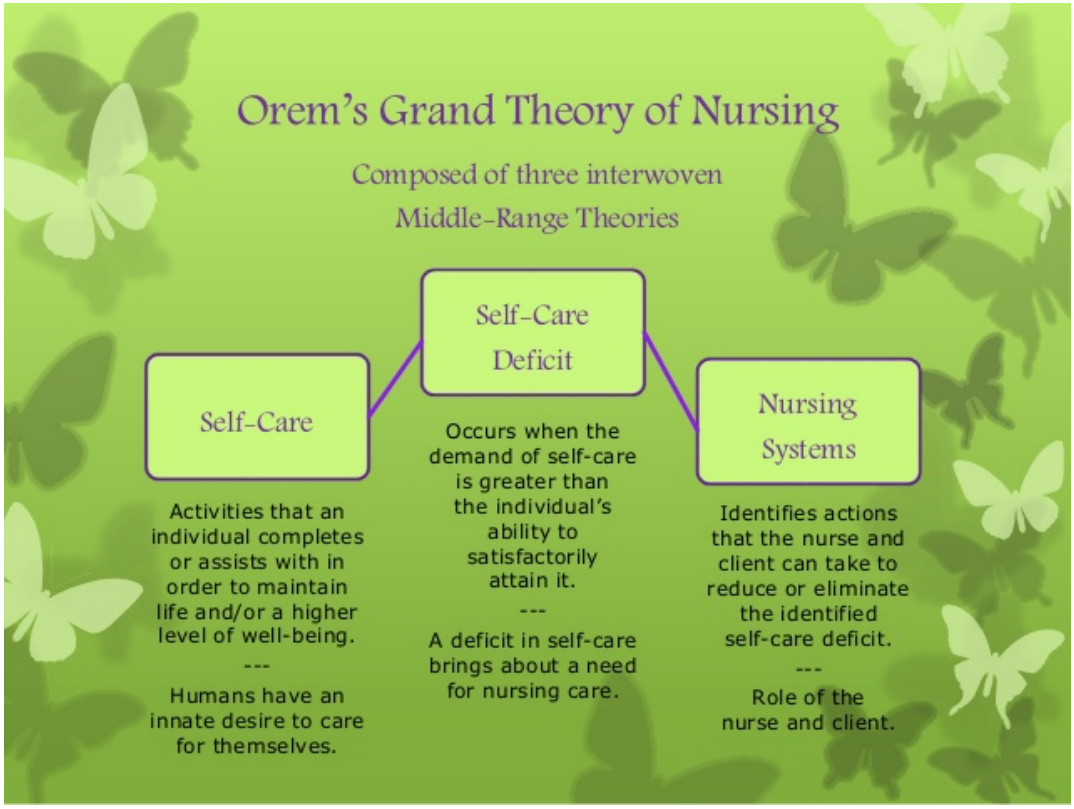
Major Concepts of Self-Care Model

Dorothea Orem's Theory of Self-care Deficit Nursing consists of three related theories which are:

1. The theory of self-care (describes and explains self-care)

2. The theory of self-care deficit (describes and explains why people can be helped through nursing); and

3. The theory of nursing system (describes and explains relationships that must be brought about and maintained for nursing to be produced). This study used the theory of Self-Care



Shrooti Shah(2015): Orem's Grand Theory of Nursing

Major Concepts of the Theory of Self-Care

1. **Self-care:** It is a learned, goal-oriented activity of individual. It is also the performance or practice of activities that individuals initiate and perform on their own behalf to maintain healthy life style and well-being.

2. **Self-care agency**: It is the human acquired ability or power to engage in self-care conditioned by age developmental state, life experience, sociocultural orientation, health and available resources.Aptitude to engage in self-care is influenced by fundamental conditioning factors, which are combinations of modifiable and non-modifiable factors. Modifiable factors include: health care system such as diagnostic and treatment modalities, pattern of living in terms of activities that individual regularly engaged in, family system, level of education, resource adequacy and availability of

socio-cultural factors; while non-modifiable factors include: age, gender, developmental state and genotype.

3. **Self-care Requisites:**These are actions directed toward the provisions of self-care. This refers to mandatory activities which adolescents require for healthy living on a daily basis. Orem presents three categories of self-care requisites as:

Universal Self-care Requisites: These requisites are associated with life processes and general well-being. Orem identifies self-care requisites as follows:

1. The maintenance of sufficient intake of air.
2. The maintenance of sufficient intake of water.
3. The maintenance of sufficient intake of food.
4. The provision of care associated with elimination processes and excrements.
5. The maintenance of a balance between activity and rest.
6. The maintenance of a balance between solitude and social interactions.
7. The prevention of hazards to human life, human functioning, and human well-being.

The promotion of human functioning and development within social groups in accordance with human potential, known human limitations and the human desire to be normal.

Developmental Self-care Requisites: These requisites are associated with human growth and developmental processes, these include; physical development, intellectual development, and psychosocial development.

Health Deviation Self-care Requisites: These are related to generic and constitutional defects of human and to structural and functional deviation. Dorothea Orem's Theory of Self-care highlighted the health deviation self-care requisites as follows:

1. Seeking and securing appropriate medical assistance.
2. Being aware of and attending to the effects and results of pathologic conditions and states.

3. Effectively carrying out medically prescribed diagnostic, therapeutic and rehabilitative measures.
4. Being aware of attending to or regulating the discomforting or deleterious effects of prescribed medical care measures.
5. Modifying the self-concept and self-image in accepting oneself as being in a particular state of health and in need of specific forms of health care.
6. Learning to live with the effects of pathologic conditions and states and the effects of medical diagnostic and treatment measures in a life-style that promotes continued personal development.

2.8 Application of the Theory to the Study

The Self-care Deficit Nursing theory identifies four main constructs that include Self-care, Self-care agency, Self-care requisites and therapeutic self-care demand. Self-care isa learned, goal-oriented activity that the adolescents initiate and perform on their own to maintain healthful functioning and optimal health status while living with SCD; which should be accomplished on a daily basis. These activities have three dimensions as categorised by Orem's,for example,Universal self-care requisites activitiesinclude bathing, mouth washing, feeding, and cooking.

Developmental self-care requisites activities are age appropriate events such as having adequate rest, avoiding strenuous activities which can trigger crisis (climbing high altitude or engaging in rigorous sports activities)and having good self-concept which implies accepting oneself as being in a particular state of health that needs specific attention. Hence adolescents living with SCD need copious intake of water, avoid exposure to infection, avoid dehydration, adopt rightful eating habits by taking balance diet, avoid extreme weather conditions and use drugs as prescribed.

Health deviation self-care requisites describes adolescent's innate ability to care for self. At this stage adolescents should be able to seek appropriate medical assistance when the need arises, keep to medical appointments, carry out medically prescribed investigations (PCV) and maintain personal and environmental hygiene in order to ensure optimum well-being.

The Self-care agency of adolescent refers to the adolescent's capacity and strength to participate in self-care. These abilities are affected by basic conditioning factors which can either be modifiable (i.e. can be modified due to increased knowledge, life style modification, empowerment and attitudinal changes) or (non-modifiable factors, that is, presence of sickle cell disease in adolescent life which was naturally endowed and cannot be changed nor modified) self-care agency often affects adolescent ability to engage in self-care.

Generally adolescent should be able to care for themselves, but when adolescents with SCD are not properly empowered they often become dependent and need assistance with self-care activities and parents often do not always give them the freedom to independently care for themselves. Also, adolescents with SCD usually have higher self-care requisites in comparison with other healthy adolescent population. This extra demand cuts across the three classifications of self-care requisites as highlighted by Orem's i.e. universal self-care requisites such as sufficient intake of air, water and food, developmental self-care requisites like regular intake of food, seeking information about SCD, avoiding unhygienic environment and health deviation Self-care requisites inform of lifestyle modification, reporting health changes as they occur, sticking to prescribed regimen. All these increase the self-care demands of adolescent with SCD. Knowledge of SCD affects the self-care agency of adolescents especially in areas of extra demand while basic conditioning factors equally influence adolescent level of knowledge of SCD.

Universal Self-care Requisites

1. The maintenance of sufficient intake of air: clients living with SCD usually have extra demand in maintaining adequate oxygen to the vital organs because of the short life span and abnormal shape of their haemoglobin, hence adolescents must ensure adequate ventilation and avoid hypoxic situations.
2. Maintenance of sufficient intake of food: Due to rapid death of red blood cells clients need a lot of protein to adequately replenish them.

3. The balance between activity and rest: clients usually have unique need in ensuring a stable balance between activity and rest.
4. Maintaining a balance between loneliness and social interaction: clients are usually stigmatised and isolated in the society.
5. The prevention of hazards to human life, human functioning and human well-being.

The self-care demand of adolescents encompasses activities that will promote physical, psychological, emotional, social and spiritual health with ability to strike a balance between these needs each day of their life. These self-care demands are further increased by the challenges of adolescent stage of life which include peer influence, adolescent exploring idea and trying to be independent of their parents and take decision on their own. Apart from the challenges outlined above, SCD, like other chronic diseases further places extra self-care demands on adolescents living with the disease. These extra demands have a negative effect on the self-care demand and self-care agency, the balance usually results in self-care deficit. Thus, when the self-care demand outweighs the capacity of the self-care agency of an individual, it usually results in poor life expectancy among adolescents with SCD.

This study provided self-care education which promotes the capacity of the self-care agency (ability to care for self) of adolescents. Educational interventions of this study encompass teaching on Self-care needs which in-turn helped adolescents to adequately care for themselves without necessarily depending on parents, guardians, care givers or care providers. Self-care education is a component of nursing agency aimed at modifying the interplay of self-care demands and self-care agency with the utmost aim of preventing self-care deficit. Therefore, self-care education is a fundamental nursing intervention which makes adolescents develop skills in such a way that self-care agency outweighs the self-care demand for the purpose of improving quality of life.

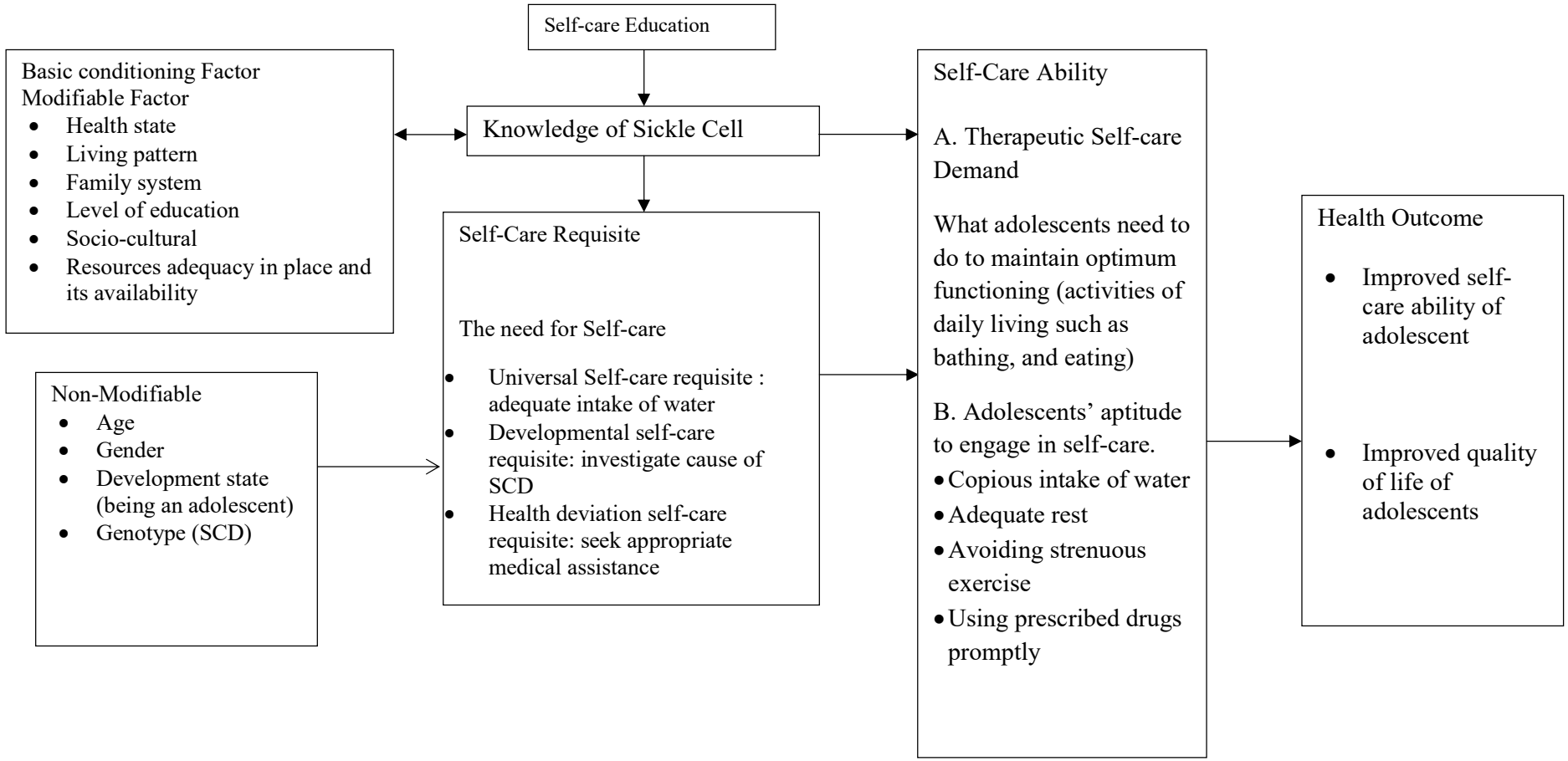


Figure 2.1: Application of Self-Care Theory to the Study

(Dorothea Orem's Theory of Self-Care Deficit Nursing)

2.9 Hypotheses

In this research, the following hypotheses were tested:

1. There is no significant difference in the level of knowledge of SCD among adolescents in the experimental and control groupsat pre- and post-intervention.

2. There is no significant difference in the knowledge of universal self-care requisites among adolescents living with SCD in experimental and control groupsat pre- and post-intervention.

3. There is no significant difference in the Self-Care ability of adolescents living with SCD in experimental and control groupsat pre- and post-intervention.

4. There is no significant difference in the quality of life of adolescents living withSCD in the experimental and control groupsat pre- and post-intervention.

CHAPTER THREE

METHODOLOGY

This chapter focuses on research design, study area, study setting, target population, study population, sampling method, instruments for data collection, validity and reliability of the instrument, ethical consideration, data collection process, method of data analysis and test of hypotheses were discussed.

3.1 Research Design

This study employed a quasi-experimental two groups (pre-test /post-test time series design) as shown in Figure 3.1. The design used a quantitative method to obtain information from adolescents with sickle cell disease. Data were obtained at three time points over a period of six months at twelve weeks interval during the wet and dry seasons in both experimental and control groups. The health institutions for this research were assigned to experimental and control groups.

Adeoyo State Hospital, Ring Road, Ibadan was assigned as the experimental group and Ekiti State University Teaching Hospital, Ado-Ekiti, and Federal Medical Center, Ido-Ekiti as the control group. The two health institutions in Ekiti emerged from the old State Hospital, Ado-Ekiti. Both are teaching hospitals within the same geographic location; thus, adolescents were recruited from both clinics to obtain a sufficient study sample.

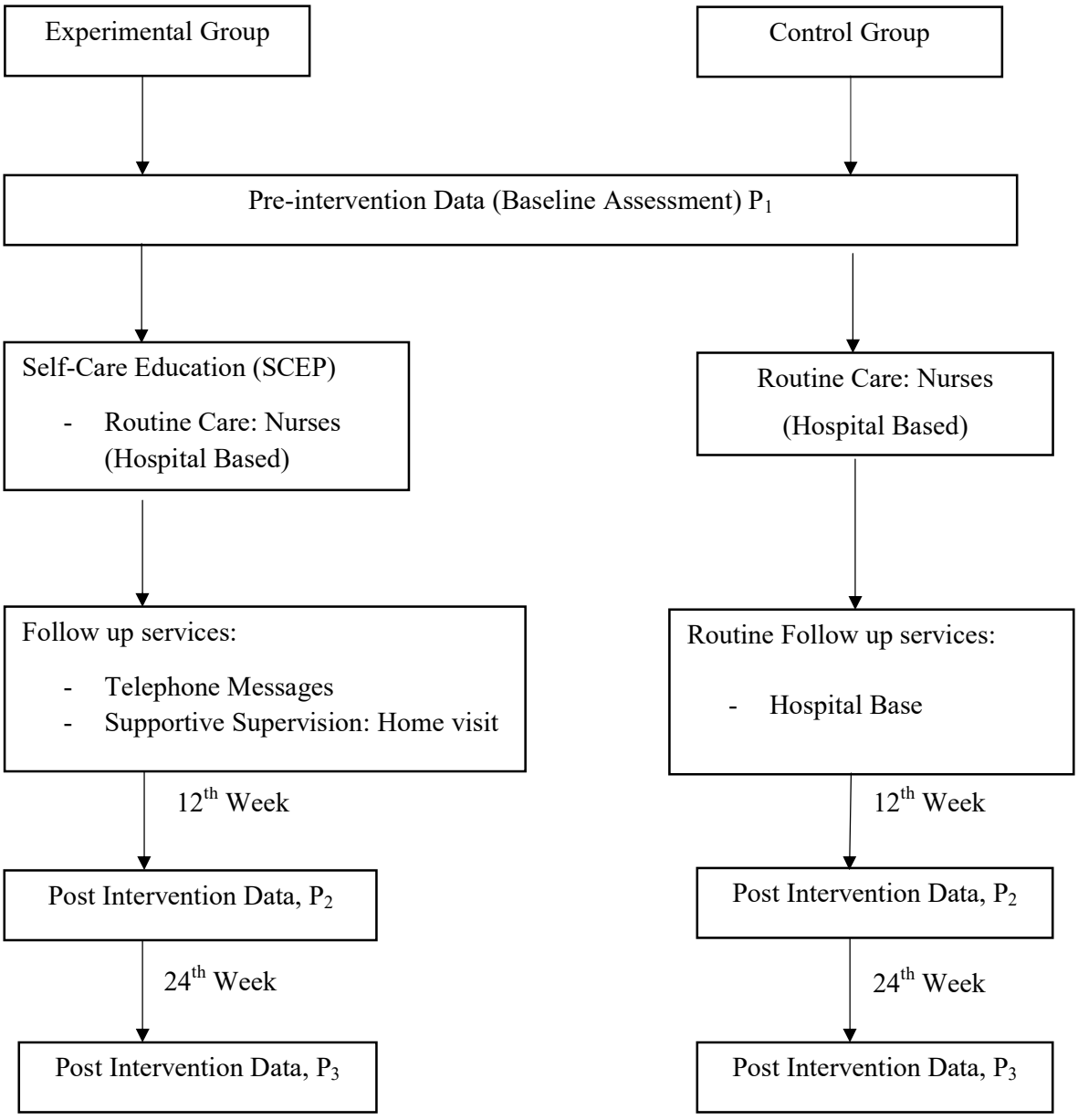


Fig. 3.1 Study Design Flow Chart

Key: Self-Care Educational Package (SCEP), Supportive supervision (SS)

3.2 Study Area

Oyo State

Oyo State was created on 3rdFebruary, 1976.The state has 11 local government areas.Ibadan is the capital of Oyo state and known to be the third most populous city in Nigeria and stands as the nation's largest city by geographical area (Wikipedia).In the city, there are three heamatology clinics, which are University College Hospital, Adeoyo State Hospital Ring Road the setting for this study. and Oni Memorial Children Hospital. Adeoyo State Hospital, Ring Road, Ibadan is located in Ibadan

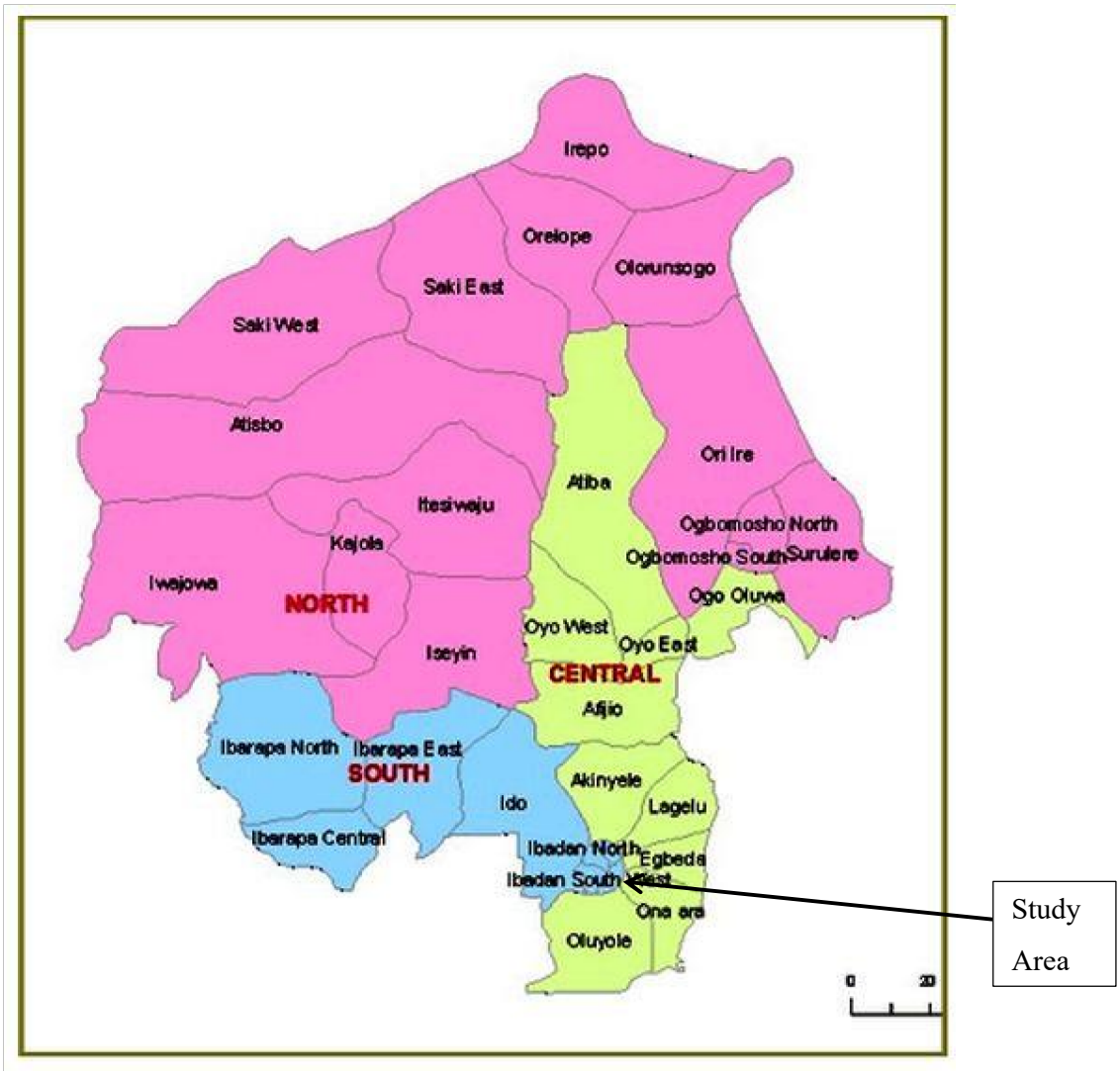


Figure 3.2: Map of Oyo State Showing the Study Area
South West Local Government Area.

Ekiti State

Ekiti State was created on 1stOctober, 1996. The state has 16 Local Government areas. There are two specialist hospitals and one State Hospital. The specialist Hospitals are Federal Medical Center, (FMC) at Ido Ekiti (which has recently been upgraded to Federal Teaching Hospital) and University Teaching Hospital in Ado Ekiti. The two hospitals emerged from the old State Hospital, Ado-Ekiti.

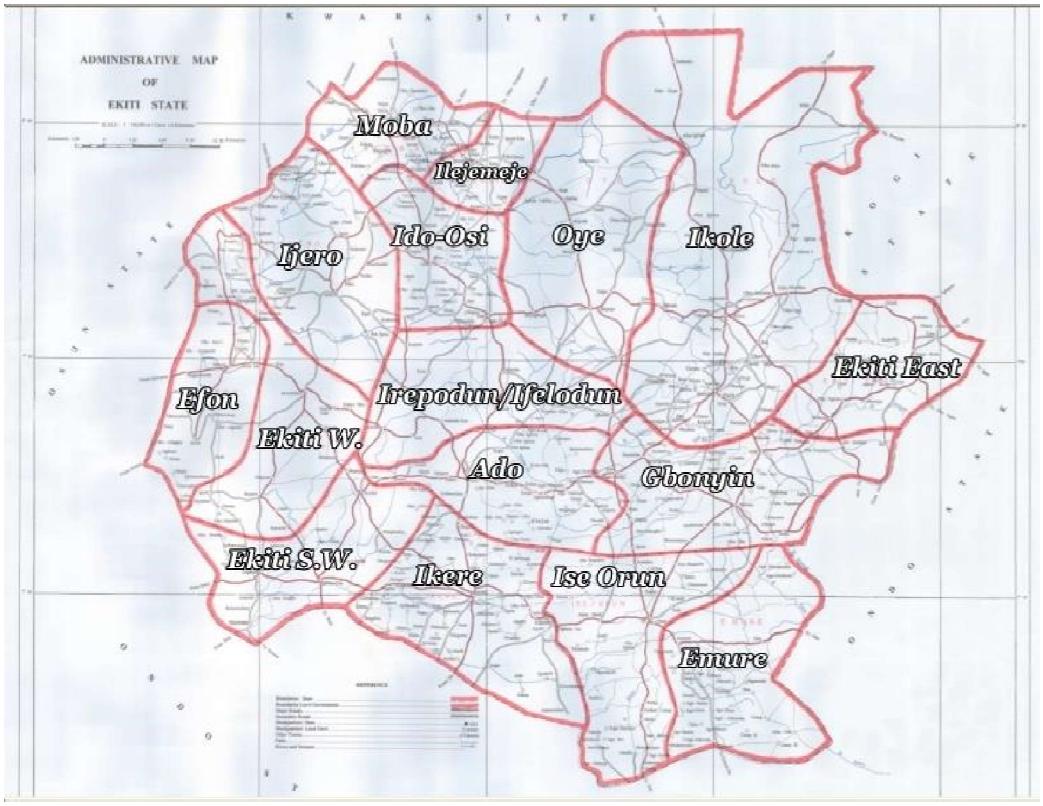


Figure 3.3: Map of Ekiti State showing the Study Area

3.3 Study Setting

Two states in South Western Nigeria (Adeoyo State Hospital Ring Road, Ibadan, Oyo State, Ekiti-State University Teaching Hospital and Federal Medical Centre, Ido Ekiti, Ekiti State) were purposively selected for this study. The selection was done after considering the states with functional clinics and clinics without support group(s).

Adeoyo State Hospital, Ring Road, Ibadan.

The Hospital was established on 21st of March, 1971 by Brigadier Robert Adeyinka Adebayo, the then Military Governor. This health facility serves as secondary level of care; its first phase started at Aba-Igbira. Haematology department was fully established in 1976 at ring road state hospitaland Dr. Ipadeola was the first haematologist that started the clinicand ran it for over ten years. His presence brought influx of clients to haematology clinic from all areas of Oyo State. Clinic day is on Tuesdays for both adult cases and child haematology. The clients usually have routine baseline investigation, most especially PCV, before consultation on clinic days. The increased client flow made the management to support the training of doctors and nurses in genetics in order to complement care given to clients.

Currently, client flow increased tremendously from average of 90 to above 250 clients per month. About 80 to 100 adolescents were seen per month. Clinic days usually come up on 3rd Tuesday of every month while haematology clinic occurs during morning shift hence clients are seen by casualty officers during afternoon and night shifts. The staff strength in the haematology clinic who attend to clients on clinic days include Doctor Ipadeola who is the haematologist, two Doctors who are medical officers, a genetic Nurse, two Nurses and two clerical staff. Presently, there is no haematologist at the clinic, the clients are seen by the Doctors on duty and when there is need for referral as regards further management, clients are being referred to haematology department, University College Hospital, Ibadan (UCH).

