UNIVERSITY OF BAHRAIN

College of Health and Sport Sciences

Department of Nursing

Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adult with Sickle Cell Disease

In Partial Fulfillment of the Requirement for the Degree of Master of Science in Adult Health Nursing

Submitted by
Hasan Abdali Khalil Ebrahim
University ID: 20052138

Supervised by
Dr. Zohour Ibrahim Mahmoud Rashwan
(Assistant Professor)
University of Bahrain

Kingdom of Bahrain
April. 2023

UNIVERSITY OF BAHRAIN

College of Health and Sport Sciences

Nursing Department

Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adult with Sickle Cell Disease

In Partial Fulfillment of the Requirement for the Degree of Master of Science in Adult Health Nursing

Submitted by

Hasan Abdali Khalil Ebrahim

University ID: 20052138

Supervised by

Dr. Zohour Ibrahim Mahmoud Rashwan

(Assistant Professor)

University of Bahrain

Kingdom of Bahrain

April, 2023

University of Bahrain
Deanship of Graduate Studies
and Scientific Research



جامعة البحرين
عمادة الدارسات العليا والبحث العلمي

Thesis Discussion Committee Decision

Student Name: Hasan Abdali Khalil Ebrahim	Student ID: 20052138
Department: Nursing	College: Health and Sport Sciences
Program: Master of Science in Adult Health Nursing	
Thesis Title: Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adults with Sickle Cell Disease.	
Supervisor's name: Dr. Zohour Ibrahim Mahmoud Rashwan	Student's GPA: 3.14

The Discussion Committee met on ___ 2nd April 2023_ In Microsoft team meeting. Upon discussing the student whose details arestated above in public, the discussion committee recommends the following:

The student is awarded a grade __**A-**_____ in the thesis subject.

☐ Without making any changes to the thesis.

☒ After making the modifications attached with this decision.

Discussion Committee Members Approval:

Name		Signature
Dr. Zohour Ibrahim Mahmoud Rashwan	(Advisor)	Dr Zohour Rashwan
Dr. Hala Sanad	(Internal Examiner)	
Dr Punitha Josephine S	(External Examiner)	

Abstract

Introduction: Sickle Cell Disease (SCD) is a chronic disease that affects millions of people globally, causing chronic pain episodes and complications that significantly impact patients' self-care capacity. Empowerment-Based Interventions (EBI) have been shown to improve self-efficacy, self-care capacity, and Health-Related Quality of Life (HRQoL) among patients with chronic diseases. The aim of this study is to investigate the effect of EBI on self-efficacy, self-care capacity, and HRQoL among adults with SCD.

Methods: A randomized controlled trial, two groups, pre-posttest study was conducted at two primary health care centers in Bahrain using a cluster sampling technique. A sample of 68 adults with SCD were randomly assigned to two groups. The EBI was implemented through structured small-group discussion sessions, individualized consultations, and follow-up sessions. Individualized consultations for self-management were done by adopting the 5A model (Assess, Advise, Agree, Assistant, and Arrange). Weekly communication was done to check the patient's progress, and both groups were re-evaluated for self-efficacy, self-care capacity, and HRQoL after one month.

Results: The results showed a significant improvement in the EBI group regarding their ability to keep doing most of the day-to-day activities as the mean score was 4.31±0.79 compared to 3.47±0.89 in the control group ($P<0.001$). Similarly, the application of the EBI enabled adults with SCD to reduce pain by using methods other than taking extra medication ($P<0.001$). Regarding self-care, adults who received the EBI exhibited a higher capacity for self-care as their mean score was 4.32±0.35 compared to 3.49±0.48 in the control group ($P<0.001$). The EBI also enabled them to develop a capacity for self-care (4.02±0.42) compared to the routine health care (3.02±0.52). As for the HRQoL, a noticeable improvement in the general health among patients in the EBI compared to the control one ($P=0.02$).

Discussion: The findings of this study support the effectiveness of EBI using the 5As model in improving self-efficacy, self-care capacity, and HRQoL among patients with SCD. The use of individualized consultations and follow-up sessions allowed for tailored interventions that addressed the specific needs of each patient. The weekly communication also allowed for monitoring of patients' progress and any necessary adjustments to the intervention. The significant improvement in self-care capacity and the ability to keep doing day-to-day activities has important implications for patients' daily lives and their ability to manage their disease. The reduction in pain without the need for extra medication is also an important benefit.

Conclusion: In conclusion, this study highlights the effectiveness of EBI using the 5As model in improving self-efficacy, self-care capacity, and HRQoL among patients with SCD. Healthcare providers should consider adopting this intervention in their practice to improve the quality of life of patients with SCD. Further research is needed to explore the long-term effects of EBI and to identify the optimal delivery methods for this intervention.

Keywords: Sickle Cell Disease; Self-efficacy; Self-care; Self-Management Activities of Daily Living.

Publications

Hasan, H., & Rashwan, Z. (2022, September 23). Empowered-Based Intervention: To What Extent Do Advanced Practice Nurses Enable Adults with Sickle Cell Disease to improve their Self-efficacy and Self-Care Capacity? Nurses Voice to Lead: Invest in Nursing for Health Security. https://educationplus.me/home/

Acknowledgment

I would like to express my deepest gratitude to **Allah** for granting me the strength, guidance, and blessings throughout this research journey. Your divine presence has been my constant source of inspiration and motivation.

I am immensely grateful to my supervisor, **Dr. Zohour Ibrahim Rashwan**, Assistant Professor of Nursing, College of Health and Sport Sciences, the University of Bahrain. Your expertise, guidance, and unwavering support have been instrumental in shaping this study. Your valuable insights and constructive feedback have significantly contributed to its quality and depth.

I extend my heartfelt appreciation to all the **adult patients with sickle cell disease** who participated in this study. Their willingness to share their experiences and insights has been invaluable. Their contributions have enhanced the understanding of ambulatory triage in the context of primary health care centers in Bahrain.

I would also like to express my gratitude to all of the **SMC staff members** who taught me in the clinical areas. Your knowledge, expertise, and mentorship have played a crucial role in shaping my nursing skills and understanding of patient care.

I am grateful to my **colleagues** at the **Shaikh Jaber Al Ahmed Al Sabah Health Centre** for their cooperation, support, and encouragement throughout this research endeavor. Their collaboration and shared insights have enriched the findings of this study.

Lastly, I would like to acknowledge everyone in the **Nursing Department** for their cooperation and support during the challenging times of the COVID-19 pandemic. Your resilience, dedication, and commitment to patient care have been truly inspiring.

To all those mentioned above, I am deeply grateful for your contributions, guidance, and support. This research study would not have been possible without your involvement and assistance. May Allah bless you all abundantly.

Sincerely,

Hasan

Dedication

I dedicate this study to my **beloved mother**, who has always been my source of inspiration and strength. Her unwavering support and encouragement have been instrumental in my academic and professional journey.

I also dedicate this study to my **sincere father**, whose guidance and wisdom have shaped my character and values. His unwavering commitment to excellence has been a constant source of motivation for me.

To my **dear wife**, who has been my pillar of support and encouragement throughout this journey. Her love and understanding have been my source of comfort and inspiration.

To my **lovely family**, who have always been there for me, providing me with the love, support, and encouragement that I needed to succeed. Their unwavering faith in me has been my source of strength and motivation.

I am grateful for their love and support, and I dedicate this study to them with all my heart.

TABLE OF CONTENT

Chapter	Page
LIST OF TABLES	ii
LIST OF FIGURES	iii
LIST OF ABBREVIATIONS	iv
CHAPTER I	
Introduction	2
Aim of the Study	5
Research Question/ Hypotheses	5
Study Significance	6
CHAPTER II	
Review of Literature	7
First outline of the review	7
Second outline of the review	10
Third outline of the review	12
Fourth outline of the review	15
Fifth outline of the review	17
Sixth outline of the review	18
Seventh outline of the review	22
Eighth outline of the review	27
Chapter II. Materials and Methods	31
Chapter IV. Results	54
Chapter V. Discussion	88
Chapter VI. Conclusion, Limitation, Recommendations and Nursing Implication	102
Chapter VII. Summary	106
REFERENCES	114
APPENDICES	133

LIST OF TABLES

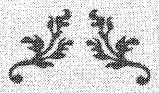
TABLE		PAGE
1.	The eight dimensions of quality of life	38
2.	Individualized consultations and follow-up sessions using 5 a's behavior change model	50
3.	Socio-demographic characteristics of adults with sickle cell disease	56
4.	Clinical data of adults with sickle cell disease	59
5.	Self-efficacy among adults with sickle cell disease in the EBI and control groups at pre, and posttest	62
6.	Comparison between self-care dimensions among adults with SCD in the EBI and control groups at pre, and post-test	65
7.	Self-care capacity among adults with sickle cell disease in the EBI and control groups at pre, and post-test	67
8.	Physical functioning among adults with sickle cell disease in the EBI and control groups at pre, and post-test	69
9.	Role limitations due to physical health among adults with sickle cell disease in the EBI and control groups at pre, and posttest	72
10.	Role limitations due to emotional problems among adults with sickle cell disease in the EBI and control groups at pre, and post-test	73
11.	Social functioning among adults with sickle cell disease in the EBI and control groups at pre, and posttest	75
12.	Pain among adults with sickle cell disease in the EBI and control groups at pre, and post-test	76
13.	Energy/fatigue among adults with sickle cell disease in the EBI and control groups at pre, and posttest	78
14.	Emotional well-being among adults with sickle cell disease in the EBI and control groups at pre, and post-test	80
15.	General health among adults with sickle cell disease in the EBI and control groups at pre, and Posttest	83
16.	Health-related quality of life among adults with sickle cell disease in the EBI and control groups at pre, and posttest	86

LIST OF FIGURES

Figure		Page
1.	Normal Structure of the Hemoglobin (Hb) Molecules	8
2.	Change in The Amino Acids Sequence of Sickled Hemoglobin	8
3.	A cross-section of a normal and abnormal red blood cell	9
4.	Gene inheritance probability for sickle cell disease	11
5.	Conceptual model: Orem' s theory of self-care nursing	23
6.	Conceptual Model of Orem's Nursing Systems Theory	25
7.	Flow Chart of Randomized HCs Selection	33
8.	Consort Flow Chart of Participants' Allocation	35
9.	5 A's Behavior Change Model	47
10.	Socio-Demographic Characteristics of Adults with Sickle Cell Disease	57
11.	Clinical Date of Adults with Sickle Cell Disease	60

LIST OF ABBREVIATIONS

ACS	**: Acute Chest Syndrome**
ADL	**: Activities of Daily Living**
CNS	**: Central Nervous System**
CT	**: Computed tomography**
EBI	**: Empowerment-Based Interventions**
ECG	**: Electrocardiograms**
Hb	**: Hemoglobin**
HbA	**: Adult Hemoglobin**
HbF	**: Fetal Hb**
HbS	**: Sickled Hemoglobin**
MRI	**: Magnetic Resonance Imaging**
RBCs	**: Red Blood Cells**
SCA	**: Sickle Cell Anemia**
SCD	**: Sickle Cell Disease**
SF-36	**: The 36-Item Short Form Survey**
VOC	**: Vaso-Occlusion**
WHO	**: World Health Organization**



Chapter I

Introduction



INTRODUCTION

Sickle Cell Disease (SCD) is an inherited autosomal recessive hemoglobinopathy in which there is a mutation in the beta polypeptide chain of the Hemoglobin (Hb) molecule (Hockenberry & Wilson, 2019; Al-Saleh et al., 2021). This mutation leads to decrease in the Hb oxygen-carrying capacity, and subsequently, hypoxemia will be evident.

Several factors will worsen the condition, such as; dehydration, acidosis, infections, hypoxia, physical exertion, climate changes, and altitude. Exposure to these factors may result in alteration in the shape of the Red Blood Cells (RBCs), which will take the sickle appearance. Moreover, the aggregation of the sickled RBCs will occlude the small blood vessels resulting in tissue ischemia. This Vaso-Occlusion (VOC), in turn, leads to a wide variety of complications as severe musculoskeletal pain, infections, heart disease, renal failure, stroke, leg ulcers, and proliferative retinopathy (Issom et al., 2021).

The Kingdom of Bahrain is one of the many countries inflicted with SCD. According to Yaqoob & Nasaif (2015), there are approximately 18,000 patients diagnosed with SCD. However, only 5,000 of them have been registered in the health ministry and are being treated either for the disease or its complications. The occurrence of any SCD associated complications profoundly impacts patients' self-care capacity (Al Raqaishi et al.,2021).

Self-care capacity refers to individuals' ability to perform Activities of Daily Living (ADL) such as dressing, bathing, eating, shopping, and cooking. It also includes the patients' participation in their general therapeutic activities using personal skills, abilities, and attitudes to improve their wellbeing, health outcomes, and Health-Related Quality of Life (HRQoL) (Ahmadi et al., 2014; Jenerette & Murdaugh, 2008). From Orem's theory standpoint, "the ability to exercise self-care among individuals, families, and groups is an important

consideration in the planning and delivery of nursing care" (Riesch & Hauck, 1988, p. 245). Promoting self-care capacity is a priority nursing intervention, particularly for adults with SCD. In order to successfully accomplish ADL as well as manage pain effectively, patients with SCD should exhibit self-efficacy (Matthie, 2015).

Self-efficacy is an internal belief in one's ability to control and manage the disease symptoms on a daily basis in order to achieve the desired outcomes (Adegbola, 2011). In this context, several studies confirmed that the greater levels of self-efficacy not only helped these patients to mitigate pain and crises but also increased their coping abilities, adherence to treatment regimens, and greater competence to perform home self-management.

Nurses play a crucial role in improving self-care capacity among patients with SCD and fostering their self-efficacy through continuous education and empowerment (Hoffman et al., 2013). Empowerment theory is a major framework for community psychology aimed to guide individuals' self-management and promote their health and wellbeing (Minkler & Wallerstein, 2012; Rappaport, 1987; Wallerstein, 2006).

Empowerment is an enabling process through which the individuals exert control over their lives by equipping them with the necessary information and extending their awareness regarding the available alternatives. This will optimize the use of their own competencies rather than being passive recipients of professional care. Castro et al. (2016) claimed that patients' empowerment is a more comprehensive concept than just patient participation and centeredness. Hence, this kind of intervention focuses on the individuals' strengths, capabilities, and adaptability. Empowerment-Based Interventions (EBI) have become a widely used approach for patients with chronic illnesses. Utilizing EBI represents a shift from a focus on ameliorating deficits and addressing risks to the development of capacity (Mogueo et al., 2021). Similar

to other chronic diseases, EBI is particularly needed among patients with SCD. In order to avoid the unfavorable consequences, such patients must take charge of their health by adopting self-care measures including, but not limited to, maintaining adequate oxygenation, hydration, healthy diet, rest, and avoiding extreme temperatures. These measures may help alleviate painful crises and reduce the need to seek health care intervention (Lee et al., 2012).

Problem Statement

Globally, millions of people are affected by SCD. Those living in sub-Saharan Africa, southern and central America, Saudi Arabia, Bahrain, India, and Mediterranean countries like Turkey, Greece, and Italy are more likely to suffer from it (Data & Statistics on Sickle Cell Disease, 2016). In the Kingdom of Bahrain, SCD is a public health issue as a result of the heterozygous advantage of sickle cell carriers, and it has a comparatively higher prevalence, which was projected to be approximately 8664 cases in 2019. The disease is frequently associated with crises that may necessitate hospitalization and frequent visits to specialized clinics. Regarding utilization of the primary health care resources, the Bahraini Ministry of health published that the total number of patients who visited the SCD specialized clinics at health centers in 2019 was 1,456 patients. Shaikh Jaber Alsabah Health center particularly had the highest number of visits (385 patients) (Ministry of health, 2019).

Furthermore, the total number of admitted patients with SCD at Salmaniya Medical Complex (SMC) was 3,434 patients in 2019 who required 22,355 days of care with an average length of stay of 6.5 days (Salmaniya Medical Complex Statistics - Ministry of Health, 2019). So, our study focuses on developing and applying an empowerment-based intervention, which can be adopted by such a vulnerable population. Home self-management is generally considered critical in coping with SCD because of its advantages in

enhancing health status and patients' quality of life, minimizing their suffering, reducing the length of stay, as well as lowering the treatment's costs (Jenerette et al., 2011).

Despite extensive efforts and advances in evidence-based sickle cell disease management, poor patient self-care capacity may be an obstacle in obtaining the desired outcomes. There is a paucity of research addressing the needs of patients with SCD in the Kingdom of Bahrain, exploring the effectiveness of different interventions in this susceptible population. The aim of the study is to investigate the effectiveness of empowerment-based interventions on promoting health-related quality of life outcomes among adult patients with sickle cell disease.

Aim of The Study

This study aims to investigate the effectiveness of EBI on the self-efficacy, self-management capacity and HRQoL among adults with SCD.

Hypotheses of The Study

The hypotheses of this study were: Adults with SCD who receive EBI exhibit higher self-efficacy, self- management capacity and HRQoL than those who do not.

Research Question

What is the effectiveness of EBI (Empowerment-Based Intervention) on self-efficacy, self-management capacity, and health-related quality of life (HRQOL) among adults with sickle cell disease (SCD)?

Study Significance

The significance of the study on empowerment-based intervention for promoting self-efficacy and self-management capacity among adults with sickle cell disease is that it can improve the quality of life of patients with chronic diseases. The study aims to empower patients to take an active role in managing their health and well-being by providing them with the necessary knowledge, skills, and resources. The study can help patients with sickle cell disease to develop self-efficacy and self-management capacity, which can lead to better health outcomes, reduced healthcare costs, and improved quality of life. The study can also contribute to the development of effective interventions for patients with chronic diseases, which can be used by healthcare professionals to improve patient outcomes.

Chapter II

Literature Review

LITERATURE REVIEW

Sickle cell disease (SCD) is a complex disorder marked by recurrent painful sensations that range in intensity from mild to fatal throughout the course of a patient's life. Sickle cell disease (SCD) refers to a group of hereditary disorders in which the adult hemoglobin (hemoglobin A, HbA) is totally or partially substituted by aberrant sickled hemoglobin (HbS) (Hockenberry, 2016).

Sickle cell disease is an umbrella term that includes different disorders. For instance, sickle cell C disorder is a heterozygous variation of SCD (HbSC). The HbSC is characterized by the presence of both HbS and hemoglobin C (HbC), where glutamic acid is replaced by Lysine at the 6^{th} position of the β chain. On the other hand, sickle thalassemia disease is a mix between sickle cell trait and β-thalassemia trait. There are two forms of sickle thalassemia disease namely β+ (beta plus) type and β0 (beta zero). In the β+ form, some healthy HbA can still be generated however there is no capacity to make healthy adult hemoglobin in the β0 form (Hockenberry, 2016). Even though, the terms SCD and sickle cell anemia (SCA) are interchangeably used, SCA is a homozygous form of SCD and is typically termed as HbSS.