Ekiti State University Teaching Hospital, Ado Ekiti

EKSUTH, Ado Ekiti was established on 1st April,2008 for the purpose of administering quality treatment to sick people in and beyond Ekiti State. HaematologyClinic was among other departments at inception having its clinic every Monday at ART building. Clients with HBSS do not have a separate clinic; other haematology cases are put together for Consultants' review and further management. The clinic is being managed by 6 staff: a doctor, 2 nurses and 3 causal workers. The average client flow for persons living with sickle haemoglobin (HBSS) ranges between 80 and 120 across ages of which 60 adolescents regularly attend clinic monthly. On each clinic day, clients usually have routine baseline investigation before consultation.

Federal Teaching Hospital, Ido-Ekiti was the second setting for control group. The hospital was established in1998 by the Federal Government, as a clinical training institution for doctors and nurses. The hospital offers Primary, Secondary and Tertiary Health Services to the neighboring towns, villages and its general public with haematology department at inception

Haematology Department usually runs its clinic on Tuesdays and Wednesdays of every week. Children between 1 and 15 years of age who have been diagnosed with Sickle Haemoglobin (HBSS) have their clinics on Tuesdays while adult haematology is on Wednesdays for persons between sixteen years and above. The clinic is being managed by a doctor, two nurses and two clerical staffs. Routine baseline investigations were mandatory for clients before consultation on clinic days. Clients usually report at the Surgical Out-Patient Department (SOPD) each clinic day for Consultants' review and further treatment. Overall client flow for all ages monthly is 150 on the average, out of which 70 adolescents were adolescents.

3.4 Target Population

Target population were adolescents within the age of 10 – 19 years with sickle cell disease who attended haematology clinic from Adeoyo State Hospital Ring Road, Oyo State, Ekiti State University Teaching Hospital, Ado-Ekiti and Federal Medical Centre, Ido-Ekiti, Ekiti State in Southwestern Nigeria.

3.5 Study Population

Study population comprised adolescents aged 10-19years, who had been diagnosed of SCD and living with the disease, who were duly registered in the haematology clinics of selected health institutions participated in the study from January to June in wet and dry seasons due to nature of SCD to know how clients adapt each season.

Selection of the Study Participants

In each study setting, the sampling frame derived from regular attendees of the clinic provided detail information about adolescents who were receiving care in the clinic. A text message for an interactive session was sent to all adolescents to discuss the proposed study on a given clinic day. During the interactive session, adolescents were given detailed explanation of the study and interested participants were duly registered for the study. The researcher and the participants agreed on the date to commence the study

3.6 Sample Size Determination

Sample size for this study was calculated using sample size formula by Chadha(2006) on sample size estimation for research.

Sample size formula

$$n = \frac{(Z_{1-\propto/2} + Z_{1-\beta})^2 2\sigma^2}{(\mu 1 - \mu 2)^2}$$

Where n is the total sample size (the size of each comparison groups),

$Z_{\propto/2}$ Is the critical value of the normal distribution at $^{\propto}/_{2}$

$Z\beta$ is the statistical power,

μ1 is the mean QoL for SCD patients who adopted self-care management (Ahmadi, Jahani, Poormansouri, Shariati, and Tabesh, 2014)

μ2 is the assuming a 50% reduction in QoL compared to the experimental group

Therefore at,

$Z_{\propto/2} = 1.96$ for a confidence level of 95%, $\propto$ at 0.05

Z$\propto$= 0.84 for a power of 80%,

μ1 = 78.84

μ_2= 72.22

$$n = \frac{(1.96 + 0.84)^2\ 2(11.82)^2)}{(78.84 - 72.22)^2}$$

n= 50.00

After substituting the value in the formula, a total of 50 was obtained for each group, with 10% attrition rate given a total of 110, thus having55samples from each group.

3.7 Sampling Method

The study utilised purposive sampling technique to select functional health institutions for SCD clientsin Oyo and Ekiti states. Simple random sampling (tossing a coin) was use to allocate study location, Adeoyo State Hospital Ring Road Ibadan as experimental setting with Ekiti State University Teaching Hospital Ado-Ekiti and Federal Teaching Hospital Ido-Ekiti as control settingthese two clinics in Ekiti State are tertiary health institutions with similar characteristics; both emerged from the (Old State Hospital, Ado-Ekiti).

Inclusion Criteria

States with functional health institutions for sickle cell clients were selected for the study. Adolescent with SCD between 10 to 19 years of age who were clinically stable during the time of data collection were eligible to participate in the study.

Exclusion Criteria

States with functional support group system (SCD clubs) for adolescents living with SCD were excluded from this study. Also, Adolescents who satisfied the inclusion criteria but had any other chronic condition were excluded from the study.

3.8 Instrument for Data Collection

Questionnaire was used for data collection. It had six sections; threesections A, C and D were self-developed by the researcher after in-depth review of literaturewhile sections B, E and Fwere modified from previous studies. The sections were:

1. Section A obtained information on social demographic characteristics of adolescents living with SCD and their parents with 14 items.
2. Section B measured SCD knowledge of adolescents. The adolescent's knowledge of SCD was measured with the adapted SCD Transition Knowledge Questionnaire (Newland, Cecil, & Fihian, 2000) which is a 42-item multiple-choice assessment of teen knowledge of SCD relevant to the preparation for transition to adult SCD services. It has a reliability coefficient of 0.79 (Newland, 2008), thus instrument is reliable for study in terms of language and understanding of expression. The questionnaire assessed the knowledge of adolescents on sickle cell disease and its implication for the blood, for inheritance of SCD, for physical features of clients living with SCD and for its management.
3. Section C assessed the self-care requisite of adolescents. This section was developed by the researcher after extensive review of literature. It had three domains: the universal self-care requisites, developmental self-care and health deviation self-care. This was used to assess knowledge of universal self-care and

self-care ability of adolescents living with SCD. It is a 22-itemsection based on Yes or No responses and had a reliability coefficient of 0.79.

4. Section D was used to evaluate the activity of daily living in form of self-care practice of SCD adolescents. This section was developed by the researcher after vast literature review which has 10 items 4-Likert scale variables. The alpha coefficient for this section was 0.92. Open ended questions were set up to further investigate other self-care practices adopted by adolescents living with SCD.
5. Section E was used to measure pain coping strategies often used by adolescents with SCD. The questions were adapted from the pain coping questionnaire (PCQ) developed by Lim (2009). It is 20 items eight subscales namely; information seeking, problem solving, seeking social support, positive self-statements, behavioral distraction, cognitive distractions, externalising, and internalising/catastrophising questionnaire of 4-point Likert scale (0 = never to, 3 = very often). The reliability for the pain coping questionnaire as documented by Lim, 2009 ranged from 0.78 to 0.86
6. Section F was used to measure the quality of life of adolescents living with SCD. Questions were adapted from sickle cell well being developed by Lim (2009). The section contains 15 items with 4-subscales using Likert scale (1 = always to 4 = Never). The sub-scale includes the following domain; Physical, Emotional, Social, and School. Internal consistency as found by Lim, 2009 for the entire measure was 0.92. Open ended questions were asked to further probe participant on life expectancy in terms of their satisfaction with life and challenges encountered as they grew up with SCD.

3.9 Validity of the Instrument

Content validity of the instrument was established through expert panel in area of study while face validity was also employed to judge the clarity of instruments before proceeding to the field. All the materials for this study were given to experts selected across the fields of nursing, medicine and sociology who had been involved in active research in this area to review the instruments for completeness and appropriateness.

3.10 Reliability of the Instrument

Back to back translation was used to establishreliability of the instrument. English version of questionnaire (Source Language Text one SLT_1) was given to first translator to translate to Yoruba (Target Language Text TLT). The Yoruba version (TLT) was translated back to English language by a second translator (SLT_2) who was uninformed and unfamiliar with the original English version. The original English version SLT_1 was compared with SLT_2 to deduce differences or similarities which were resolved. The SLT_2 was found to be closely similar with SLT_1, thus depicting that the questionnaire was consistent in the two languages spoken in the study setting.

Internal consistency reliability was done to ascertain if the construct (test items) produce similar results. Twenty questionnaires were given to SCD clients. This was used to determine the internal consistency reliability of the tool usingCronbach's alpha ($\propto$). The Cronbach alpha coefficient is usually between 0 -1.0, where Cronbach alpha coefficient greater than 0.70 shows strong connection among the responses to different items on the scale used in this study. From the reliability test, the Cronbach alpha for SCD knowledge, pain coping abilities, self-care requisites, self-care practice, and quality of life were 0.70, 0.72, 0.79, 0.92 and 0.73 respectively. The validity of the SCD Transition Knowledge questionnaire has been adjudged by Newland, Cecil, & Fithian, (2000). The validity of the pain coping questionnaire inventory has been evaluated and verified in a number of ways: factors structure and criterion validity (Tobin, Holroyd, Reynolds, & Wigal, 1985) and construct validity (Tobin et. al. 1983).

A pilot test was done to show the confirmed reliability of the instruments used for this study and the Cronbach alpha coefficient was assessed for each section of the questionnaire. The pilot test was carried out in State Specialist Hospital, Akure and Federal Medical Center, Owo, in Ondo State with total participants of 104 SCD adolescents. The SCD knowledge transition questionnaire has a reliability coefficient of 0.84; the instrument is therefore reliable. Internal consistency was established for self-care requisites items where the Cronbach alpha was 0.79 and also for self-care practice items (0.73). The self-developed questionnaire was tested for internal relationship and the correlation coefficient was 0.754. The PCQ measure has internal consistency with 0.75 Cronbach's alpha. The sickle cell disease quality of life scale (SCD-QOL) scale has internal consistency of 0.80, hence the items were reliable.

3.11 Ethical Consideration

A proposal of the study was submitted to Health Research Ethic committee of each of the study settings to obtain clearance for the study in each setting. The proposal was reviewed and the researcher was invited for an oral interview in line with submitted proposal to ensure clarity of the research protocol and necessary corrections were made. After this, the researcher was given ethical approval from each study setting. Administrative permission was also obtained from all the health institutions of study. The purpose of the study was explained, participation was made voluntary and participants were notified of their right to withdraw without coercion or discrimination at any time of the research.

Confidentiality

Respondents' name was not inserted on filled questionnaire; all information given was for research purpose. Data obtained were in custody of the researcher, persons who were not involved in this research (as members of the team) did not have access to information of participants thus anonymity was ensured.

Beneficence

Self-care educational module was used to enrich adolescents' knowledge on self-care management of painful crisis and preventive strategies to build their self-care ability thus ensuring age appropriate coping skills. Adolescents in the control group received the intervention to acquire same knowledge with the adolescents of experimental group for ethical reason

Non-maleficence

Adolescents were not exposed to physical or emotional harm.

Physical: No invasive procedure in terms of blood transfusion or blood test.

Emotional: Questions were carefully worded to transcend unnecessary worries about SCD and their health status

Informed consent

Verbal and written consents were received from all the respondents, assent of those who were less than 18years were equally obtained. Also, a note which explained the study and phone numbers of researchers were sent to the parents for attestation before commencing the study.

Meetings were held with the head of Haematology Department and staff of each clinic in all the settings, to explain to them the objective of the research and to seek their consent to conduct the study among their clients. Meeting with adolescents was also scheduled, where the study's purpose, benefits and stages were explained in detail. The informed consent form was given to adolescents who are 18 years and above and assent were obtained from adolescents who are less than 18 years and inform consent form were sent to their parents. At the end of the briefing, adolescents who were willing to participate in the study were enrolled and date of interaction and subsequent intervention was scheduled.

All participants were given opportunity to clarify issues bothering their minds. Researcher put an end to relationship among clients by appreciating adolescents in all groups; gave her phone contact for the client while phone contacts of all participants were obtained. Each health institutionwas given the report of activities at the end of research.

3.12 Data Collection Process

Study spanned six months, data collection occurred during wet and dry seasons. The steps of this study were as follows:

Step 1- The planning period
Step 2- Pre-intervention period
Step 3- Intervention period
Step 4- Post-intervention period

The planning period (Step 1)

This involved familiarisation visits to the study sites. During this period, six research assistants were recruited forthe study at the study site. The assistants were trained for two days (two assistants for each study location). At this time, research assistants were

given detailed explanation of proposal for proper understanding of the study objectives. They were taught how to utilise the questionnaire for data collection through demonstration and repeat demonstration, interpersonal relationship and research ethics were equally discussed. They asked questions for clarification and this was responded to.

The training wasdirected at equipping them for their functions during study which includes setting up the training venues, organising study centres, sorting of questionnaires into Yoruba and English versions, keeping records of events by taking photographs during intervention, and distribution of writing materials and handbook of self-care educational package after intervention. They also accompanied the researcher to clients' residence for home visit.

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Pre-Intervention period (Step 2)

In each group i.e. experimental and control group, on the set clinic date as agreed with participants, the researcher identified participants who agreed to participate in the study at the registration desk and they were reminded of their intent to participate and informed consent form was retrieved. After the routine checkup, interested participants met with the researcher in the designated hall. Out of eighty-two adolescents thatregistered for study only sixty-seven showed up for study in experimental setting while seventy-six adolescents reported for study out of seventy-nine that registered in the control group.

A brief recap of study information for all adolescents that registered was given; this was followed by collection ofbaseline data (P_1). Research assistants distributed questionnaire that was used to obtain quantitative data on SCD knowledge, self-care requisites and self-care practice, pain-coping and quality of life from the adolescents.

However, participants in the experimental group were told during their briefing to wait for the intervention while participants in control group continued with the routine care

Intervention period (Step 3)

The intervention had two main activities: educational intervention and supportive supervision. The first activity; Self-care education intervention (USING SCEP MODULE) was given to adolescents in experimental group immediately after the baseline data (P_1) was obtained.

Adolescents were seen once a week on clinic days for four weeks and educational programme took place in the hospital hall. Researcher was the facilitator for all sessions, teaching 1 module per week for 4 weeks, each module spanned 45 minutes. Flip-chart board and projector were used during educational sessions while research assistants helped in distribution of writing materials (A folder containing jotter, biro, ruler and SCEP hand book). They equally took attendance of respondents, photographs and maintained orderliness during sessions. Cash incentive of N500 was given to adolescents that participated in study as transport fare for each session. Self-developed Self-care Educational Intervention Package (SCEP) which was used to teach adolescents on weekly basis is summarised below:

Module 1: Concept of SCD with emphasis on genetics and biology, inheritance of SCD, and personal information that would help adolescent make voluntary decisions towards eradication of SCD and complications of SCD were taught.

Module 2: Management of painful crises / Self-care Management and preventive health care strategies were taught in second week. Adolescents were briefed on factors that triggers painful crisis (i.e. dehydration, extreme weather, strenuous exercise, anxiety and fear). Preventive strategies such as hand washing, copious intake of water, adequate rest and food safety tips were dully explained.

Module 3: Coping and cognitive / age-appropriate pain management techniques were taught in third week to help adolescents who are living with SCD develop an active problem-focused coping strategy. This entails in-depth understanding and proper utilisation of diverse relaxation techniques such as imagery, massage and prayer meditation in relieving pain.

Module 4: Development of Self-Competence, assertiveness and self-efficacy, adolescents were encouraged to develop positive self-concept as regards appearance,

values and beliefs towards SCD. They were encouraged to pay attention to personal needs and desires, take good care of themselves and engage in activities they enjoy by using their talent and abilities to promote health. They were advised to feel good about themselves and to spend time with individuals that would make them feel good.
Further details of module are attached in appendix 3.

The second activity is supportive supervision which commenced at 5th week of study. Researcher and research assistant had a follow-up on Adolescents for five months through home visit in the third week of each month. Also, tips for healthy living stated in SCEP booklet were sent as text messages to adolescents in the experimental group.

Utilisation of SCEP handbook and mastery of contents in each module of SCEP were assessed orally during the home visit. Questions and clarification were attended to and participants were encouraged to use the handbook.

Post-intervention Period (Step 4)

This is also known as evaluation. It involved collection of end line data using the same instruments used in step 2 above. The first post intervention data (P_2) was obtained (eight weeks) after receiving self-care education which was the twelve weeks of study (3months) followed by second post intervention data (P_3) which was collected 12weeks after P_2 at 24thweek of study (6months). Thus, data were collected(threetimes) consecutively with the same questionnaire from a total of 115 adolescents (59 and 56) that completed the study in experimental and control group respectively. Study recorded a fall out of 8 and 19 among adolescents in both groups respectively.

3.13Method of Data Analysis

Data collected were analysed using descriptive statistics and inferential statistics. All analyses were carried out using the Statistical Package for the Social Sciences (SPSS 21.0). Demographic variables were coded serially as they appeared on the instrument, frequencies and percentages of the demographic variables were shown in tables while continuous variables were summarised as mean and standard deviations.

Frequency and percentages of the data obtained in sections B to F were presented in tables and the mean scores were obtained. The independent t-testwas used to compare the data between the groups. More so, baseline data were compared with post intervention data. This was done using Repeated Measures of ANOVA (baseline to 12th week and 12th week to 24th week). Chi-square was used to compare data in order to establish an association between the information gathered. Significant level was declared at 5%.

Objective 1: To assess level of SCD knowledge among adolescents living with SCD in experimental and control groups at pre and post intervention.

This objective was evaluated using the adapted SCD transition questionnaire in section B. The adapted questionnaire has 42-item dichotomous questions which assessed adolescents' knowledge of SCD relevant to preparation for transition to adult SCD services. In each of the questions, only one answer is correct given a total obtainable score of 42 marks (Newland, Cecil, & Fithian, 2000). In this study, correct response was scored 1 and wrong response was scored 0, hence, the highest mark was 42, while lowest score was 0. The level of SCD knowledge among participants was categorised using the mean score obtained in each group at the different intervals with scores lower than the mean was classified as below average, equivalent to mean and above the mean score were classified as good level of knowledge. This was also done for data collected at 12th week and 24th week of study

Objective 2: To evaluate knowledge of universal self-care requisites among adolescents with SCD in the experimental and control groups pre and post intervention.

The self-developed questionnaire was used to assess the knowledge of universal self-care requisite of adolescents contained in section C of the research instrument with 10-dichotomous questions. Incorrect option was scored 0 while correct option was scored 1; the overall maximum score obtainable is 10 while 0 was the minimum obtainable score. Results of universal self-care requisite knowledge were presented in tables for the three phases of data collection. The level of knowledge of universal self-care requisites of the participants was categorised using the mean score; scores lower than the mean score was classified as poor while scores equivalent to mean score and greater than mean score were classified as good. This was done for data collected at baseline, 12th and 24th weeks.

Objective 3: To evaluate the self-care ability of adolescents living with SCD in the experimental and control groups pre- and post-intervention.

This objective was evaluated using the questionnaire on developmental Self-care, health deviation self-care, activity of daily living and the pain coping as contained in section C, D and E, respectively in the research instruments. Developmental and health deviation self-care action were assessed with 12-items dichotomous questions (5 and 7 respectively) with the incorrect option as 0 and the correct as 1. Hence minimum score obtainable is 0 and maximum obtainable is 12.
Activity of daily living was assessed with ten items Likert scale with 4-level options. Score awarded to each item ranges from 1 (never) to 4 (very frequent).
Maximum score obtainable is 40 while minimum score obtainable is 10.

The pain-coping ability of the participants was assessed with 20 items of 4-point Likert scale with a score of 0 (never) to 3 (very often). Minimum score obtainable is 0 while maximum score obtainable is 60.

The level of developmental self-care, health deviation self-care, activity of daily living practices and pain-coping ability of participants were categorised using the mean score where the scores lower than the mean were classified as poor level of activities of daily living while scores equivalent to the mean score and greater than the mean score were classified as good level of activities of daily living practice

A composite score of self-care ability was computed with developmental requisites, health deviation requisites, activity of daily living practice and pain coping scale were used. Self-care ability has the minimum obtainable score of 30 and maximum obtainable score of 112. The level of self-care ability was also obtained by categorising the scores using the mean score. Scores lower than the mean was classified as poor self-care ability, scores equivalent to the mean score was classified as moderate self-care ability and scores greater than the mean score was classified as good self-care ability. This was done for data obtained at baseline, 12th and 24th weeks. Open ended questions which assessed other activity of daily living practices were analysed and grouped under similar theme and presented in bar charts.

Objective 4: To assess the quality of life of adolescents living with SCD in the experimental and control groups pre and post intervention.

Modified SCD-QoL scale was used to determine adolescents' quality of life contained in section F (Lim, 2009). The adapted, modified scale had 15 items with the scores ranging from 1 = Very Frequent to 4 = Never. The maximum score that could be obtained was 60 while the minimum score was 15. The level of quality of life of participants were categorised with the mean QoL score. Scores lower than the mean QoL score were classified as poor QoL, scores equivalent to the mean scores were classified as moderate QoL while scores greater than mean score were classified as good

QoL. This was done for data obtained at baseline, 12th and 24th weeks. Open-ended questions which assessed feelings of adolescents living with SCD and challenges which they faced while living with SCD, were analysed and grouped under similar theme and presented in bar charts

3.14 Hypotheses Testing

The hypotheses were tested using inferential statistics at confidence level set at 95%.

H_0 1: There is no significant difference in the level of SCD knowledge score among adolescents living with SCD in the experimental and control groups.

The independent t-test was used to compare the scores obtained between the control and experimental groups at baseline, 12th and 24th weeks with significance set at $p<0.05$.

Repeated measure of ANOVA was used to examine the outcome of self-care education on disease knowledge among adolescent having SCD at statistical significance level of $p<0.05$ using the three-point intervals within each group.

H_0 2: There is no significant difference in knowledge of universal self-care requisite among adolescents livingwith SCD in the experimental and control groups.
Independent t-test was used to compare the scores obtained between the control and experimental groups at baseline, 12th and 24th weeks with significance set at $p<0.05$.

Repeated measure of ANOVA was used to investigate the effect of self-care education on knowledge of universal self-care requisite of adolescent having SCD across the 3 levels of study.

H_0 3: There is no significant difference in self-care ability among adolescents living with SCD in experimental and control groups.

Independent t-tests were used to compare the scores of self-care ability between the control and experimental groups at baseline, 12th and 24th weeks with significance set at $p<0.05$.

Repeated measure of ANOVA was used to evaluate the outcome of self-care education on the overall self-care ability score of adolescents living with SCD across the 3 levels of study within each group.

H_0 4: There is no significant difference in the quality of life of adolescents living withSCD in the experimental and control groups.

Independent t-tests were used to compare the scores obtained between the control and experimental groups at baseline, 12th and 24th weeks with significance set at $p<0.05$.

Repeated measure of ANOVA was also used to evaluate the outcome of self-care education on quality of life of adolescent having SCD across 3 levels of study within each group.Theindependent sample t-test was used to establish the difference in quality of life (QoL) between the groups at statistical significance level of $p<0.05$.

CHAPTER FOUR

RESULTS

This chapter describes the study findings with respect to participants social demographic characteristics, sickle cell disease knowledge, self-care ability and their quality of life.

One-hundred and forty-three (143) copies of the questionnaire were distributed to participants in experimental and control groups. However, 115 copies were found to be suitable for data analysis from adolescents who participated consistently in all the phases of the study, there were 59participants in the experimental group and 56participants from thecontrol group. This study has a response rate of 80.4%, pre and post intervention.

4.1 Social Demographic Characteristics of Participants

The study has a response rate of 80.4%. The mean age of 15.7±2.7 and 14.8±3.8 years were found for participants in the experimental and control groups respectively. In the experimental group, 52.4% were males compared to 51.8% in control group. Also, In the experimental group, 47.5% were females, while control group, had (48.2%). female participants. The participants were largely of the Yoruba ethnic group, 91.5% and 91.1% for the experimental and control groups. Among the participants, 69.5% and 37.5% in the experimental and control groups, respectively, had siblings who were not living with SCD (See Table 4.1).

Table 4.1: Socio-Demographic Profile of SCD Participants

Variable	Experimental (n=59) Frequency (%)	Control (n=56) Frequency (%)	χ^2	*p* value
Gender				
Female	28(47.5)	27(48.2)	0.01	0.935
Male	31(52.4)	29(51.8)		
Age (years)	**Mean**=15.7 ± 2.7	**Mean**=14.8 ± 3.8	2.05	0.359
10-13	14(23.7)	20(35.7)		
14-17	27(45.8)	23(41.7)		
18-19	18(30.5)	13(23.2)		
Religion			9.95	0.001
Christianity	34(57.6)	47(83.9)		
Islam	25(42.4)	9(16.1)		
Ethnicity			5.96	0.113
Yoruba	54(91.5)	51(91.1)		
Igbo	4(6.8)	2(3.6)		
Hausa	1(1.7)	3(5.4)		
Father's Occupation			76.42	0.001
Artisan	10(16.9)	2(3.6)		
Trader	17(28.8)	10(17.9)		
Civil Servant	9(15.3)	25(44.6)		
Clergyman	5(8.5)	1(1.8)		
Farmer	4(6.8)	8(14.3)		
Professional	5(8.5)	4(7.1)		
Others	3(5.1)	3(5.4)		
Unemployed	6(10.2)	3(5.4)		
Mother's Occupation			97.38	0.001
Civil servant	7(11.9)	8(14.3)		
Home maker	7(11.9)	2(3.6)		
Artisan	5(8.5)	7(12.5)		
Teacher	7(11.9)	5(8.9)		
Trader	33(55.9)	34(60.7)		
Number of siblings			9.83	0.132
Nil	16(27.1)	7(12.5)		
1-4	34(57.6)	44(78.8)		
5 and above	9(15.3)	5(8.9)		
Number of siblings with SCD			11.88	0.003
No	41(69.5)	21(37.5)		
Yes	18(30.5)	38(62.5)		

Table 4.2 showed participants information on medication and sickle cell related diseases.Last admission experience on account of SCD crises was within a mean of 8.9±6.3 and 11.0±10.0 weeks prior to the commencement of the study for experimental and control group participants respectively. The number of SCD-related crises per year among participants was1.2±1.3 and 2.26±2.69 for the experimental and control groups respectively. A difference was found in the recent SCD crisis, last admission experience, and average number of crisis per year between the experimental and control groups ($p<0.05$).

Table 4.2: Participants Information on Medication Utilisation and SCD-related crises

Variable	Experimental Group (n=59) Frequency (%)	Control Group (n=56) Frequency (%)	χ^2	*p* -value
Medication use responsibility				
Self	21(35.6)	18(32.1)	0.36	0.551
Parents/Guardian	38(64.4)	38(67.9)		
Financial Support(NGO, GOVT.)				
Yes	23(39.0)	5(8.9)	12.11	0.046
No	36(61.0)	51(91.1)		
Last SCD crisis (days)	Mean=10.7±7.2	Mean=11.3±9.3	16.42	0.006
Nil	13(22.0)	11(19.6)		
1-5	6(10.2)	11(19.6)		
6-10	5(8.9)	5(8.9)		
11-15	21(35.6)	4(7.1)		
16-20	3(5.1)	5(8.9)		
>20	11(18.6)	18(32.1)		
Last Admission (weeks)	Mean=8.9±6.3	Mean=11.0±10.0	14.13	0.015
Nil	23(38.9)	16(28.6)		
1-5	4(6.7)	10(17.8)		
6-10	5(8.5)	3(5.4)		
11-15	15(25.4)	4(7.1)		
16-20	3(5.1)	5(8.9)		
>20	9(15.3)	18(32.1)		
Number of Crises Per Year	Mean=1.2±1.3	Mean=2.26±2.69	11.22	0.011
Nil	29(49.2)	23(41.1)		
1-2	23(39.0)	12(21.4)		
3-4	3(5.1)	11(19.6)		
5 and above	4(6.7)	10(17.9)		

4.2 Knowledge of Sickle Cell Disease among Participants

The knowledge of the adolescents regarding various aspects of SCD is shown in table 4.3. Participants response on specific blood cells which sickle cell affects showed that 27.1% versus 35.7 % participants from experimental and control groups hadcorrect response. The response increased in the experimental group to 83.1% at 12th week and 89.8% at 24th week.Control group participants had correct response of 55.4%that haemoglobin in red blood cells do not transport water round the body and 39.0% of adolescents in experimental group also responded correctly. The proportion of the respondent in the experimental groupincreased to 74.6% and 78.0% at 12th week and 24th week, respectively, maintaining correct responses that haemoglobin does not carry water throughout the body.

Table 4.3: Knowledge of Adolescents on aetiology of Sickle Cell Disease (Correct Responses)

Items: Which of the following statements is correct about Underlisted items	Control (n=56)			Experimental (n=59)		
	Baseline %	12th week %	24th week %	Baseline %	12th week %	24th week %
SCD is a condition that affects white blood cells	60.7	67.9	64.3	40.7	81.4	93.2
Sickle cell disease affects red blood cells	35.7	44.6	44.6	27.1	83.1	89.8
The platelets are also affected by SCD	71.4	71.4	71.4	67.8	89.8	88.1
RBC in SCD can cause problems because they can become too large	67.9	73.2	71.4	76.3	86.4	83.1
RBC in SCD can cause problems because they can become too soft	69.6	69.6	71.4	57.6	76.3	84.7
RBC in SCD can cause problems because they can become sickle-shaped and hard	51.8	55.4	53.6	27.1	67.8	76.3
RBC in SCD can cause problems because they can become round and hard	58.9	58.9	55.4	76.3	76.3	88.1
Haemoglobin carries vitamins within human body	64.3	60.7	66.1	76.3	67.8	83.1
Haemoglobin transports minerals to the body systems	58.9	58.9	60.7	50.8	83.1	83.1
Haemoglobin in RBC conveys oxygen all over the body	32.1	39.3	44.6	39.0	59.3	83.1
Haemoglobin distributes water to organs in the body	55.4	55.4	57.1	39.0	74.6	78.0

The result of frequency distribution of knowledge about SCD inheritance, physical features and management. 61.0% of experimental group participants had correct responses about the origin of SCD while control group participants had (57.1%) at baseline. At 12th week, there is no difference in the participants response (61.0% vs 60.7%) in both groups. However,at 24th week participants correct response about origin of sickle cell disease in the experimental and control group was(96.6% vs 64.3%) respectively. The knowledge of respondents on if SCD can cause bleeding problem was computed; result showed that 86.4% of respondents in experimental group answered correctly at baseline that SCD doesn't cause bleeding problem while 62.5% of respondents in the control group equallyanswered correctly. Also, knowledge on if female SCD respondents can have their own children, result revealed that 42.4% and 58.9% of experimental and control groups' participants had correct knowledge respectively. At 12th week, there was a difference between the correct responses from the experimental and control group (84.7% vs. 64.3%). At 24th week thedifference in the correct responses between the participant in the experimental and control group further increased to (93.2% vs. 62.5%). About the physical features of adolescents with SCD, 49.2% and 44.6% of experimental and control groups' participants stated that SCD adolescents generally have slow development than their peers respectively at base line. At 12th and 24th weeks, there was an increase in responses of participants in experimental group to 69.5% vs 84.7% respectively compared to participants score in the control group 51.8% vs 58,9%.

Table 4.4: Knowledge of Participants on Inheritance and Physical Features of Sickle Cell Disease (Correct Responses)

Items	Control (n=56)			Experimental (n=59)		
	Baseline %	12th week %	24th week %	Baseline %	12th week %	24th week %
SCD is inborn	57.1	60.7	64.3	61.0	61.0	96.6
SCD is contagious (if you sit close to a person having SCD)	75.0	76.8	80.4	91.5	96.6	94.9
SCD can cause bleeding problem	62.5	73.2	64.3	86.4	93.2	93.2
Poor diet can cause SCD	66.1	66.1	67.9	8.5	66.1	79.7
SCD adolescents may be shorter than their age	42.9	44.6	42.9	23.7	74.6	79.7
Adolescents living with SCD may mature later than peers	44.6	51.8	58.9	49.2	69.5	84.7
Adolescents living with SCD may get tired easily	50.0	50.0	50.0	40.7	69.5	81.4
A woman with SCD can sustain her pregnancy with good medical care	41.1	50.0	41.1	3.4	62.7	72.9
A female with SCD cannot have children	58.9	64.3	62.5	42.4	84.7	93.2
A female with SCD should receive special care when pregnant	58.9	60.7	66.1	6.8	59.3	86.4
A male with SCD cannot father a child	58.9	58.9	62.5	69.5	91.5	94.9
Sickle cell clients should not have children	67.9	69.6	78.6	71.2	89.8	94.9
An adolescent with SCD should consider the nearness of college to the medical care before choosing a college to attend	53.6	60.7	73.2	37.3	78.0	86.4
Adolescents should consider the rules of the school concerning absence due to illness	44.6	48.2	58.9	64.4	81.4	86.4

The knowledge of participants on SCD management and general care of teenagers with SCD is displayed in Table 4.5.From the results 42.4% participants responded correctly in experimental group at baselinecompared to 66.1% of participants response in the control who had correct responses of the statement that SCD patient is not best treated after the pain is severe. However, at 12th week(79.7% vs. 67.9%) and 24th week(74.6% vs. 69.6%). there was an increase in correct responses of participants in the experimental and control groups.Investigating adolescents' response on knowledge of wearing warm clothes by individual with SCD during cold weather. The result showed that 32.2% and 55.4% of experimental group and control group participants had correct knowledge. At 12th and 24th weeks, there was increase in correct responses of participants in experimental group (52.5% and 91.5%, respectively) while responses of participants in the control group were(67.9% and 76.8%).

Table 4.5: Knowledge of Participants on SCD Management **(**Correct Responses**)**

Items	**Control (n=56)**			**Experimental (n=59)**		
	Baseline %	12th week %	24th week %	Baseline %	12th week %	24th week %
SCD patient should be given treatment after severe pain	66.1	67.9	69.6	42.4	79.7	74.6
SCD patient is best treated in the hospital	46.4	57.1	55.4	57.6	67.8	81.4
Sickle cell patient is best treated at home when the symptoms first begin	42.9	44.6	76.8	15.3	49.2	84.7
Sickle cell patient is best treated with narcotics only	76.8	85.7	85.7	39.0	79.7	89.8
In cold weather, SCD patient should wear warm clothes	55.4	67.9	76.8	32.2	52.5	91.5
In cold weather, SCD patient should stay home	51.8	58.9	51.8	79.7	91.5	84.7
SCD patient should never go outside during cold	58.9	60.7	58.9	67.8	88.1	81.4
In cold weather, SCD patient should cancel doctor's appointments	71.4	83.9	80.4	44.1	89.8	91.5
During sickle cell pain, a patient should drink plenty of water	50.0	58.9	66.1	32.2	62.7	86.4
During sickle cell pain, a patient should go to the emergency room right away	41.1	42.9	55.4	67.8	72.9	76.3
During sickle cell pain, a patient should always stay home from school or work	41.1	46.4	50.0	79.7	84.7	79.7
During sickle cell pain, a patient should limit intake of food	58.9	60.7	60.7	50.8	83.1	89.8
Ability of adolescents to manage problems alone should be considered when choosing college to attend	46.4	53.6	62.5	39.0	76.3	88.1
SCD clients take penicillin every day to treat infections	44.6	66.1	57.1	33.9	62.7	81.4
Individuals having SCD take penicillin every day to increase appetite	57.1	66.1	64.3	69.5	83.1	94.9
Persons diagnosed of sickle cell disease take penicillin every day to prevent painful episodes	39.3	62.5	50.0	54.2	81.4	78.0
Children who have SCD take penicillin every day to decrease risk of serious infection	33.9	46.4	44.6	44.1	76.3	83.1

Level of SCD Knowledge of the Participants at Baseline, 12th and 24th Weeks

Distribution of level of knowledge about SCD across the base line, 12th week and 24th weeks is shown in Figure 4.1. There was higher proportion of poor level of knowledge about SCD in the control group (66.1% vs. 44.1%) than the experimental at base line. The result further showed that 55.9% of respondents in experimental group at base line, had good knowledge of SCD, this increased at 12th week, 57.6% had good knowledge and at 24th week, majority (71.2%) were observed to have good knowledge of SCD.

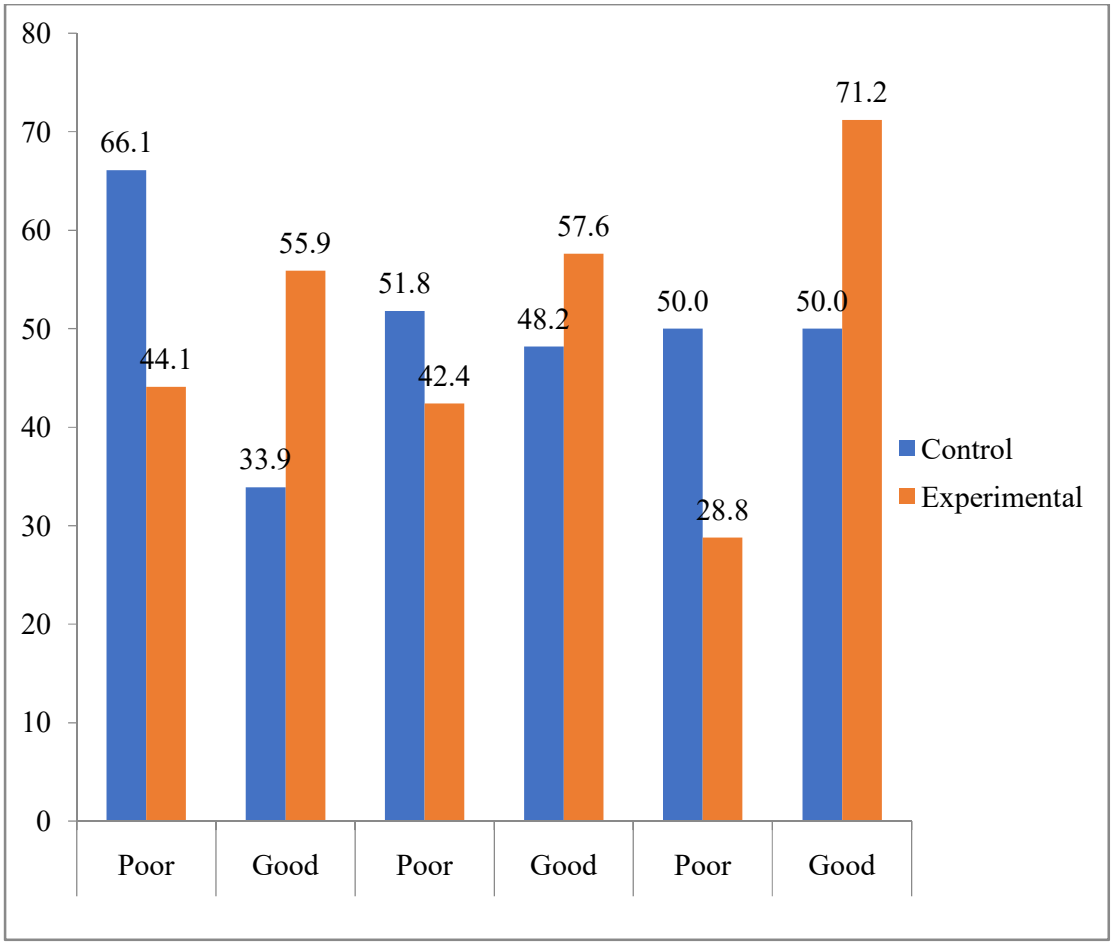

Figure 4.1: Level of Knowledge on SCD of Participants Pre and Post Intervention

4.3 Knowledge of Universal Self-Care Requisites among Participants

The universal self-care requisitesknowledge for adolescents living with SCD in Table 4.6 showed the percentage of correct response distribution among adolescents in the two groups. The result showed that none of the control group participants had correct response on items 5 and 7 at baseline, 12th week and 24th weeks (0.0%). At 12th and 24th weeks, participants in the experimental group had correct response of 74.6% and 76.3% respectively.Also,from this table (55.9%) of participants in the experimental groupand (67.9%) participants of the control group had correct knowledge that SCD patient needs sufficient intake of air to stay healthy. The proportion of participants in the experimental group at 12th and 24th weeksincreased from 55.9% to 74.6% and 84.7%, respectively, confirming that SCD patient needs sufficient intake of air to stay healthy.

Table 4.6: Frequencies of correct responses on Universal Self-care Requisites knowledge

Knowledge items	**Control Group (n=56)**			**Experimental Group (n=59)**		
	Baseline %	12th Week %	24th Week %	Baseline %	12th Week %	24th Week %
Adequate intake of air	67.9	73.2	69.6	55.9	74.6	84.7
Appropriate intake of water	66.1	58.9	69.6	74.6	79.7	86.4
Satisfactory intake of food	73.2	75.0	58.9	67.8	81.4	93.2
Regular and prompt defecation (excreta)	64.3	57.1	67.9	55.9	76.3	76.3
Regular physical exercise	0.0	0.0	0.0	0.0	74.6	76.3
Adequate rest	50.0	75.0	57.1	76.3	71.2	71.2
Maintain privacy (i.e. isolation, loneliness, or separateness)	0.0	0.0	0.0	0.0	79.7	74.6
Be a member of a support group for SCD	51.8	53.6	53.6	52.5	76.3	83.1
Ensure balance between privacy / support group interaction	67.9	51.8	71.4	61.0	74.6	76.3
Avoid hazards (i.e. physical, social, spiritual or psychological)	71.4	78.6	91.1	54.2	71.2	74.6

Level of Universal Self-Care Requisites Knowledge of participants in the study

The result in figure 4.2 showed categorisation of universal self-care requisites knowledgeamong adolescents in the experimental and control groups. Participants in experimental and control group had good knowledge at baseline64.4% vs 66.0% respectively while at 12th and 24th weeks,knowledge of participants in experimental group increased to 72.9% and 84.7% respectively. Thus, participants in experimental group showed an increase in the knowledge of universal self-care requites across the study period.

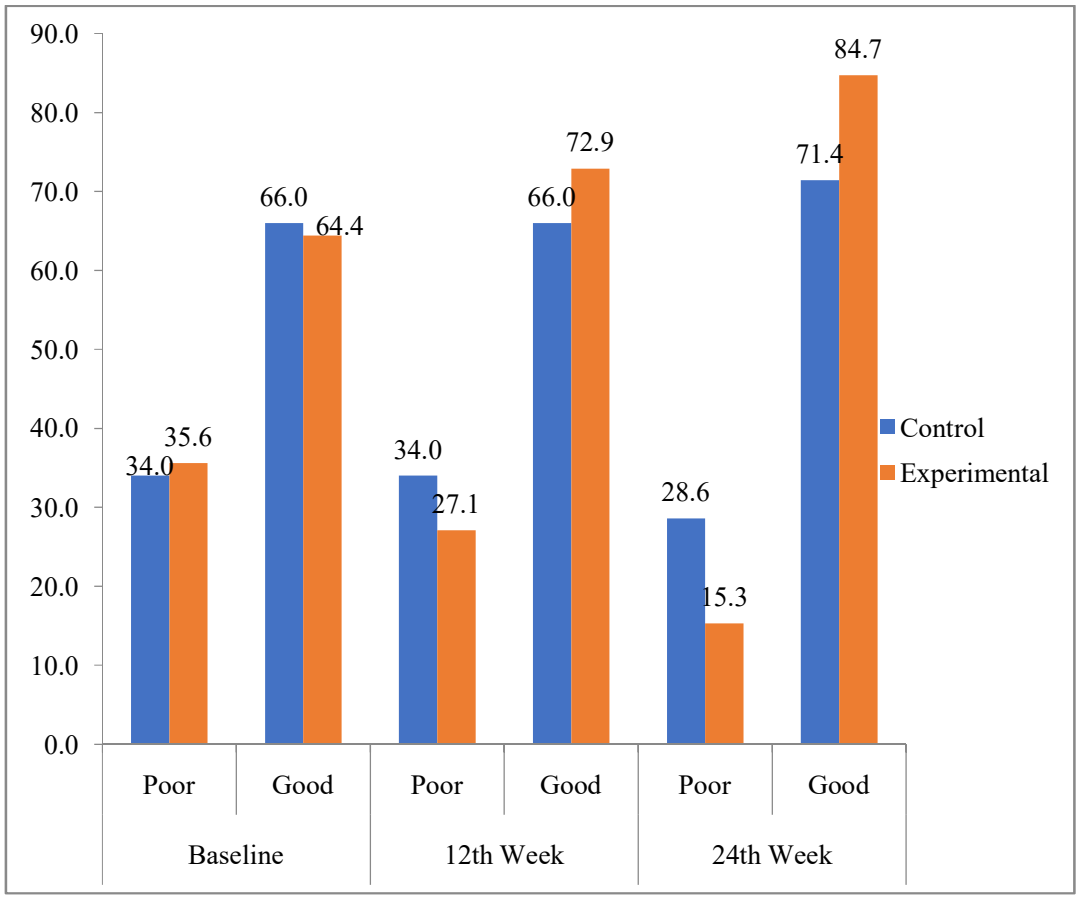

Figure 4.2: Level of Knowledge of Universal Self-Care Requisites of Adolescents Pre and Post intervention

Developmental Self-Care of Participants Living with SCD

The percentage distribution of correct responses of adolescents' knowledge about developmental self-care requisites is shown in Table 4.7. From the result, participants in both groups had similar response at base line, their responses showed that SCD patients should seek information or investigate the cause of SCD with the value of 33.9% vs. 33.9% respectively.At 12th week and 24th weeks, the proportion of participants with correct knowledgeincreased to 66.1% and78.0% in the experimental group while control group equally had increasedvalue to 51.8% and 55.4% at 12th and 24th weeksrespectively.

Table 4.7: Frequency of Correct Response on Developmental Self-care of Participants

Developmental self-care requisites	Control Group (n=56)			Experimental Group (n=59)		
	Baseline %	12th Week %	24thWeek %	Baseline %	12th Week %	24th Week %
Able to feed self promptly or regular intake of food	48.2	57.1	55.4	40.7	78.0	84.1
Avoid sleeping or living in overcrowded room	39.3	39.3	55.4	52.5	62.7	78.0
Seeking information about SCD or investigate cause of SCD	33.9	51.8	55.4	33.9	66.1	78.0
Isolate yourself during crises	58.9	71.4	35.7	45.8	72.9	66.1
Avoid residing in unhygienic environment	51.8	53.6	64.3	67.8	69.5	78.0

Level of Developmental Self-Care of Participants

The categorisation of developmental self-care requisite isshown in Figure 4.3. The results showed that participants had above average score (good) for developmental self-carein experimental and control groups (67.8% vs. 55.4%) at base line. The percentage of participant with good level of developmental self-careincreasedto 81.4% at 12th week and 89.8% at 24th week respectively in the experimental group. However, percentage score of participants in control group equally increased at 12th and 24th weeks to 58.9% vs 85.7% this might be due to exposure to questionnaire for the three stages of data collection.

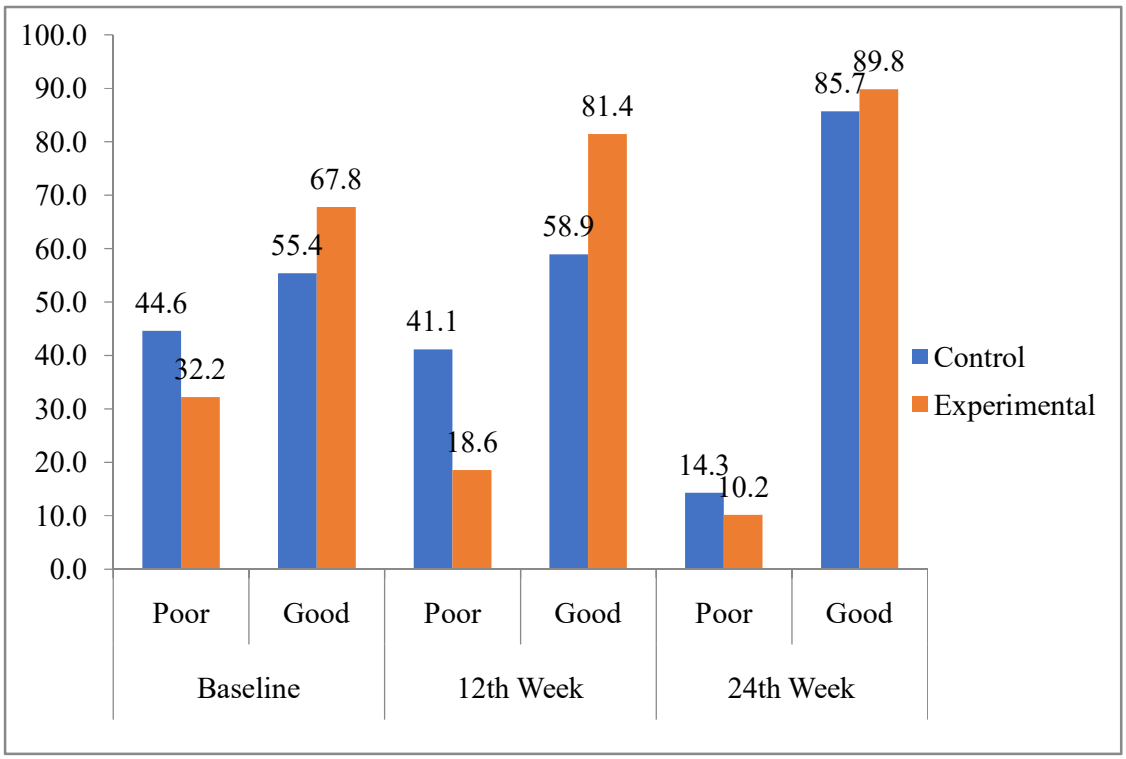

Figure 4.3: Level of Developmental Self-Care of the Participants Pre and Post intervention

Health Deviation Self-Care Requisites of Participants

The percentage distribution of correct responses for health deviation self-care requisitesof adolescents with SCD is presented in Table 4.8 Responses of participants as regards seeking and securing medical assistance showed that 49.2% and 53.6% of participant in experimental and control groups believed that seeking and securing medical assistance were required to stay healthy. However, percentage of correct responses of participants in experimental groupincreased to 91.5% at 12th week which later dropped to71.2% at 24th week which might be due to lack of financial support for medical treatment while there were slight changes in responses of participants in control group across study.

Table 4.8: Frequency of Correct Responses on Health Deviation Requisites Self-Care of Participants

Health Deviation self-care requisites	**Control Group (n=56)**			**Experimental Group (n=59)**		
	Baseline %	12th Week %	24th Week %	Baseline %	12th Week %	24th Week %
Procuring appropriate medical assistance	53.6	53.6	58.9	49.2	91.5	71.2
Adjusting life style to accommodate changes that emanate from SCD	51.8	51.8	57.1	47.5	71.2	76.3
Report perceived changes in health to care-givers promptly	55.4	55.4	64.3	47.5	71.2	84.7
Have good self- concept	46.4	46.4	50.0	49.2	62.7	76.3
Follow your regimen strictly	50.0	50.0	60.7	42.4	59.3	81.4
Having knowledge of potential problems of SCD	44.6	44.6	44.6	37.3	55.9	62.7
Learn to live with SCD throughout lifetime	39.3	39.3	46.4	45.8	67.8	81.4

Level of Self-care Requisites during Health Deviation of Participants

The categorisation of adolescents' scores as regards level of knowledge on health deviation self-care requisites isshown in figure 4.4. Theresult showed that higher proportion of participants in the control group (57.1%) had good score of health deviation self-care requisites than participants from the experimental group (50.8%) at baseline. At 12th and 24th weeks percentage of participants that had good score in the experimental groupincreased to 59.3% and 83.1% respectively than responses from control group participants.

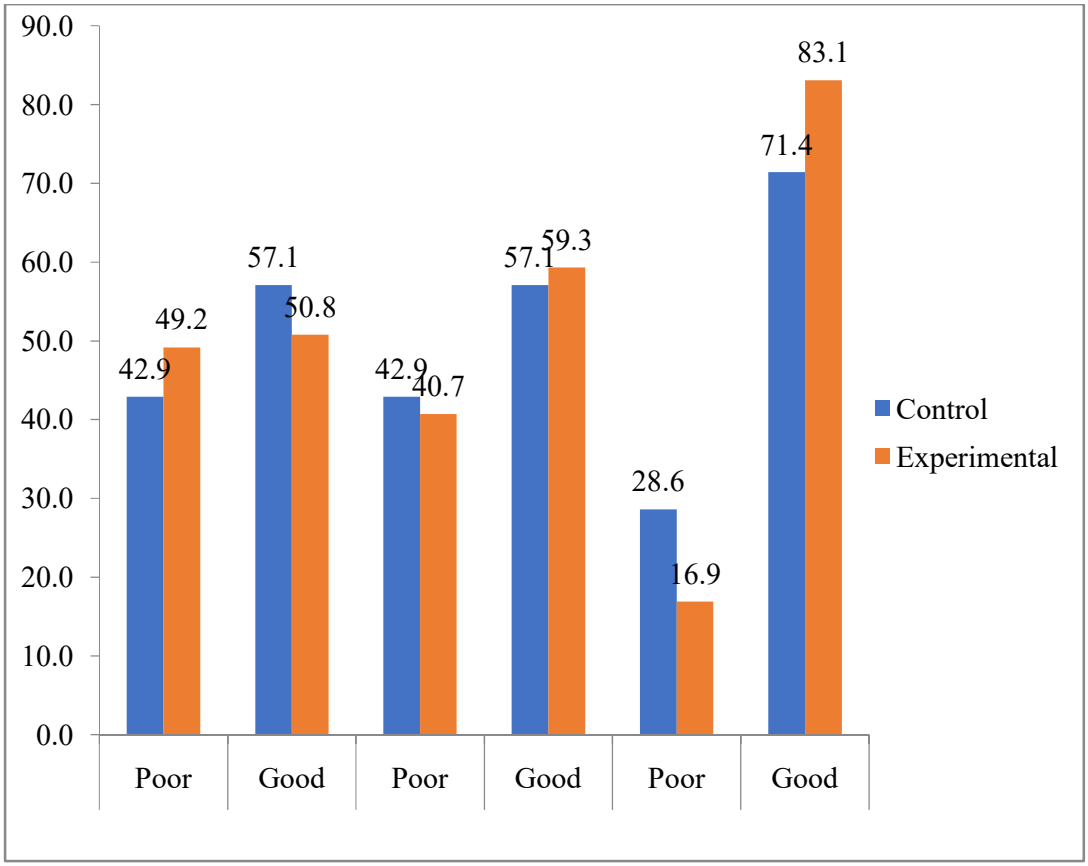

Figure 4.4: Level of Health Deviation Self-Care of Participants of Pre and Post intervention

Activity of Daily Living Practice of Participants

The frequency distribution of responses for activity of daily living (ADL) practices of participants living with SCD is presented in Table 4.9 to Table 4.11 at baseline, 12th and 24th weeks respectively. In experimental group at baseline, 50.8% did not bath themselves daily and 49.2% equally did not wash mouth on daily basis while in the control group 42.9% and 42.9% did not take their bath nor wash their mouths respectively on a daily basis. Participants who had correct responses as regards going to school themselves each day in experimental and control group at baseline were 35.6% vs 17.9%respectively. At 12th week percentage response of participants increases to 61.0% vs 33.9% which further increased to 64.4% in the experimental group while control group had 25.0%.