There are several pathophysiological changes affecting the hemoglobin (Hb) molecules in patients with SCA. There are two main known types of Hb namely fetal and adult (postnatal) Hb. Normally, the fetal Hb (HbF) consists of two α and two γ polypeptide chains. While adult hemoglobin (HbA) is composed of two α and two β polypeptide chains (Figure 1).

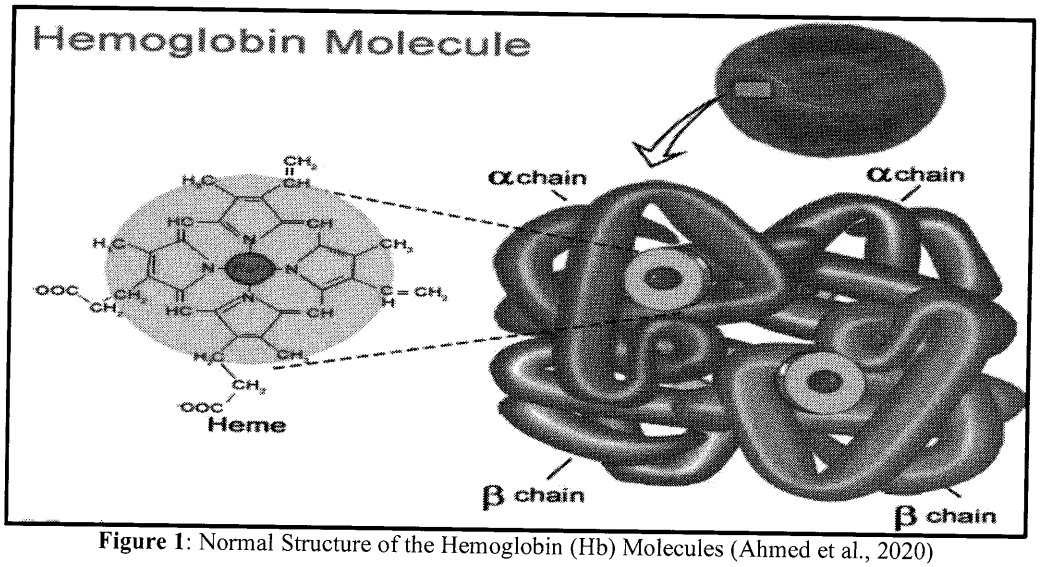


Figure 1: Normal Structure of the Hemoglobin (Hb) Molecules (Ahmed et al., 2020)

The β chain basically consists of two pairs of seven amino acids; Valine-Histidine-Leucine-Threonine-Proline-Glutamic Acid-Glutamic Acid. In SCA, HbS is the product of a single base pair mutation. The sickled hemoglobin (HbS) is caused by the replacement of the negatively charged (Polar) glutamate in residue in the globin gene on chromosome 11 with the uncharged (non-polar), hydrophobic valine at position six of hemoglobin's beta polypeptide unit (Figure 2). The substitution occurs due to a change in one of the β globin gene's nucleotides from adenine to thymine (Mandal et al., 2020).

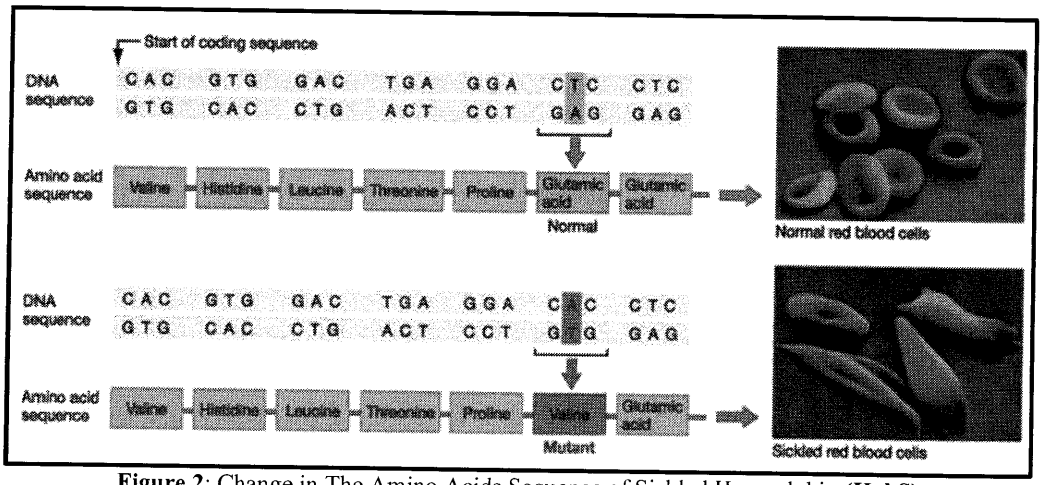


Figure 2: Change in The Amino Acids Sequence of Sickled Hemoglobin **(HgbS)**

Because the valine sticks out of the chain and interacts with neighboring non-polar amino acids as a consequence of this mutation, the beta polypeptide chains become sticky under low oxygen circumstances. The molecules bind together and eventually form a huge fibrous polymer, which causes the RBCs to deform into a "C" or sickle shape (Mandal et al., 2020). The sickling process occurs to a greater extent under certain circumstances such as dehydration, acidosis, hypoxia, and rising temperatures where the HbS changes its molecular structure to form long, thin crystals. When these filamentous crystals reach the cell wall, it transforms from the flexible RBC disk to a crescent or sickle-shaped RBC. The blood viscosity of patients with crystallized HbA is substantially much higher than the normal population (Olubiyi et al., 2019). As a result, sickled red blood cells get stuck in small blood vessels. This process represents the basic mechanisms leading to hemolytic anemia and to vaso-occlusive events in the microcirculation.

The sickling response is reversible when appropriate oxygen and hydration are provided. During this period, RBCs are visually indistinguishable from regular erythrocytes. After repeated instances of sickling and unsickling, RBCs become irreversibly sickled (Hockenberry, 2016) as illustrated in (Figure 3).

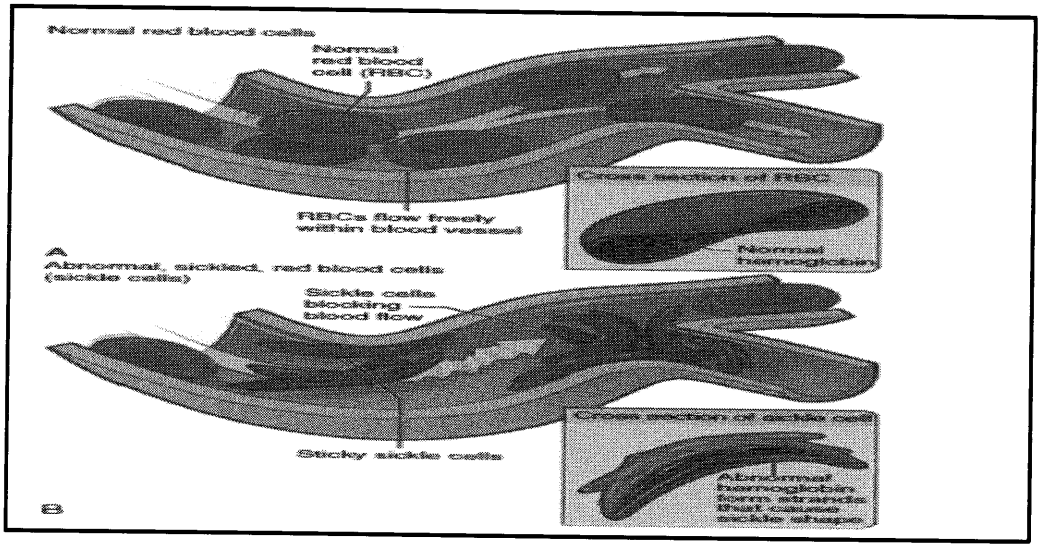


Figure 3: A, Normal red blood cells (RBCs) flowing freely in a blood vessel. The inset image shows a cross-section of a normal red blood cell with normal hemoglobin. **B,** Abnormal, sickled red blood cells clumping and blocking blood flow in a blood vessel. (From National Heart, Lung, and Blood Institute: What is sickle cell anemia? Bethesda, MD, 2008).

The sickled erythrocytes are unstable and hemolysis can occur both during intravascular flow and as a result of the stagnation of sickled cells in the crowded spleen. Due to the low life span of the RBCs, hyperplastic bone marrow is attempting to compensate for a lack of RBCs by increasing erythropoiesis (Hockenberry, 2016). However, the rate of RBCs breakdown is higher than the rate of production resulting in normocytic normochromic anemia. With increased hemolysis, hemosiderosis may develop. It is an excessive accumulation of iron deposits called hemosiderin in the tissues of different organs such as the liver, bone marrow, spleen, kidneys, and lymph nodes (Lamoureux et al., 2021).

The occurrence of SCD differs in various geographic locations. The incidence of SCD is approximately 8% among blacks, whereas the prevalence of sickle cell trait (SCT) amongst people of west Africa is estimated as high as 40 percent. It is believed that SCD affects approximately 20–25 million people worldwide, with the majority of those affected living in sub-Saharan Africa (Riley& Riley, 2019). In addition, approximately 100,000 individuals, most of whom are black, are believed to be carriers of the illness in the United States (Yacoub et al., 2019).

Sickle cell disease is an autosomal recessive genetic condition. Patients may get SCD in one of three ways. If both parents have SCT, then the individual has a 25% risk of having SCD, a 50% chance of having SCT, and a 25% chance of not having either illness. The second one has a 50% probability of inheriting SCD and a 50% chance of inheriting SCT if one parent has SCD and the other has SCT. Thirdly, if both parents have SCD, the patients will develop SCD with 100% certainty (Chatterjee et al., 2018).

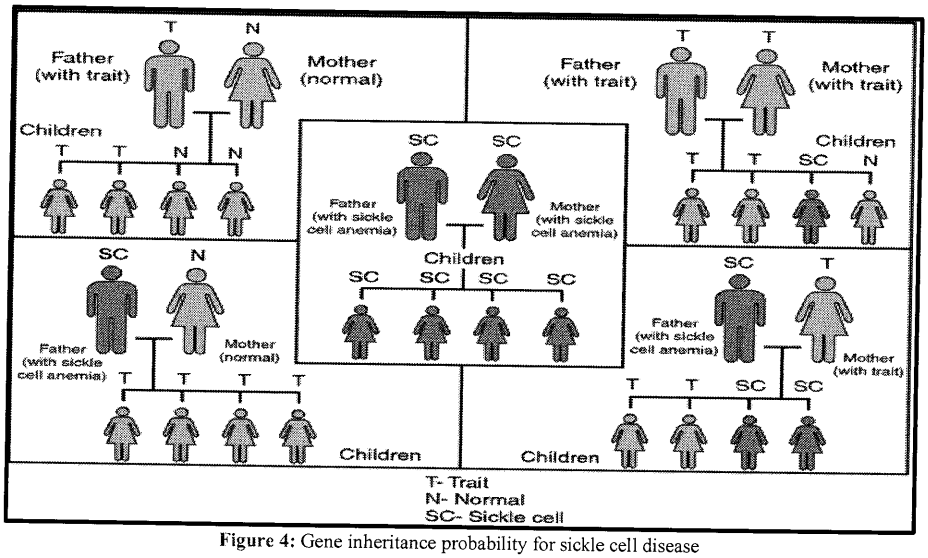


Figure 4: Gene inheritance probability for sickle cell disease

("Miller-Keane Encyclopedia & Dictionary of Medicine, Nursing & Allied Health 7th Edition," Elsevier)

Into the bargain, sickle cell trait RBCs contain one copy of normal adult hemoglobin (HbA) and one copy of mutant hemoglobin (HbS). Around 35%–45% of total hemoglobin is HbS and the remaining is HbA, resulting in the hemoglobin genotype HbAS. The HbS is caused by a missense mutation in which valine substitutes glutamic acid in the chain's sixth codon. The presence of HbA attenuates the HbS phenotype, decreasing the likelihood of polymer formation. Therefore, the majority of individuals with SCT exhibit no symptoms and have normal hematological characteristics (Jefferson et al, 2021). Nonetheless, the accumulated studies indicate that hypoxia may precipitate sickle-related consequences such as splenic infarction, thrombosis, papillary necrosis, and mortality SCT (Kehinde & Osundiji, 2020). The most common consequence is non-painful gross hematuria, which occurs predominantly throughout the adolescent and adult years. Extreme or prolonged deoxygenation, such as flying in an unpressurized aircraft or

participating in military training, may result in splenic sequestration and severe anemia, which can be fatal (Hockenberry, 2016).

Aforementioned, numerous variables contribute to the disease's clinical manifestations, the most significant of which are sickle RBC obstruction, vascular inflammation, and rapid RBC degradation. The aberrant adhesion, tangling, and enmeshing of inflexible sickle-shaped RBCs, which occurs in conjunction with the inflammation reaction, causes vaso-occlusion which is a temporary obstruction of the microcirculation. The lack of blood circulation to neighboring cells creates local hypoxia, which eventually leads to tissue infarction and ischemia.

Vaso-occlusive pain crisis are the most distinguishing symptom of SCD. They are the most prevalent reason for patients to go to the emergency room or be admitted to the hospital, according to Morrone et al., (2017). The most common clinical manifestation of SCD is a vaso-occlusive crisis (VOC), which occurs when the blood vessels are blocked. Ischemia may occur in the area whenever the microcirculation is compromised (Badawy et al., 2018).

The frequency, duration, onset, and location of the VOC vary among individuals with SCD. It is possible for some individuals to have as many as six or even more incidents per year, while others may only have occurrences on an irregular basis or none at all, depending on the individual (Issom et al., 2021). Generally speaking, each individual has a predictable sequence of crises that occur in their lives. The experience of the pain crisis may start at any time and can continue from a few hours to a few days. It might also come to an end just as abruptly and unexpectedly as it began, depending on the circumstances. The VOC can affect any portion of the body while the stomach muscles, bone fragments, joint capsules, and soft tissue are the most frequently impacted parts. The VOC is usually manifested by acute severe pain, dactylitis, acute joint necrosis or avascular necrosis, and acute abdomen (Jenerette et al., 2015).

Sickle cell disease has adverse effect on different body organs such as spleen, liver, kidney, bone marrow, lungs and heart (Hockenberry, 2016). The spleen could become engorged with sickled cells due to congestion. Infarction occurs as a result of the recurrent assault to the splenic sinuses. The functional cells are slowly replaced by fibrotic tissue until the spleen has shrunk in size, and a fibrous mass has completely replaced which results in splenic dysfunction contributes significantly to an individual's increased vulnerability to bacterial infections. In fact, patients with SCA are especially prone to infection because they lack the spleen, which filters germs and stimulates the production of vast numbers of phagocytic cells to fight infection (Piel et al., 2017).

The liver has also been transformed in both function and appearance. Because of anemia and capillary obstruction, liver failure and necrosis result from excessive injury of hepatic blood flow, resulting in liver problems and necrosis. The presence of severe hepatomegaly is usually remaining throughout infancy and into young adulthood. The breakdown of RBCs results in producing a substance known as bilirubin, which results in gallstone build-up (Piel et al., 2017). Gallstones are associated with a high bilirubin level in a patient's bloodstream. Moreover, cholecystectomy may be recommended if the patient experience frequent right upper abdomen pain episodes (Khandekar et al., 2019).

The patients' kidneys could be also affected due to clogging of glomerulus and tubule arterioles with the sickled RBCs and hemosiderin which could result in tissue necrosis and eventually scarring. One of the most common symptoms of renal ischemia is the presence of blood in the urine enuresis and sometimes the development of nephrotic syndrome (Khandekar et al., 2019).

The increased bone marrow production of RBCs leads to osteoporosis, enlargement of the medullary gaps, and weaken the cortices. Skeletal deformities, such as kyphosis and lordosis, may develop due to the weakness of the bone, which is especially common in the thoracic and lumbar regions of the body (Hockenberry, 2016). As a result of persistent hypoxia, recurrent events result in bone infarction and necrosis, and marrow degradation develops over time (Zhang & Pan, 2021). Long bones are the most typically impacted, but pain bouts can occur in any bone marrow-containing component, such as the ribs, chest, vertebral, and skull. The development of pulmonary fat embolism in patients with SCD can be a life-threatening consequence of bone marrow rupture, and it can induce acute chest syndrome (ACS) which is a potentially serious complexity that can be triggered by lung contamination or sickle cells trying to block blood vessels in the lungs, leading to chest pain, fever, and breathing difficulty (Issom et al., 2021).

Patients with SCD may develop cerebrovascular stroke due to hypercoagulation. Symptoms of a stroke include convulsions, numbness in the legs and limbs, trouble speaking, and unconsciousness. The blood flow to organ systems including the brain is also inhibited by the blockage of sickle cells, resulting in chronic low blood oxygen levels (Piel et al., 2017). If left untreated, low levels of oxygen-rich blood may harm the central nervous system (CNS) (Badawy et al., 2018).

Nonetheless, patients with SCD are more likely than others to develop pulmonary hypertension, a disorder characterized by high blood pressure in the lungs (Weir et al., 2018). This problem mostly affects adults, and it is a potentially fatal condition. Breathing difficulties and tiredness are common symptoms of pulmonary hypertension. Furthermore, heart difficulties are mainly caused by the stress of chronic anemia, which can lead to decompensation and failure in the long term. Cardiomegaly can be shown on

chest radiographs, and a systolic circulation murmur is heard repeatedly due to the anemia, which can be challenging to diagnose. Septal hypertrophy, cardiomegaly, and decreased contractility are all detected on an echocardiogram (Aujla et al., 2020).

As a result, SCD can also lead to long-term eye damage and perhaps blindness by clogging small veins that bring blood to the eyes (Piel et al., 2017). Leg ulcers, which are open sores on the legs, maybe another complication caused by SCD. In addition, male patients may also have intense persistent penile erections (priapism) and impotence as a result of a blockage in blood flow (Zhang & Pan, 2021). On the other hand, pregnant women with SCD are more likely to experience elevated blood pressure and blood clot formation. They are also at great risk of miscarriage and premature labor (Yacoub et al., 2019).

Although SCD is most typically reported during the newborn and first year of life, it may not be discovered until the toddler or preschool years. Early detection (before the infant is two months old) allows for the implementation of appropriate proactive steps to reduce the severity of the condition. Amniocentesis is a different kind of diagnostic test. It can detect SCD before birth by studying the fluid surrounding and supporting the fetus. A needle extracts a representative fraction of amniotic fluid (Piel et al., 2017).

Several specialized tests are available to identify aberrant proteins in individuals who are heterozygous or homozygous for the disease. When blood smears are inspected, sickle cells, RBCs, or both may be observed (Yacoub et al., 2019). Since the erythrocyte recovers to its normal discoid shape when exposed to oxygen, even in the homozygous form of the illness, no sickled cells may be present. When sickle cells are identified, diagnostic testing for SCD rather than SCT is frequently positive. The sickle turbidity test (Sickledex) is one of the rapid tests used for the diagnosis of SCD. The blood

sample is obtained from a fingertip or heel stick that shows the number of sickled RBCs (Zanoni et al., 2021).