Table 4.9: Activity of Daily Living Practices of Participants at Baseline

Self-Care Practice	Control Group (n=56)				Experimental Group (n=59)			
	Never	Sometimes	Frequent	Very Frequent	Never	Sometimes	Frequent	Very Frequent
I take my bath by myself every day	42.9	5.4	0.0	51.8	50.8	18.6	1.7	28.8
I wash my mouth by myself every day	42.9	14.3	0.0	42.9	49.2	18.6	3.4	28.8
I cook my food by myself everyday	57.1	19.6	0.0	23.2	66.1	18.6	1.7	13.6
I go to school/workplace by myself daily	55.4	26.8	0.0	17.9	59.3	3.4	1.7	35.6
I observe my siesta daily	50.0	19.6	0.0	30.4	59.3	13.6	1.7	25.4
I avoid participating in strenuous exercises daily	51.8	21.4	0.0	26.8	55.9	13.6	0.0	30.5
I avoid going late to my school/workplace daily.	50.0	25.0	0.0	25.0	57.6	10.2	0.0	32.2
I take time to rest when I am tired everyday	51.8	8.9	0.0	39.3	57.6	15.3	0.0	27.1
I use my drugs as prescribed by the physicians	57.1	5.4	0.0	37.5	54.2	1.7	0.0	44.1
I do not skip my drugs as prescribed	26.8	8.9	0.0	64.3	64.4	8.5	0.0	27.1

Table 4.10: Activity of Daily Living Practices of Participants at12th Week

Self-Care Practice	Control Group (n=56)				Experimental Group (n=59)			
	Never	Sometimes	Frequent	Very Frequent	Never	Sometimes	Frequent	Very Frequent
I take my bath by myself every day	23.2	8.9	0.0	67.9	25.4	1.7	0.0	72.9
I wash my mouth by myself every day	17.9	5.4	0.0	76.8	8.5	5.1	15.3	71.2
I cook my food by myself everyday	41.1	21.4	0.0	37.5	33.9	37.3	0.0	28.8
I go to school/workplace by myself daily	33.9	32.1	0.0	33.9	16.9	6.8	15.3	61.0
I observe my siesta daily	32.1	21.4	0.0	46.4	33.9	25.4	1.7	39.0
I avoid participating in strenuous exercises daily	23.2	44.6	0.0	32.1	20.3	35.6	1.7	42.2
I avoid going late to my school/workplace daily.	32.1	12.5	0.0	55.4	33.9	15.3	0.0	50.8
I take time to rest when I am tired everyday	28.6	16.1	0.0	55.4	16.9	15.3	15.3	52.5
I use my drugs as prescribed by the physicians	39.3	8.9	0.0	51.8	10.2	20.3	1.7	67.8
I do not skip my drugs as prescribed	53.6	5.4	0.0	41.1	32.2	15.3	0.0	52.5

Table 4.11: Activity of Daily Living Practices of Participants at 24th Week

Self-Care Practice	Control Group (n=56)				Experimental Group (n=59)			
	Never	Sometimes	Frequent	Very Frequent	Never	Sometimes	Frequent	Very Frequent
	%	%	%	%	%	%	%	%
I take my bath by myself every day	26.8	3.6	0.0	69.6	6.8	6.8	11.9	74.6
I wash my mouth by myself every day	33.9	5.4	0.0	60.7	3.4	5.1	18.6	72.9
I cook my food by myself everyday	41.1	21.4	0.0	37.5	11.9	27.1	20.3	40.7
I go to school/workplace by myself daily	55.4	19.6	0.0	25.0	5.1	22.0	8.5	64.4
I observe my siesta daily	41.1	39.3	0.0	19.6	10.2	20.3	18.6	50.8
I avoid participating in strenuous exercises daily	44.6	23.2	0.0	32.1	10.2	23.7	18.6	47.5
I avoid going late to my school/workplace daily.	51.8	19.6	0.0	28.6	15.3	28.8	1.7	54.2
I take time to rest when I am tired everyday	39.3	33.9	0.0	26.8	15.3	10.2	15.3	59.3
I use my drugs as prescribed by the physicians	48.2	3.6	0.0	48.2	10.2	5.1	15.3	69.5
I do not skip my drugs as prescribed	44.6	5.4	0.0	50.0	18.6	30.5	0	50.8

Level of Activity of Daily Living Practices among Participants

The responses of participants as regards activity of daily living practice were obtained and they were graded. From the result in figure 4.5,The result showed that percentage of participants in the experimental group that had good self-care practice as regards daily living activities significantly increased from 47.5% at baseline to 57.6% at 12th week and 62.7% at 24th week. However, adolescents in the control group had (57.1.0%) level of practice as regards daily living activities at baseline, 12th week and 24th week across the study period.

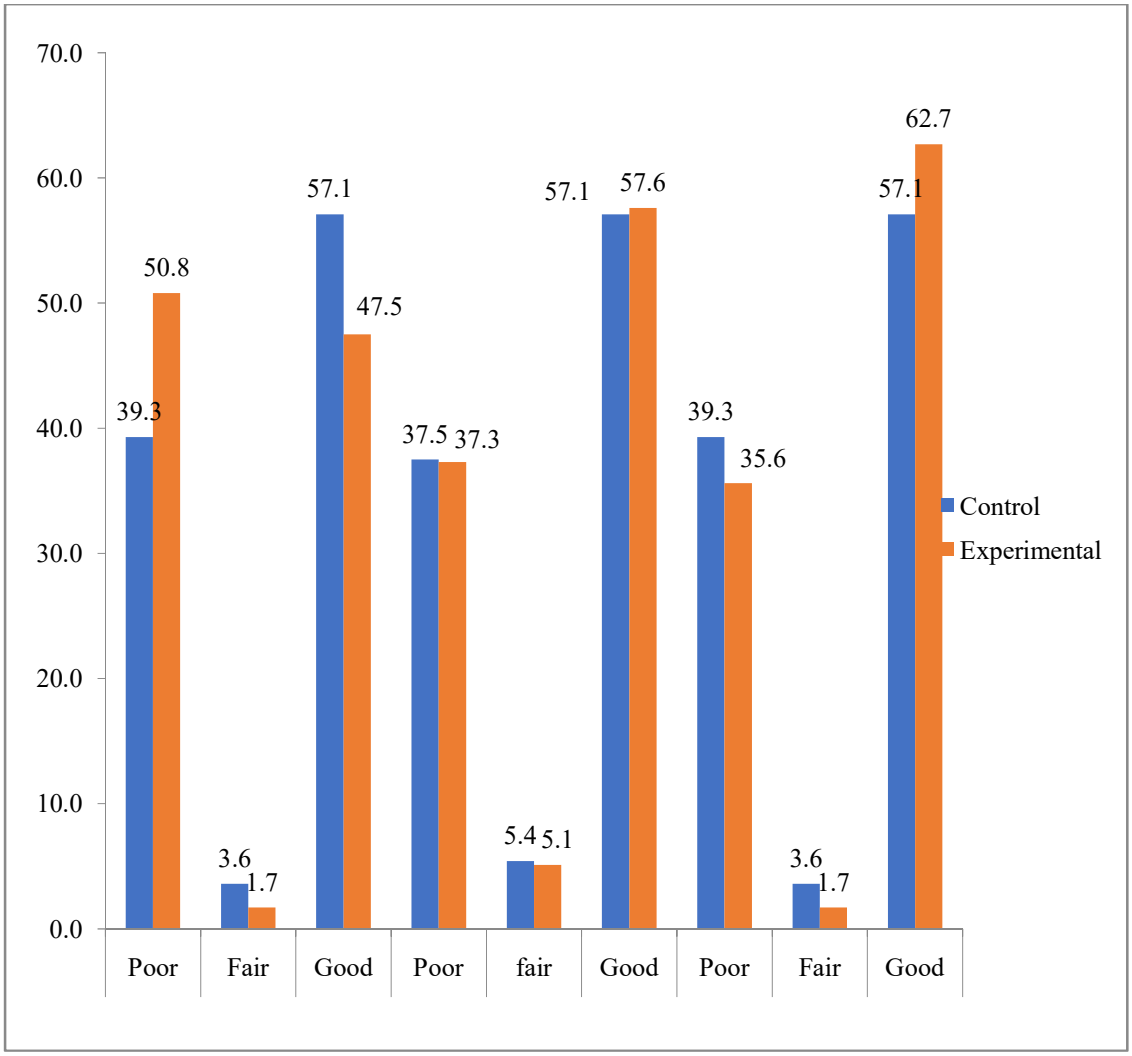

Figure 4.5: Level of Activity of Daily Living Practices of Participants Pre and Post intervention

Other Activity of Daily Living Practices Adopted by Participants at Baseline

Further result for daily living activitiesshowedpercentage response of the participants on adopted self-care practices when faced with SCD crises. In response to questions on the steps taken to prevent diseases and exposure to infections as SCD adolescents was presented in figure 4.6, 32.9% of participants in the experimental group adopted proper covering of body as a means of preventing diseases andexposure to infections while 20.5% use prescribed medications andadequate rest. In the control group, participants responded that they also, use prescribed medication andadequate rest as the major means of preventing the diseaseand from being exposed to infections.

The result presented in figure 4.7 showed the strategies adopted by both the participants and those who care for themin the experimental and control groups in coping with pain during crises. In the experimental group, 31.5% indicated that the major action they took in relieving pain during crises was the use of prescribed medication, 21.9% drink a lot of water with hot water massage and rest, while 19.2% used prescribed medication and drank plenty of water. In the control group, 48.2% used prescribed medications to relieve pain during crises, and 19.6% ensured regular intake of water, hot water massage and rest to relieve pain. Also, result in figure 4.8 showed percentage responses of participants stating who takes responsibility (who gives care) during crises. In the experimental group, result revealed that 30.1% of participants' parents care for them while mothers cared for 28.6% in the control group.

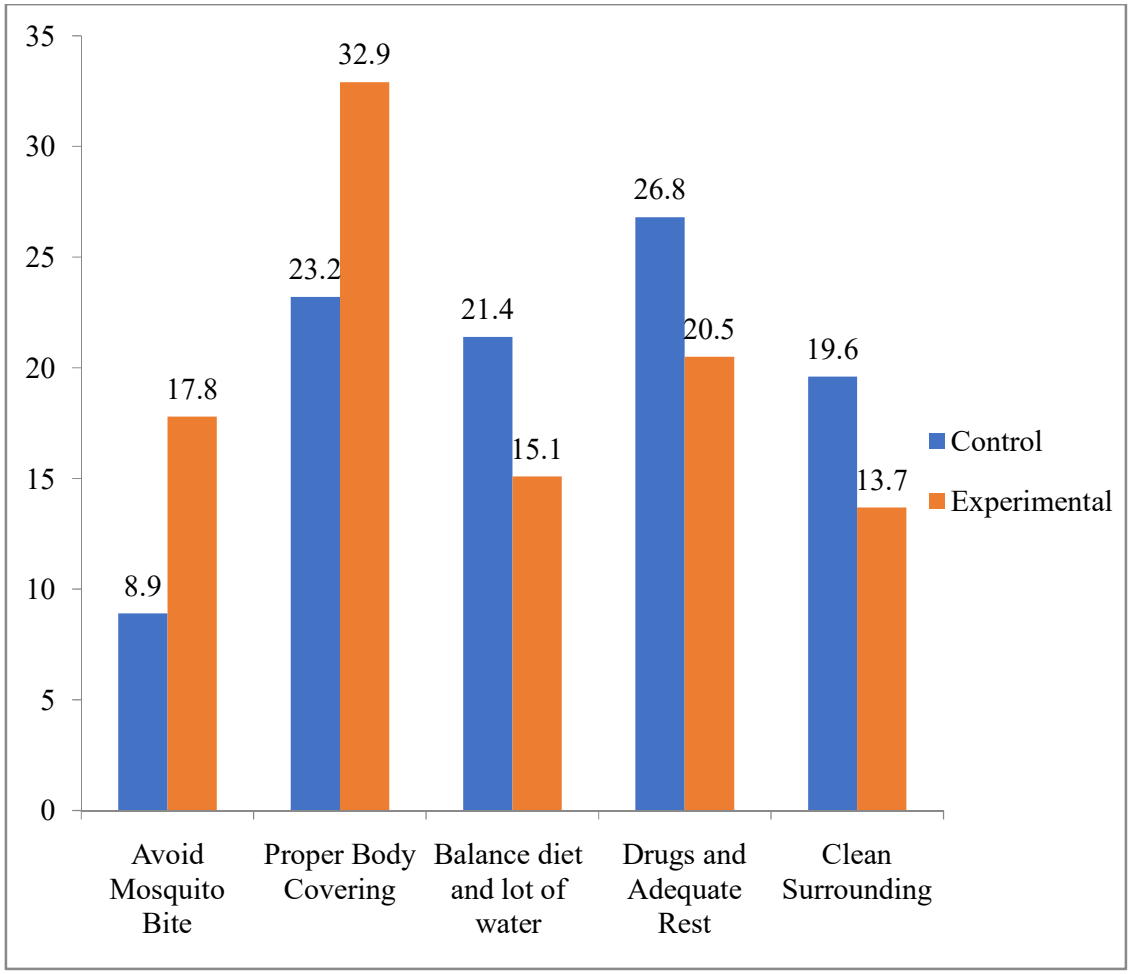

Figure 4.6: Actions towards Prevention of Infection by participants

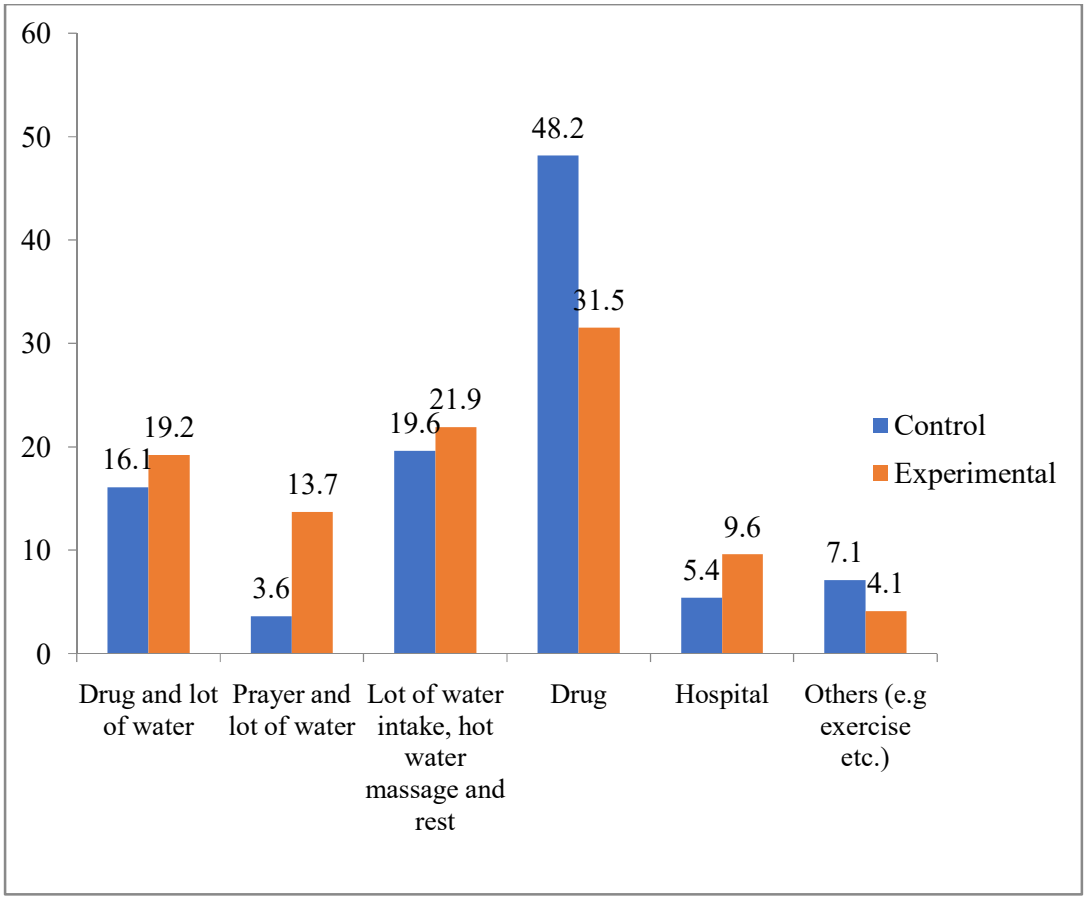

Figure 4.7: Daily Living Actions towards Pain Relieve by Participants

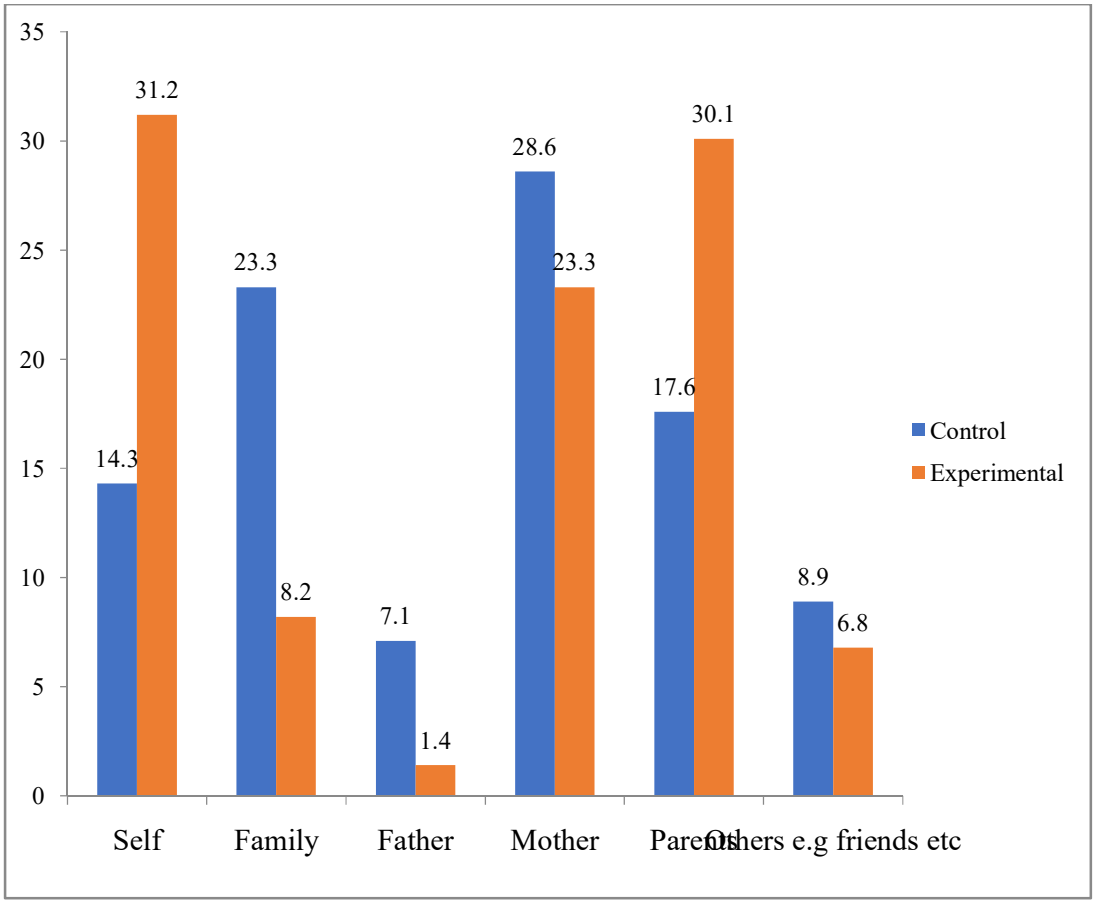

Figure 4.8: Participants Caregiver during Crisis at Baseline

Drugs used in Prevention and Management of Pain

The medication often used among participants of both groups when managing and preventing painful crises include folic acid, diclofenac, paludrine and jobelyn. Other medication includes analgine, astimine combasunate, and paracetamol, table 4.12 shows the details.

Table 4.12: Drugs often used in Prevention and Management of Pain among Participants

	Control Group (n=56) Frequency (%)	Experimental Group (n=59) Frequency (%)
Folic Acid	45(80.4)	50(84.7)
Diclofenac	44(78.6)	47(79.7)
Jobelyn	40(71.4)	38(64.4)
Paludrine	38(67.9)	39(67.2)
Analgine	16(28.6)	10(16.9)
Astimine	20(35.7)	11(18.6)
Combisunate	8(14.3)	10(16.9)
Paracetamol	21(37.5)	15(25.4)
Others	5(8.9)	15(25.4)

Pain Coping Ability of Participants

The result of pain coping ability of participants in experimental and control group is shown in table 4.13, 4.14 and 4.15 at baseline, 12th week and 24th weeks respectively. The result showed that 66.1% versus 35.7% of the participants in experimental and control group never asked questions about pain. However, at 12th and 24th weeks percentage response of participants who never asked questions about pain reduced to (3.4%) in experimental group. This impliesthat self-care education has improved the knowledge and confidence of adolescents todiscuss pain whenever it is experienced.

Also, none of the participants in experimental group have searched for pain relieving measures at base line while in the control group 8.9% of the participants have searched for measures of pain relief. At 12th and 24th weeks, participant responses increased to (49.2% and 61%) in experimental group while responses of participants in the control group decreased to 7.1%, which might be due to lack of information as regards measures of pain relief.

Table 4.13: Pain Coping Abilities of Participants at Baseline

Pain Coping items	Control Group (n=56)				Experimental Group (n=59)			
	Never	**Hardly Ever**	**Some-times**	**Often**	**Never**	**Hardly Ever**	**Some-times**	**Often**
	%	%	%	%	%	%	%	%
Inquire about your pain	35.7	57.1	7.1	0.0	66.1	32.2	1.7	0.0
Pay attention to the pain to ensure pain is improving	7.1	46.4	46.4	0.0	47.5	47.5	5.1	0.0
Share pain experience with a friend	14.3	58.9	26.8	0.0	57.8	40.7	1.7	0.0
Nervousness of not always having pain	53.6	17.9	8.9	19.6	37.3	40.7	22.0	0.0
Get explanation from care providers about SCD pain	42.9	48.2	8.9	0.0	47.5	42.4	10.2	0.0
Search for pain relieving measures	35.7	55.4	8.9	0.0	59.3	40.7	0.0	0.0
Discuss your pain with a friend	58.9	39.3	1.8	0.0	20.3	72.9	6.8	0.0
Do not engage in uncooperative actions while in pain	64.3	25.0	5.4	5.4	20.3	47.5	27.1	5.1
Get materials on pain management	33.9	55.4	7.1	3.6	45.8	52.5	1.7	0.0
Ponder on various methods of managing pain	50.0	41.1	8.9	0.0	25.4	62.7	11.9	0.0
Do something I enjoy	16.1	39.3	44.6	0.0	50.8	45.8	3.4	0.0
Try to forget it	39.3	42.9	17.9	0.0	59.3	37.3	3.4	0.0
Believe in other measures of helping yourself	64.3	23.2	8.9	3.6	20.3	69.5	10.2	0.0
Understand your body mechanism	48.2	44.6	7.1	0.0	49.2	42.4	8.5	0.0
Believe all will be well	67.9	23.2	8.9	0.0	54.2	44.1	1.7	0.0
Control your temper outburst while in pain	55.4	3.6	3.6	37.5	40.7	16.9	35.6	6.8
Explore various method of pain management and utilise the most suitable method	39.3	50.0	10.7	0.0	35.6	55.9	8.5	0.0
Believe you are capable of controlling situations as they occur	26.8	48.2	25.0	0.0	45.8	42.4	11.9	0.0
Do not curse or swear aloud	5.4	8.9	16.1	69.6	37.3	20.3	23.7	18.6
Do not worry much about the pain	44.6	44.6	8.9	1.8	20.3	50.8	28.8	0.0

Table 4.14: Pain Coping Ability of Participants at 12th Week

Pain Coping items	Control Group (n=56)				Experimental Group (n=59)			
	Never	**Hardly Ever**	**Some-times**	**Often**	**Never**	**Hardly Ever**	**Some-times**	**Often**
	%	%	%	%	%	%	%	%
Inquire about your pain	17.9	53.6	28.6	0.0	3.4	49.2	44.1	3.4
Pay attention to the pain to ensure pain is improving	26.8	50.0	23.2	0.0	1.7	54.2	39.0	5.1
Share pain experience with a friend.	28.6	41.1	30.4	0.0	1.7	57.6	39.0	1.7
Nervousness of not always having pain	41.1	23.2	25.0	10.7	0.0	27.1	54.2	18.6
Get explanation from care providers about SCD pain	25.0	46.4	28.6	0.0	0.0	47.5	27.1	25.4
Search for pain relieving measures	37.5	55.4	7.1	0.0	1.7	49.2	49.2	0.0
Discuss your pain with a friend	23.2	67.9	8.9	0.0	0.0	44.1	54.2	1.7
Do not engage in uncooperative actions while in pain	53.6	8.9	28.6	8.9	0.0	47.5	35.5	16.9
Get materials on pain management	42.9	48.2	8.9	0.0	0.0	49.2	33.9	16.9
Ponder on various methods of managing pain	30.4	44.6	25.0	0.0	1.7	57.6	33.9	6.8
Do something I enjoy	19.6	48.2	32.1	0.0	0.0	37.3	61.0	1.7
Try to forget it	44.6	48.2	7.1	0.0	0.0	45.8	54.2	0.0
Believe in other measures of helping yourself	50.0	17.9	5.4	26.8	00	33.9	50.8	15.3
Understand your body mechanism	33.9	57.1	8.9	0.0	0.0	45.8	47.5	6.8
Believe all will be well	14.3	50.0	35.7	0.0	0.0	40.7	57.6	1.7
Control your temper outburst while in pain	44.6	12.5	16.1	19.6	0.0	37.3	47.5	15.3
Explore various method of pain management and utilise the most suitable method	37.5	55.4	7.1	0.0	3.4	57.6	33.9	5.1
Believe you are capable of controlling situations as they occur	10.7	44.6	44.6	0.0	0.0	45.8	54.2	0.0
Do not curse or swear out loud	16.1	7.1	46.4	30.4	0.0	13.6	30.5	55.9
Do not worry much about the pain	10.7	17.9	10.7	60.7	0.0	15.3	35.6	49.2

Table 4.15: Pain Coping Ability of Participants at 24th Week

Pain Coping items	**Control Group (n=56)**				**Experimental Group (n=59)**			
	Never	**Hardly Ever**	**Some-times**	**Often**	**Never**	**Hardly Ever**	**Some-times**	**Often**
	%	%	%	%	%	%	%	%
Inquire about your pain	21.4	37.5	41.1	0.0	3.4	61.0	35.6	0.0
Pay attention to the pain to ensure pain is improving	30.4	41.1	28.6	0.0	8.5	67.8	22.0	1.7
Share pain experience with a friend.	10.7	42.9	46.4	0.0	10.2	52.5	37.3	0.0
Nervousness of not always having pain	42.9	14.3	7.1	35.7	1.7	37.3	47.5	13.6
Get explanation from care providers about SCD pain	10.7	53.6	35.7	0.0	8.5	50.8	40.7	0.0
Search for pain relieving measures	46.4	44.6	8.9	0.0	0.0	39.0	47.5	13.6
Discuss your pain with a friend	7.1	73.2	19.6	0.0	1.7	55.9	40.7	1.7
Do not engage in uncooperative actions while in pain	42.9	25.0	10.7	21.4	0.0	33. 9	52.5	13.6
Get materials on pain management	44.6	46.4	8.9	0.0	0.0	59.3	40.7	0.0
Ponder on various methods of managing pain	23.2	35.7	41.1	0.0	0.0	69.5	30.5	0.0
Do something I enjoy	16.1	37.5	46.4	0.0	0.0	52.5	39.0	8.5
Try to forget it	37.5	50.0	12.5	0.0	0.0	37.3	49.2	13.6
Believe in other measures of helping yourself	55.4	17.9	12.5	14.3	5.1	28.8	52.5	13.6
Understand your body mechanism	10.7	67.9	21.4	0.0	0.0	47.5	49.2	3.4
Believe all will be well	46.4	44.6	8.9	0.0	8.5	52.5	39.0	0.0
Control your temper outburst while in pain	53.6	12.5	7.1	26.8	6.8	40.7	37.3	15.3
Explore various method of pain management and utilise the most suitable method	37.5	53.6	8.9	0.0	0.0	52.5	42.4	5.1
Believe you are capable of controlling situations as they occur	25.0	48.2	26.8	0.0	0.0	11.9	66.1	22.0
Do not curse or swear out loud	33.9	12.5	12.5	41.1	0.0	22.0	15.3	62.7
Do not worry much about the pain	12.5	17.9	14.3	55.4	3.4	35.6	20.3	40.7

Level of Pain Coping Ability among Participants Living with SCD

The categorisation of participants scores as regards pain coping ability is shown in figure 4.9. The result showed that participants in experimental and control group had poor pain coping ability at baseline. At12th and 24th weeks, percentage score of participants with good pain coping ability increased to 52.5% and 55.9% respectively in experimental group whilethe score in the control group increased from 35.7% to 46.4% at 12th and 24th weeks respectively.