If the result of the sickledex test is positive, hemoglobin electrophoresis is essential. It is an accurate, rapid, and specific test used to differentiate between the heterozygous and homozygous types of SCD as well as the percentage distribution of the various hemoglobin. In this test, the hemoglobin is separated into individual hemoglobin utilizing high-voltage electrophoresis (Frömmel, 2018). When the patterns generated by the separated peptides are printed on paper as a result of the separation process, this is referred to as protein fingerprinting. However, some of the patients who test positive for atypical hemoglobin concentration may not necessarily have SCD. Hence, more testing is necessary before a definitive diagnosis can be reached.

Patients with SCD should also undergo frequent lab testing, particularly urine tests, to monitor for potential side effects such as renal problems or infections (Yacoub et al., 2019). Other diagnostic tests are used to track the severity of the disease, the occurrence of sickling episodes, and long-term effects. Many patients have regular electrocardiograms (ECGs), computed tomography (CT) scans of the head and abdomen, magnetic resonance imaging (MRI) of the joints, and echocardiograms due to the prevalent consequence of progressive organ failure during recurrent crises (Foster & Prevost, 2012).

The management of SCD requires a focused effort on the treatment of chronic pain and the prevention of complications. Since sickle cell crises often result in severe pain, an opioid and a non-opioid analgesic would be included in the standard pain management regimen. Strong opioids such as morphine, fentanyl, and pethidine, are either used alone or in conjunction with non-steroidal anti-inflammatory medications. Morphine is the most commonly utilized drug in the treatment of these episodes due to its widespread availability and high level of familiarity. It may be administered

orally, rectally, subcutaneously, intramuscularly, or intravenously depending on the patient's clinical situation. Besides, Fentanyl is a synthetic opioid that was also used in a similar case, it is less toxic than morphine. Pethidine is another opioid agonist that has been used to treat pain crises associated with SCD. It is administered either intramuscularly or intravenously.

Unfortunately, pain relievers can help reduce discomfort, but they cannot prevent crisis situations from occurring. Hence, frequent RBCs transfusions and the medications such as hydroxyurea may be effective in lowering the HbS level in the blood (Nader et al., 2018). Patients with SCD may also need oxygen therapy and rigorous hydration with IV fluids e.g., isotonic solutions before being released when they are deemed stable (Zhang & Pan, 2021).

Transfusions of RBCs is a substantial component of SCD therapy. Approximately 90% of patients receive at least one transfusion throughout their lifespan (Singhal et al., 2017). The transfusions may be used to increase the total HbA or decrease the HbS level or treat SCD problems, such as Acute chest syndrome. Moreover, a routine long-term transfusion regimen to avoid SCD complications (Fortin et al., 2018).

Hydroxyurea is one of the main treatments of SCD that raises the concentration of HbF in RBCs. Such HbF molecules consist of two α and two γ polypeptide chains. So, the composition of the produced Hb lacking the defective β polypeptide chains which is the primary cause of sickling. Besides, several studies showed that HbF slows the development of HbS in humans as the high level of HbF may lessen the severity of the sickness. Because of the obstacle to HbS polymerization by HbF, this may be conceivable (Hebert et al., 2020). The hydroxyurea treatment maintains the RBCs round and flexible structure (Chatterjee et al., 2018).

Nursing Management of Patients with Sickle Cell Disease

The advanced practice nurse (APN), without a doubt, plays a crucial role in the management of patients with SCD in both the community and clinical settings. For successful management of the SCD. They should utilize their seven core competencies in addressing the physical and psychosocial problems and concerns of patients with SCD and managing such problems (Zhang & Pan, 2021). These competencies include: (1) clinical expert or direct care, (2) expert coaching and advice, (3) consultation, (4) research/evidence-based practice, (5) clinical and professional leadership, (6) collaboration, and (7) ethical decision-making.

Mentoring the pain and discomfort of patients is one of the important competencies of APNs. They may use a standardized age-appropriate pain assessment tool (e.g., a numerical rating scale from 0 to 10) to measure the severity of pain. The level of vaso-occlusive discomfort should not only be determined by patient behavior or other clinical indicators (e.g., heart rate and blood pressure) (Dequeker, 2018). Preconceived ideas about pain can lead to imprecise pain evaluations and, consequently, inadequate treatment of the resulting discomfort. Even though patients suffering from chronic pain may not exhibit any outward signs of discomfort, the pain control procedure can be challenging for everyone involved in the patient's care (Issom et al., 2021). To guide evaluation and management, APNs must rely on the patient's subjective characterization of pain. Nurses must understand the harsh and unpredictable nature of pain, as well as the critical requirement for efficient pain management. Acute pain that is not alleviated is unpleasant and demeaning, and it may progress to chronic pain, drug addiction, and low health-related quality of life (Ludwig et al., 2018).

Because patients with SCD are at high risk for a life-threatening thrombotic event, such as a myocardial infarction or stroke, a comprehensive physical assessment is conducted to establish baseline data and is repeated until the crisis resolves (Foster & Prevost, 2012). For instance, awareness, cognition, memory, motor abilities, and pupillary reflexes are all part of a comprehensive neurological evaluation that indicates CNS problems (Foster & Prevost, 2012).

Nursing interventions are extremely important for pain control, education programs, and preventative measures against subsequent sickle cell crises. Patients' problems and concerns are relayed to nurses, who make nursing judgments and provide suggested treatment (Edwards et al., 2001). The major goal of nursing management of SCD is to alleviate the patient's suffering and make them feel better. Nursing care is based on the identified type of pain and its distinct features. Some discomfort may be relieved with merely IV fluids and oxygen therapy, while others may need further measures. Among these

measures pain should be treated quickly and aggressively. Patients who seem to be suffering from vaso-occlusive pain need immediate triage, evaluation, and analgesic treatment. It is vital to do frequent pain evaluations and provide appropriate medications until pain relief is achieved. Side effects of opioids, especially respiratory depression, should be continuously monitored and handled as soon as feasible. Oral or intravenous hydration should be initiated to decrease the consequences of sickling. If the vaso-occlusive pain is accompanied by another condition, such as stroke or acute chest syndrome, a transfusion may be necessary (Benenson & Porter, 2018).

Nurses should advocate for treatment that is evidence-based and not based on unpleasant anecdotes. Vaso-occlusive pain, both acute and chronic, is often handled at home. Nurses should urge patients to adhere to an

individualized strategy of pain management that may include opioid analgesics and nonpharmacological adjuvant interventions (Benenson & Porter, 2018).

Psychosocial care is another aspect of pain management. It has three important components: psychological, social, and spiritual (Santos et al., 2017). Nurses are active in the establishment of support networks for patients and families. Nurses help patients with SCD communicate professionally by improving their psychological well-being (Daniels, 2015). This connection has an effect on the judgments made, as well as their strength and ability to carry them out. Nurses with strong communication and evaluation skills may establish a trusting relationship with patients (Smith et al., 2018). These two abilities contribute to the therapeutic interaction between the clinician, the patient, and their caregivers. Nurses ensure that each patient receives tailored physical, symptomatic, and psychosocial treatment. Professional psychosocial care has been shown to be extremely beneficial for patients with SCD, as it alleviates both psychological and physical distress, improves care quality and quality of life, promotes coping mechanisms, and significantly decreases the pain threshold (Omolola et al., 2020).

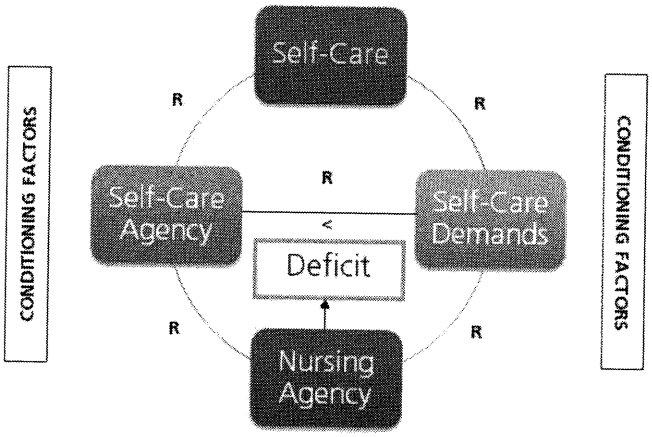
As an educator, APNs can support long-term care by educating patients and their families (Tavares et al., 2017). They must be capable of using their knowledge to provide efficient health instructions which optimize the benefits of clinical treatment and gradually improve patients' ability to cope with their condition (Benenson & Porter, 2018). Such instructions focus on compliance with medication, non-pharmacologic pain management techniques, recognition of emergency indicators and precipitating events, and lifestyle adjustments (Aich et al., 2019). To enhance compliance with prescribed medication, patients need regular monitoring. Nurses should help to enable them to avoid medication errors, evaluate side effects, and educate them to improve awareness of drug side effects (Benenson & Porter, 2018).

Unlike acute illness, SCD is a chronic condition that mandates patients' compliance with the prescribed treatment plan. The APNs' responsibilities, particularly in the home and community setting, are tied to patient self-management. As a result, nurses' roles can be expanded or redirected to improve clients' self-management and overall self-care abilities for patients with SCD.

To manage SCD effectively, patients must display a variety of complex abilities that enhance self-efficacy and self-management and inhibit SCD-related issues. Self-efficacy pertains to an individual's belief in his or her capacity to carry out the behaviors required to achieve the desired outcome. It indicates an individual's belief in their capacity to exercise control over their own motivations and behaviors (Al Nasiri et al., 2020). Self-care management is described as the capacity to contribute to favorable performance, which includes enhancing and/or sustaining one's health condition and life excellence (Nagshabandi & Abdulmutalib, 2019).

Conceptual Framework

Conceptual framework of Orem's theory



Orem's Lack of Self-Care Nursing theory serves as a conceptual framework for nursing practice. Three interconnected concepts are identified by the theory: self-care, self-care deficit, and nursing systems. Self-care refers to the activity's individuals perform to maintain their health and well-being, whereas a self-care deficit is an inability to perform these activities due to physical, psychological, or developmental limitations. Nursing systems are the interventions nurses use to assist patients in meeting their own self-care needs.

Theoretical Framework

Empowerment

Empowerment is a theoretical model for understanding the process and consequences of efforts to exert control and influence over decisions that affect one's life (Zimmerman, 1995). It is vital to draw a line of demarcation between the principles that underpin an empowerment approach to social change and the theory of empowerment. The value orientation of empowerment offers recommendations for objectives, aims, and tactics for putting change into action (Rappaport, 1981). The empowerment theory offers both guiding principles and a structural framework for the organization of information. The development of empowerment theory helps progress the construct beyond a transitory trend and political manipulation. Another benefit of this advancement is that it helps advance the construct (Zimmerman & Warschausky, 1998).

Empowerment Theory offers a unique conceptual framework for developing programs to promote positive clinical outcomes. It incorporates the

idea that health promotion necessitates not only that individual develop specific skills and positive assets, but also that they become motivated to actively apply these skills and knowledge (Zimmerman, 1995; 2000). Thus, Empowerment Theory-based programs concentrate on developing positive assets, connecting receivers to local resources, and promote engaging in community service activities (Yacoub et al., 2019). Health, prevention, and health education should be the focus of empowerment rather than only concentrating on the disease and its treatment. Solving problems, boosting one's self-esteem, and establishing trust are all examples of empowerment abilities. When the patient is empowered, health and well-being may be maximized (Borimnejad et al., 2018).

Empowerment-based interventions (EBI) are becoming increasingly popular as a treatment option for patients suffering from chronic diseases. When EBI is used, it marks a change away from focusing on alleviating deficits, mitigating risks, and advancing capacity (Zanoni et al., 2021). As other patients with other chronic illnesses, EBI is especially important in patients with SCD. To prevent the negative repercussions, such patients must take control of their well-being by adopting self-care measures that are not restricted to maintaining the necessary oxygenation and water intake, eating a healthy diet, resting, and avoiding extreme heat and humidity. These measures may help relieve painful crises and reduce medical intervention (Druye et al., 2020).

Managing SCD becomes easier for adults with this condition when they take control of their health. Practicing self-care in the home helps individuals manage their distress and therefore avoid experiencing a painful crisis (Zhang & Pan, 2021). As a result, self-care activities are critical for enhancing safety and well-being. Self-care refers to both one's presumed ability to participate

in overall treatment activities to improve one's health standard of living and actual participation in those operations (Zanoni et al., 2021). It is essential to focus on pain control and water intake to avoid infectious diseases and other issues associated with SCD. For instance, receiving routine checkups, staying hydrated, eating healthily, getting enough sleep, and avoiding high temperatures are good general techniques. These available strategies could be called "self-actions" and are essential in preventing a pain crisis (Lacerda et al., 2019).

Because patients take the initiative in their health care, EBIs are extremely beneficial; it is critical for patients to be involved in the management of their own care. Adults living with SCD must be informed about the disease, fully comprehend their options for treatment, and make good decisions for their well-being (Zhang & Pan, 2021). Adults with SCD should have access to a toolkit to monitor their health care and manage their illness (Zanoni et al., 2021). Nurses can also collaborate with patients on which non-pharmacologic independent consultant treatments are the most effective in relieving their discomfort (Badawy et al., 2018). Patients may also benefit from nurses' explanations of the significance of hydration in preventing VOCs, which can be accomplished by increasing fluid retention and decreasing intravascular volume. Water intake may be encouraged unless it is contraindicated by certain medical conditions (Tanabe et al., 2019).

The implementation of heat is generally considered reassuring. However, the implementation of ice is not recommended in VOCs since vascular constriction worsen the condition by decreasing oxygen supply (Badawy et al., 2018). Cognitive-behavioral, neurofeedback, prayer, muscle relaxation, acupuncture, hypnosis, herbal treatments, and megavitamins are some of the other non-pharmacologic treatments that are commonly used in

SCD (McClafferty, 2017). Care notebooks or binders that patients can use to arrange all of their SCD-related medical information in one place and carry with them everywhere they go (such as medical visits, emergency visits, vacations, and places of work) will assist patients in keeping track of all of their healthcare data over time (Matsuda et al., 2018).

Caring for an adult with SCD places significant physical and psychological requirements on those who provide services (Zhang & Pan, 2021). It is possible to empower individuals with SCD by educating them about reducing or preventing circumstances that can hasten the disease. For instance, keeping adults with SCD comfortable is essential to avoid challenging circumstances and too much physical activity. Through this route, interaction and education can help assert control over a patient's well-being while simultaneously preserving their freedom (Badawy et al., 2018).

Theory of Self-Care Deficit

Orem's general theory of nursing in three related parts includes theory of self-care, theory of self-care deficit, and theory of nursing system.

The Self-Care Theory, developed by Dorothea Elizabeth Orem (1991) is utilized to explain the complexity and processes involved in the self-care of individuals. Orem recognized three core nursing sciences: (a) self-care; (b) self-care agency; and (c) human assistance for persons with health-related self-care deficits. Orem defined self-care as practice of activities that individual initiates and perform on their own behalf in maintaining life, health and wellbeing. While the self-care agency is a human ability which is "the ability for engaging in self-care", conditioned by age developmental state, life experience sociocultural orientation health and available resources (Matthie et al., 2015).

Orem's general theory of nursing is made up of three linked theories; (1) the theory of self-care, which describes why and how people care for themselves; (2) the theory of self-care deficit, which describes and explains why people can be helped through nursing; and (3) the theory of nursing systems, which describes and explains the relationships that must be established and maintained for nursing care.

Self-care theory contains three categories of self-care requisites such as universal requisites e.g. sufficient intake of air, water, food, and prevention of hazards to human life well-being and promotion of human functioning.... etc.; developmental self-care requisites; and health deviation self-care requisites; e.g. illness, injury, or disease.

Orem referred to the therapeutic self-care demand as "totality of self-care actions to be performed for some duration in order to meet self-care

requisites by using valid methods and related sets of operations and actions". Self-care requisites which is an action directed towards provision of self-care. Individuals experience self-care deficit when self-care demand exceeds self-care capabilities. The Self-Care Deficit Theory describes nursing as "the act of aiding individuals in providing and managing self-care in order

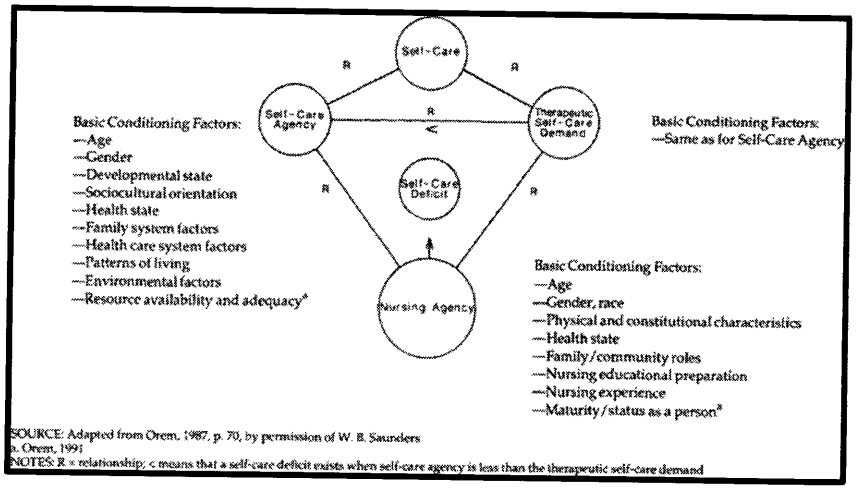


Figure 5. Conceptual model: Orem' s theory of self-care nursing. R, relationship; <, deficit relationship, current or projected. Used with permission from Orem, D. E. (1980). Nursing: Concepts of practice. New York: McGraw-Hill.

to maintain or enhance human functioning at the home level of effectiveness." So, nursing is required when an individual is incapable or limited in the provision of continuous effective self-care. Orem identifies five methods of helping (1) Acting for and doing, (2) Guiding, (3) Supporting, (4) Providing an environment promoting personal development in relation to meet future demands, and (5) Teaching (Figure 5).

As for theory of nursing systems, Orem described how the patient's self-care needs will be met by the nurse, the patient, or both. The theory identifies three classifications of nursing system to meet the self-care requisites of the patient, (1) wholly compensatory system, (2) partly compensatory system, and (3) supportive – educative system. Wholly compensatory nursing system is employed when there are physical barriers to self-care. It focuses on providing for needs that the client cannot meet by providing protection techniques and protection devices, providing positioning devices and positioning techniques, providing equipment for activities of daily living such as feeding, bathing, toileting, transferring, dressing, and grooming and aiding with instrumental activities of daily living such as using transportation, preparing meals, shopping for food. Partial compensatory nursing system is employed when barriers affect the individual's ability to perform some self-care activities. They can meet their own essential needs but with assistance by performing management of body functions, performing maintenance of equipment, performing dressing techniques that are appropriate to the condition or disabilities present, and for postoperative client in ambulating. However, supportive-educative system that used when individuals can meet their own needs but cannot understand, learn, or perform them due to environmental barriers. Individuals having the needs are socially competent enough to meet their needs but need to be taught how by teaching and training, making known the self-care skills needed for maintenance and recovery from illness, injury,

or health conditions for individuals, families, and communities, assistance in the development of environmental conditions that promote wellness (Figure 6).