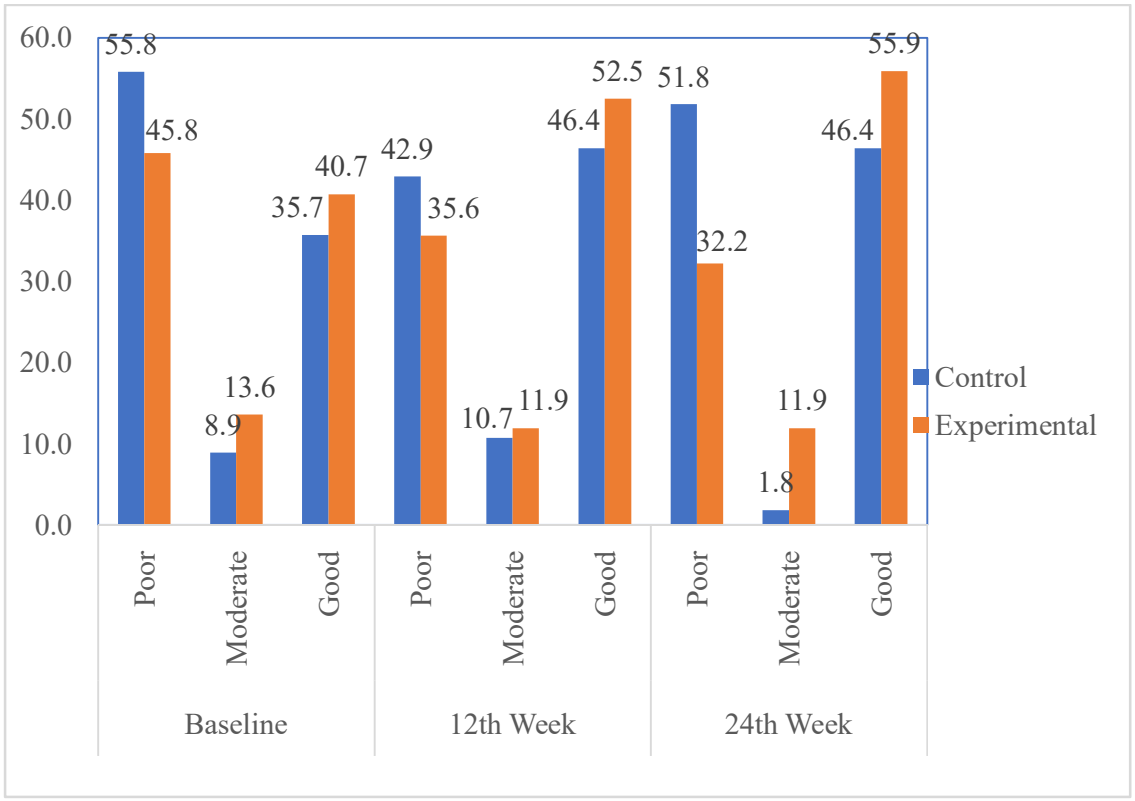

Figure 4.9: Level of Pain Coping Ability of Participants Pre and Post Intervention

4.4 Self-Care Ability of Participants Living with SCD

Theself -care abilityof participants living with SCD were categorised and presented in figure 4.10. The result showed that participants had similar self-care ability score (45.8% versus 44.6%). At 12th and 24th weeks,self-care ability of participantssignificantly increased to57.6% and 66.1% in experimental group while control group participants maintained the baseline scores across the study period.

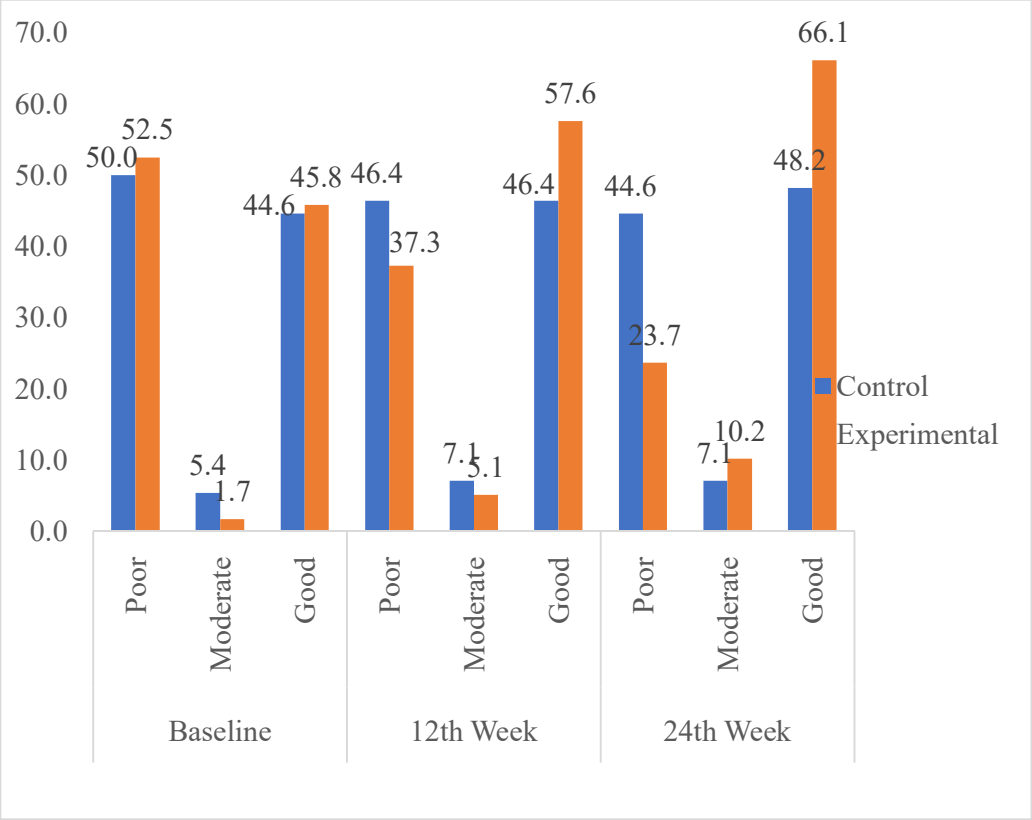

Figure 4:10: Self-care Ability Rating of Participants Living with SCD

4.5Quality of Life of Participants Living with SCD

The result of quality of life for the participants across the 3 levels of study is shown in Table 4.16, 4.17 and 4.18.At baseline,participants who have difficulty in class concentrationwere 32.2% versus 39.2% in experimental and control group respectively. At 12th and 24th weeks, percentage of participant who had difficulty in class concentration reduced to 15.3% and 3.4% in experimental group. However, percentage of participants who had difficulty in class concentration in control group increased to 46.5% and 44.7%at 12th week and 24th weeks.

Result of participants who could not participate in regular activities in experimental and control groups were 50.8% versus 51.8% at baseline. At 12th and 24th weeks, percentage reduced to 44.1% and 20.3% respectively in the experimental group.

Table 4.16: Quality of Life of Participants at Base Line

During the past one month	Control Group (n=56)				Experimental Group (n=59)			
	Never	Sometimes	Frequently	Very Frequently	Never	Sometimes	Frequently	Very Frequently
	%	%	%	%	%	%	%	%
I have difficulty of concentrating in class	42.9	17.9	19.6	19.6	25.4	42.4	22.0	10.2
Controlling my pain is almost a challenge	35.7	17.9	19.6	26.8	47.5	13.6	30.5	8.5
I could not participate in regular activities with friends	26.8	21.4	21.4	30.4	33.9	15.3	27.1	23.7
I don't use all drugs given to me	25.0	23.2	17.9	33.9	32.2	18.6	25.4	23.7
I have little vitality	42.9	8.9	14.3	33.9	42.4	11.9	25.4	20.3
I can't play as desired	16.1	30.4	32.1	21.4	35.6	27.1	23.7	13.6
I hardly spend time with friends	19.6	25.0	21.4	33.9	32.2	18.6	30.5	18.6
I sensed a dull, soft pain	44.6	16.1	0	39.3	55.9	8.5	1.7	33.9
I was disturbed	55.4	12.5	5.4	26.8	59.3	5.1	0	35.6
I am not happy with myself	37.5	28.6	16.1	17.9	39.0	20.3	22.0	18.6
My teachers cared for me singly from peers	55.4	7.1	16.1	21.4	45.8	15.3	13.6	25.4
Other kids harassed me	35.7	23.2	21.4	19.6	42.4	20.3	18.6	18.6
I believe I am actually unequal with my age group.	26.8	10.7	33.9	28.6	40.7	10.2	35.6	13.6
I was not able to cope with my school work	33.9	28.6	23.2	14.3	28.8	35.6	20.3	15.3
My friends pressurised me	32.1	17.9	21.4	28.6	42.4	15.3	32.2	10.2

Table 4.17: Quality of Life of Participants at 12th Week

During the past one month	Control Group (n=56)				Experimental Group (n=59)			
	Never	Sometimes	Frequently	Very Frequently	Never	Sometimes	Frequently	Very Frequently
	%	%	%	%	%	%	%	%
I have difficulty of concentrating in class	21.4	32.1	41.1	5.4	33.9	50.8	11.9	3.4
Controlling my pain is almost a challenge	35.7	33.9	1.8	28.6	27.1	23.7	40.7	8.5
I could not participate in regular activities with friends	16.1	44.6	12.5	26.8	23.7	32.2	42.4	1.7
I don't use all drugs given to me	12.5	42.9	14.3	30.4	44.1	42.4	11.9	1.7
I have little vitality	37.5	28.6	12.5	21.4	62.7	22.0	6.8	8.5
I can't play as desired	19.6	51.8	10.7	17.9	28.8	37.3	37.3	6.8
I hardly spend time with friends	25.0	42.9	10.7	21.4	55.9	35.6	6.8	1.7
I sensed a dull, soft pain	28.6	2.9	10.7	17.9	64.4	15.3	15.3	5.1
I was disturbed	19.6	44.6	25.0	10.7	44.1	6.8	33.9	15.3
I am not happy with myself	179.	32.1	32.1	17.9	32.2	42.4	20.3	5.1
My teachers cared for me singly from peers	21.4	39.3	19.6	19.6	67.8	18.6	10.2	3.4
Other kids harassed me	37.5	35.7	12.5	14.3	57.6	23.7	16.9	1.7
I believe I am actually unequal with my age group.	17.9	33.9	26.8	21.4	37.3	37.3	20.3	5.1
I was not able to cope my school work	51.8	19.6	10.7	17.9	71.2	15.3	11.9	1.7
My friends pressurized me	44.6	28.6	3.6	23.2	72.9	27.1	0.0	0.0

Table 4.18: Quality of Life of Participants at 24th Week

During the past one month	Control Group (n=56)				Experimental Group (n=59)			
	Never	Sometimes	Frequently	Very Frequently	Never	Sometimes	Frequently	Very Frequently
	%	%	%	%	%	%	%	%
I have difficulty of concentrating in class	16.1	39.3	42.9	1.8	45.8	50.8	1.7	1.7
Controlling my pain is almost a challenge	26.8	28.5	23.2	21.4	44.1	49.2	6.8	0.0
I could not participate in regular activities with friends	3.6	33.9	32.1	30.4	30.5	49.2	18.6	1.7
I don't use all drugs given to me	5.4	33.9	23.2	37.5	16.9	54.2	18.6	10.2
I have little vitality	14.3	26.8	26.8	32.1	71.2	25.4	1.7	1.7
I can't play as desired	8.9	60.7	12.5	17.9	35.6	52.5	6.8	5.1
I hardly spend time with friends	10.7	44.6	3.6	41.1	28.8	42.4	25.4	3.4
I sensed a dull, soft pain	23.2	0.0	58.9	17.9	64.4	27.1	5.1	3.4
I was disturbed	30.4	41.1	10.7	17.9	74.6	13.6	8.5	3.4
I am not happy with myself	10.7	28.6	25.0	35.7	33.9	32.2	20.3	13.6
My teachers cared for me singly from peers	19.6	37.5	12.5	30.4	57.6	18.6	11.9	11.9
Other kids harassed me	33.9	41.1	10.7	14.3	59.3	23.7	6.8	10.2
I believe I am actually unequal with my age group.	25.0	30.4	21.4	23.2	61.0	32.2	5.1	1.7
I was not able to cope with my school work	23.2	30.4	30.4	16.1	59.3	25.4	5.1	10.2
My friends pressurised me	41.1	23.2	12.5	23.2	66.1	16.9	3.4	13.6

Level of Quality of Life of the Participants in Control and Experimental Groups

The result of QoL among participants in both groups across baseline, 12th week and 24th week is presented in figure 4.11. The result showed that participants withgood QoL in the experimental and control group were 49.2% vs. 44.6% at baseline. The proportion of participants with good QoL in the experimental group significantly increase at 12th week and 24th week (54.2% and 62.7%) respectively.

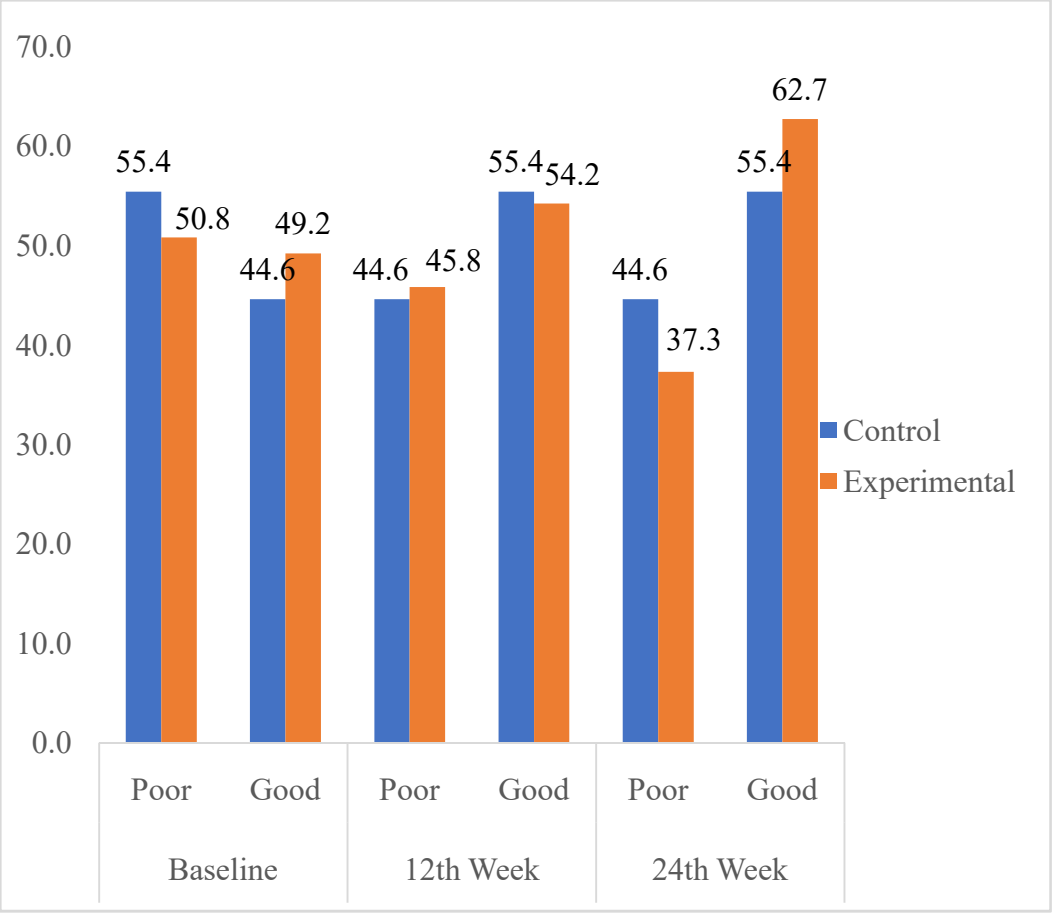

Figure 4.11: Level of Quality of Life among Participants Pre and Post Intervention

The Quality of Life Indexes in the EG and CG at Base line

The open-ended responses were used to further assess participants quality of life. The result in figure 4.12 further showed that 17.9% of the participant in control group had financial and relationship challenges while participants in the experimental group (17.8% and 13.7%) equally experienced relationship and financial challenges.

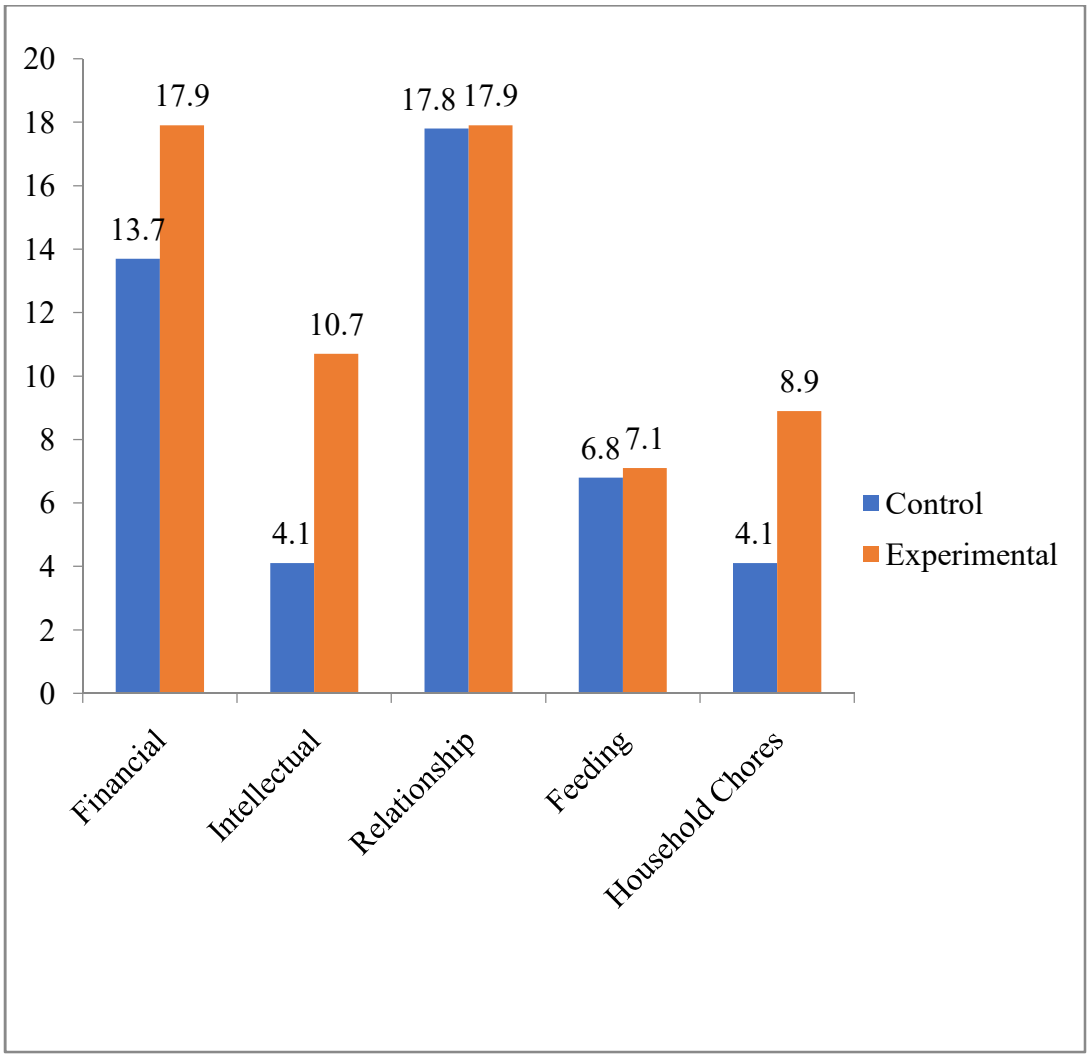

Figure 4.12: Challenges Experienced among Participants at Baseline

4.6 Hypothesis Testing

Hypothesis 1: There is no statistically significant difference in knowledge of SCD between adolescents in the experimental and control groups.

Thecontrol group participants had higher mean (M = 22.96, SD= 3.08) than the experimental group participants (M = 20.93, SD= 3.22) at baseline and the difference in mean was statistically significant (t (113) = 3.42, p = 0.001). Also, at the 12th and 24th weeks, the participants in experimental group had statistically significant higher mean compared to control group $t(113)$ = 12.30, p = 0.001 and $t(113)$ = 14.25, p = 0.001 respectively. Therefore, the null hypothesis was **REJECTED**.

Furthermore, repeated measure ANOVA was used for within group difference test. In the experimental group, there was an improvement in the mean score (df =2; p =0.001). This showed that self-care educational intervention had significantly increased the SCD knowledge among the participants in the intervention group.

Table 4.19: Repeated Measures of ANOVAon SCD Knowledge of Participants

	Control (n=56) Mean(SD)	Experimental (n=59) Mean(SD)	t-test	df	*p*-value
Baseline	22.96(3.08)	20.93(3.22)	3.42	113	0.001
12th Week	24.43(3.26)	32.00(3.33)	12.30	113	0.001
24th Week	25.20(4.78)	35.93(3.18)	14.25	113	0.001
df	2	2			
p -value	0.001	0.001			

Hypothesis 2: There is no statistically significant difference in the knowledge of universal self-care of participants in both experimental and control groups.

At baseline (P1), there was no significant difference between the means (t(113)=0.594, p=0.554) of the control and experimental. However, the mean comparisons of 12th and 24th weeks in the two groups (control and experimental) were significantly different with lower mean score in the CG in comparison to the EG at both 12th and 24th weeks *(*t(113) = 6.00, p = 0.001 and t(113) = 7.38, p = 0.001 respectively). Thus, the null hypothesis was **REJECTED** at 12th and 24th weeks.

Furthermore, repeated measure ANOVA was used to ascertain the difference in mean within the groups (control and experimental). Only participants in experimental group had a significant difference in the mean score (df =2; p =0.001).

Table 4.20: Repeated Measures of ANOVAon SCD Knowledge of Universal Self-Care Requisite among Participants

	Control Group (n=56) Mean(SD)	**Experimental Group (n=59) Mean(SD)**	T	Df	*p*-value
Baseline	5.21(2.02)	4.98(2.15)	0.594	113	0.554
12th Week	5.23(2.46)	7.59(1.70)	6.00	113	0.001
24th Week	5.39(2.02)	7.97(1.71)	7.38	113	0.001
df	2	2			
F-ratio	0.12	47.46			
p-value	0.89	0.01			

Hypothesis 3: There is no significant difference in the self-care ability of participants in experimental and control groups.

The result indicated that there was statistically significant mean difference between self-care ability of the two samples (control and experimental groups) across the three phases of the study. At baseline (t (113) = 2.58, p = 0.011, two tailed), at 12th week (t (113) = 12.91, p = 0.001, two tailed) and at 24th week (t (113) = 12.28, p = 0.001, two tailed). There was higher mean in the control compared to experimental pre-test while at post-tests, the EG had higher mean scores than CG. Hence, the null hypothesis was **REJECTED** postintervention.

Also, repeated measure ANOVA was used to test score difference within the groups (experimental and control). The mean score for the participants ability to care for self in the experimental group significantly increased post-intervention from the baseline (df=2; p=0.001). Also, there wasa significant increase among the control group (df=2; p=0.001) across the 12th and 24th week as shown on table 4.21

Table 4.21: Repeated Measures of ANOVA on Self-Care Ability of Participants Living with SCD

	CG (n=56) Mean(SD)	EG (n=59) Mean(SD)	t-test	Df	*p*-value
Baseline	63.48(9.45)	58.31(11.84)	2.58	113	0.011
12th Week	68.01(7.90)	88.14(8.76)	12.91	113	0.001
24th Week	70.04(9.43)	88.97(6.97)	12.28	113	0.001
df	2	2			
F-ratio	10.661	214.57			
p value	0.01	0.01			

Hypothesis 4: There is no significant difference in the quality of life of participants living with SCD in the EG and CG

There was no statistically significant difference between the control and experimental groups at baseline (t (113) = 1.58, p= 0.111) as seen in Table 4.22. However, at 12th and 24th weeks, there was statistically significant score difference between the two groups (t (113) = 5.52, p = 0.001 and (t (113) = 9.45, p = 0.001, respectively). Therefore, the null hypothesis was **REJECTED** post intervention.

In addition, repeated measure ANOVA was used to test the difference within groups at the three phases of the study. There was statistically significant difference within the three phases of the study in the experimental group (df=2; p=0.001) while in the control group there was no significant difference across 12th and 24th weeks. (df =2; p=0.151).

Table 4.22: Repeated Measures of ANOVA Quality of Life of Participants Living with SCD

	CG (n=56) Mean(SD)	EG (n=59) Mean(SD)	t –test	df	*p-value*
Baseline	39.54(7.63)	41.95(8.66)	1.58	113	0.111
12th Week	40.73(8.01)	48.08(6.20)	5.52	113	0.001*
24th Week	37.83(7.30)	49.20(5.51)	9.45	113	0.001*
df	2	2			
F-ratio	1.91	23.78			
p value	0.151	0.001			

CHAPTER FIVE

DISCUSSION OF FINDINGS,CONCLUSION AND RECOMMENDATIONS

This chapter presents findings of the study in line with objectives of study. Four objectives were assessed and each of these objectives was discussedwith the existing literature. The section also discusses the limitation of study, implication of findings to community health nursing practice, contribution to knowledge, suggestions for furtherconclusion and recommendations.

5.1Demographic Profile of Participants.

Findings of study showed that there is no difference in gender of participants but there was a marginal difference in their mean age in both groups.This finding is similar to findings of Olakunle *et al.,* (2013) which assessed the knowledge and attitude of Secondary School students in Jos. Amr et al., (2011) also reported similar findings among participantsin Saudi Arabia in a study that assessed health related quality of life of adolescents with sickle cell disease.

The findings of this study showed that participants' in experimental and control groups have siblings who are equally living with SCD. The finding confirmed that more than one child can be a client; while others have the sickle cell traits which is similar to findings of Bhagat, *et al.,* (2014) which reported that more than one sibling was having SCD. Having two or more children with SCD could be traumatic and overwhelming for parents and caregivers: thus, the need for self-care education as a major nursing intervention for clients and for all care providers. Sansom-Daly et al., 2012 and Grove *et al.,* (2014) also affirmed that SCD had an impact on an adolescent's psychosocial well-being and at the same time, placed significant stress on family's emotion, finance, and physical activities. Thus, self-care education is germane to building the strength and capacity of family members while caring for SCD client.

Furthermore, the finding of this study revealed that the use of medication was mostly the responsibility of the parents or guardians. This is consistent with reports from other studies, where the responsibility and burden of medication use by adolescents with SCD was hinged on parents and guardians (Logan et al., 2002; Kayle *et al.,* 2016). A systematic review showed that there was moderate medication adherence in children with SCD (Walsh et al., 2014). Kayle *et*

al., (2016) revealed that shifting medication responsibility from parents to SCD adolescents exerted adaptive challenges for both.

The average number of SCD-related crises was between 1 and 2 per year among adolescents. This is similar to a study that assessed the healthcare utilization of adolescents living with sickle cell disease (Julie et. al., 2019). However, the frequency, severity and duration of SCD crises vary considerably in literature; some studies reported a range of 5 and 7 days (Ballas *et al.,*, 2005).

5.2 Knowledge of Sickle Cell Disease among Adolescents.

Findings from this study showed that basic knowledge of SCD among adolescents living with SCD was average at baseline. This corroborates the results of Abubakar *et al.,* (2010), in which larger percentage of participants had good understanding of sickle cell disease. However, existent findings are in contrast with findings from other studies within and outside the country that reported low level of SCD knowledge in general public (Olakunle *et al,* 2013). Furthermore, studies on knowledge about personal genotype among children with SCD and their parents having SCD were largely reflective of poor SCD knowledge (Ezenwosu *et al.,* 2015). Consequently, poor SCD knowledge in the general public and even among SCD clients have supported the World Health Organisation's reporton the Healthy People 2020 objectives as regards sickle cell resolution priority on increasing the proportion of individuals who are aware of their genotype (USDHHS 2013).