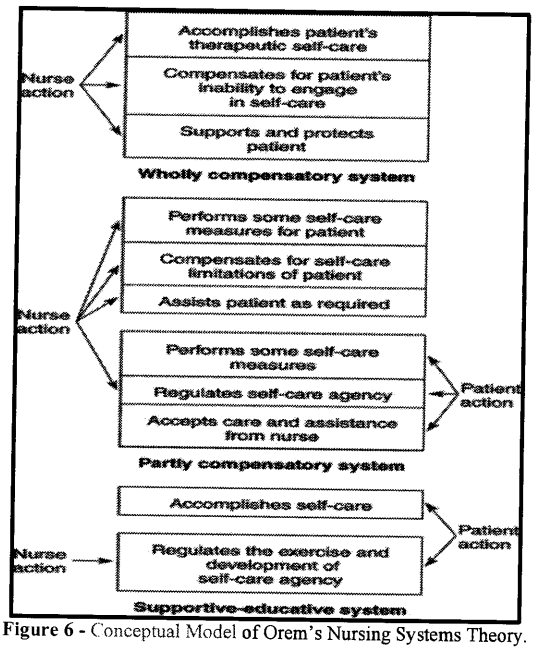


Figure 6 - Conceptual Model of Orem's Nursing Systems Theory.

This idea is founded on the concept that every human being is capable of self-care. In accordance with Orem's Self-Care Deficit Theory, caregivers of patients with SCD at the home and hospital level may need to first gain the capacity to identify and prioritize the patient's unmet self-care needs. This must be followed by a comprehensive evaluation of effective ways to assist patients with SCD in overcoming or compensating for self-care inadequacies in order to provide a sustained and appreciable HRQoL, health, and well-being in exchange for decreased vulnerability.

Self-care is crucial for the successful management of a chronic disease or condition (Zhang & Pan, 2021). Self-care at home helps in personal pain regulation and, subsequently, in the prevention of pain crises in SCD. Educating patients about self-care activities equips them with the knowledge and tools necessary to manage their chronic disease.

Nonetheless, self-care practices of patients with SCD are still restricted inside the hospital system (Shook et al., 2021). It necessitates extra therapies, such as educational programs that promote awareness and educate families, especially healthcare professionals, in their combined efforts to improve care engagement and problem management. They serve as educators by acquainting these individuals with efficient self-care techniques. In this context, the nurse plays a critical role in aiding patients with SCD and their family members with self-care (Yacoub et al., 2019). The nurse guides, supports, inspires, and monitors the support-education process, making their participation critical in enhancing the HRQoL of the person with SCD and their family members.

Adults with SCD may benefit from professional nurses' assistance in building a sense of self-care, self-efficacy, and self-management skills. While patient performance provides the basis for self-management, healthcare providers are responsible for assisting patients with self-management (Sickle Cell Disease Ontology Working Group, 2019). As previously said, self-management does not exist in isolation from medical therapy; rather, it is designed to support the patient in becoming an active partner with healthcare professionals rather than an antagonistic one. As a result, patients and health care professionals collaborate to promote self-management (Yacoub et al., 2019). Three major components enhance self-management assistance: comprehension, patient education, capacity, and social facilitation for health maintenance and behavior modification (Shook et al., 2021). Education or literacy levels are crucial when it comes to assisting patients with SCD in making informed treatment choices. Education in self-management and conventional care are two separate forms of education.



Chapter III

Materials and Methods



MATERIALS

Research Design

This research was a randomized controlled trial (two groups, pre-posttest) study designed to determine the causal effect of an intervention on a target population.

Settings

Primary health care is the bedrock of health care delivery in the Kingdom of Bahrain. It is the initial point of contact for anyone looking for healthcare. The research was carried out in two locations: Shaikh Jaber Al-Ahmed Al-Subah Health Center (HC), which is one of the largest health centers and operates 24 hours a day, including weekends and holidays, and Budaiya HC, which operates for 12 hours on weekdays. Both HCs provide a wide range of services that enable people to live a healthy life. These include healthy behavior promotion and disease detection; diagnosis and treatment; and rehabilitation services. Furthermore, patients have access to family medical services provided by competent family physicians, community health nurses, health promotion experts, and social workers, as well as therapeutic and preventative treatments. To provide the highest levels of care for patients and the working team, the nursing department efficiently leads and participates in many committees, including the Health Promotion and Infection Control committees. While waiting for their turn in the treatment room, patients with SCD at the aforementioned health centers attend once or twice daily, waiting for their turn in the treatment room to take their prescribed medications. If the patient needs to visit their family physician, he or she may register and see the family physician, both for SCD and

non-SCD patients. The SCD patients at Shaikh Jaber al Subah HC and Budaiya HC were also contacted, and the majority of them accepted to participate after learning about the possible advantages of the impending study.

Population, Sample

Cluster sampling technique was used to find out the study settings and subjects. According to health sectors distribution, the Kingdom of Bahrain consists of five main governorates. One governorate was randomly chosen (Northern governate). The Northern Governate includes seven HCs; Shaikh Jaber Al-Ahmed Al-Subah HC, Budaiya HC, Hamad Town HC, Kuwait HC, Aali HC, and Mohamed Jassim Khano HC. Two HCs were randomly selected; Shaikh Jaber Al-Ahmed Al-Subah HC, and Budaiya HC as illustrated in (Figure 1).

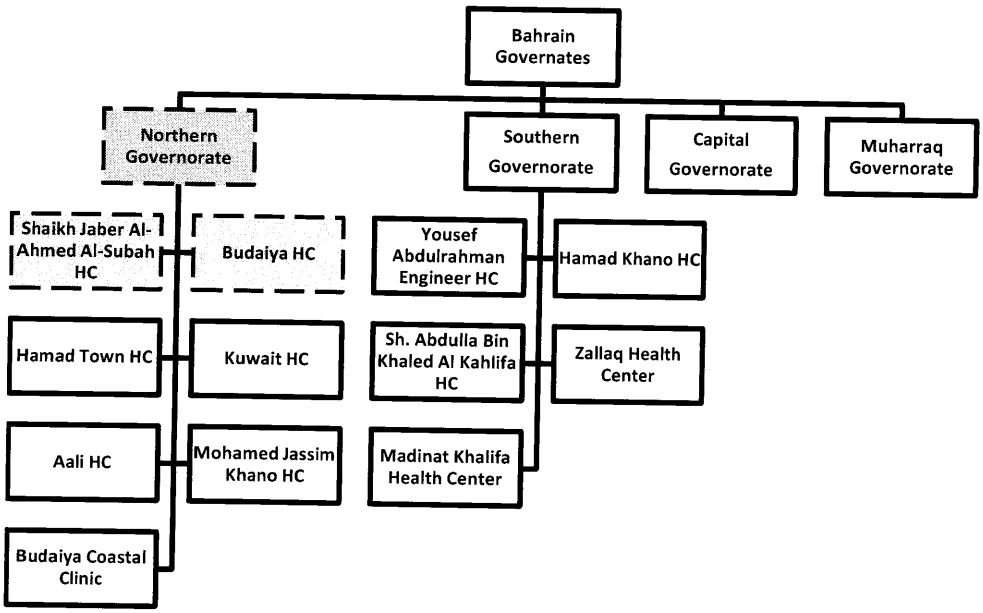


Figure 7. Flow Chart of Randomized HCs Selection.

Sample Size

The sample size is estimated using the EBI-info software version 10 with the following parameters: a population size of 149 patients, a confidence coefficient of 90%, an anticipated frequency of 50%, and an acceptable error of 5%. The sample size must be at least 66 patients.

Participants

To get the samples, the electronic medical records of all adult patients with SCD were accessed and a list of the eligible patients who fulfilled the inclusion criteria was obtained. Then they were invited to participate in the study by providing them with basic information about the study's objectives and outline.

During the research period (starting in February and ending in May 2022), 122 of 149 eligible patients expressed their willingness to participate in the study. After withdrawals at various points of the study, the ultimate number of participants was 68. The patients were randomly allocated to one of two groups: the intervention group (36 patients received the empowerment-based intervention and the control group (32 patients received the routine care of the health center). One participant was assigned to the EPI group, and the next one assigned to the control group, (Figure 8).

CONSORT
TRANSPARENT REPORTING of TRIALS

CONSORT 2010 Flow Diagram

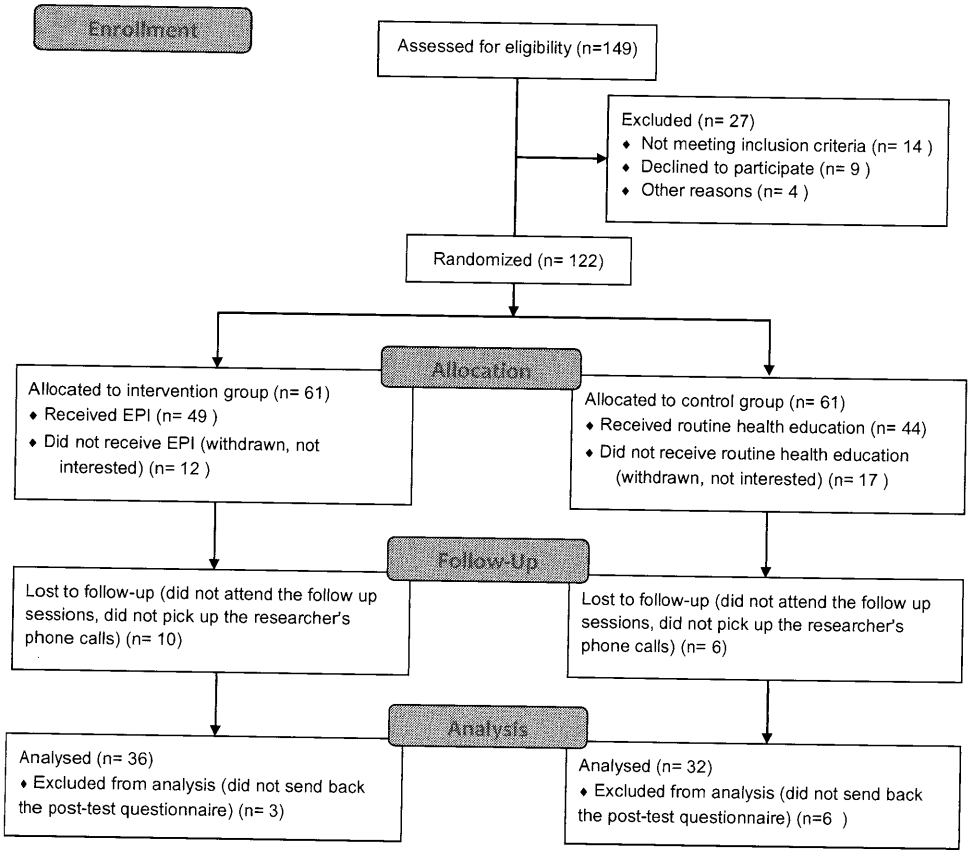


Figure 8. Consort Flow Chart of Participants' Allocation.

Inclusion & Exclusion Criteria

All adult patients with SCD who fulfilled the following inclusion criteria; receiving treatment from primary health care facilities, being able to read and write and having the chance to attend the educational sessions comprised the study subjects. While, patients who have history of mental illness were excluded from the study.

Sampling Technique

- **Measurement Tools**

Three tools were used to collect the necessary data. The tools used to collect data consisted of the demographic information questionnaire, the Self-care Agency Scale, the Sickle Cell Self-Efficacy Scale, and the SF36 questionnaire. The initial assessment addressed patients' socio-demographic characteristics and clinical data. Socio-demographic characteristics encompasses age, gender, level of education, occupation, marital status, and family type. Furthermore, clinical data includes any SCD inheritance from parents, having a family member with SCD, the presence of chronic illness, and previous surgeries, as well as the frequency of blood transfusions and hospital admissions in the preceding year.

Tool I: Sickle Cell Self-Efficacy Scale (SCSES) (Appendix I)

This scale was designed by Edwards et al. (2000) to assess the self-appraisals of adult patients with SCD for their ability to engage in daily functional activities (see appendix A). It is composed of nine items rated on a five-point Likert scale ranging from '1=not at all sure', '2=Not Sure' '3=Neither" 4=Sure' to '5=very sure'. The total scores ranged from 9 to 45, with higher scores indicating greater

self-efficacy. The theoretical framework on which the SCSES is based is Bandura's social learning theory which refers to an individual's judgment of his or her capacity to perform specified tasks (Edwards et al.2000). The reliability and validity of the SCSES are attested to by Cronbach's alpha of 0.89 and substantial positive correlations between SCSES scores and standardized measures of self-esteem, mastery, and locus of control. The predictive validity of the SCSES increased with self-efficacy levels.

Tool II: The Appraisal of the Self-Care Agency Scale-Revised (ASAS-R) (Appendix II)

This scale was originally developed by Kearney and Fleischer (1979) in accordance with Orem's self-care theory and revised by to assess the level of health-related self-care capacity. The original scale consisted of 43 items and it under went many revisions. Wang & Laffrey (2000) reduced the items to 24 items and then Souza et al. (2010) revised the scale and reveled the short form that consisted of 15 items where participants rate their responses on 5-point Likert-type items ranging from 1 (totally disagree) to 5 (totally agree).

The ASAS-R is a 15-item, three-factor scale:

- **Factor 1: Having Power for Self-Care**: Consisted of six items, item number 1,2,3,5,6 & 10.
- **Factor 2: Developing Power for Self-Care:** Consisted of five items, item number 7,8,9,12 &13.
- **Factor 3: Lacking Power for Self-Care:** Consisted of four items, item number 4,11,14 &15. These four items were reverse- coded.

A higher total score indicates greater self-care agency and the maximum possible score is 75 (Damásio & Silvia, 2013; Sousa et al., 2010) (Table 1).

The ASA-R has been demonstrated to be a reliable (Content Relevancy indices > 0.7) and valid (AVE > 0.5) instrument in measuring self-care agency in measuring general population self-care initiatives.

Tool III: The 36-Item Short Form Survey (SF-36) (Appendix III)

The 36-Item Short Form Survey (SF-36) was originally developed by RAND Corporation (1990) to measure patients' health status and outcomes. The SF-36 could also be used in outpatient settings for adult patients with chronic illness (ware et al., 2000). Moreover, in this research, the Arabic version of the SF-36 questionnaire was utilized to measure health-related quality of life and it consisted of 36 questions that assessed eight dimensions of health-related quality of life (Table 1).

Table 1: The Eight Dimensions of Quality of Life.

Dimension	No. of Items	Items
1. Physical functioning	10	3, 4, 5, 6, 7, 8, 9, 10, 11 & 12
2. Role limitations due to physical health	4	13, 14, 15 &16
3. Role limitations due to emotional problems	3	17, 18 &19
4. Energy/fatigue	4	23, 27, 29 & 31
5. Emotional well-being	5	24, 25, 26, 28 & 30
6. Social functioning	2	20 & 32
7. Pain	2	21 & 22
8. General health	5	1, 33, 34, 35 & 36

The RAND 36-Item Health Survey is scored in two steps. First, pre-coded numeric values are recoded according to the scoring key in Table 2. It should be

noted that all elements are assessed, with a higher score indicating a better condition of health. Furthermore, each item is rated on a scale of 0 to 100.

In step 2, the scale scores are calculated by averaging the elements on the same scale. As a result, scale scores indicate the average of all scale items responded by the respondent.

- **Scoring System**

Each item includes a continuous quantitative scale ranging from 0 to 100, with higher scores indicating a more favorable circumstance. The 36-Item Short Form Survey include 6 different scoring system as follows:

a) Items Number: 1, 2, 20, 22, 34, 36 were rated on 5-point Likert scale; 1 = Excellent (score 100), 2 = Very good (score 75), 3 = Good (score 50), 4 = Fair (score 25), and 5 = Poor (score 0).

b) Items Number: 3, 4, 5, 6, 7, 8, 9, 10, 11, 12 were rated on 3-point Likert scale;1 = Yes, limited a lot (score 0), 2 = Yes, limited a Little (score 50), and 3 = No, Not limited at All (score 100).

c) Item Number: 13, 14, 15, 16, 17, 18, 19 were rated on 2-point Likert scale; 1= Yes (score 0) and 2= No (score 100).

d) Item Number: 21, 23, 26, 27, 30 were rated on 6-point Likert scale; 1 = All of the time (score 100), 2 = Most of the time (score 80), 3 = A good bit of the time (score 60), 4 = Some of the time (score 40),5 = A little of the time (score 20), and 6 = None of the time (score 0).

e) Item Number: 24, 25, 28, 29, 31 were rated on 6-point Likert scale; 1 = All of the time (score 0), 2 = Most of the time (score 20), 3 = A good bit of the time (score 40), 4 = Some of the time (score 60),5 = A little of the time (score 80), and 6 = None of the time (score 100).

f) Item Number: 32, 33, 35 were rated on 5-point Likert scale; 1 = Definitely true (score 0), 2 = Mostly true (score 25), 3 = Don't know (score 50), 4 = Mostly false (score 75), and 5 = Definitely false (score 100).

- **Validity and Reliability of SF-36**

The SF-36 has been shown to be valid and sensitive to clinical changes among adults with sickle cell disease. All sub-scales were found to be reliable, with Cronbach's alpha coefficients were physical functioning (α= 0.93), role-physical (α= 0.84), and energy/fatigue (α= 0.86), The mental health dimension also encompasses emotional well-being (α= 0.90), Role functioning/emotional (α= 0.83), social functioning (α= 0.85), bodily pain (α= 0.78), and general health (α= 0.78).

Arabic Translation

Since all the participants were not able to respond to the English version of the quassionare, the researcher utilized the Arabic version of the 36-Item Short Form Survey (SF-36). However, the Sickle Cell Self-Efficacy Scale (SCSES) and the Appraisal of the Self-Care Agency Scale-Revised (ASAS-R) were translated into Arabic using World Health Organization (WHO) forward-back translation protocol (Younan et al., 2019). (Appendices IV)

- **Step1: Forward Translation**

Initially, the researcher established a panel of three independent bilingual native Arabic speakers' experts who are familiar with the Bahraini terms and

expressions to translate the tools. The experts were medical professionals who were by virtue acquainted with the underlying concepts, objectives, scope and application procedures of the ASAS-R and SCSES among adults with SCD. The researcher was the most familiar one by the design and methodology of the study, so he supervised the translation process. The two translations were judged for equivalence by the tripartite bilingual expert panel. The significant discrepancies in the translation were resolved by selecting the simplest Arabic wording/phrase.

A group of four monolingual individuals (exclusively Arabic speakers) thoroughly read the translated tools and highlighted unambiguous statements or expressions. The monolingual group was not familiar with the content of the untranslated version of the tool. Two of them have some formal education, so the comprehensibility of the translated tools was also tested.