Furthermore, this study reported that Self-care Education had significant outcome on SCD knowledge across three time points (i.e. baseline, 12th and 24th week). These findings on SCD knowledge implied that improved knowledge was the strength in building adolescents' self-care abilities for enhanced quality of life. Similar studies also found that health education interventions had significant effect on SCD knowledge; specifically, the studies were conducted among adolescents living with SCD (Schwartz *et al.,* 2006; Barakat et al., 2010). Olatona *et al.,* (2012) reported a significant increase in the level of understanding and attitude towards sickle cell disease and screening uptake among corps members.

Guobadia (2015) in a study which assessed the effect of SCD education intervention among college students showed that having SCD education would improve students' knowledge. In

addition, a systematic review by Asnani *et al.,* (2016) detected the impact of educational interventions on enhancing patient knowledge of sickle cell disease and depression. The review concluded that the increase in patients' knowledge was sustained for a longer period. However, the findings of this study did not significantly differ in the SCD knowledge score of the control group across baseline, 12th and 24th weeks of the study while adolescents with SCD in the experimental group had greater improvement in SCD knowledge across weeks. It was implied that educational intervention was required to significantly modify SCD knowledge among adolescents living with SCD as shown in study findings, thus reinforced report of previous studies that education intervention could significantly improve SCD knowledge among persons living with SCD and in other populations (Lanzkron et al., 2013; Quinn et al., 2010; Yanni et al., 2009).

Generally, the universal self-care knowledge of adolescents was on the average in this study which is similar to findings ofprior studies which assessed the self-care knowledge and practices of persons having sickle cell disease (Matthie *et al., 2015,* Ahmadi*et al.,*2014). In line with the result of this research, Jaffer et al., (2009) also found low to moderate self-care knowledge among persons having SCD. However, Matthie (2013) suggested that a better understanding of self-care could help healthcare providers equip patients with the necessary resources and skills to participate in the management of their disease, especially for people without proper self-care in the home setting who usually have pain crises and subsequent hospitalisations. Furthermore, the study reported that self-care management was an adaptive strategy for persons with SCD in terms of building their capacity, such that they could have control and good coping strategy. This implies that self-care education is expedient in management of clients with SCD as apparent in present study that educational intervention significantly improved the universal self-care, across baseline, 12th and 24th weeks.

5.3Self-Care Ability of Adolescents living with SCD

This study investigated different aspect of self-care ability, in respect of developmental self-care, health-deviation self-care, activity of daily living practices and pain-coping strategies of adolescents were used to substantiate self-care ability of SCD adolescent. Generally, the developmental self-care findings significantly increased across weeks in experimental group

compared to the increase in findings of control group at 12th week which was not sustained at 24th While health deviation self-care findings of adolescents significantly increased across weeks in experimental group with a slight increase at 24th in the control group, the increase could be linked to familiarity of respondents to questionnaire over the study period.

Self-care education is vital in management of clients with SCD as educational intervention significantly improved the developmental self-care and health deviation self-care of SCD adolescents across baseline, 12th and 24th weeks in experimental group. Present findings corroborate Matthie *et al.,* (2015), who advocated development of informed intervention that might improve daily self-care behaviours among young adults with SCD.

Similar studies have shown that individuals with SCD can benefit from self-care interventions in the form of social support, SCD self-efficacy and access to education (Schulman-Green *et al.,*, 2012). As indicated in this study, adolescents in experimental group had good self-care practice compared to adolescents in control group this could be related to knowledge acquired from self-care educational intervention which had prepared adolescents for adoption of healthy lifestyle that seemed pragmatic in prevention and management of sickle cell disease. Also, Open-ended questionnaire approach was also used to obtain detailed information on self-care practices of adolescents living with SCD in the study population. Adolescents posited that using medication to relief pain, drinking a lot of water, hot water immersion/hot toweling massage and rest as the most common self-care practices each day. The finding of the study is consistent with Ahmadi *et al.,* (2015) submission, which documented home treatment as massage, hot shower, hot water bag, use of liquids, rest and cognitive / behavioural techniques as factors that helped clients to deal with pain. However, this finding is contrary to Brandow *et al.,* (2010) which stated that non-or-poor adherence to medications was common among children and adolescents living with SCD. Furthermore, non-or-poor adherence to the regimen reduces the effectiveness of medicines, puts patients at risk of serious complications and significantly increases healthcare costs (LeLeiko *et al.,* 2013). Therefore, self-care ability of adolescents with SCD depends on SCD knowledge, self-care requisite, daily living self-care practices, and their pain-coping strategies.

5.4 Pain Coping Strategies of Adolescents Living with SCD

In this study, pain-coping strategies of adolescents were generally poor as most of the participants in this study never engaged in the pain coping skills at baseline. These findings corroborate findings of other studies which found poor coping strategies among persons with SCD and further stressed that the coping strategies are important predictors of pain and adjustment (Anie and Green, 2015). Adzika*et al.,*(2017) reported prayers and other religious activities as coping strategy in which most participants had no clear ideas of how to deal with pain and their day-to-day challenges. Hildenbrand *et al.,* (2015) revealed that children who readily utilised coping strategies like self-calming statements and diverted attention had better pain coping, less health care utilisation and improved well-being, while children who endorsed negative statements exhibited: greater distress, pain severity and more health care utilisation.

Similarly, Sanders *et al.,* (2010) assessed pain coping and health care utilisation among individuals with sickle cell disease. Findings revealed that young people with SCD were more likely to cope if they ignore the pain or utilise heat massage, while other patients were likely to cope through hope and prayers which corroborate study findings. Furthermore, Gil (2001) reported increased inconsistent pain-coping efforts among SCD adolescents in their study.

From this study, within group comparison across baseline, 12th and 24th weeks in the intervention group showed that pain-coping improved significantly. This finding suggested that self-care educational intervention which focused on non-pharmacologic pain management strategy is pertinent to building self-care ability of adolescents living with SCD. This finding is consistent with reports of earlier researchers where educational intervention had been found to improve SCD pain-coping abilities of the sufferers. Gil *et al.,* (2000) found that training significantly improved coping skills among adults leaving with sickle cell disease. However, Anie and Green (2015) concluded in a systematic review that evidence of the effectiveness of psychological therapies in sickle cell disease was currently limited; therefore, a systematic review clearly identified the need for well-designed, adequately powered, multicenter randomised controlled trials to assess the effectiveness of specific sickle cell disease interventions.

Furthermore, study revealed that adolescent living with SCD who received the Self-care Education Intervention had significant improvement in their pain-coping abilities over the six

months of intervention. Literature has identified different methods often aimed at improving pain coping in SCD such as cognitive behavioural therapy, self-regulation strategies, behavioural change interventions, psychosocial treatments and educational programmes (Edwards and Edwards, 2010). However, literature is divided on the effect of educational interventions on pain coping in SCD. Some studies found cognitive coping training as a better intervention with significant effects on pain coping in SCD compared with health educational intervention (Schwartz *et al.*2007; McClellan*et al,* 2009). On the contrary, Barakat *et al.,* (2010) found that educational programme in SCD led to better coping, as participants were able to manage pain during crises.

Also, unrestricted approach was used to obtain detailed information on pain coping skills, prevention and management among adolescents with SCD in the study population. Participants' responses were drugs and lot of water; prayer and lot of water; lot of water intake, hot water massage and rest, drug, hospital, and exercise. In line with the report of this study, use of medication during crises in SCD was described as a common pattern in many studies (Sanders *et al.,*2010; Oliver-Carpenter *et al.,* 2011). Equally, hot water bath or immersion or use of hot towel is a common practice aimed at pain relief among SCD patients (Ahmadi *et al.,* 2015).

Although, most of the adolescents in this study did not report bathing with hot herbs or concussion, as reported by other researchers in other study settings.However, there are traditional beliefs that bathing with hot herbs helps to cure or relief sickle cell disease pain, this support finding of Ameh *et al.,*(2012) which confirmed utilisation of herbal therapy in management of clients with SCD, but did not verify importance of hot herbal bath and other traditional concussion in pain management thus the need for further study in adolescent's assertion. The Systemic review conducted by Paula *et al.,* (2010) concluded that children and adolescents who had chronic pain were likely to have fewer friends, might be lonely, could be bullied by their peers compared to children and adolescents without pain. Since the hallmark of SCD is pain;SCD adolescents require in-depth understanding of pharmacological and non-pharmacological pain management through self-care education.

5.5 Quality of Life of Adolescents Living with SCD.

Pre-intervention quality of life of the adolescents in this study was fair, as the score was 40.7 out of the total score of 60 thus yielding a percentage score of 67.9%. Study which assess life expectancy of persons having sickle cell disease, especially their overall well-being is emerging. McClish *et al.,* (2005) in a study which explored personal satisfaction among sickle cell patients found that the standard of living was generally poor. Another study carried out by Dale *et al.,*(2011) found that the overall well-being of children and adolescents living with sickle cell disease was lower in all domains evaluated when compared with healthy children.

Study findings showed that quality of life scores of the adolescents in the intervention group increased significantly across baseline, 12th and 24th week. In keeping with the need to improve quality of life in SCD, some scholars have recommended and implemented psychological intervention that borders on self-management method (Ahmadi et al., 2015), cognitive-behavioural therapy (Anie, 2005), patient education (Barakat *et al.,* 2006), or special education (Anie and Green, 2006) in order to improve the general well-being of patients. However, sickle cell disease is reported to be associated with psychosocial afflictions which are often overlooked or under-managed in the management of sufferers (Brewer, 2010; Vilela *et al.,* 2012; Guobadia, 2015). Also, findings of this study disclosed that most (60%) adolescents in experimental and control group have not felt good about themselves in the last one month. These submissions corroborate the findings of (Jenerette and Brewer, 2010; Vilela *et al.,* 2012), which reported that the life expectancy of youth having sickle cell disease is often impaired and it commonly manifests psychosocial outcomes such as low self-image esteem, frustrations and depression.

Furthermore, result of study revealed that the Self-care Education Intervention induced significant improvement in the knowledge of SCD, Self-Care ability, which subsequentlyimproved the quality of life of participants in the experimental group.These findings are consistent with submissions of Ahamadi *et al.,*(2015) which reported that QoLscores of participants greatly improved after the implementation of self-management programme. However, Asnani *et al.,* (2016) systematic review concluded that educational interventions had no significant effect on the overall well-being of patients living with SCD. Atkin et al., (2006)

affirmed that psychosocial interventions in SCD appeared to work for some people and not others, because they were sensitive to the context in which they were introduced. The significant difference in the effect of self-care educational intervention as regards life expectancy of adolescents with sickle cell disease might also be context sensitive.

Open ended information on overall well-being of adolescents living with sickle cell disease was measured in both groups to elicit information aboutchallenges which seems devastating as they are growing up. This becomes necessary because some of the adolescents seen in the course of the field workdoes not want to accept their present SCD status and experiences associated with the condition. Adolescents in this study seemed to be religious and hoped for healthier well-being as a means of coping with different challenges. The possible religious disposition meant that adolescents with SCD might become focused and mentally prepared towards healthy lifestyle. Religiousness was found to be an effective means of improving lives in distressing situation (Cotton *et al.,* 2006).

Furthermore, findings showed that financial challenge was common among SCD adolescents. Literature is replete with the socio-economic toll of SCD on people living with it and the economic toll of SCD may be worse in resource-limited settings such as Nigeria (de Medeiros *et al.,* 2015, Santos and Gomes, 2013; Aljuburi *et al.,* 2013). Adolescents having SCD who are from low socio-economic background may therefore be faced with poorer health outcomes due to financial constraints (Adegoke *et al.,* 2015) which may translate into other psychosocial afflictions (Grove *et al.,* 2014). Current study alsoidentified that persons living with SCD had challenges with relationship this is in agreement with findings of Umana and Ojebode (2010)which investigated the factors that individuals would consider in whom to marry and if the individual would continue with the marriage even if both were sickle cell carriers.

Also, Santos and Gomes (2012) reported reduced quality of life in all domains in their study, of which emotional effect account for not being engaged in marital relationship. Further investigation on emotional domain among adolescents confirmed that majority of the respondents were single (65.6%) as against(29.4%) who were married and did not want to take responsibility of caring for spouse with SCD, because of social stigma as most believe clients were prone to untimely death no matter the care despite huge cost.

5.6 Limitations of the Study

This study was carried out with inclusion and exclusion criteria. Clients who were in boarding school and those who were writing examination in schools could not participate in the study. This may affect the generalisation of study finding.

Recruitment process took longer than scheduled, sequel to reduced client flow. Home-visit, snowballing and radio announcement wereused to acquire designated sample size. Thisnecessarysnowballing and radio announcement were not part of the study protocol.

Most of the clients could not afford transportation fee and this disturb the response rate of participants, as some of the adolescents who registered for the study could not complete the study. Hence,researcher made transport arrangement for the participants at each contact period throughout the study.

The costof care was huge as most participants could not afford it. This accounts for unwillingness of participants to fulfill clinic appointmentsand share lived experiencesas expected. Each participant received a sum of five hundred naira as financial assistance at each contact period throughout the study.

The researcher encouraged parents to provide financial support to ensure that participants receive optimum care. Participants were also encouraged to join SCD club to be in a forum where people shared their feelings about sickle cell disease.

5.7 Implication of Findings for Community Health Nursing Practice

Findings of the study showed that self-care educational intervention significantly increased SCD knowledge among adolescents living with SCD, their self-care ability and quality of life. Community Health Nurses should therefore be at the forefront in adopting self-care educational intervention in educating adolescent with SCD. Having good health seeking behaviour is important to improved self-care ability and successful transition of adolescents to adulthood. Schools, homes, health facilities and SCD clubs are appropriate places for community health nurses to reach adolescents who have SCD to offer comprehensive self-care educational programmes in a bid to promote, restore, and maintain their health status.

Community health nursesare persons who are stocked educationally with competencies to assess the health needs of people in a given population. Hence, community health nurses are the link between the clients, governmental organisations and some non-governmental agencies as supported by Sebastian (2008) who theorized that nurses should know about community agencies that offer health and social services for vulnerable populations in order to facilitate follow up care and appropriate referral when the need arise and to ensure achievement of desired outcome.

Another role of the community health nurse is to develop health programmes that will help promote attainment of optimal health among adolescents as bolstered by Gitterman (2001) who stated that an important role of a community health nurse is to assist individual through "difficult life transitions or stressful events." This study and other studies have shown that adolescents undergo stressful situations during crises. (Laura *et al.,* 2016). Furthermore, advocacy is core for community health practice such that the nurse is in a position to influence health policies as regards adolescents' health. Care of clients living with SCD needs sustenance at all levels, thus advocacy is vital to clients' survival. In essence, community health nurse must liaise with government, non-governmental organisations and health philanthropies on issues like financial constraint, stigmatisation, fear of disease outcome, unstable relationship and poor performance in school or chosen career which adolescents claimed to be bothersome and devastating to their health. Therefore, there is need to institute educational programmes that will improve the knowledge and standard of life of SCD clients in general.

The self-care educational package used for this research could be adopted by health care providers and care givers as treatment protocol in caring for adolescents with SCD and other chronic diseases. Also, community health nurses should have steady refresher training on various educational programmes (self-care education) that would build the aptitude of clients towards unpretentious management of SCD, such that community health outreaches can adopt the SCEP module as a means of care.

5.8 Contribution to Knowledge

This study has made a significant contribution in the area of development of self-care educational package (SCEP). This training package can be used by all stakeholders working with

SCD adolescents and clients who are living with chronic illnesses in both governmental and non-governmental organisations to facilitate in-depth knowledge and development of positive coping skills that would enhance worthy quality of life. Also, the study has increased participants understanding through the assessment of self-care education on self-care ability and life expectancy (QoL) of SCD in Nigeria.

This study developed a tool for universal self-care requisites, using basic tenets of Dorothy Orem's Self-care Theory. Also, Maslow's hierarchy theory of need was utilised in developing check list for self-care practice, thus subsequent studies in this area may find the tool appropriate. Findings of this study would contribute to data pool on issues affecting self-care ability, pain-coping and overall quality of life of clients with sickle cell disease to resolve dearth of literature on self-care requisite and practices among SCD adolescents in Nigeria.

5.9 Suggestions for Future Study

- Future researcher needs to replicate present study in other health facilities, of the remaining states in the country to buttress study findings.
- The scope of further studies should be broadened to include young adults and adults living with SCD who were not within the study scope.
- Research outcomes recommend utilisation of self-care educational package in future studies to ascertain the effectiveness of the intervention package used in this study.

5.10 Recommendations

Based on the findings of this study, the following recommendations were made:

- Inclusion of self-care education in routine care of persons living with SCD. Focus of teaching should be on self-care,most especially for adolescent to reduce dependency and promote optimum health.

- Health policies should focus on health needs of adolescents with sickle cell disease and ensure health programs areinstituted at each level of health care institutions to improve lifeexpectancy.
- Government should intensify effort to establish support groups for persons living with SCD.The group will notify the adolescents about theavailable educational programmes for SCD through media such as radio, television, leaflets, posters, and billboardswith a view of improving self-care ability of SCD adolescents and keep them abreast of current issues as regards the management of sickle cell disease.
- Cost of health careshould be subsidised as most adolescents have financial challenges in seeking care from the available health institutions.

5.11 Summary and Conclusion

This study assessed outcome of nursing intervention in form of Self-care Education on Self-care Ability and Quality of Life of Adolescents with Sickle Cell Disease in South-western Nigeria, using quasi experimental design. Results from the study revealed that adolescents with sickle cell disease have average knowledge of SCD, poor pain coping abilities, poor knowledge of self-care requisites and poor self-care practices with moderate life expectancy pre-intervention. However, adolescents' knowledge, pain-coping abilities, self-care practices and standard of living significantly increased after self-care educational intervention.

Adolescents reported financial and relationship challenges as the major issues influencing their quality of life. The common self-care practices which were reported by the adolescents are using medication to relief pain, drinking a lot of water and usage of hot water immersion/hot toweling massage during crises.

The literature review focused on adolescents' self-care ability utilising SCD knowledge, self-care requisite, pain-coping abilities, life expectancy (QoL) and personal concept of self-care and self-practices. The review emphasised the need for educational intervention among adolescents and clients with SCD.

Stakeholders (governmental and non-governmental organisations) should make effort to increase awareness of general population on aetiology, pathogenesis, and possible outcome of SCD when managed properly. This study concluded that Self-care Educational Intervention has the potential to improve the understanding of SCD, self-care ability and enhanced quality of life of SCD adolescents throughout their lifetimes.

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APPENDIX 1

INFORMED CONSENT FORM

Title of Research:Outcome of Nursing Intervention on Self-care Ability and Quality of Life of Adolescents Living with Sickle Cell Disease in Oyo and Ekiti States

Name: Funmilola Adenike Faremi

Address: Department of Nursing, Faculty of Clinical Sciences, College of Medicine, University of Ibadan.

Sponsor of research: Self-sponsored

Purpose of the research: This research is being conducted to determine the impact of self-care education on adolescents ability to voluntarily care for themselves while living with SCD. Also, adolescents are expected to make decisions that will promote healthy living.

Procedure of the research: Respondent willbe asked to complete the questionnaire themselves if they can read and write. Research assistants will be on ground to clarify difficult areas and interpret Yoruba version to client who cannot read or write. You will be invited to participate in four teaching sessions, each session will last for 45 minutes and take place twice a week; Tuesday for child haematology and Thursday for adult haematology. You will be required to answer questions in sections A to F of the questionnaire for this study, same quetionnaire will be repeated three times within six months.

Expected duration of research: This research will take about 1hour of your time at each contact.

Cost to the participants: Your participation in this research will not cost you anything, financially because your transportation fare will be paid on the days you will attend the teaching sessions.

Benefit: The research will help you understandthe importance of self-care education as a measurethat will improve your SCD knowledge, assist you in coping successfully with the illness, increase your ability to manage SCD pain or to take prompt action when the need arises and to have positive concept of quality of life.

Confidentiality: The research does not require recording **y**our name. Coding of the information obtained from you will be carried out using numbers and this will not be traceable to you. Your nameor your phone numbers will not appear in any publication or reports that originate from this study.

Voluntariness: Your participation in this research is completely voluntary.

Alternatives to participation: If you decide not to participate, this will not affect your treatment or the way the nurses relate with you in any way.

Due inducements: You will not be paid any fees for participating in this research but your transportation fare will be provided and you will be given refreshment after each of the four teaching sessions.

What happens to research participants when the research is over: The findings of this research will be communicated to the nurses and doctors taking care of you and you will be informed if we notice anything that may affect your health.

Any apparent or potential conflict of interest

There is no conflict of interest on the part of the researcher

Participants Details and Intention to participate in the study:

I have read the description of this consent along with the purpose, methods and benefits of the study to my satisfaction. I wish to participate in the study, knowing fully that I can withdraw any time from the study.

NAME: _____

DATE: _____

SIGNATURE: _____

Researcher Contact:

PHONE NUMBER: _____08033826198_____

Phone nos.:08033826198 and 08056096782

E-mail: nfaremi@yahoo.com

APPENDIX 2

QUESTIONNAIRE

Outcome of Nursing Intervention on Self-Care Ability and Quality of Life of Adolescents Living with Sickle Cell Disease in Oyo and Ekiti States

Dear respondent,

I am a postgraduate student of the Department of Nursing, University of Ibadan. I want to share from your experience of how sickle cell disease has affected your general well-being. The information obtained would go a long way in developing appropriate policy for the alleviation of this problem in our society.

However, this questionnaire would take about 60 minutes of your time. Honest response to the following questions would be highly appreciated. Your identity will be treated with strict confidentiality. You are also at liberty to withdraw from the study anytime without prejudice.

If you have understood the explanation given about the study and you will like to participate in the study please write your details below:

Respondent's Name: _____

Signature: _____Date_____

Phone No: _____

Thank you.

Faremi, F. A.

+2348033826198
nfaremi@yahoo.com; nfaremi@gmail.com

SECTION A: BACKGROUND/SOCIO-DEMOGRAPHIC DATA

1. Gender: ___1. Male ___ 2. Female
2. Religion: ____Christianity _____ Islam ____ Traditional
3. Age in year (At last birthday)_____
4. Ethnicity: ___Yoruba ___ Hausa ____ Igbo _____ Others, please specify _____
5. Number of siblings _____
6. How many of your siblings have SCD? _____
7. Father's occupation: _____
8. Mother's occupation: _____
9. Who is responsible for making sure that you take your medication? Self [ ] Parent/guardian [ ] Friend [ ] Relatives [ ]
10. When was the last time that you had SCD crisis_____
11. When was the last time you were admitted in the hospital as a result of SCD? _____
12. On the average how many SCD crises do you usually experience in a year? _____
13. How many SCD crises did you experience in the last 3 months? _____
14. Are you a member of any support group (i.e. sickle cell club) : Yes [ ] No [ ]

SECTION B: KNOWLEDGE OF RESPONDENTS ABOUT SICKLE CELL DISEASE

THE SCD TRANSITION KNOWLEDGE QUESTIONNAIRE (Newland, Cecil & Fihian, 2000)

Directions: Tick correct options

		True	False
	Knowledge of Adolescents on aetiology of Sickle Cell Disease		
16.1	SCD is a condition that affects white blood cells		
16.2	Sickle cell disease affects red blood cells		
16.3	The platelets are also affected by SCD		
17.1	RBC in SCD can cause problems because the can become too large		
17.2	RBC in SCD can cause problems because the can become too soft		
17.3	RBC in SCD can cause problems because the can become sickle-shaped and hard		
17.4	RBC in SCD can cause problems because the can become round and hard		
18.1	Haemoglobin carries vitamins within human body		
18.2	Haemoglobintransports minerals to the body systems		
18.3	Haemoglobin in RBC conveys oxygen all over the body		
18.4	Haemoglobindistributes water to organs in body		
	Knowledge of Participants on Inheritance and Physical Features of Sickle Cell Disease		
19.1	SCD is inborn		
19.2	SCD is contagious (if you sit close to a person having SCD)		
19.3	SCD can cause bleeding problem		
19.4	Poor diet can cause SCD		
19.5	SCD adolescents may be shorter than their age		
20.1	Adolescents living with SCD may mature later than peers		
20.2	Adolescents living with SCD may get tired easily		
20.3	A woman with SCD can sustainher pregnancy with good medical care		
20.4	A female with SCD cannot have children		
20.5	A female with SCD should receive special care when pregnant		

20.6	A male with SCD cannot father a child		
21.1	Sickle cell clients should not have children		
21.2	An adolescent with SCD should consider the nearness of college to the medical care before choosing a college to attend		
21.3	Adolescents should consider the rules of the school concerning absence due to illness		
	Knowledge of Participants on SCD Management		
22.1	SCD patient should be given treatment after severe pain		
22.2	SCD patient is best treated in the hospital		
22.3	Sickle cell patient is best treated at home when the symptoms first begin		
22.4	Sickle cell patient is best treated with narcotics only		
23.1	In cold weather, SCD patient should wear warm clothes		
23.2	In cold weather, SCD patient should stay home from school or work		
23.3	SCD patient should never go outside during cold		
23.4	In cold weather, SCD patient should cancel doctor's appointments		
24.1	During sickle cell pain, a patient should drink plenty of fluids		
24.2	During sickle cell pain, a patient should go to the emergency room right away		
24.2	During sickle cell pain, a patient should always stay home from school or work		
24.3	During sickle cell pain, a patient should limit intake of food		
25.1	Ability of adolescents to manage problems alone should be considered when choosing college to attend		
25.2	SCD clients take penicillin every day to treat infections		
25.3	Individuals having SCD take penicillin every day to increase appetite		
25.4	Persons diagnosed of sickle cell disease take penicillin every day to prevent painful episodes		
25.5	Children who have SCD take penicillin every day to decrease risk of serious infection		

SECTION C: SELF-CARE REQUISITES OF ADOLESCENTS LIVING WITH SICKLE CELL DISEASE

DIRECTIONS: Tick the correct answer.

Universal self-care requisites:

Which of the following are your needs to stay healthy as a person with SCD?

	YES	NO
Adequate intake of air		
Appropriate intake of water		
Satisfactory intake of food		
Regular and prompt defecation (excreta)		
Regular physical exercise		
Adequate rest		
Maintain privacy (i.e. isolation, loneliness, or separateness)		
Be a member of a support group for SCD		
Ensure a balance between privacy / support group interaction		
Avoid hazards (i.e. physical, social, spiritual or psychological)		

Developmental self-care requisites

Tick yes or no as it relates with the pattern of developmental skill you are exhibiting as you grow

	YES	NO
Able to feed self promptly or regular intake of food		
Avoid sleeping or living in overcrowded room		
Seek information about SCD or investigate cause of SCD		
Isolate yourself during crises		
Avoid residing in unhygienic environment		

Please, answer the following questions on how SCD has affected your developmental process as an adolescent living with sickle cell;

a) At what age did you attain puberty (secondary sexual characteristics such as pubic hairs for boys and girls, breasts development and voice cracking in boys? ……

b) Do you remember things easily? a) Yes b) No

c) Have you ever developed emotional feelings for the opposite sex, a) Yes b) No

If Yes, at what age? , ……

d) Have you experience broken emotional relationship because of SCD?

a) Yes b) No

e) Has any friend left you because of SCD? a) Yes b) No

f) Are you allowed by your parents to take decisions on your own? a) Yes b) No

g) Are you taller than your mates? a) Yes b) No

h) As a boy,

i. Have you ever experienced wet dream a) Yes b) No

ii. Have you ever had priapism? a) Yes b) No

iii. If yes to h (ii) above, when did it happen? a) Day b) Night

i) As a girl,

i. At what age did you start menstruation? ……

ii. Do you experience painful menstruation a) Yes b) No

Health deviation self-care requisites

Which of the following do you engage in to support your health status during or after crises?

	YES	NO
Procuring appropriate medical assistance		
Adjusting lifestyle to accommodate changes that emanate from SCD		
Report perceived changes in health to caregivers promptly		
Have good self- concept		
Followyour regimen strictly		
Have knowledge of potential problems of SCD		
Learn to live with SCD throughout lifetime		

SECTION D: ACTIVITY OF DAILY LIVING PRACTICE OF ADOLESCENTS LIVING WITH SCD

DIRECTIONS: Tick the most appropriate answer applicable to you

Activities of daily living	**Never**	**Sometimes**	**Frequent**	**Very Frequent**
I take my bath by myself every day				
I wash my mouth by myself every day				
I cook my food by myself everyday				
I go to school/workplace by myself daily				

I observe my siesta daily				
I avoid participating in strenuous exercises daily				
I avoid going late to my school/workplace daily.				
I take time to rest when I am tired everyday				
I use my drugs as prescribed by the physicians				
I do not skip my drugs as prescribed				

Please specify the following activities as applicable to you.

28. What do you do to relieve your pain when you are in crisis?

_____

29. Who cares for you when you have crisis?

_____

30. What do you do to prevent yourself from having infection or being exposed to infection?_____

SECTION E: PAIN-COPING QUESTIONNAIRE.

Answer the questionsbelow on how you cope with pain during crisis

When I am hurt or in pain for a few hours or days, I….	Never	Hardly Ever	Some-times	Often	Very Often
Inquire about my pain					
Pay attention to the pain to ensure pain is improving					
Share pain experience with a friend					
I am nervous of not always having pain					
Get explanation from care providers about SCD pain					
Search for pain relieving measures					
Discuss my pain with a friend					

Do not engage in uncooperative actions while in pain					
Get materials on pain management					
Ponder on various methods of managing pain					
Do something I enjoy					
Try to forget it					
Believe in other measures of helping myself					
Understand my body mechanism					
Believe all will be well					
Control my temper outburst while in pain					
Explore various method of pain management and utilize the most suitable method					
Believe I'm capable of controlling situations as they occur					
Do not cursenor swear aloud					
Do not worry much about the pain					

SECTION F: QUALITY OF LIFE OF THE RESPONDENTS

During the past one month	Always	Often	Sometimes	Never
I havedifficulty of concentrating in class				
Controlling my pain is almost a challenge				
I could not participate in regular activities with friends				
I don't use all drugs given to me				
I have little vitality				
I can't play as desired				
I hardly spend time with friends				
I sensed a dull, soft pain				
I was disturbed				
I am not happy with myself				
My teachers cared for me singly from peers				
Other kids harassed me				
I believe I am actually unequal with my age group.				
I was not able to cope with my school work				
My friends pressurised me				

(A) Describe how you feel living with sickle cell disease:

a. Satisfied (b)Dissatisfied (c) Depressed (d) Anxious (e) Lonely (f) Hopeful (g) Hopeless (h) Others, please specify it……

(B) State the challenges you face living as SCD Client

Financial Challenge _____

Intellectual Challenge _____

Relationship Challenge_____

Feeding Challenge _____

Household Chores Challenge: _____

(C) Describe in your own words what you understand about self-care: (What you do to maintain your health by yourself daily)

_____

_____

(D) What does your caregiver (someone who takes care of you during crisis) do for you during crisis? _____

_____

_____

ÌWÉ-ÌFỌ̀RỌ̀-WÁNILẸ́NUWÒ

Èrè Akitiyan Èto Ìtọ́jú-Ara-Ẹni Tó Dángájíá Lórí Ìmọ̀ Nípa Àrùn, Ìgbé Ayé Tó Sunwọ̀n Àti Ìléra Tó Gbópọn Láàárín Àwọn Ọ̀dọ́ Tí Wọ́n Ní Àrùn Arunmọléegun Ní Gúsù Ìlà-Oòrùn Nigeria

Ẹ̀yin Olùkópaà mi Ọ̀wọ́n,

Ọmọ ilé-ẹ̀kọ́ àgbà onípò-kejì ti ẹ̀kọ́sẹ́ ìṣègùn Nọ́ọ̀sì, Ilé ẹ̀kọ́ gíga Yunifásítì ti Ìbàdàn ni mo jẹ́. Mo sì ńṣe ìwádìí lórí àkòrí ọ̀rọ̀ tí ó dá lórí Èrè Akitiyan Èto Ìtọ́jú-Ara-Ẹni Tó Dángájíá Lórí Ìmọ̀ Nípa Àrùn, Ìgbé Ayé Tó Sunwọ̀n Àti Ìléra Tó Gbópọn Láàárín Àwọn Ọ̀dọ́ Tí Wọ́n Ní Àrùn Arunmọléegun Ní Gúsù Ìlà-Oòrùn Nigeria. Mo fẹ́ mọ̀ nípa àwọn ìríríi yín àti ipa tí àrùn arunmọléegun ńkó nínú ìlera yín. Àbájáde èsì àbọ̀ ìwadìí yìí yíò ràn wá lọ́wọ́ láti lè gbé àwọn ètò tí ó múnádóko kalẹ̀ láti lè dojúkọ àrùn yí ní àwùjọ wa.

Ìfọ̀rọ̀wánilẹ́nuwò yìí yíò gbà wá ní àbọ̀ ìṣẹ́jú láti parí. Mo sì fún un yín ní ìdánilójú wípé gbogbo èsì tí ẹ bá fi ṣọwọ́ sí wa kò ní lu jáde bí ó ti wulẹ̀ kí ó rí. Bákannáà, gbogbo àwọn èsì tí ẹ bá fi ṣọwọ́ránṣẹ́ sí wa yíò wúlò púpọ̀ fún níní ìmọ̀ ìjìnlẹ̀ kíkún si ní ọjọ́ iwájú.
Ìdáhùn títọ́ sí àwọn ìbéèrè tí a là kalẹ̀ yíò jẹ́ ohun ìwúrí lọ́pọ̀lọpọ̀. Bákannáà, ẹ ní ànfààní láti yẹra fún ètò ìwádìí yìí nígbà tí ó bá wù yín láìsí ìyọnu.

Ẹ ṣé púpọ̀.

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Tì ò bà wúọ̀ làti kòpa nínù iwàádì yíì, jọ̀wọ́ kọ ápẹ̀jùwe rẹ sì ísálẹ́:

Ọrùkọ Olúdàhún: _____

Íbuwọ̀lú: _____Ọjọ́ _____

Nọ̀mbá Ẹ̀ro-ìbánisọ̀rọ̀: _____

Ẹsè.

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ÌWÉ-ÌBÉÈRÈ-ÌFỌ̀RỌ̀WÁNILẸ́NUWÒ (Arunmọ́éegun)

APÁ KÌNŃÍ: ÀYẸ̀WÒ ÌPÍLẸ̀

1. Akọ àbí Abo: ___Ọkùnrin ___Obìnrin
2. Ẹ̀sìn: ____Ìgbàgbọ́ _____ Mùsùlùmí ____ Ìbílẹ̀
3. Ọjọ́ orí ní Ọdún (Ní ọjọ́ ibi to kẹ́yìn) _____
4. Ẹ̀yà: ___Yorùbá ___ Haúsá ____ Ìgbò _____ Òmíràn, jọ sà pé júwe_____
5. Iye ọmọ iyá_____
6. Mèélò nínú àwọn ọmọ iyá rẹ lóní àrùn SCD? _____
7. Isẹ́ Baba: _____
8. Isẹ́ Ìyá: _____
9. Tani ẹnitì ò se ámòjùtòo lìló ógún rẹ? Íwọ [ ] Óbì/Alàgbátọ̀[ ] Ọ́rẹ̀ [ ] Ojùlúmọ́ [ ]
10. Ígbá wo ni o ni rógbódíyán árún inù ẹ́jẹ́ kẹ̀yín_____
11. Ígbá wo ni o di éró ilè íwósán nìtorì rógbódíyan árún inù ẹ́jẹ́ kẹ̀yín?_____
12. Òdiwọ́n ápapọ́, ẹ́meélò ni o maa ni írìrì rógbódíyán árún inù ẹ́jẹ́ arunmọ́éegunlọ̀dùn? _____
13. Rógbódíyán árún inù ẹ́jẹ́ SCD mèélò lotinì nìwọ́n osú mẹ̀ta sẹ̀yín_____
14. Ńjẹ̀ owá nínù ẹgbẹ̀ íránwọ́ ílera kankan (bì kilobu árún inù ẹ́jẹ́):

Bẹ́ẹ́ni [ ] Bẹ̀ẹ́kọ̀ [ ]

APÁ KEJÌ: ÌMỌ̀ OLÙDÁHÙN LÓRÍ ÀRÙN INÚ ẸJẸ̀ SCD

ÌWÉ-ÌBÉÈRÈ-ÌFỌ̀RỌ̀WÁNILẸ́NUWÒ-ÌSÍNÍPÒ ÌMỌ̀ TÍ ÀRÙN INÚ ẸJẸ̀ ARUNMỌLÉEGUN

ÀWỌN ÌLÀNÀ: Fa ìlà yíká ìdáhùn tó dára

		Ọ̀títọ́ ni	Irọ́ ni
16	Àrùn arunmọléegun jẹ́ àrùn tí ó ńbá:		
16.1	Ẹ̀yà-ara ẹ̀jẹ̀ pupa jà		
16.2	Ẹ̀yà-ara ẹ̀jẹ̀ fúnfún jà		
16.3	Ẹ̀yà-ara pẹ̀rẹ̀sẹ̀ tí ó wà nínú ẹ̀jẹ̀ jà		
17	Ẹ̀yà-ara ẹ̀jẹ̀ pupa ninu àrùn arunmọléegun lè dá wàhálà sílẹ̀ nítoríwípé wọ́n lè:		
17.1	Tóbi ju bí ó ti yẹ lọ		
17.2	Rọ̀ ju bí ó ti yẹ lọ		
17.3	Rí róbótó tí wọn yíò sì le		
17.4	Bí akọ́rọ́ tí wọn yíòdà sì le		
18	Hemoglobin nínú ẹ̀yà-ara ẹ̀jẹ̀ pupa ńgbé _____ káàkiri ara:		
18.1	Èròjà aṣaralóoré vítámínì		
18.2	Èròjà aṣaralóoré		
18.3	Atẹ́gùn		

18.4	Omi		
19	Àrùn arunmọ́éegun jẹ́:		
19.1	Àrùn àjogúnbá (láti ọ̀dọ̀ òbí sí ọmọ)		
19.2	Àrùn àkóràn (gẹ́gẹ́bí òfinkìn)		
19.3	Ìsun ẹ̀jẹ̀		
19.4	Àrùn àìjẹ oúnjẹ tí ó níláárí tó		
20	Nígbà tí a bá ní ìrora àrùn arunmọ́éegun, ó yẹ kí aláìsàn		
20.1	Mu omi tí ó pọ̀ dáradára		
20.2	Dúró sílé ní gbogbo ìgbà		
20.3	Lọ sí Yàrá Pàjáwìrì ní kíákíá		
20.4	Fètò sí oúnjẹ jíjẹ		
21	Kílódé tí àwọn ọmọdé tí ó ní àrùn arunmọ́éegun SCD ṣe máa ńlo egbògi penicillin lójoojúmọ́?		
21.1	Láti tójú àwọn àìsàn àkọ́ràn		
21.2	Láti mú kí ó wù wọ́n láti jẹun		
21.3	Láti dènà de orísìírísìí ìrora		
21.4	Láti dènà ìṣokùnfà àìsàn àkọ́ràn		
22	Ọmọdé tí ó ní àrùn arunmọ́éegun leè jẹ́ pé:		
22.1	Kéré ju àwọn ẹgbẹ́ rẹ̀ lọ		
22.2	Dàgbà lẹ́yìn ìgbà tí àwọn ẹgbẹ́ rẹ̀ tí dàgbà		
22.3	O má n tètè rẹ̀ẹ́ púpọ̀		

22.4	Obìnrin tí ó ní àrùn arunmọ́éegun lè ru oyún rẹ̀ dé ipò ìbímọ pẹ̀lú ètò ìtọ́jú tí ó pé ye		
23	Obìnrin tí ó ní àrùn arunmọ́éegun:		
23.1	Kò lè bímọ		
23.2	Nílò ètò ìlera tí ó ṣe pàtàkì nínú oyún		
23.3	Ọkùnrin tí ó ní àrùn arunmọ́éegun kò lè bímọ		
23.4	Kí ẹnikẹ́ni tí ó ní àrùn arunmọ́éegun má ṣòpò láti bímọ rárá		
24	Ọ̀nà tí ó dára jùlọ láti tọ́jú ìrora àrùn arunmọ́éegun ni		
24.1	Lẹ́hìn tí ìrora náà bá le gidi gan		
24.2	Nínú ilé nígbà tí a bá kofìrí àwọn àmì ìfarahàn-an rẹ̀		
24.3	Ní ilé-ìwòsàn		
24.4	Pẹ̀lú àwọn egbògi tí ó wà fún ìrora nìkan		
25	Ní àkókò òtútù, ó dára kí ẹni tí ó bá ní àrùn arunmọ́éegun kí ó		
25.1	Wọ àwọn aṣọ tí ó móoru.		
25.2	Dúró sí ilé láì lọ sí ilé-ìwé tàbí ibi iṣẹ́.		
25.3	Má lọ sí ìta rárá.		
25.4	Fagilé gbogbo àyẹ̀wò pẹ̀lu dókítà rẹ̀		
26	Ọ̀dọ́ tí ó ní àrùn arunmọ́éegun ńfẹ́ mọ irú ilé-ẹ̀kọ́ gíga tí òún lè lọ. Kíni àwọn ohun tí ó yẹ kí á kíyèsi?		
26.1	Bí ó ṣe súnmọ́ ilé-ìwòsàn sí		
26.2	Akitiyan láti lè ṣe ìtọ́jú ara rẹ̀		

26.3	Òfin ilé-ẹ̀kọ́ náà lórí pípa ilé-ìwé jẹ nítorí àìlera		

APÁ KẸTA : OHUN ÀMÚNLÒ ÌDÁTỌ́JÚARA FÚN ỌDỌ́ TÍ ÓÚN GBÉ PẸ̀LÚ ÀRÙN ARUNMONLÉEGUN

ÀWỌN ÌLÀNÀ: Fa ìlà yíká ìdáhùn tó dára.

Ohun àmúnlò ìdátọ́júara kárí-ayé:

Èwo nínú àwọn wọ̀nyi ni ohun tí o nílò láti wà ní ìlera pípé?

s/n		BẸ́Ẹ̀NI	BẸ́Ẹ̀KỌ́
27.	Gbígba afẹ́fẹ́ tí ó tó sára		
28	Mímu omi tí ó tó		
29	Jíjẹ oúnjẹ tí ó tó		
30	Síṣe ìgbọ̀nsẹ̀ lásìkò àti déédé (ìgbẹ́ àti ìtọ̀)		
31	Síṣe eré ìdárayá déédé		
32	Ìsimin tó péye		
33	Títọ́jú ìparamó (i.e. ìdáyàtọ́, ìdáwà, tàbí yíyàsọ́tọ̀)		
34	Jíjẹ́ ọ̀kan nínú ẹgbẹ́ ìranilọ́wọ́ fún SCD		
35	Níní ìdánilójú ìdiwọ̀n ìbásepọ̀ láàrin ẹgbẹ́ ìdáyàtọ̀ / ìranilọ́wọ́		
36	Dídènà àwọn àjálù (i.e. nípa tara, nípa àwùjo, nípa tí ẹ̀mí tàbí èròngbà)		

Díd àgb àsó kè àw ọn ohu n àm únl ò ìdàt ọ́jú ara

37	Agbára láti jeun kíákíá fún ra rẹ̀ tàbí oúnjẹ jíjẹ nígbàkúgbà		
38	Dèna sísùn tàbí gbé nínú yàrá ọ̀pọ̀ ènìyàn		
39	Wíwá ìròyìn nípa SCD tàbí síṣe ìwáàdí ohun tó fa SCD		
40	Yíya ara rẹ̀ sọ́tọ̀ nígbà ísóro		
41	Dèna gbígbé ní agbègbè tí kò dára fún ìlera ara		

Àwọn ohun àmúnlò fún ìyípadà ìlera ìdátọ̀júara

42	Wíwá àti gbígba ojúlówó ìsègùn fún ìrànlọ́wọ́		
43	Yíyí ìgbé ayé ẹni padà láti fi àyè gba gbogbo ohun tó bá súyọ nínú SCD		
44	Ríròyìn àwọn àyípadà tí o rí nínú ìlera rẹ fún àwọn afúninítọ̀ju láìfọ̀tápè		
45	Ní èrò rere fún ara rẹ (i.e. gbà pé owà nínú ipò ìlera pàtàkì kan àti pé o nílò irú ìtọ́jú ìlera kan tó se pàtàkì)		
46	Lo ògùn àti se ètò ìlera rẹ dáradára (i.e. carryout medically prescribed diagnostic, therapeutic and rehabilitative measure)		
47	Níní ìmọ̀ nípa àwọn ojúlówó ìsòro SCD (i.e. Mo nípa àwọn ìyípadà tó wà nípa ìnira tó súyọ lára àwọn ètò ìlera tí a yàn fún ọ)		
48	Kọ láti gbé ìgbéayé pẹ̀lu SCD títí ìgbésí ayé rẹ		

Àwọn Ìdojúkọ tí ó wà nínú Ìdàgbàsókè Arunmọ́éegun

Jọ̀wọ́, dáhùn àwọn ìbéèrè wọ̀nyí nípa bí Arunmọ́léegunse dènà àwọn ètò ìdàgbàsókè rẹ gẹ́gẹ́ bí ọ̀dọ́mọdé tí ó ní àrùn arunmoléegun;

a) O tó ọmọ ọdún méèló kí o tó di ọ̀dọ́ (Àwọn orísirísi ohun ìtọ́kasí àti di ọ̀dọ́, gẹ́gẹ́ bíi irun-abẹ́ àti irun-àyà fún àwọn ọ̀dọ́mọkùnrin àti àwọn ọ̀dọ́mọbìnrin, gígún ọmú, ohùn kíkẹ̀ fún àwọn ọ̀dọ́mọkùnrin àti bẹ́ẹ̀ bẹ́ẹ̀ lọ) ……..……

b) Ǹjẹ́ o ma ńrántí àwọn nkàn láìsí wàhálà? a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

c) Ǹjẹ́ o ti ní èrò ìfẹ́ àtinúwá sí ọ̀rẹ́kùnrin tabi ọ̀rẹ́bìnrin rí, a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

Tí ó bá jẹ́ bẹ́ẹ̀ni, o tó ọmọ ọdún méèló, …….……

d) Ǹjẹ́ o ní ìjákulẹ̀ nínú ìbásepọ̀ nítorí Arunmọ́léegunrí
a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

e) Ṣé àwọn ọ̀rẹ́ rẹ kò fi ọ́ sílẹ̀ nítorí Arunmọ́léegunbí a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

f) Ṣé àwọn òbí rẹ gbà fún ọ láti dá èrò ara re pa a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

g) Ǹjẹ́ o ga púpọ̀ ju àwọn ẹgbẹ́ rẹ lọ bí? a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

h) Irú òògùn wo ni o ma ńlò nì òrèkóòrè láti dènà tabí gba àkóso lọ́wọ́ ròǵbòdìyàn Arunmọ́léegun……

i) Gẹ́gẹ́ bí ọ̀dọ́mọkùnrin,

i. Ǹjẹ́ o ti ni ibalopo oju orun ri a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

ii. Ǹjẹ́ nkàn ọmọkùnrin rẹ ti le ní àle sílẹ̀ rí a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

iii. Tí ó bá jẹ́ bẹ́ẹ̀ni fún (ii) lókè, nígbàwo ni ó sẹlẹ̀ a) Ọ̀ṣán b) Alẹ́

j) Gẹ́gẹ́ bí ọ̀dọ́mọbìnrin,

i. O tó ọmọ ọdún méèló kí o tó bẹ̀rẹ̀ ṣíí ṣe nkàn oṣù ……

ii. Ṣé o má n ní ìninilára tí o bá ń se nkàn oṣù a) Bẹ́ẹ̀ni b) Bẹ́ẹ̀kọ́

APÁ KẸRIN: OHUN SÍSE FÚN DÍDÁTỌ́JÚARA ÀWỌN ỌDỌ́ TÓ ŃGBÉ PẸ̀LÚ ARUNMỌLÉEGUN

ÀWỌN ÌLÀNÀ: Fa ìlà yíká ìdáhùn tó dára jù fún ọ̀.

s/n	**Àwọn àsàyàn isẹ́-síṣe fún ìgbé ayé ojoojúmọ́**	**Gbogbo Ìgbà**	**Lóòrèkóòrè**	**Nígbàkọ̀ọ̀kan**	**Rárá**
49	Mo má n wẹ̀ fún ra mi ní ọjọ́ gbogbo				
50	Mo má n fo enu fún ra mi ní ọjọ́ gbogbo				
51	Mo má ńse oúnjẹ mi fún ra mi ní gbogbo ọjọ́				
52	Mo máa ń lọ ilé ìwé/ilé isẹ́ fún ra mi lójojúmọ́				
53	Mo máa ń sun orun ọ̀sán lójojúmọ́				
54	Mo yàgò fún kíkópa nínú àwọn eré ìdárayá tó lágbára lójojúmọ́				
55	Mo dènà pípẹ́ lọ sí ilé ìwé/ilé isẹ́ mi lójojúmọ́				
56	Mo ya àkókò sọ́tọ̀ láti simin nígbàtí ó bá rẹ̀ mí ní gbogbo ọjọ́				
57	Mò ń lo àwọn ògùn mi gẹ́gẹ́ bí akọ́sẹ́ mọsẹ́ onísègùn se sọ fún mi				
58	Mi kò se aláìmá lo ògùn mi gẹ́gẹ́ bí wọ́n se sọ fún mi				

Jọ̀wọ́ yànàná àwọn ohun-síṣe wọ̀nyí gẹ́gẹ́ bí ó se wúlò fún ọ.

59. Kíni o maa ńse láti se ìdíkù ìrora rẹnígbàtí o báwà nínú ròg bòdìyàn?

_____

60. Àwọn wo ló ń se ìtọ́jú rẹ nígbàtí o bá ń dojúkọ ròg bòdìyàn?

_____

61. Kíni o máa ńse láti dènà a ti ní àrùn tàbí wà níbi tí o ti le kó àrùn fún ara rẹ?

APÁ KAÀRÚN: ÒDINWÒN ỌGBỌ́N-ÌMÚMỌ́RA

Gbogbo èniyàn lóní àkókò kan tí ase ohun tó dùn wọ́n tàbí wọ́n wà nínú ìrora fún wákàtí díẹ̀ àti púpọ̀. Fún àpẹrẹ, o le ti ní orí fífọ́, inú ríro, pajá-pajá ẹsẹ̀, ìrora ìsẹ́po ti (orúnkún àti ojúgun), ẹ̀yìn ríro, ìrora etí, tàbí fún obìnrin, ìrora nkàn osù, àti bẹ́ẹ̀bẹ́ lọ. Àwọn ohun tó wà nísàlẹ́ wọ̀nyí ni ó maa ńse nígbàtí óbá wà nínú ìrora fún wákàtí tàbí ọjọ́ díẹ̀.

ÒDINWÒN ỌGBỌ́N-ÌMÚMỌ́RA PCQ

Fa ìlà yípo àkókò fún ìbéèrè kọ̀ọ̀kan láti sàfihàn bí ó tiń ṣe àwọn ohun tí a kójọ wọ̀nyí.

ÀWỌN ÌLÀNÀ: R – Rárá, KR – Kòdájú Rárá, N – Nígbàkọ̀ọ̀kan, L – Lóòrèkóòrè

s/n	Nígbàtí ẹnìkan bá se ohun tó dùn mí nígbàtí mo wà nínú ìrora fún wákàtí tàbí ọjọ́ díẹ̀, Mo….	**R**	**KR**	**N**	**L**	**DL**
62	Bèèrè ìbéèrè nípa ìrora yẹ́n					
63	Fojú sùnùkùn wo ìrora yẹ́n àti ọ̀nà ìbáwò lórí rẹ̀					
64	Bá ọ̀rẹ́ sọ̀rò lórí bó se ń semí					
65	Ríronú pé màá ma wà nínú ìrora					
66	Bíbèèrè ìbéèrè lọ́wọ́ nọ́ọ̀sì tàbi dókítà onísègùn òyìnbó					
67	Ríronú lórí ohun tó ye kin se láti dín ìrora náà kù					
68	Bíbá enìkan sọ̀rọ̀ nípa bó se ń semí					
69	Síṣe ohun tó máyọ̀ lọ́wọ́ tó sì ń dára yá					
70	Síṣe ìwádìí fún àlàyé síwájú					

71	Ríro onírúru ọ̀ná láti kojú ìrora yìí					
72	Síṣe ohun tí mo kúdùn láti máa se					
73	Gbígbìyànjú láti gbàgbé rẹ̀					
74	Rírò pé ohun Kankan kò ránmi lọ́wọ́					
75	Níní ìmọ̀ si lórí bí agbo ara mi ṣén sisẹ́					
76	Síṣọ ọ̀rọ̀ ìtùnú sí ara mì pé ńkan yíò dára					
77	Bíbínú sí ara mì tàbí fífi ìbínú gba ǹkan					
78	Síṣe orísirísi ohun láti dín ìrora yìí kù títítí mo fi rí ọ̀nà àbáyọ					
79	Síṣọ fún ara mi pé, mo le kojú ohun kóhun tó bá sẹlẹ̀					
80	Sí ṣépè tàbí gí gégùń pẹ̀lú ariwo					
81	Ríronú púpọ̀ nípa ìrora yìí					

APÁ KẸFÀ: ÒDIWỌ̀N-OJÚLÓWÓ ÌGBÉAYÉ OLÙDÁHÙN

OJÚLÓWÓ ÌGBÉAYÉ ÀRÙN ARUNMỌLÉEGUN (SCD-QoL)

Àwọn ìbéérè wọ̀nyí wà fún àwọn ọmọdé tó ní àrùn inú ẹ̀jẹ̀. Ìdáhùn rẹ yíò jẹ́ kíá mọ bí àrùn yìí se rí àti bí ìtọ́jú rẹ̀ seń ràn ẹ́ lọ́wọ́. Ìdáhùn won yìí yíò ràn ẹ́ lọ́wọ́ àti àwọn ènìyàn bíi tìrẹ ní ọjọ́ iwájú.
Kòsí ìdáhùn tó dára tàbí tí kòdára! Tí àti dáhùn kò bá yéọ, mú ìdáhùn tó súnmó o jù.

Láàrín osù kan sẹ́yìn:

S/n	Láàrín osù kan sẹ́yìn	Gbogbo Ìgbà	Lóòrèkóòrè	Nígbàkọ̀ọ̀kan	Rárá
82	Moní ìsòro gbígbọ́ràn nínú Kílàsì				
83	Mo ní ìsòro láti dá ìrora rẹ dúró				
84	Mo ní agbára láti se ohun tí àwọn ẹgbẹ́ mí ń se				
85	Mo lo gbogbo ògùn mi				
86	Mo ní agbára kékeré				
87	Mí ò le seré nígbàtí mo fẹ́				
88	Mo lo àkókò mi pẹ̀lú ọ̀rẹ́				
89	Mo ní ìrírí ìrora díẹ̀				
90	Ìrònú bámi				
91	Mo ní ìrírí tó dára nípa ara rà				
92	Àwọn olùkọ́ mi tọ́jú mi lọ́nà tó yàtọ̀				
93	Àwọn ọmọ yókù múmi seré				
94	Mo ròpé mo yàtọ̀ sí àwọn ọmọ yókù tí a jọjẹ́ ọmọ ọjọ́ orí kanńà				
95	Mi ò le kojú isẹ́ ilé-ìwé mi				

96	Mo kófìrí ìtinisisé láti ọwọ́ àwọn ọ̀rẹ́ mi				

APPENDIX 3

EDUCATIONAL PACKAGE

MODULE 1

Unit 1: UNDERSTANDING SICKLE CELL DISEASE: TIPS FOR CLIENTS AND FAMILY

1.0 MODULE OBJECTIVES

At the end of this module, participants should understand:

1. The meaning of SCD
2. Signs and symptoms of SCD
3. How SCD is inherited
4. Treatment options of SCD
5. Complications of SCD

1.1 MODULE OUTLINE

- Introduction
- Meaning of Sickle Cell Disease (SCD)
- Signs and symptoms of SCD
- Inheritance of SCD
- Treatment of SCD
- Complications of SCD

1.2 INTRODUCTION

It is important that individual clients understand SCD so that he/she can take an active role in prevention of crisis and management of his/her health. This is pertinent in choosing the best

possible course of action in managing individual health. A proper understanding of SCD will go a long way in assisting clients in monitoring their health and management of the disease.