The bilingual group who originally translated the tools discussed the comments of the monolingual group, and some modifications were made to make sure that the wording accurately reflected the meaning of the original document. Finally, the translated tools were checked for grammar.

- **Step2: Backward Translation**

The Arabic-translated version of ASAS-R and SCSES was back-translated into English by two independent professional translator who were unfamiliar with

the questionnaire. The back translation was reviewed by the bilingual panel of experts in order to resolve any discrepancies between the two back translations and the original English versions. The panel repeated translation and back-translation until achieving a successful meaning.

METHODS

Data Collection/ Procedure

- **Pilot Study**

A pilot study was carried out on seven patients (10%) with SCD from the previously mentioned settings to test the feasibility, applicability, and clarity of the research tools and length of completion time. Participants who were involved in the pilot study were excluded from the total study sample.

- **Initial Assessment (Pre -Test)**

For both empowerment-based intervention (EBI) and control groups, the researcher initially collected the baseline data by assessing the patients' demographic and clinical characteristics, self-efficacy, self-care capacity and health-related quality of life using tools I, II, and III.

- **Empowerment-Based Interventions**

For the study group, the EBI was applied. It is an integrative educational program under the patient-centered care approach that emphasizes collaborative interaction with patients. The EBI implemented through structured (a) small group discussion sessions, (b) individualized consultations, and (c) follow-up sessions.

- **Group Discussion Sessions**

In the group discussion sessions, the researcher focused on topics relevant to SCD management such as (pain crisis, warning signs, the cases that need a referral to the emergency department).

- **Session's Objectives**

1- Describe basic information about the SCD.
2- Discuss the health complications caused by SCD.
3- Explain self-management strategies that prevent sickling and SCD complications.
4- Emphasize compliance of medication and therapeutic regimen.
5- Illustrate the measures for managing pain crisis.

- **Teaching Strategies**

The researcher delivered the educational sessions and utilized different teaching strategies such lecturing, group discussion, role -play, video-based, problem-based and case-based learning.

- **Target Audience**

Participants have been divided into small groups and each group consists of six patients.

Sessions Topics and The Content

- **Basic Information About SCD**

In this session the researcher defined SCD and described the pathophysiological changes, clinical manifestation, diagnostic measures and therapeutic management. The researcher also discussed the health complications of SCD such as pain crises, strokes, infections, acute chest syndrome, eye disease, hand and foot syndrome (dactylitis). Moreover, the warning signs of sickling such as severe fatigue or exhaustion; numerous episodes of pain crises; hand and foot swelling; recurrent infections; and visual disturbance were clarified (Osunkwo et al., 2021). It is crucial that every patient with sickle cell disease knows when to visit an emergency department or seek care at an urgent-care center if they have symptoms such as chest pain, fever more than 38.5 degrees Celsius, difficulty breathing, chest discomfort, abdominal (belly) swelling, severe headache, sudden weakness or loss of sensation and movement, or seizure.

Self-Management Strategies to Prevent SCD Complications

In this session, the researcher discussed the self-management strategies that prevent SCD complications such as hydration, dietary regimen & supplements, sports and exercise, minimize infections, medication compliance, and non-pharmacological pain management.

- **Hydration**

The researcher exhibited several hydration tactics such as smart phone applications, challenge bottles, competitive games, and others that stimulate higher water intake via reminders and make hydration more enjoyable and straightforward (Brugnara, 2018).

- **Dietary Regimen & Supplements**

The session also addressed the optimal nutritional regimen. This includes consuming nutrient-dense foods such as Spinach, Blueberries, Broccoli, Asparagus, Eggs, Avocado, oats, and so on. The researcher also emphasized the importance of glutamine, L-arginine, adding folic acid to the diet and vitamin D supplements (Farmani Anoosheh & Keikhaei, 2022).

- **Sports and Exercise**

The researcher highlighted some exercises that help stimulate blood circulation and work to stimulate vital processes, such as running and walking exercises, elongation exercises, and yoga exercises, as well as other sports like brisk walking or walking distance, cycling outside or in a classroom, and dance fitness, such as Zumba, taking each patient's condition into account by listing some advice like setting own pace and start playing slowly. The researcher equipped the participants during sports and exercise. These include (1) taking sufficient rest in between sessions and exercises, (2) drinking sufficient water before, during, and after physical activity, (3) maintaining stable body temperature, (4) stopping exercising in case of having cramps, discomfort, swelling, weakness, or shortness of breath, and (5) seeking medical assistance immediately in case of experiencing any signs or consequences of the condition (Ogu et al., 2021).

- **Minimize Infections**

Since patients with SCD are immunocompromised, the researcher recommended participants receive compulsory vaccines such as pneumococcal, meningococcal, and seasonal influenza by posting the schedule that has been recommended by the Bahrain ministry of health. Additional infection control

precautions such as hand washing and appropriate food preparation or cooking, were explained.

- **Other Instructions**

During the session, strategies to reduce disease complications were presented and supported by studies, such as avoiding stress and stop smoking to minimize vasoconstriction, avoid being in high-altitude and prevent extreme temperatures.

- **Medication Compliance**

The researcher emphasized the compliance with the prescribed medication such as using over-the-counter ibuprofen and/or acetaminophen for minor discomfort, and using at home the physician-prescribed pain medications, such as controlled-release morphine or hydroxyurea, for moderate to severe pain.

- **Non-Pharmacological Pain Management**

In this session, the researcher displayed several pain management strategies other than the use of pain medication. These strategies include massaging the painful body part, consuming fluids, having warm shower, the use of hot water bag or placing warm towels on the affected part and rest (Ajinkpang et al., 2022). In addition, cognitive and behavioral techniques including relaxation, deep breathing, distraction techniques such as mental imagery, and repeating positive phrases to adapt to pain. Physiotherapy, heat and cold treatments, acupuncture, and distraction through activities (reading, video games, and movies), may alter the patient's attention and assist in reducing tension and pain (Ezenwa et al., 2021).

Individualized Consultations and Follow-Up Sessions

Patients in the study group also received individualized consultations regarding self-management using the 5A model (Assess, Advise, Agree, Assistant, and Arrange) Figure 9. This model, proposed by (Glasgow, et al, 2002; Whitlock, et al, 2002), offers a valuable foundation for delivering behavior change interventions.

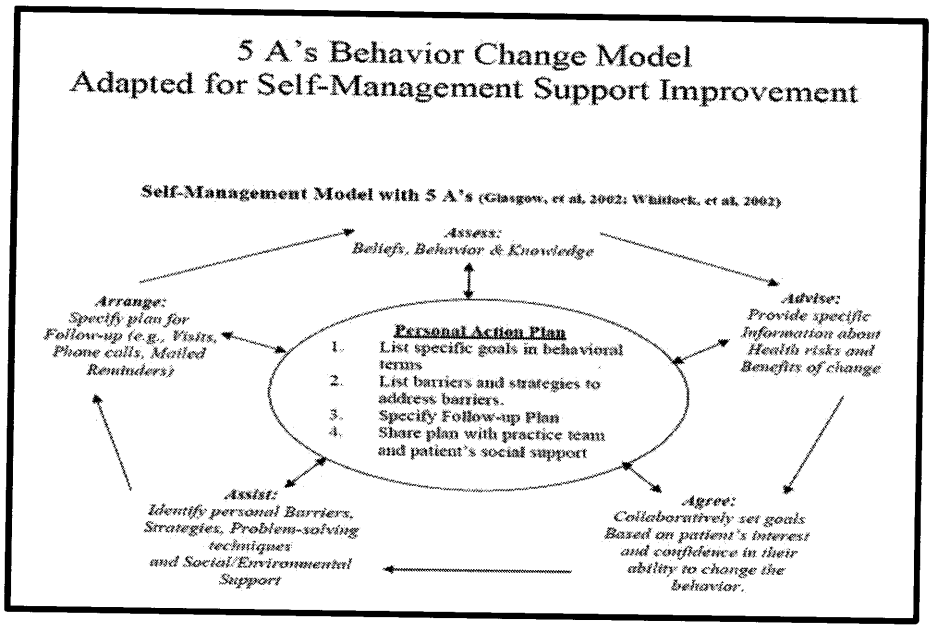


Figure 9: 5 A's Behavior Change Model. (Glasgow, et al, 2002; Whitlock, et al, 2002)

- **Step 1, Assess**

Initially, the researcher conducted individualized interviews with patients to examine their health habits, attitudes, and disease knowledge by asking questions such "Can you tell me about behavioral health risks? ","What is your health educational needs other than that provided in general discussion session? ". The assessment results were interpreted as a reflection of the patient's situation and as motivators for behavioral change in the patient. Their motivations and suggestions for improving their lives were also explored.

- **Step 2, Advice**

At this stage, the researcher provided detailed, individualized behavior modification advices regarding the personal health risks associated with SCD and its poor management as well as benefits of behavioral change and the drawbacks of the lack of disease control.

- **Step 3, Agree**

The patients and the researcher agreed upon the behavioral change as well as the activities required to achieve the goals. Then, personally meaningful and priority behavioral SMART goals (Specific, Measurable, Attainable, Relevant, Time-bound) were set (Cheng et al., 2019). In order to develop behavioral objectives, participants were instructed to record the situations that induced pain crises in diaries and then provide the diaries the following session.

- **Step 4, Assist**

At the assistance stage, patients were empowered by allowing them to make informed choices, raise the awareness of their own personal power, frame positive outlook, and formulate proactive self-management patterns. Participants received tailored advice to help them regain control over their health and strengthen their capabilities (Ahmadi et al., 2015; Łuczyński et al., 2016; Zoffmann and Kirkevold., 2012). The researcher enabled the patient to integrate critical self-management skills (i.e., action planning, problem-solving, and relapse prevention) into daily life. Patients were invited to the individualized session in the meeting room of the Shaikh Jaber Al-Ahmed Al-Subah health center.

- **Step 5, Arrange**

The researcher established follow-up schedule. Weekly communications with the patients had been made through social interworking sites to check the patient's progress, establish continuous interaction, provide ongoing assistance/support, and adjust the self-management plan as needed (Glasgow et al., 2002). Individualized requirements were fulfilled a week later, either in person or by phone. Each patient's performance was reviewed after one month of the study intervention by checking adherence to the specified continuous connection.

Table 2: Individualized Consultations and Follow-Up Sessions Using 5 A's Behavior Change Model

Steps	*Objectives*	*Main content*
ASSESS	Identifying patients' needs.	- Assess needs and set behavioral objectives. - Evaluating patients' self-management skills. - Discussing each patient's individual experience in managing SCD.
ADVICE	Provide detailed and personalized behavior modification recommendations, including information about personal health risks and benefits.	- Patients were counselled on the advantages of behavioral modification. - Patients were advised about the risks of disease control noncompliance. - Based on the patient's interests and willingness, the patient and researcher agreed on behavioral modification strategies.
AGREE	Collaboratively set personally meaningful behavioral SMART goals (Specific, Measurable, Attainable, Relevant, Time-bound).	- A written agreement between the patient and the researcher about the patient's behavior changes efforts. - Appropriate and agreeable behavioral objectives were developed depending on the patient's interest and priority.
ASSIST	Aid the patient in achieving agreed-upon goals by acquiring the skills, confidence, and social/environmental supports for behavioral change, supplemented with adjunctive medical treatments when appropriate.	- Patients were asked to perform deep breathing and relaxation exercises twice a day, each time for 10 to 15 minutes, and check them in the daily record checklists. - Patients were provided a demonstration on stretching exercises. - Patients were informed about the disease and its management through slides and images. - Patients were asked to discuss their successful experiences with pain control or other problems so that they could more easily adopt the successful experiences of each other. - patients were taught problem-solving techniques, were helped to identify barriers to behavior change, and were acquainted with overcoming those barriers. - Adequate feedback was provided and enough time was allocated to answering patients' questions. The assistance stage continued throughout the follow-up period.
ARRANGE	Established weekly follow-up schedule.	- Establish weekly interaction, by providing the researcher's telephone number to the patients to provide on-going assistance and support and to adjust the treatment plan as needed, including referral to more intensive or specialized treatment.

Control Group

Patients in the control group received standard health education from SCD clinics in the HC. The clinic employs a nurse, a physician, a health record clerk, a laboratory technician, a social worker, and a health promotion specialist to provide integrated patient health services. It consists of both preventative and curative services. The nurses at the health center provide patients with information regarding factors that may cause vaso-occlusion and precipitate VOCs, when to seek emergency care, and continue to educate patients on the significance of regular medical examinations and screening.

Program Evaluation (Post -Test)

The patients in both EBI and control groups were reassessed for self-efficacy and self-management capacity after one-month using tools I, II, and III.

Ethical Considerations

Approval for conducting the study was obtained from the ethical research review board of the College of Health and Sport Sciences. Official approval for conducting the study was also obtained from the Ethical Research Committee of the Primary Healthcare responsible Authorities (Appendix VI). Written informed consent was obtained from the participants after explaining the aim and objectives of the study. Participation in the study was entirely voluntary. The right to refuse, participate, or withdraw from the study was emphasized. Confidentiality of the obtained data was assured, and participants' anonymity was respected.

Statistical Analysis

The Statistical Package for Social Sciences (SPSS) version 23 was utilized for data analysis. Descriptive statistics included numbers, percentages, mean and standard deviations to describe demographic characteristics, self-efficacy, self-management capacity, and quality of life. Data were tested for normality using the Kolmogorov-Smirnov test. In Inferential statistics, the Chi-square and Fisher's Exact tests were used to test the significance between the study and control groups regarding self-efficacy and self-management capacity and quality of life. Further, the comparison between the patients in the two study groups regarding their mean age, total scores of three tools before, and after the EBI were made by using Mann–Whitney (Z) tests. All of the statistical analyses were considered significant at $P \leq 0.05$.

Chapter IV

Results

Results

The results of the current EBI will be presented in four parts as follows:

Part I: Characteristics and Clinical data of Adults with SCD.

Part II: Effect of Empowerment-Based Intervention on Self-efficacy among Adults with SCD.

Part III: Effect of Empowerment-Based Intervention on Self-Care Capacity among Adults with SCD.

Part IV: Effect of Empowerment-Based Intervention on Health-related quality of life among Adults with SCD.

Part I: Characteristics and Clinical data of Adults with SCD

A. Socio-demographic Characteristics of the Adults with SCD

Table 3 and figure 10 present the socio-demographic characteristics of adults with sickle cell disease. It is revealed that nearly one-half of the patients in both the EBI and control groups had 30 to less than 40 years (47.2% and 43.8% respectively). The mean age of the patients in the EBI group was 35.03±7.93 years and 36.47±9.27 years in the control group. Moreover, 75.0% of the adults with SCD in the EBI group and 87.5% of those in the control group were males.

Regarding educational level, it is observed that more than half of patients in both groups held bachelor's degrees (58.3 % and 56.2 % respectively). Further, 69.4% of the EBI group were married compared to 56.2 % of the control group. One-quarter of patients in both groups were from nuclear families (25.0%). The majority of patients in the control group were employers (90.6%) compared to 77.8% of those in the EBI one. Homogeneity among the two groups is noticed as no significant statistical differences were found between them regarding all the sociodemographic characteristics of adults with SCD.

Table 3: Socio-Demographic Characteristics of Adults with SCD

Socio-demographic Characteristics		EBI Group (n=36) No. (%)	Control Group (n=32) No. (%)	Sig.
Age				
	<30	9(25.0)	6(18.8)	F^{ET}= 1.81 P=0 .899
	30- <40	17(47.2)	14(43.8)	
	40- <50	8(22.2)	9(28.1)	
	50 & more	2(5.6)	3(9.3)	
	Mean ±SD	35.03±7.93	36.47±9.27	Z^{MW}=-0.578 P=0.563
Gender				
	Male	27 (75.0)	28(87.5)	F^{ET}= 1.712 P=0.229
	Female	9 (25.0)	4(12.5)	
Educational level				
	Primary	1(2.8)	1(3.1)	F^{ET}=0.539 P=0.965
	Secondary	3(8.3)	2(6.2)	
	Bachelor	21 (58.3)	18(56.2)	
	Postgraduate	11(30.6)	11(34.4)	
Marital Status				
	Married	25 (69.4)	18(56.2)	F^{ET}=3.46 P=0.172
	Single	1(2.8)	5(15.6)	
	Divorced	10(27.8)	9(28.1)	
Type of Family				
	Nuclear family	9 (25.0)	8(25.0)	$\chi 2$=0.801 P=0.709
	Extended Family	22 (61.1)	17(53.1)	
	Cluster family	5 (13.9)	7(21.9)	
Work				
	Employed	26 (77.8)	29(90.6)	F^{ET}= 1.712 P=0.229
	Unemployed	8(22.2)	3(9.3)	

Z^{MW}: Mann Whitney Test F^{ET} Fisher's Exact Test $\chi 2$: Chi-square Test Significant at *$P \leq 0.05$

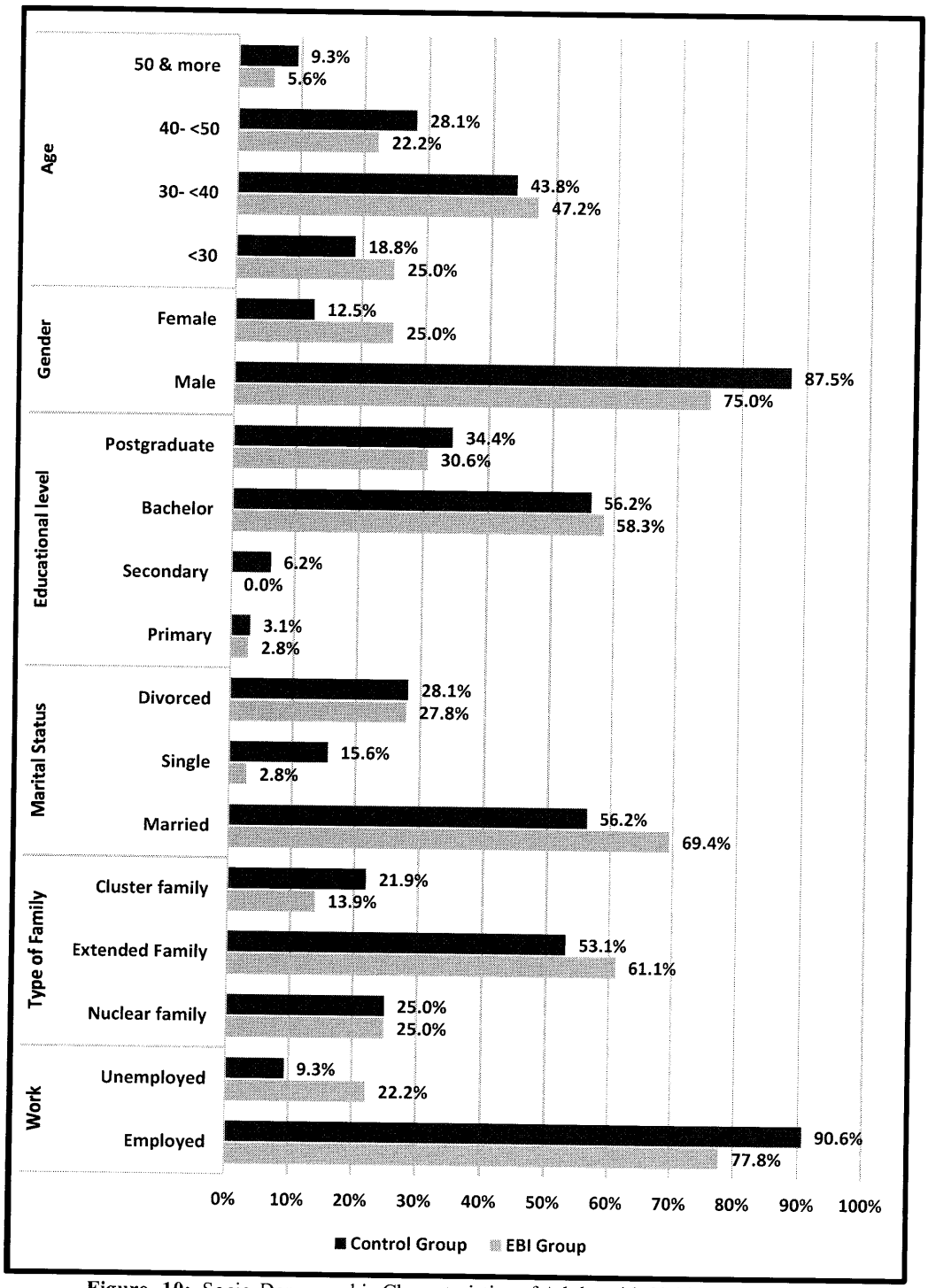


Figure- 10: Socio-Demographic Characteristics of Adults with Sickle Cell Disease.