1.3 MEANING OF SICKLE CELL DISEASE (SCD)

1.3.1 What is sickle cell disease?

It is a genetic disease resulting from defective haemoglobin. The red blood cells contain a red coloured pigment called haemoglobin (A) which picks up oxygen in the lungs and takes it around the body. In people with sickle cell disease, this red pigment is called haemoglobin "S" which often changes shape when there is shortage of oxygen.

1.3.2 How do people get sickle cell disease?

It is passed on from parent to child, which implies both parents pass on the defective gene to the child. It is not infectious but naturally endowed.

1.4 INHERITANCE OF SCD

SCD is often categorised into three groups:

a. Healthy people: They are people with normal haemoglobin i.e. haemoglobin "A", thus they have "AA"
b. Carriers of SCD: They have partly normal haemoglobin "A" and partly sickle haemoglobin "S", thus known as "AS"
c. The sufferer of SCD: they have sickle haemoglobin from both parents, thus they have "SS".

NOTE: Carriers seldom have symptoms; because they have partly normal haemoglobin, but the problem occurs in abnormal or stressful conditions like running at high altitude or in places with low oxygen.

Sufferers: A sufferer of SCD has inherited haemoglobin "SS" from the parent. The following examples are combinations of genotypes that can result in having SS.

Table 1: Genotype inheritance pattern

Genotype of the two parents	Possible outcome
AA x AA	All AA
AA x AS	½ AA, ½ AS
AA x AC	½ AA, ½ AC
AA x SS	All AS
AA x CC	All AC
AA x SC	½ AS, ½ AC
AS x AS*	¼ AA, ½ AS, ¼ SS
AS x AC*	¼ AA, ¼ AS, ¼ AC, ¼ SC
AS x SS*	½ AS, ½ SS
AS x CC*	½ AC, ½ SC
AS x SC*	¼ AS, ¼ AC, ¼ SS, ¼ SC
AC x AC	¼ AA, ½ AC, ¼ CC
AC x SS	½ AS, ½ SC
AC x CC	½ AC, ½ CC
AC x SC	¼ AS, ¼ AC, ¼ SC, ¼ CC
SS x SS*	All SS
SS x CC*	All SC
SS x SC*	½ SS, ½ SC
CC x CC	All CC

CC x CC	All CC
CC x SC*	½ SC, ½ CC
SC x SC*	¼ SS, ½ SC, ¼ CC

1.5 SIGNS AND SYMPTOMS OF SICKLE CELL DISEASE

1.5.1 How the symptoms evolve

Sickle cells are broken down by the body faster than normal blood cells; this results in fewer red blood, which often causes a condition called ANAEMIA. Anaemia is associated with tiredness and buzzing noise in the ears. Also breaking down of red cells brings yellow pigmentation of skin & eye as a result of released bilirubin. Sickle cell clients are vulnerable to infections which subsequently result in "anaemic crises".

The red blood cells change shape (sickling) when:

- The cell does not have enough oxygen e.g. in high altitude or air flight.
- The body needs a lot of oxygen e.g. physical exercise/exertion
- The body is dehydrated
- The outside temperature is low

Vaso-occlusive crises result when clumps of cells get stuck in minute blood vessels and stop the blood flow. In this situation various organs of the body are unable to get enough blood, when it occurs in the bones (arms, legs, back) it is referred to as painful bone crisis.

The lungs: Sudden breathlessness and tightness of the chest may indicate a blockage, this is called lung infarction when there is sudden and continuous pain in the belly it indicates a blockage in the gut, this is called bowel infarction. If the blockages occur within the brain it is called brain infarction or CVA. Other symptoms of reduced brain function can result in not being able to think clearly or poor memory.

The kidneys: As a result of small blood vessels in the kidneys, clumps of sickle cells can get stuck and cause problems of kidney function/blood in the urine or passing a lot of urine.

The penis: At times clump of cells can block the vessels of the penis, this often results in a long-lasting painful erection called priapism.

The eyes: The blocking of a blood vessel in the eye can cause deterioration in eyesight

1.5.2 Signs & symptoms of SCD

The signs and symptoms of sickle cell disease are different in each person; some people have mild symptoms while others have severe symptoms and are often hospitalised.

Severe symptoms:can be associated with the degree of damage to tissue or organs by sickle red blood cells.

Mild symptoms include fatigue, polyuria, paleness, jaundice, and shortness of breath. Slow growth is common among children due to anemia

Acute symptoms: Fever (temperature is above 38.5^0C for more than 24 hours), headache, painful crises, and sudden increase in paleness or jaundice. Hand-foot syndrome (swollen painful hands and feet), poor eyesight, tightness of the chest or sudden breathlessness, leg ulcers, presence of blood in the urine and painful erection of the penis

Warning signs of crises

SIGNS	SYMPTOMS
FEVER	38.3 ^{0}C or higher
PALLOR	• Noticeable change in complexion, lips, fingernails
BREATHING	• Dyspnea (difficulty breathing) • Tachypnea (fast rate of breathing) • Stertorous breathing (laboured breathing)
HEADACHE	• Sudden or constant • Dizziness
HEARTBEAT	• Tachycardia (rapid heartbeat) • Pounding

PAIN	• Head • Chest • Joints • Abdomen (abdominal distention) • Penis (prolonged erection)
SWELLING	• Hands • Feet • Joints (with redness)
MUSCULAR WEAKNESS	• Either side of the body

1.6 TREATMENT OF SCD

The clients are expected to take antibiotics to treat infection and it can also be used as prophylaxis

- They are advised to take extra fluids and pain killers when the need arises
- Folic acid is often used to help in the synthesis of blood.
- Blood transfusion is essential in cases of severe anemia, painful crises, lung infarction or during surgery.
- In clients with severe sickle cell disease, providers often use a medication called hydroxyurea to reduce frequency of painful crises and acute chest syndrome.
  - NOTE: Hydroxyurea is used to prevent crisis & not to treat crisis when it occurs.
- Babies and young children need daily doses of penicillin vaccination against childhood diseases with particular reference to pneumonia meningitis, influenza, and hepatitis to prevent infection.

1.7 COMPLICATIONS OF SCD

Common complications of SCD include:

- Chronic hemolytic anaemia
- Aplastic crises (stop making RBCs)
- Acute splenic sequestration (the spleen traps RBC)

- Painful crisis: Sickle cells do not move easily through small blood vessels, they usually get stuck and prevent blood flow, this results in pain that starts suddenly. This pain ranges from mild to severe and can last for any length of time.
- Bone and chest bacterial infections (common in children): common infections include influenza, meningitis, and hepatitis.
- Acute chest syndrome (ACS): this results from blockage of blood flow to the lungs and causes chest pain, coughing, difficulty in breading and fever. The symptom can be life-threatening if not properly managed. ACS is similar to pneumonia
- kidney failure
- Gall bladder stones and inflammation
- Vascular necrosis
- Stroke: this occurs when there is inadequate blood flow to the brain, stroke can be a lifelong disability and can cause learning problems
- Visual impairment: SCD affects blood vessels in the eye, this can result in long-time damage of the blood vessels
- Hand and foot syndrome (common in children): this occurs as a result of poor venous return and usually associated with fever.

Summary of SCD complications

1.1 ORGAN/TISSUE INVOLVED	*PROBLEMS CAUSED*
KIDNEY	• Inability to control urination • Haematuria (blood in the urine) • Unconcentrated urine • Frequent urination • Kidney disease

SPLEEN	• Splenic sequestration (pooling of blood in the spleen) • Scared spleen becomes non-functional by age two contributing to increased risk for serious infections • Abdominal pain
LUNGS	• Pneumonia • Acute Chest Syndrome (sickling in the chest)
BONES	• Infection • Aseptic necrosis (breakdown of the bone)
BRAIN	• Stroke • Headache
SKIN	• Slow healing leg ulcers
PENIS	• Priapism (painful unwanted erection)
EYES	• Sickle cell retinopathy (changes in the blood vessels in the eye)
LIVER	• Enlarged liver • Gallstones • Jaundice (yellowing of eyes and skin)

MODULE 2

Unit 2: PREVENTION OF CRISIS/SELF CARE MANAGEMENT

2.0 MODULE OBJECTIVES

At the end of this module, the participants should understand:

1. Sickle cell disease crises
2. How to prevent infections
3. How to prevent SCD complications
4. How to engage in therapeutics behaviour /self-care management
5. How to take action to access resources that will improve their quality of health

2.0 MODULE OUTLINE

- Sickle cell disease crises
- Prevention of infection
- Prevention of SCD complications
- Engaging in therapeutics behavior/Self-care management
- Taking actions to access resources that will improve the quality of life

2.1 SICKLE CELL DISEASE CRISES

Persons with SCD who arefeeling and looking well and have been free from acute symptoms for at least two weeks are regarded as being in a steady state of health. A steady-state is the usual state of being until sickle cell crisis, acute infection or some other acute illness interrupts it. The goal of management of SCD is to achieve and maintain steady state of health.

A sickle cell crisis is a non-infective episode of acute illness that can be attributed, largely or entirely to sickle cell disorder. The most dramatic and most frequent event is the pain crisis, but the most critical, life-threatening events include anemia crisis, acute chest syndrome, acute girdle syndrome and stroke.

The frequency of crisis is often used as a measure of the severity of the sickle cell syndrome. Each crisis episode represents a reduction in the quality and quantity of individuals (quality because of the suffering involved, quantity because of the time lost to illness).

Causes of Anaemia Crisis

Causes	Possible trigger factors
Excessive rate of red cell breakdown (hyper-hemolytic crisis)	Infections e.g. malaria; G6PD
Acute splenic sequestration	Unknown
Acute hepatic sequestration	Unknown
Acute splanchnic sequestration or girdle syndrome	Unknown, possible infection
Acute pulmonary sequestration	Unknown
Bone marrow depression	Erythropoietin (EPO) deficiency in kidney failure
Bone marrow failure (aplastic crisis)	Parvovirus B19 infection

2.1.1 Pain Crisis and its Treatment

The direct cause of sickle cell pain is unknown. A painful crisis is unpredictable. It may start suddenly or it may give warning signs. The following factors may trigger painful crises, but in many cases the trigger is unknown.

1. Dehydration (dryness from inadequate water in the body)
2. Infections (such as malaria, colds, urine infections, throat infections, chest infections)
3. Extreme weather conditions (too cold or too hot)
4. Strenuous physical exercise
5. School examinations
6. Menstrual periods in young girls
7. Excessive tiredness
8. Anxiety and fear
9. Smoking (it can reduce the amount of oxygen the red cells pick up in the lungs)
10. High attitudes (less oxygen in the air)

2.1.2 Non-drug treatment of pain

- Avoiding trigger factors
- Applying moderate heat (great care must be taken to avoid causing burns or scalds). Many affected people find relief by applying a hot towel or a hot water bottle to the site of the pain, followed by massaging with a menthol-containing balm.
- Some patients find that mild exercise reduces the level of pain.
- Relaxation therapy may be used to reduce anxiety
- Aromatherapy, massage therapy, and stimulation of nerves by a machine (TENS) may be useful.

2.2 PREVENTION OF INFECTION

Prevention of infection is an essential ingredient to healthy living with SCD. Infections have been implicated in many of the complications that arise from SCD. The best defence against complications is to prevent infection

The sufferer ways of preventing infections include:

2.2.1 Handwashing

Common illnesses like influenza are dangerous for a client with SCD and can be prevented by frequent hand washing. Washing hands is one of the best ways to prevent infections. People with SCD, their families, and other caretakers should wash their hands with soap and clean water many times each day.

Wash your hands before:

- Making food
- Eating

Wash your hands after:

- Using the bathroom
- Blowing your nose, coughing, or sneezing
- Shaking hands
- Touch people or things that can carry germs, such as:
- Diapers or child who has used the toilet
- Food that has not been cooked
- Animals or animal waste
- Trash
- A person who is sick

2.2.2 Food Safety

Salmonella, a type of bacterium in some foods and some other infectious microorganisms, can be especially harmful to a client with SCD. To avoid exposure to this and other bacteria and to stay safe when cooking and eating; it is essential to wash vegetables and fruits well before eating them, cook meat until it is done, juices should run clear and there should be no pink inside.

2.2.3 Vaccines and Penicillin

Vaccines are a great way to prevent many serious infections. Adults and children with SCD should have an influenza vaccine every year, as well as the pneumococcal vaccine and others. Penicillin can help prevent infections. Clients with SCD should take penicillin.

2.2.3 Learn healthy habits

Drinking 8 to 10 glasses of water every day and eating healthy food will help to maintain hydration and proper nutrition. People with SCD should maintain balanced body temperature, getting neither too hot nor cold. Participating in physical activity to help stay healthy is very important. However, it is important that you do not overdo it, rest when tired, and drink plenty of water.

2.2.4 Find good medical care

SCD is a complex disease. Good quality medical care from health professionals who know about the disease can help prevent some serious problems. Often the best choice is to be managed by a hematologist. It is important that you seek help when you:

a. Have pain anywhere in the body that did not go away with treatment at home

b. Any sudden problem with vision

2. Get support: Find a support group or community-based organisation that can provide information, assistance, and support.

2.3 PREVENTION OF COMPLICATIONS

a. You need to live a healthy life:

- Get enough rest daily
- Eat a varied diet
- Have minimum exercise (do not overdo it)

b. Avoid stress:

- Have enough sleep daily
- Avoid stressful situations
- Do not work yourself up to a point of exhaustion

c. Avoid dehydration:

- Drink a lot of fluid, especially in hot weather. Also, if you have fever, vomiting, and diarrhoea you need copious water intake

d. Avoid cold:

- Avoid swimming in cold water and dress warmly in winter.
- After swimming, have a warm birth and dry off quickly.

e. Avoid infection:

- Maintain good personal hygiene
- Apart from normal vaccination like DTP **v**accination with pneumovax is strongly recommended (the first dose at age 2 to 3 years repeat at 5 years when there is any indication).

2.4 SELF CARE MANAGEMENT

2.4.1 Nutritional Management

There is no special diet for people with sickle cell disease; however, recent research shows that people with sickle cell need about 20 percent more calories than others to fuel their production of red blood cells. Not getting enough calories may lead to delays in growth and maturation. As a result of some of the pain medications that people with SCD take, they often come down with constipation. Therefore, food rich in fibre is critical to their health, whole grains and fruits will help prevent or treat constipation. People with sickle cell disease need extra folic acid in order to

produce red blood cells more quickly. These can be found in foods such as grains, fruits, and leafy green vegetables.

2.4.2 Self-care management of physical complications of SCD

Chronic anemia

If you have reduced stamina or notice yellowing of eye and skin; it is likely you have chronic anemia

- ❖ You will need to break from strenuous activities
- ❖ You need to rest till you are able to build your stamina

If your PCV result is low or suddenly drops. It is likely you have an infection that affects red blood cells thus breaking it down faster than normal. You may experience the following symptoms:

- ❖ Headache
- ❖ Irritability
- ❖ Poor appetite
- ❖ Rapid heartbeat
- ❖ Paleness or pale color in palms and skin

You will need to see your doctor immediately. A blood transfusion may be necessary.

If you have pains: it usually results from blockage of blood flow by the sickled red cell that will result in low oxygen to the tissue. The pain could be due to fever, infection, exposure to extreme cold, physical exhaustion, and unusual stress or anxiety. When pain is severe the person might need hospitalisation.

Body temperature management High body temperature

- Do not sit directly opposite fan or air conditioner
- Wear jacket during cold
- Take adequate water

- Never apply a cold pack on the pain site (this will increase vessel constriction and cause more pain.
- Moist heat application (this will dilate the blood vessels and increase blood flow to the affected site.

Dehydration

This often occurs as a result of vomiting, diarrhoea or fever. This is also a major cause of pain episodes. Symptoms include wrinkled skin, excessive thirst, poor skin turgor, heart palpitation, weakness, and decreased urine output.

- Copious water intake
- If as a result of diarrhoea, use Oral Rehydration Therapy
- If severe, hospitalisation might be required

Splenic sequestration

This usually occurs when there are sickling cells in the spleen. This brings about sudden entrapment of a large amount of blood in the spleen. The symptoms include; weakness, irritability, unusual sleepiness, paleness, big spleen (swollen in the left side of the abdomen), fast heartbeat and pain in the left side of the abdomen.

- You will need to take a lot of fluid
- Use prescribed analgesic
- See your doctor

Priapism (painful swelling of the penis)

This is usually due to trapped red blood cells; it often occurs without sexual excitement and affects any age even young children. The major symptom is unwanted erection which may be more than 24 hours.

- Take plenty of fluid to enhance the flushing of dead cells
- See your doctor if symptom persists

2.5 PREVENTION OF CRISIS

These steps are important in the prevention of crisis:

- You have to avoid the intake of alcohol
- Avoid smoking
- Learn to manage emotional and physical stress effectively
- Treat infection immediately

MODULE 3

UNIT 3 COPING WITH SICKLE CELL DISEASE

3.0 MODULE OBJECTIVES

At the end of this module, the participants should understand:

1. How to manage pain
2. Common relaxation technique for people with SCD
3. How to reduce and avoid stress

3.1 MODULE OUTLINE

- Introduction
- Pain management in SCD
- Relaxation technique
- Coping with stress

3.2 INTRODUCTION

Family coping is imperative in the management of SCD, parents/caregivers need to plan for the comfort of their wards with SCD. Caregivers have to think ahead (each morning) about what their wards will do during the day. This discussion will assist the client in ensuring comfortable conditions such as putting on clothes and jackets or sweater during cold weather, taking time to rest when tired, sharing feelings with friends and family when worried, irritable, and depressed or having unstable focus. Caregivers should praise their wards appropriately

3.3 MANAGEMENT OF SCD RELATED PAIN

Pain is an uncomfortable and highly personal experience that can be unnoticeable to others.
Though pain is a universal experience, the nature of the experience is peculiar to the person depending on the type of pain experienced, the psychological context or meaning, and the response to the pain.

3.3.1 Factors affecting the pain experience

Ethnic and Cultural Values: Ethnic background and cultural heritage have long been recognised as factors that influence both a person's reaction to pain and the expression of that pain. Behaviour related to pain is part of the socialisation process. Although there appears to be little variation in pain threshold, cultural background can affect the level of pain that an individual is willing to tolerate**.**

Developmental Stage: The age and phase of development of an individual with SCD is a significant variable that will affect both the reaction and expression of pain.

Environment and Support Network: A strange environment can compound the pain.A lonely individual who does not have a support network can perceive pain as severe, wher eas an individual who has support from people around him will perceive less pain. Some people prefer to withdraw when they are in pain, whereas others prefer the distraction of people and activities around them. The family caregiver will give a person with SCD pain significant support.

Experiences of past pain: Previous experiences of pain can change individual pain sensitivity.People with SCD who often experience pain are more at risk of expected pain than ind ividuals without pain.Pain relief measure's success or lack of success also influences the expectat ions of a person for relief and future response to interventions.

3.3.2 Pharmacological Management of pain

This involves the utilisation of various pain killer drugs to manage pain. Common drugs range from opioid analgesic to nonopioid/nonsteroidal anti-inflammatory drugs (NSAIDS) and co-analgesic drugs.

3.3.3 Non-pharmacologic Pain Management

Non – pharmacologic pain management comprises of a multitude of physical, cognitive and behavioural therapy which includes pain management strategies for the body, mind, spirit and social interaction.

Target domain of pain control	Intervention
Body Massage	Applying heat Electric stimulation (TENS) Positioning, bracing (selective immobilization) Acupressure Diet, nutritional supplements Exercise, pacing activities
Mind	Relaxation, imagery Self-hypnosis Pain diary, journal writing Distracting attention Re-patterning thinking Attitude adjustment Reducing fear, anxiety, and stress Information about pain
Spiritual healing	Prayer meditation Self-reflection Meaningful rituals Energy work
Social interaction	Functional restoration Improved communication Family therapy Problem-solving Vocational training Support

3.4 RELAXATION TECHNIQUE

Proper understanding and utilisation of relaxation techniques will ensure effective coping with SCD.

People with SCD should pay attention to the following relaxation techniques:

- The client should pay attention to breathing:
  - Breath slowly and deeply than usual
  - As you inhale, think about fresh air coming slowly to your chest, fingers, and toes
  - As you breathe out imagine that any tension stored in any part of your body is moving out into space
  - Let your body relax as you breathe in and out.
- The client should picture himself/herself a place where you feel calm and happy
  - Think of the detail you will see in this place
  - Imagine sounds you might enjoy there and think about what you would like to touch, taste, and smell in your favorite place
  - Take slow breaths and let yourself take a vacation in your mind
- If notice that your wards often think about situations or events in your life and feeling angry, anxious, or discouraged. Encourage him/her to:
  - Use the relaxing, breathing technique to shift his/her mind ‘s focus
  - Ask him/herself about the stressful situation
  - Think about how to respond to it (differently from the usual ways)
  - Reflect on how you can source assistance in terms of ideas from people around.

- Ask for help if you cannot think through
- Source for support (emotional, financial, social and spiritual) at difficult times.

➢ Relaxation techniques in pain management

- Massage clients when experiencing pain
- Listen to solemn music
- Use heating pad with caution (do not use cold pad)

3.4 COPING WITH STRESS

Stress is a positive change like marriage, job promotion or building a house, it can also be negative such as failing an examination or loss of loved ones. Depending on the type of stress an individual is undergoing. They need to be realistic about their situation and open their mind to receive help from significant people. Stress can also complicate the disease process in people with SCD.

3.4.1 Benefits of stress management

- You will sleep better
- You will have good control of your weight
- You will be in a better mood
- You will have less pain
- You will seldom be sick

3.4.2 Strategies for coping with stress

Several strategies can be beneficial to clients with SCD to manage and cope with stress. Some of the strategies that can be adopted include:

Exercise: Regular, mild, non-strenuous exercise promotes both physical and emotional health. Physiologic advantages comprise of improved muscle tone, increased cardiopulmonary function, and weight control. Psychological advantages comprise relief of tension, a feeling of well-being and relaxation.

Sleep: Sleep regains the body's energy level and is an important aspect of stress management. To ensure adequate sleep, people with SCD will need to attain and maintain a high level of satisfaction as regards the management of pain and also learn methods that will enhance peace of the mind.

Time control: Usually, people who manage their time effectively experience less stress because they feel more in control of their circumstances

Stress relief methods: These methods are listening to music, singing, dancing, and meditating. All these could be used to release tension within the mind.

MODULE 4

UNIT 4.0 SELF COMPETENCE

4.0 MODULE OBJECTIVES

At the end of this module, the participants should understand:

1. Self-concept
2. Component of self-concept
3. Factors that affect self-concept
4. Self-esteem
5. Behaviours that enhance self-esteem

4.1 MODULE OUTLINE

1. Self-concept
2. Component of self-concept
3. Factors that affect self-concept
4. Self-esteem
5. Behaviours that enhance self-esteem

4.2 SELF-CONCEPT.

Self-concept is individual consciousness and a mental image of oneself. People that have positive self-concept are able to cope with the difficulties associated with sickle cell diseases, develop and sustain interpersonal relationships and withstand psychological and other SCD problems.

Self-concept includes perceptions in terms of appearance, values, and beliefs which influence individual behaviour. Self-concept influences the following:

- How one thinks, talks and acts
- How one sees and treats another person
- Choices one makes
- One's ability to give and receive love
- Ability to take action and to change things

There are four dimensions of self-concept:

- self-knowledge: the knowledge that one has about oneself including insight into one's abilities, natures, and limitation
- self-competence: what one expects of oneself; maybe a realistic or unrealistic expectation
- social self: how a person is perceived by others and society
- Social evaluation: the appraisal of oneself in relationship to others, events, or situations.

4.3 COMPONENTS OF SELF-CONCEPT

4.3.1 Personal Identity

This is the awareness of individuality and uniqueness in terms of name, sex, age, race, ethnic origin or culture, occupation or roles, talents and other situational characteristics like marital status and education. It also includes individual beliefs, values, personality, and character.

4.3.2 Body Image

Body image is the conscious and unconscious feelings about one's appearance. It includes clothing, makeup, hairstyle, jewelry, and day-to-day body shape. Cultural and societal values also influence a person's body image.

4.3.3 Role Expectation

This is how someone is able to perform a task given to him or her according to his/her own personal judgment. It predicts the way he or she feels about himself/ herself.

4.4 FACTORS THAT AFFECT SELF-CONCEPT

To enhance the self-concept of people with SCD, the caregivers must good communication skills. Caregivers can help clients in the following ways:

- Encourage clients to express their feelings
- Allow them to participate in the family decision-making process like other children
- Answer their question appropriately and with utmost sincerity, do not ignore them
- Encourage them to give detailed information as regards their health
- Assist them to explore their positive qualities and strengths
- Encourage them to express positive self-evaluation more than negative self-evaluation
- Encourage them to make a positive assertion about their health status

4.5 SELF ESTEEM

Self-confidence is a personal assessment of one's value in terms of personal standards and effectiveness compare to their peer performances. An individual with a high self-confidence has a sense of meaning, skill, the capacity to deal with life, and control over his / her health status.

4.6 BEHAVIOUR THAT ENHANCES SELF ESTEEM

Pay attention to your own needs and wants: Listen to what your body, your mind, and your heart are telling you. For instance, if your body is telling you that you have been sitting down too long, stand up and stretch. If your heart is longing to spend more time with a special friend, do it. If your mind is telling you to clean up your basement, listen to your favorite music, or stop thinking bad thoughts about yourself, take those thoughts seriously.

Take very good care of yourself: As you were growing up you might not have learned how to take good care of yourself. In fact, much of your attention might have been on taking care of others, on just getting by, or on "behaving well." Begin today to take good care of yourself. Treat yourself as a wonderful parent would treat a small child or as one very best friend might treat another. If you work at taking good care of yourself, you will find that you feel better about yourself. Here are some ways to take good care of yourself:

- Eat healthy foods and avoid junk foods.

- Exercise: Moving your body helps you to feel better and improves your self-esteem. Arrange a time every day or as often as possible when you can get some exercise, this should be done in moderation.

- Do personal hygiene tasks that make you feel better about yourself–things like taking a regular shower or bath, washing and styling your hair, trimming your nails, brushing and flossing your teeth?

- Plan fun activities for yourself. Learn new things every day.

Take time to do things you enjoy: You may be so busy, or feel so badly about yourself, that you spend little or no time doing things you enjoy-things like playing a musical instrument, doing a craft project etc.

Take full advantage of your own special talents and skills: make things for yourself, family, and friends.

Dress in clothes that make you feel good about yourself.

Give yourself rewards—you are a great person. Listen to a CD or tape.

Spend time with people who make you feel good about yourself—people who treat you well. Avoid people who treat you badly.

Make your living space a place that honours the person you are: Whether you live in a single room, a small apartment, or a large home, make that space comfortable and attractive for you. If you share your living space with others, have some space that is just for you--a place where you can keep your things and know that they will not be disturbed and that you can decorate any way you choose.

Display items that you find attractive or that remind you of your achievements or of special times or people in your life.

Begin to do things that will make you feel better.

Make it a point to treat yourself well every day: Before you go to bed each night, write about how you treated yourself well during the day.

Developing Positive Affirmations: Affirmations are positive statements that you can make about yourself that make you feel better about yourself. They describe ways you would like to feel about yourself all the time. They may not, however, describe how you feel about yourself right now.

Explore your feelings: It is very essential to recognize the distinction between healthy and unhealthy feelings. The situation around you may make you happy or unhappy, i.e. having a bad day doesn't make you a failure, keep improving your challenges until you overcome the difficulties.

Future objectives: set realistic and achievable future objectives and meet the dreams of life. Do not underestimate yourself. You have the ability to accomplish anything and you can

achieve your objectives with some hard work and dedication.Without this self-confidence, achieving a good lifestyle can be hard – remain positive, build confidence in yourself.