B. Clinical data of Adults with SCD

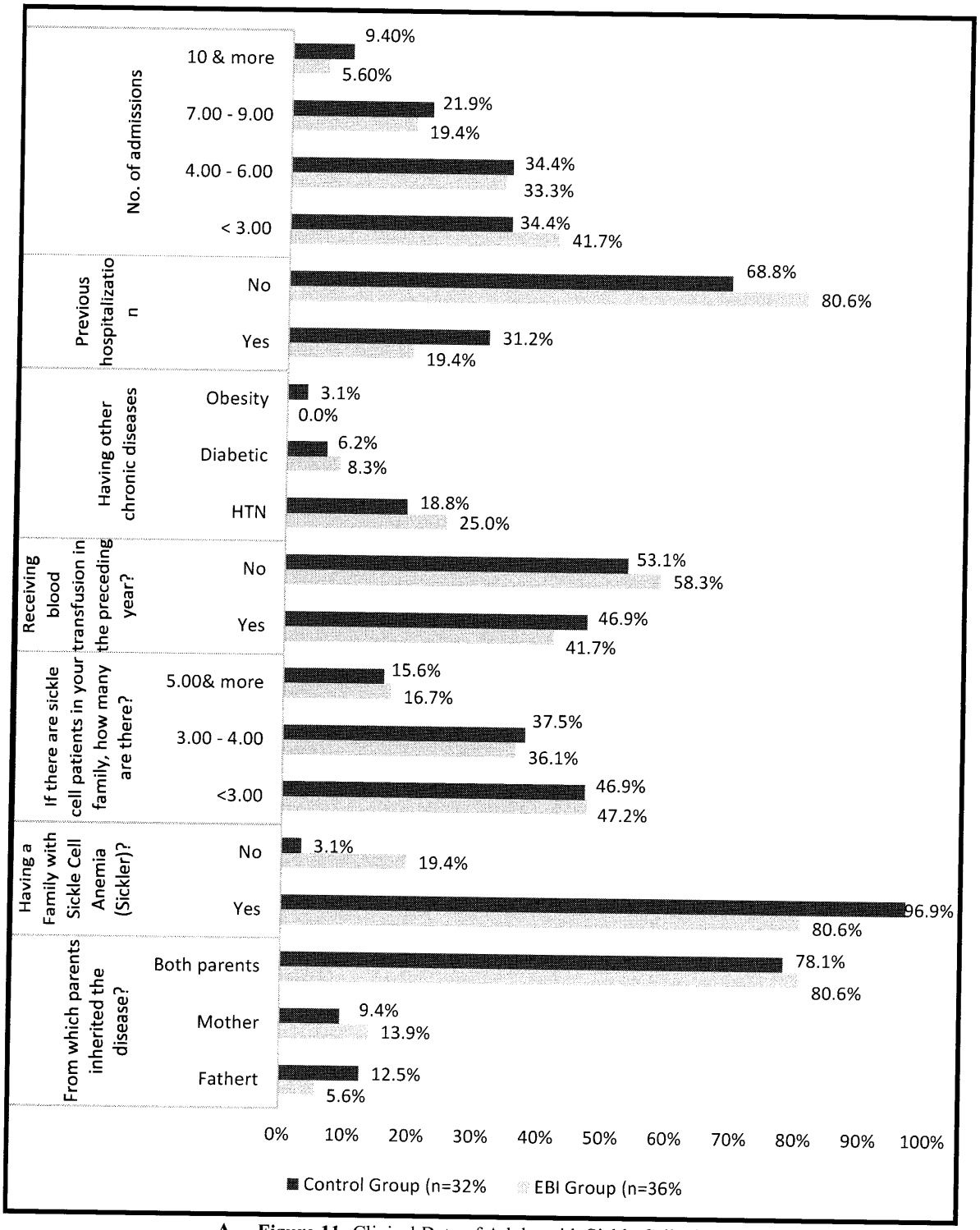
Table 4 and figure 11 illustrate the clinical data of adults with SCD. It is clear that 80.6% and 78.1% of patients in both groups inherited the disease from their both parents. The majority of patients in the EBI and control group had a family member with SCD (80.6% and 96.9% respectively).

Regarding blood transfusions, 41.7% and 46.9% patients in both groups received blood in the preceding year. Nearly the same percentage among both groups were admitted to hospital 4-6 times (33.3% and 34.4% respectively). Besides, 19.4% and 15.6% in both groups had previous surgeries respectively.

Table 4 Clinical Data of Adults with SCD

Clinical Data	EBI Group (n=36) No. (%)	Control Group (n=32) No. (%)	Sig.
From which parents inherited the disease?			
Father	2(5.6)	4(12.5)	F^{ET}=1.23
Mother	5(13.9)	3(9.4)	P=0.562
Both parents	29(80.6)	25(78.1)	
Having a Family with Sickle Cell Anemia (Sickler)?			
Yes	29 (80.6)	31(96.9)	F^{ET}=4.34
No	7(19.4)	1(3.1)	P=0.037
If there are sickle cell patients in your family, how many are there?			
≤ 2.00	17(47.2)	15(46.9)	$\chi2$=0.021
3.00 - 4.00	13(36.1)	12(37.5)	P=0.990
5.00& more	6(16.7)	5(15.6)	
Receiving blood transfusion in the preceding year?			
Yes	15(41.7)	15(46.9)	$\chi2$= 0.186
No	21(58.3)	17(53.1)	P=0.807
Having other chronic diseases			
Hypertension	9 (25.0)	6(18.8)	F^{ET}=1.601
Diabetic	3(8.3)	2(6.2)	P=0.750
Obesity	0(0.0)	1(3.1)	
Previous hospitalization			
Yes	7(19.4)	10(31.2)	$\chi2$=0.021
No	29(80.6)	22(68.8)	P=0.990
No. of admissions			
≤ 3	15(41.7)	11(34.4)	F^{ET}=0.749
4- 6	12(33.3)	11(34.4)	P=0.905
7- 9	7(19.4)	7(21.9)	
10 & more	2(5.6)	3(9.4)	
Previous surgeries			
Yes	7(19.4)	5(15.6)	$\chi2$=4.321
No	29(80.6)	24(84.4)	P=0.690
Type of surgeries			
Splenectomy	2(5.6)	2(6.2)	
Knee Replacement	1(2.8)	1(3.1)	F^{ET}=1.749
Hip Replacement	2(5.6)	0(0.0)	P=0.605
C-Section	1(2.8)	0(0.0)	
Kidney Transplant	1(2.8)	0(0.0)	
Cholecystectomy	0(0.0)	2(6.2)	

F^{ET} Fisher's Exact Test **$\chi2$: Chi-square Test** **Significant at $^{*}P\leq0.05$**



A. Figure 11: Clinical Data of Adults with Sickle Cell Disease

Part II: Effect of Empowerment-Based Intervention on Self-efficacy among Adults with SCD

Table 5 illustrates self-efficacy among adults with SCD in the EBI and control groups at pre, and posttest. It is noticed that the mean score of the patients in the EBI group reported that their ability to keep doing most of the day-to-day activities was 2.83±1.36 compared to 2.94±1.24 among patients in the control group before the program with no significant statistical differences. A significant improvement was found in the EBI group as the mean score was increased to 4.31±0.79 compared to 3.47±0.89 in the control group (P<0.001).

The same table highlights that the application of the EBI enabled adults with SCD to reduce SCD pain by using methods other than taking extra medication improved from 2.58±1.34 to 3.87±1.07 after the intervention compared to 2.89±1.24 and 3.22±1.16 for the control group with significant statistical differences between the two groups (P<0.049). It was observed that the mean score of patients who control the frequency of tiredness enhanced after the program from 3.18± 1.32 to 4.14±0.93 whereas the mean score among the control group decreased from 3.30±1.16 to 3.19±1.33. Concerning the ability to deal with the frustration of SCD, the patients who received EBI reported higher scores in the posttest (3.83±0.94) compared to the pre-test (2.97±1.16) and a significant statistical difference was noticed between the two groups (P<0.001). Generally, the mean total score showed a significant improvement among patients in the EBI group from 27.75±7.99 to 27.72±6.05 compared to 28.28±4.57 and 38.56±10.39 in the control group (P<0.001).

Table 5: Self-efficacy among Adults with SCD in the EBI and Control Groups at pre, and posttest.

Items	Pre-test			Post-test		
	EBI Group (n=36)	Control Group (n=32)	Significance	EBI Group (n=36)	Control Group (n=32)	Significance
Patients' ability to:						
1. Do something to cut down on most of the pain during a pain episode.	2.31±1.26	2.72±1.14	Z^{MW}=-0.152 P=0.88	3.94±1.01	3.25±1.22	Z^{MW}=-4.063 $P<0.001$***
2. Keep doing most of the do day-to-day activities.	2.83±1.36	2.94±1.24	Z^{MW}=-0.151 P=0.88	4.31±0.79	3.47±0.98	Z^{MW}=-4.637 $P<0.001$***
3. Keep SCD pain from interfering with sleep.	2.78±1.38	2.411.34	Z^{MW}=-1.454 P=0.15	4.31±0.71	3.53±1.14	Z^{MW}=-2.968 $P<0.001$***
4. Reduce SCD pain by using methods other than taking extra medication.	2.58±1.34	2.89±1.24	Z^{MW}=-1.604 P=0.11	3.78±1.07	3.22±1.16	Z^{MW}=-1.942 P=0.049*
5. Control how often or when getting tired.	3.18±1.32	3.30±1.16	Z^{MW}=-0.643 P=0.52	4.14±0.93	3.19±1.33	Z^{MW}=-3.100 $P<0.001$***
6. Do something to help in feeling better in case of being sad or blue.	3.03±1.32	2.84±1.17	Z^{MW}=-0.643 P=0.52	4.21±1.89	3.59±1.01	Z^{MW}=-4.179 $P<0.001$***
7. Manage the life from day to day as compared with other people with SCD.	2.31±0.98	2.41±1.13	Z^{MW}=-0.274 P=0.78	4.02±1.38	2.78±1.31	Z^{MW}=-3.940 $P<0.001$***
8. Manage SCD symptoms so that enjoy doing things.	3.01±1.05	3.11±1.30	Z^{MW}=-1.623 P=0.10	4.03±1.06	3.31±1.20	Z^{MW}=-2.549 P=0.01**
9. Deal with the frustration of having SCD.	2.97±1.16	2.81±1.28	Z^{MW}=-0.741 P=0.46	3.83±0.94	3.00±1.22	Z^{MW}=-2.856 $P<0.001$***
Mean Total Score	27.75±7.99	28.28±4.57	Z^{MW}=-0.83 P=0.72	27.72±6.05	38.56±10.39	Z^{MW}=-6.12 P<0.001***

Z^{MW}: Mann Whitney Test *Significant at *$P\leq0.05$ **$P<0.01$ ***$P<0.001$

Part III: Effect of Empowerment-Based Intervention on Self-Management Capacity among Adults with SCD

Table 6 explicates the comparison between self-care dimensions among adults with SCD in the EBI and control groups at pre- and post-EBI. Regarding having the capacity for self-care, it was found that the mean score of patients in the EBI group who made the needed adjustments to stay healthy was 2.61±1.18 before the application of the program compared to 2.53±1.29 for the control group. This means increased to 4.17±0.56 among the EBI group after the application of the program compared to 3.09±1.28 in the control group with a significant statistical difference($P<0.001$).

It was clear that the mean score of the patients in the EBI group who set new priorities in the measures that they took to stay healthy was 2.53±1.03 compared to 2.88±1.26 among the control one. Meanwhile, this means was raised to 3.83±0.68 in the EBI group compared to 3.16±1.19 for those who received routine health education ($P=0.02$).

The table also showed that the mean score of patients in the EBI group who looked for better ways to take care of themselves increased from 3.08±1.00 to 4.03±0.88 after receiving the program. However, a slight increase in the mean scores of this self-care practice among patients in the control group was noticed (2.84±1.04 for the pretest and 3.17±0.78 for the posttest). In addition, it is noticed that the application of the EBI enhanced the patients' ability to evaluate the effectiveness of things that help them to stay healthy. As the mean scores of patients in the EBI group increased from 2.17±1.23 to 4.36±0.72 compared to 2.47±1.02 and 3.03±0.97 among patient in the control group ($P<0.001$).

Regarding developing capacity for self-care, it was observed that patients in EBI group changed some of the old habits in order to improve their health. As their mean scores were raised to 4.25±0.60 after the application of the program compared to 3.25±1.57 among patients who received the routine care. A significant statistical difference was observed after the application of the program P=0.003.

Table 6 also highlights that the EBI reduced the patients' self-care deficit. Before EBI, the mean score of the patients 2.89±1.19 of patient of EBI group reported that they were not able to care for themselves in the way they would like compared to 2.52±1.22 among the control group. The mean score raised to 9.7±9.4 for patients in EBI group after the application of the program and declined to 2.84±1.02 among the control group with a significant statistical difference between the two groups (P<0. 001).

Table 6: Comparison Between Self-care dimensions among adults with SCD in the EBI and Control Groups at pre, and post-test.

Items	Item	Pre-test			Post-test		
		EBI Group (n=36)	Control Group (n=32)	Significance	EBI Group (n=36)	Control Group (n=32)	Significance
		Mean± SD	Mean± SD		Mean± SD	Mean± SD	
Having the capacity for self-care							
1. As circumstances change, I make the needed adjustments to stay healthy		2.61±1.18	2.53±1.29	Z^{MW}=-0.12 P=0.90	4.17±0.56	3.09±1.28	Z^{MW}=-3.63 P<0.001***
2. If my mobility is decreased, I make the needed adjustments		3.31±1.06	3.38±1.29	Z^{MW}=-0.25 P=0.81	4.09±0.58	3.69±1.18	Z^{MW}=-1.60 P=0.11
3. When needed, I set new priorities in the measures that I take to stay healthy		2.53±1.03	2.88±1.26	Z^{MW}=-0.26 P=0.80	3.83±0.68	3.16±1.19	Z^{MW}=-4.15 P<0.001***
5. I look for better ways to take for myself		3.08±1.00	3.34±1.04	Z^{MW}=-0.84 P=0.40	4.28±0.88	3.97±0.78	Z^{MW}=-1.99 P=0.05*
6. When needed, I manage to take time to care for myself		2.97±1.06	2.91±1.23	Z^{MW}=-3.22 P<0.001***	4.18±0.55	3.10±0.95	Z^{MW}=-2.85 P<0.001***
10. I regularly evaluate the effectiveness of things that I do to stay healthy		2.17±1.23	2.47±1.02	Z^{MW}=-0.99 P=0.32	4.36±0.72	3.03±0.97	Z^{MW}=-5.05 P<0.001***
Developing capacity for self-care							
7. If I take a new medication, I obtain information about the side effects to better care for myself		3.03±1.32	2.53±0.95	Z^{MW}=-1.02 P=0.31	3.75±1.57	3.19±1.40	Z^{MW}=-6.11 P<0.001***
8. In the past, I have changed some of my old habits in order to improve my health		2.44±1.08	2.72±1.30	Z^{MW}=-0.84 P=0.40	4.25±0.60	3.25±1.57	Z^{MW}=-2.12 P=0.03*
9. I routinely take measures to ensure the safety of myself and my family		2.93±8.23	2.88±1.01	Z^{MW}=-1.08 P=0.28	3.98±0.85	3.06±0.88	Z^{MW}=-3.47 P<0.001***
12. I am able to get the information I need, when health is threatened		2.94±1.01	2.96±1.41	Z^{MW}=-0.66 P=0.51	4.44±0.84	3.12±1.02	Z^{MW}=-5.39 P<0.001***
13 I seek help when unable to care for myself		2.69±1.09	2.78±1.10	Z^{MW}=-0.28 P=0.78	3.89±0.62	3.50±1.14	Z^{MW}=-1.25 P=0.21
Lacking capacity for self-care							
4. I often lack the energy to care for myself in the way that I know I should		3.14±1.15	3.01±1.26	Z^{MW}=-0.62 P=0.54	3.78±1.12	3.28±1.17	Z^{MW}=-1.72 P=0.09
11. In my daily activities, I seldom take time to care for myself		2.19±1.04	2.56±1.19	Z^{MW}=-1.22 P=0.22	4.03±1.06	2.94±1.32	Z^{MW}=-4.65 P<0.001***
14. I seldom have time for myself		2.86±1.15	2.91±1.28	Z^{MW}=-0.54 P=0.59	3.56±1.40	3.03±1.15	Z^{MW}=-2.02 P=0.04*
15. I am not always able to care for myself in a way I would like		2.89±1.19	2.52±1.22	Z^{MW}=-0.28 P=0.78	3.97±0.94	2.84±1.02	Z^{MW}=-4.19 P<0.001***

Z^{MW}: Mann Whitney Test Significant at *$P \leq 0.05$ ***$P < 0.001$

Table 7 portrays self-care capacity among adults with SCD in the EBI and control groups at pre, and post-EBI. It was found that the mean score of the patients in the EBI group with regards to having the capacity for self-care before the EBI was 3.28±0.61 compared to 3.50±0.73 among patients in the control group with no significant statically differences (P=0.26). A significant improvement in the capacity for self-care among patients who received the EBI as their mean score was 4.32±0.35 compared to 3.49±0.48 in the control group (P<0.001).

The same table highlights that the application of the EBI enabled adults with SCD to develop their capacity for self-care as their scores improved from 3.26±1.84 to 4.02±0.42 after the intervention compared to 2.90±0.54 and 3.02±0.52 for the control group with significant statistical differences between the two groups (P<0.001). Concerning lacking the capacity for self-care, the patients who received EBI reported higher scores in the post-test (3.83±0.74) compared to the pre-test (2.77±0.66) and a significant statistical difference was noticed between the two groups (P<0.001).

Adults with SCD who received the EBI showed a significant improvement in the overall score (48.02±11.10 for the pre and 61.36±4.54 for the post-intervention) compared to 47.60±8.23 and 49.50±5.58 for the control group and highly significant differences between the groups were found (P=0.003).

Table 7: Self-Care Capacity among adults with Sickle Cell Disease in the EBI and Control Groups at Pre, and Post-test.

Item	Pre-test		Significance	Post-test		Significance
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
Having the capacity for self-care	3.28±0.61	3.50±0.73	Z^{MW}=-1.130 P=0.26	4.32±0.35	3.49±0.48	Z^{MW}=-5.876 $P<0.001^{***}$
Developing capacity for self-care	3.26±1.84	2.90±0.54	Z^{MW}=-1.011 P=0.31	4.02±0.42	3.02±0.52	Z^{MW}=-6.074 $P<0.001^{***}$
Lacking capacity for self-care	2.77±0.66	2.98±0.81	Z^{MW}=-0.754 P=0.45	3.83±0.74	3.07±0.63	Z^{MW}=-6.648 $P<0.001^{***}$
Overall Scale	48.02±11.10	47.60±8.23	Z^{MW}=-0.45 P=0.65	61.36±4.54	49.50±5.58	Z^{MW}=-6.37 P=0.003**

Z^{MW}: Mann Whitney Test Significant at *$P\leq0.05$ **$P< 0.01$ ***$P< 0.001$

Part IV: Effect of Empowerment-Based Intervention on Health-related quality of life among Adults with SCD

Table 8 reveals physical functioning among adults with SCD in the EBI and control groups at Pre, And Post Empowerment- Based Intervention. It is revealed that more than half of the patients who received the EBI reported their ability to perform vigorous activities compared to only 15.6% of those patients in the control one.

As a baseline assessment, it was noticed that 41.7% of the patients in the EBI group and 59.4% in the control group reported that moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf were limited. However, the vast majority of the patients in the EBI group reported that such kind of activities was not limited at all after applying the instructions provided to them in the program 94.4%. On the other hand, the percentage of the patients in the control group who reported limitations in moderate activities slightly increased to 62.5%.

Climbing several flights of stairs was an obvious problem reported by 66.7% and 53.1% of patients in the EBI and control groups respectively. In comparison between receiving the EBI and routine care, these percentage declined to 27.8% in the EBI group compared to slight decline in patients in the control group (46.9%). Regarding the patient's ability to walk, all the patients who received the EBI expressed their ability to walk several blocks compared to only 18.7% among those who received routine healthcare ($P<0.001$). Similarly, all the patients in the EBI expressed their ability to independently bath or dress themselves, while 28.1% of patients in the control group reported that such activities are limited a lot and a highly significant statistical difference was found between the two groups ($P<0.001$)

It is clear that there were highly significant statistical differences between EBI and control groups regarding all items of physical functioning ($P<0.001$ for each).

Table 8: Physical Functioning Among Adults with SCD in the EBI and Control Groups at Pre, and Post-test.

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36) No. (%)	Control Group (n=32) No. (%)		EBI Group (n=36) No. (%)	Control Group (n=32) No. (%)	
3. Vigorous activities, such as running, lifting heavy objects,participating in strenuous sports						
- Yes, limited alot (0)	21(58.3)	12(37.5)	F^{ET}=5.94	4(11.1)	11(34.4)	F^{ET}= 36.40
- Yes, limited alittle (50)	15(41.7)	16(50.0)	p=0. 705	10 (27.8)	16(50.0)	P<0.001***
- No, not limited atall (100)	0 (0.0)	4(12.5)		22 (61.1)	5(15.6)	
4. Moderate activities, such as moving a table, pushing avacuum cleaner, bowling, or playing golf						
- Yes, limited alot	6 (16.7)	5(15.6)	F^{ET}=2.46	0 (0.0)	4(12.5)	F^{ET}= 47.62
- Yes, limited alittle	15(41.7)	19(59.4)	p=0. 314	2(5.6)	20(62.5)	P<0.001***
- No, not limited atall	15(41.7)	8(25.0)		34(94.4)	8(25.0)	
5. Lifting or carrying groceries						
- Yes, limited a lot	6 (16.7)	14 (43.8)	F^{ET}=5.94	0 (0.0)	13 (40.6)	F^{ET}= 39.40
- Yes, limited a little	21 (58.3)	12 (37.5)	p=0. 572	1 (2.8)	13 (40.6)	P<0.001***
- No, not limited atall	9 (25.0)	6 (18.8)		35 (97.2)	6 (18.8)	
6. Climbing several flights of stair						
- Yes, limited alot	24 (66.7)	17 (53.1)	F^{ET}=2.63	10 (27.8)	15 (46.9)	F^{ET}=26.81
- Yes, limited alittle	12 (33.3)	13 (40.6)	p=0. 221	21 (58.3)	15 (46.9)	P<0.001***
- No, not limited atall	0 (0.0)	2 (6.2)		5 (13.9)	2 (6.2)	
7. Climbing one flight of stairs						
- Yes, limited alot	6 (16.7)	6 (18.8)	F^{ET}=0.181	2 (5.6)	5 (15.6)	F^{ET}=26.23
- Yes, limited alittle	16 (44.4)	13 (40.6)	p=0.992	0 (0.0)	14 (43.8)	P<0.001***
- No, not limited at all	14 (38.9)	13 (40.6)		34 (94.4)	13 (40.6)	
8. Bending, kneeling, or stooping						
- Yes, limited alot	13 (36.1)	9 (28.1)		1 (2.8)	8 (25.0)	
- Yes, limited alittle	8 (22.2)	7 (21.9)		14 (38.9)	7 (21.9)	
- No, not limited atall	15 (41.7)	16 (50.0)	F^{ET}=5.97 p=0.353	21(58.3))	17 (53.1)	F^{ET}= 18.97 P<0.001***

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36) No. (%)	Control Group (n=32) No. (%)		EBI Group (n=36) No. (%)	Control Group (n=32) No. (%)	
Table 8: Continue						
9. Walking more than a mile						
- Yes, limited alot	8 (22.2)	7 (21.9)	F^{ET}=16.55 p=0.624	6 (16.7)	7 (21.9)	F^{ET}=13.42 p=0.061
- Yes, limited alittle	19 (52.8)	15 (46.9)		17 (47.2)	15 (46.9)	
- No, not limited atall	9 (25.0)	10 (31.2)		13 (36.1)	10 (31.2)	
10. Walking several blocks						
- Yes, limited alot	9 (25.0)	11 (34.4)	F^{ET}=2.85 p=0.271	0 (0.0)	10 (31.2)	F^{ET}=56.39 P<0.001***
- Yes, limited alittle	15 (41.7)	16 (50.0)		0 (0.0)	16 (50.0)	
- No, not limited atall	12 (33.3)	5 (15.6)		36 (100.0)	6 (18.7)	
11. Walking one block						
- Yes, limited alot	11(30.6)	4(12.5)	F^{ET}=4.00 p=0.137	11(30.6)	0 (0.0)	F^{ET}=18.28 P<0.001***
- Yes, limited alittle	13(36.1)	11(34.4)		13 (36.1)	1 (2.8)	
- No, not limited atall	12(33.3)	17(53.1)		12 (33.3)	35 (97.2)	
12. Bathing or dressing yourself						
- Yes, limited alot	8 (22.2)	7(21.9)	F^{ET}=0.137 p=0.814	0 (0.0)	9 (28.1)	F^{ET}=20.39 P<0.001***
- Yes, limited alittle	7(19.4)	7(21.9)		0 (0.0)	7(21.9)	
- No, not limited atall	21(58.3)	18(56.2)		36(100.0)	16 (50.0)	

F^{ET} Fisher's Exact Test **Significant at *$P \leq 0.05$ ***$P < 0.001$**

Table 9 shows role limitations due to physical health among adults with SCD in the EBI and control groups at pre and posttest. It was revealed that 30.6 % of patients in the EBI group did not cut down the amount of time that they spent on work or other activities. This percentage increased to 80.6% after the application of the program. Meanwhile, the percentage of those patients in the control group remained almost the same (34.4 % at the pretest and 37.5% at the posttest) with a significant statistical difference *(P<0.001)*.

The table also revealed that 69.4 % of patients in the EBI group accomplished physical activity less than they would like. A significant decline in the patients' accomplishment was noticed after receiving the EBI (8.3%). Whereas, the percentage of patients in the control group showed a slight decline from 75.0% to 68.8% after receiving the routine health care (*P<0.001*).

Role limitations due to physical health also reflected that 36.1% of patients in EBI group were not limited in the kind of work or other activities. This percentage increased to 88.9 % of those patients after EBI. Furthermore, 34.4% of the patient in the control group slightly increased to 37.5 after the program.

Regarding, the difficulty in performing work or other activities, it was found that 75.0% and 68.8% of patients in EBI and control groups reported such problems at the pretest. After the program, the majority of patients in the EBI group reported that such work difficulty faded (88.9%) among patients in the EBI group compared to 40.6%. Significant statistical differences were noticed in all the role limitations due to physical health ($P<0.001$).

Table 9: Role Limitations due to Physical Health among Adults with SCD in the EBI and Control Groups at pre, and posttest.

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
13. Cut down the amount of time you spent on work or other activities						
- Yes (0)	25(69.4)	21(65.6)	$\chi2$=0.11	7 (19.4)	20(62.5)	F^{ET}= 22.94
- No (100)	11(30.6)	11(34.4)	p=0.799	29(80.6)	12(37.5)	P<0.001***
14. Accomplished less than you would like						
- Yes (0)	25(69.4)	24 (75.0)	$\chi2$=0.11	3 (8.3)	22 (68.8)	F^{ET}= 30.41
- No (100)	11 (30.6)	8 (25.0)	p=0.799	33 (91.7)	10 (31.2)	P<0.001***
15. Were limited in the kind of work or other activities						
- Yes (0)	23 (63.9)	21 (65.6)	$\chi2$=0. 022	4 (11.1)	20(62.5)	F^{ET}= 22.25
- No (100)	13 (36.1)	11 (34.4)	p= 1.000	32 (88.9)	12(37.5)	P<0.001***
16. Had difficulty performing the work or other activities (for example, it took extra effort)						
- Yes (0)	27 (75.0)	22 (68.8)	$\chi2$=0 329	4 (11.1)	19(59.4)	F^{ET}= 22.27
- No (100)	9 (25.0)	10 (31.2)	p=0. 566	32 (88.9)	13 (40.6)	P<0.001***

F^{ET} Fisher's Exact Test **$\chi2$: Chi-square Test** **Significant at *$P \leq 0.05$ ***$P < 0.001$**

Role limitations due to emotional problems among adults with SCD in the EBI and control groups at pre, and post-test is displayed in Table 10. It is evident that one-quarter of patients in the EBI group cut down the amount of time that they spent on work or other activities (25.0%). After the program, only 8.3% of those patients exhibited that behavior. Meanwhile, a slight decline in this role limitation among patients in the control group (from 30.2% to 28.1%) with a significant statistical difference where *P*-value was 0.003.

Fortunately, 66.7% of patients in the EBI group who didn't do work or other activities as carefully as usual before the program decreased to 38.9% after the application of EBI. On the other hand, 50 % of patients in the control group declined to only 46.9%. A significant statistical difference was evident after the application of the program $P<0.001$.

Table 10: Role limitations due to emotional problems among adults with SCD in the EBI and Control Groups at Pre, and Post-Test.

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
17. Cut down the amount of time you spent on work or other activities						
- Yes (0)	9 (25.0)	10 (31.2)	$\chi2=13.07$	3 (8.3)	9 (28.1)	$F^{ET}=4.56$
- No (100)	27 (75.0)	22 (68.8)	$p=0.759$	33 (91.7)	23 (71.9)	$p=0.003^{**}$
18. Accomplished less than you would like						
- Yes (0)	25 (69.4)	17 (53.1)	$\chi2=3.19$	5 (13.9)	17 (53.1)	$\chi2=16.37$
- No (100)	11 (30.6)	15 (46.9)	$p=0.133$	25 (78.12)	15 (46.9)	$P<0.001^{***}$
19. Didn't do work or other activities as carefully as usual						
- Yes (0)	24 (66.7)	16 (50.0)	$\chi2=1.94$	14 (38.9)	15 (46.9)	$\chi2=13.70$
- No (100)	12 (33.3)	16 (50.0)	$p=0.219$	22 (61.1)	17 (53.1)	$p=0.002^{**}$

F^{ET} Fisher's Exact Test $\chi2$: Chi-square Test Significant at $*P\leq0.05$ $**P<0.01$ $***P<0.001$

Table 11 illustrates social functioning among adults with SCD in the EBI and control groups at pre, and posttest. It was observed that 27.8% and 18.8% of patients in EBI and control groups reported that physical health or emotional problems moderately interfered with their normal social activities with family, friends, neighbors, or groups before the application of the program. After application to the EBI program, it is noticed that 38.9% of patients in the EBI group did not report such social limitation at all compared to only 3.1% with a significant statistical difference between both groups where $P<0.001$.

As for the frequency of limitations in social activities, it is observed that more than one-quarter of the patients in both groups (27.8% and 31.2%) faced such limitations for some of time during the past 4 weeks. Following the instruction provided throughout the EBI enabled the patient to overcome such social limitations as none of them reported the problem at the posttest compared to 15.6% of patients in the control group ($P<0.001$).

Table 11: Social Functioning among Adults with SCD in the EBI and Control Groups at pre, and posttest.

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
20. Physical health or emotional problems interfered with your normal social activities, during the past 4 weeks						
- Not at all	3 (8.3)	1(3.1)		14 (38.9)	1(3.1)	
- Slightly	7 (19.4)	3 (9.4)	F^{ET}=6.90	22 (61.1)	3 (9.4)	
- Moderately	10 (27.8)	6 (18.8)	p=0.120	0 (0.0)	5 (15.6)	F^{ET}=19.77
- Quite a bit	13 (36.1)	17(53.1)		0 (0.0)	18 (56.2)	$P<0.001^{***}$
- Extremely	3 (8.3)	5(15.6)		0 (0.0)	5 (15.6)	
32. Frequency of having physical health or emotional problems interfered with your social activities During the past 4 weeks						
- All of the time	6 (16.7)	2 (6.2)	F^{ET}=3.42	0 (0.0)	0 (0.0)	F^{ET}= 15.12
- Most of the time	7 (19.4)	6 (18.8)	p=0.502	0 (0.0)	3 (9.4)	$P<0.001^{***}$
- Some of the time	10 (27.8)	10 (31.2)		5 (13.9)	14 (43.8)	
- A little of the time	7 (19.4)	11 (34.4)		12 (33.3)	10 (31.2)	
- None of the time	6 (16.7)	3 (9.4)		19 (52.8)	5 (15.6)	

F^{ET} Fisher's Exact Test **Significant at *$P\leq 0.05$ ***$P< 0.001$**

Table 12 displays pain among adults with SCD in the EBI and control groups at pre, and posttest. It is clear from the table that 13.9% of patients in the EBI group complained of severe pain during the past 4 weeks at the initial assessment. Whereas, none of the participants reported such complaint after receiving the EBI (0.0%). On the other side, the percentage of patients in the control group who suffered from severe pain during the past 4 weeks increased from 25% to 28.1%. A highly significant statistical difference was found regarding pain interference with normal work where *P value* was less than 0.001.

Table 12: Pain among adults with SCD in the EBI and Control Groups at pre, and posttest.

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
21.How much bodily pain have you had during the past 4 weeks?						
- None	5 (13.9)	0 (0.0)		0 (0.0)	0 (0.0)	
- Very mild	13 (36.1)	6 (18.8)		0 (0.0)	4 (12.5)	
- Mild	6 (16.7)	6 (18.8)	F^{ET}=17.03 p=0.046	26 (72.2)	7 (21.9)	F^{ET}=43.96 $P<0.001^{***}$
- Moderate	3 (8.3)	12 (37.5)		10 (27.8)	12 (37.5)	
- Severe	5 (13.9)	8 (25.0)		0 (0.0)	9 (28.1)	
- Very severe	4 (11.1)	0 (0.0)		0 (0.0)	0(0.0)	
22.During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?						
- Not at all	8 (22.2)	7(21.9)		0 (0.0)	0 (0.0)	
- A little bit	9 (25.0)	8 (25.0)	F^{ET}=11.64	10 (31.2)	5 (15.6)	F^{ET}= 1.80
- Moderately	9 (25.0)	11 (34.4)	p=0. 017*	14 (43.8)	13 (40.6)	$P<0.001^{***}$
- Quite a bit	6 (16.7)	0 (0.0)		6 (18.8)	12 (37.5)	
- Extremely	4 (11.1)	6 (18.8)		2 (6.2)	2 (6.2)	

F^{ET} Fisher's Exact Test Significant at $*P \leq 0.05$ $**P < 0.01$ $***P < 0.001$

Table 13 portrays energy/fatigue among adults with SCD in the EBI and control groups at pre and posttest. It was found that 19.4% of the patients in the EBI group, compared to 25.0% of the patients in the control group, felt full of pep for a little of the time before the EBI. This percent increased to 47.2% and 37.5% among patients in EBI and control groups at the posttest, respectively, with a significant statistical difference (P=0.009).

Concerning energy, it was found that 11.1% of patients in the EBI group compared to 18.8% of patients in the control group had a good bit of energy at the initial assessment. These percentages showed a significant increase to 44.4% after the application compared to 21.9% among the control group who received routine care. It was also revealed that 13.9% of the EBI group reported that they felt tired all of the time before the program, compared to 9.4% in the control group. None of those patients complained of tiredness after receiving EBI, compared to 12.5% in the control group (P=0.022).

Table 13: Energy/Fatigue Among Adults with SCD in The EBI and Control Groups at pre, and posttest

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
21. Did you feel full of pep?						
- All of the time	0 (0.0)	2 (6.2)		0 (0.0)	3 (9.4)	
- Most of the time	3 (8.3)	5 (15.6)	F^{ET}=11.64	0 (0.0)	5 (15.6)	F^{ET}=13.76
- A good bit of the time	10 (27.8)	7 (21.9)	p=0. 017*	1 (2.8)	4 (12.5)	p=0.009**
- Some of the time	10 (27.8)	8 (25.0)		11 (30.6)	4 (12.5)	
- A little of the time	7 (19.4)	8 (25.0)		17 (47.2)	12 (37.5)	
- None of the time	6 (16.7)	2 (6.2)		7 (19.4)	4 (12.5)	
27. Did you have a lot of energy?						
- All of the time	9 (25.0)	1 (3.1)		0 (0.0)	2 (6.2)	
- Most of the time	7 (19.4)	4 (12.5)	F^{ET}=4.67	10 (27.8)	6 (18.8)	F^{ET}=4.77
- A good bit of the time	4 (11.1)	6 (18.8)	p=0. 465	16 (44.4)	7 (21.9)	p=0.044*
- Some of the time	4 (11.1)	9 (28.1)		2 (5.6)	7 (21.9)	
- A little of the time	8 (22.2)	8 (25.0)		6 (16.7)	7 (21.9)	
- None of the time	4 (11.1)	4 (12.5)		2 (5.6)	3 (9.4)	
29. Did you feel worn out?						
- All of the time	4 (11.1)	0 (0.0)		0 (0.0)	3 (9.4)	
- Most of the time	5 (13.9)	7 (21.9)	F^{ET}=4.45	0 (0.0)	3 (9.4)	F^{ET}=13.75
- A good bit of the time	4 (11.1)	4 (12.5)	p=0.505	7 (19.4)	8 (25.0)	p=0.009**
- Some of the time	11 (30.6)	9 (28.1)		10 (27.8)	9 (28.1)	
- A little of the time	9 (25.0)	10 (31.2)		12 (33.3)	8 (25.0)	
- None of the time	3 (8.3)	2 (6.2)		7 (19.4)	1 (3.1)	
31.Did you feel tired?						
- All of the time	5 (13.9)	3 (9.4)		0 (0.0)	4 (12.5)	
- Most of the time	7 (19.4)	6 (18.8)	F^{ET}=4.02	3 (8.3)	5 (15.6)	F^{ET}=16.63
- A good bit of the time	10 (27.8)	10 (31.2)	p=0.557	5 (13.9)	10 (31.2)	p=0.022*
- Some of the time	6 (16.7)	9 (28.1)		14 (38.9)	8 (25.0)	
- A little of the time	5 (13.9)	3 (9.4)		8 (22.2)	4 (12.5)	
- None of the time	3 (8.3)	1 (3.1)		6 (16.7)	1 (3.1)	

F^{ET} Fisher's Exact Test Significant at *$P \leq 0.05$ **$P < 0.01$

Table 14 displays emotional well-being among adults with SCD in the EBI and control groups at pre and posttest. It is clear that more than one quarter of the patients who received the EBI reported that they had to be a very nervous person all of the time (25%), compared to only 6.2% of those patients in the control group. It is noteworthy that none of the patients in the EBI group reported being nervous after attending the program, compared to 3.1% in the control group (P=0.011).

Felting so down in the dumps for some of the time was reported by 27.8% and 3.1% of patients in the EBI and control groups, respectively, at initial assessment. In a comparison between receiving the EBI and routine care, this percentage declined to 25% in the EBI group compared to a tenth-fold increase in patients in the control group (31.2%).

Regarding patients' feeling calm and peaceful, 22.2 % of the patients who received the EBI felt calm and peaceful a good bit of the time, compared to only 21.9 % among those who received routine healthcare. This percent showed an increase in the EBI to 38.9 % while the percentage remained the same (21.9%) among those who received routine care.

It is revealed from the same table that 33.3% of patients in the EBI group reported that they had felt downhearted and blue before the program compared to 25.0% in the control group. A remarkable decline in such emotional problems was noticed among patients in the EBI group after receiving the program as the percentage decreased to 13.9%, while the percentage rose to 28.1% of those in the control group. Fortunately, the percentage of patients who expressed their feelings of happiness most of the time increased from 13.9% to 41.7% among patients in the EBI group, compared to 15.6% to 31.2% among those patients in the control one. There

were highly significant statistical differences between the EBI and control groups regarding all items of emotional well-being ($P<0.001$ for each).

Table 14: Emotional Well-Being Among Adults with SCD in the EBI and Control Groups at pre, and post-test

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
24. Have you been a very nervous person?						
- All of the time	9 (25.0)	2 (6.2)		0 (0.0)	1 (3.1)	
- Most of the time	7 (19.4)	6 (18.8)	F^{ET}=6.56	2 (5.6)	4 (12.5)	F^{ET} 13.80
- A good bit of the time	4 (11.1)	7 (21.9)	p=0. 255	6 (16.7)	6 (18.8)	p=0 .011*
- Some of the time	4 (11.1)	7 (21.9)		10 (27.8)	9 (28.1)	
- A little of the time	8 (22.2)	7 (21.9)		16 (44.4)	8 (25.0)	
- None of the time	4 (11.1)	3 (9.4)		2 (5.6)	4(12.5)	
25. Have you felt so down in the dumps that nothing could cheer you up?						
- All of the time	4 (11.1)	3 (9.4)		0 (0.0)	3 (9.4)	
- Most of the time	6 (16.7)	3 (9.4)	F^{ET}=11.85	0 (0.0)	6 (18.8)	F^{ET}= 25.97
- A good bit of the time	6 (16.7)	8 (25.0)	p=0.033	0 (0.0)	3 (9.4)	*P<0.001***
- Some of the time	10 (27.8)	1 (3.1)		9 (25.0)	10 (31.2)	
- A little of the time	7 (19.4)	8 (25.0)		11 (30.6)	9 (28.1)	
- None of the time	3 (8.3)	9 (28.1)		16 (44.4)	1(3.1)	
26. Have you felt calm and peaceful?						
- All of the time	6 (16.7)	1 (3.1)		9 (25.0)	2 (6.2)	
- Most of the time	9 (25.0)	2 (6.2)	F^{ET}=10.34	10 (27.8)	5 (15.6)	F^{ET}= 12.786
- A good bit of the time	8 (22.2)	7 (21.9)	p=0.062	14 (38.9)	7 (21.9)	p=0.016*
- Some of the time	6 (16.7)	10 (31.2)		2 (5.6)	8 (25.0)	
- A little of the time	3 (8.3)	7 (21.9)		1 (2.8)	8 (25.0)	
- None of the time	4 (11.1)	5 (15.6)		0 (0.0)	2(6.2)	

Table 14 Continue						
28. Have you felt downhearted and blue?						
- All of the time	0 (0.0)	1 (3.1)		0 (0.0)	0 (0.0)	
- Most of the time	9 (25.0)	5 (15.6)	F^{ET}=3.42	0 (0.0)	7 (21.9)	F^{ET}=19.96
- A good bit of the time	6 (16.7)	1 (3.1)	p=0.502	1 (2.8)	4 (12.5)	*P<0.001* ***
- Some of the time	12 (33.3)	8 (25.0)		5 (13.9)	9 (28.1)	
- A little of the time	6 (16.7)	7 (21.9)		17 (47.2)	10 (31.2)	
- None of the time	3 (8.3)	10 (31.2)		13 (36.1)	2(6.2)	
30. Have you been a happy person?						
- All of the time	4 (11.1)	2 (6.2)		6 (16.7)	1 (3.1)	
- Most of the time	5 (13.9)	5 (15.6)	F^{ET}=3.42	15 (41.7)	10 (31.2)	F^{ET}=19.24
- A good bit of the time	11 (30.6)	5 (15.6)	p=0.502	7 (19.4)	5 (15.6)	*P<0.001* ***
- Some of the time	8 (22.2)	5 (15.6)		8 (22.2)	8 (25.0)	
- A little of the time	5 (13.9)	12 (37.5)		0 (0.0)	7 (21.9)	
- None of the time	3 (8.3)	3 (9.4)		0 (0.0)	1 (3.1)	

F^{ET} Fisher's Exact Test **Significant at *$P \leq 0.05$ ***$P < 0.001$**

Table 15 depicts the general health among adults with SCD in the EBI and control groups at pre and posttest. It is observed that approximately one third of patients in both the EBI and control groups (30.6% and 31.2%, respectively) reported good health at initial assessment. Meanwhile, a notable increment in the percentage was noticed among patients in the EBI after application, while the percentage remained the same among patients in the control group. There was a significant statistical difference between both groups, $P<0.001$.

At the initial assessment, it was observed that 55.6% and 34.4% of patients in both the EBI and control groups reported the same level of health in general compared to one year ago among patients in the control group. Fortunately, more than half of the patients in the EBI group reported that their general health is much better now than one year ago after application of the program (53.1%) compared to 16.7% among patients in the control group ($P<0.001$).

Overall, the same table highlighted that 27.8% of the EBI group reported that their health was definitely excellent before the program compared to 25%. This percent decreased to 21.9% after the program and remained the same among the EBI group. A statistically significant difference was observed, $P<0.002$.

Table 15: General health among adults with SCD in the EBI and Control Groups at pre, and posttest

Item	Pre-test		Sig.	Post-test		Sig.
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
	No. (%)	No. (%)		No. (%)	No. (%)	
1. In general, would you say your health is						
- Excellent	1 (2.8)	1 (3.1)		1 (3.1)	2 (5.6)	
- Very good	1 (2.8)	5 (15.6)		6 (18.8)	12 (33.3)	$F^{ET}=16.66$
- Good	11 (30.6)	10 (31.2)	$F^{ET}=3.42$	18(56.2)	10 (31.2)	$p=0.001^{***}$
- Fair	16 (44.4)	13 (40.6)		7 (19.4)	8 (22.2)	
- Poor	7 (19.4)	3 (9.4)	$p=0.502$	4 (11.1)	0 (0.0)	
2. Compared to one year ago, how would you rate your health in general now?						
- Much better now than one year ago (0)	3(8.3)	6 (18.8)		17 (53.1)	6 (16.7)	
- Somewhat better now than one year ago (25)	4 (11.1)	8 (25.0)	$F^{ET}=5.30$	5 (15.6)	12 (33.3)	$F^{ET}=33.64$
- About the same (50)	20 (55.6)	11 (34.4)	$p=0.253$	4 (12.5)	10 (27.8)	$P<0.001^{***}$
- Somewhat worse now than one year ago (75)	9 (25.0)	7 (21.9		8 (25.0)	5 (13.9)	
33. I seem to get sick a little easier than other people						
- Definitely true	6 (16.7)	5 (15.6)		1 (2.8)	3 (9.4)	
- Mostly true	10 (27.8)	9 (28.1)	$F^{ET}=1.32$	1 (2.8)	11 (34.4)	$F^{ET}=11.28$
- Don't know	12 (33.3)	8 (25.0)	$p=0.892$	16 (44.4)	8 (25.0)	$p=0.019^{*}$
- Mostly false	5 (13.9)	5 (15.6)		9 (25.0)	6 (18.8)	
- Definitely false	2(8.3)	5(15.6)		9(25.0)	3(12.5)	

34. I am as healthy as anybody I know						
- Definitely true	8 (22.2)	9 (28.1)	F^{ET}=1.11	7 (19.4)	5 (15.6)	F^{ET}=3.75
- Mostly true	5 (13.9)	6 (18.8)	p=0.884	11 (30.6)	7 (21.9)	
- Don't know	13 (36.1)	11 (34.4)		12 (33.3)	10 (31.2)	p=0.431
- Mostly false	8 (22.2)	5 (15.6)		5 (13.9)	10 (31.2)	
- Definitely false	2(5.6)	1(3.1)		1(2.8)	0(0.0)	
35. I expect my health to get worse						
- Definitely true	6 (16.7)	4 (12.5)	F^{ET}=1.25	3 (8.3)	3 (9.4)	F^{ET}=2.06
- Mostly true	10 (27.8)	8 (25.0)		8 (22.2)	11 (34.4)	
- Don't know	14 (38.9)	13 (40.6)	p=0.902	6 (16.7)	6 (18.8)	p=0.747
- Mostly false	3 (8.3)	2 (6.2)		13 (36.1)	9 (28.1)	
- Definitely false	3 (8.3)	5 (15.6)		6 (16.7)	4(9.4)	
36. My health is excellent						
- Definitely true	10 (27.8)	8 (25.0)	F^{ET}=732	10 (27.8)	7 (21.9)	F^{ET}=16.07
- Mostly true	9 (25.0)	10 (31.2)	p=0.994	11 (30.6)	9 (28.1)	p=0.002**
- Don't know	5 (13.9)	4 (12.5)		9 (25.0)	6 (18.8)	
- Mostly false	10 (27.8)	9 (28.1)		2 (5.6)	10 (31.2)	
- Definitely false	2 (5.6)	1 (3.1)		4 (11.1)	0 (0.0)	

F^{ET} Fisher's Exact Test **Significant at *$P \leq 0.05$ **$P < 0.01$ ***$P < 0.001$**

Table 16 portrays the health-related quality of life among adults with SCD in the EBI and control groups at pre and posttest. Before the EBI, the mean score for physical functioning among patients in the EBI group was 45.56±19.99 compared to 51.09±17.26 among patients in the control group, with no statistically significant differences (P=0.29). Patients who received the EBI showed a significant improvement in their physical functioning, as their mean score was 77.64±8.49 compared to 59.67±17.07 in the control group at the posttest (P<0.001).

Prior to the application of the EBI, there was no significant statistical difference between the EBI and control groups in terms of role limitations due to physical health (P = 0.84). After application of the EBI, patients' mean scores dramatically increased, from 30.56±29.34 to 64.28±13.73 compared to a slight increase in the main score among patients in control group 31.25±27.68 to 35.16±27.75 (P<0.001).

Concerning energy/fatigue, patients who received EBI had a significantly higher posttest mean score (67.50±11.57) compared to the pre-test (52.08±15.95). However, the mean score declined among those patients who received routine healthcare from 51.33±10.66 to 49.63±12.55 and a statistically significant difference between the two groups was observed (P<0.001). The same table demonstrates that the EBI enabled adults with SCD to improve their emotional well-being, as their scores increased from 41.74±31.13 to 61.25±14.91 following the intervention, compared to 43.00±16.11 and 44.42±10.67 for the control group, with statistically significant differences between the two groups (P<0.001).

Its noteworthy that the mean scores of pain were mainly similar in both EBI and control groups (49.22±13.65 and 51.13±12.84 respectively) prior to the application of the program (P<0.01). In a comparison between those who received the EBI and those who received routine care, the mean scores of quality of life related to pain dimension increased to 76.44±10.93 versus 60.38±20.08 (P<0.001).

Overall, adult with SCD who received the EBI reported a better general health and the posttest 73.19±9.79 compared to 49.16±13.04 for those in the control one. A significant statistical difference in terms of general health after the application of EBI was observed, where the P value=0.02.

Table 16: Health-related quality of life among adults with SCD in the EBI and Control Groups at pre, and posttest

Subcategories SF-36	Pre-test		Significance	Post-test		Significance
	EBI Group (n=36)	Control Group (n=32)		EBI Group (n=36)	Control Group (n=32)	
- **Physical functioning**	45.56±19.99	51.09±17.26	Z^{MW}=-1.049 P=0.29	77.64±8.49	59.67±17.07	Z^{MW}=-6.784 P<0.001***
- **Role limitations due to physical health**	30.56±29.34	31.25±27.68	Z^{MW}=-0.205 P=0.84	64.28±13.73	35.16±27.75	Z^{MW}=-6.458 P<0.001***
- **Role limitations due to emotional problems**	44.73±14.90	45.21±14.51	Z^{MW}=-3.106 P=0.64	71.67±16.67	50.41±11.17	Z^{MW}=-4.292 P<0.001***
- **Energy/fatigue**	52.08±15.95	51.33±10.66	Z^{MW}=-2.184 P=0.03*	67.50±11.57	49.63±12.55	Z^{MW}=-5.265 P<0.001***
- **Emotional well-being**	41.74±31.13	43.00±16.11	Z^{MW}=-2.178 P=0.03*	61.25±14.91	44.42±10.67	Z^{MW}=-2.881 P<0.001***
- **Social functioning**	53.75±14.41	53.75±17.78	Z^{MW}=-0.346 P=0.73	58.03±9.77	54.88±17.31	Z^{MW}=-0.458 P=0.65
- **Pain**	49.22±13.65	51.13±12.84	Z^{MW}=-2.493 P= P=0.01*	76.44±10.93	60.38±20.43	Z^{MW}=-6.154 P<0.001***
- **General Health**	53.19±9.79	45.16±13.04	Z^{MW}=-0.222 P=0.82	73.19±9.79	49.16±13.04	Z^{MW}=-2.428 P=0.02*

Z^{MW}: Mann Whitney Test Significant at *P≤0.05 **P< 0.01 ***P< 0.001



Chapter V

Discussion



DISCUSSION

Sickle cell disease (SCD) is a widespread problem around the world. It is one of the most common reasons for admission in Bahrain and has the highest rate for multiple readmissions (Ali, 2017). The chronic nature of the disease, recurrent pain crises, and the possible debilitating complications make patients with SCD prone to deficient self-care capabilities, psychological stress, depressive symptoms, and a poor quality of life. In order to avoid such negative consequences, patients must have control over their health. Since self-care practices are basic requirements for fostering a satisfying life and self-esteem, advanced practice nurses may empower these patients to promote their health and well-being. Empowerment-based interventions equip patients with the necessary information and extend their awareness regarding the various measures that enhance their self-efficacy to perform self-care, encourage independence, alleviate pain, prevent complications, and ultimately improve their health-related quality of life (Minkler & Wallerstein, 2012).

According to Bandura (1997), self-efficacy is an individual's belief in their ability to control their own functioning in the face of life-altering events. The level of self-efficacy can provide the foundation for motivation and well-being among patients with chronic illnesses such as SCD, and it is essential for achieving their accomplishments. In this regard, the results of the present study showed that the patients in both the EBI and control groups had low self-efficacy at the initial assessment. Adegbola (2011) cited that despite the increasing lifespan of individuals with SCD, paradoxically, they report decrements in self-efficacy, coping skills, and HRQOL. Thus, those patients are frequently seeking emergency healthcare while suffering from unbearable pain crises. Goldstein-Leever et al. (2020) found a strong correlation between self-efficacy and HRQOL that gives direction for developing patients' holistic interventions. In addition,

Edwards (2001) also declared self-efficacy as a predictor of adult adjustment to SCD.

Like other chronic illnesses, SCD is best managed by promoting holistic health and comprehensive self-care strategies that mitigate pain crises, reduce hospitalizations, optimize HRQOL, and prevent premature deaths (AlSaleh et al., 2021). The use of these strategies assists patients to exhibit self-efficacy, take charge of life situations, and have a great expectation of being successful with the outcome (Edwards et al., 2001). The results of the present study are consistent with Nagshabandi and Abdulmutalib (2019), who found that only a small proportion of the studied patients with SCD in Jeddah, Saudi Arabia, were guaranteed their ability to do most of the activities day after day and practice something to feel better. Likewise, a small percentage of those patients reported the efficacy of the medication in controlling their feelings of tiredness, dealing with the frustration of having SCD, and managing their lives compared with other people suffering from SCD. So, the authors recommended a multimodal program that improves self-efficacy and self-management, inhibits problems associated with SCD, and promotes the disease-controlling process (Nagshabandi & Abdulmutallab, 2019).

Several studies documented the impact of empowerment interventions based on Orem's nursing theory on the health-related quality of life and self-efficacy among patients with different chronic illnesses (Cheng et al., 2019; Khademian et al., 2020). In parallel, the results of the present study showed a significant increment in the level of self-efficacy among patients who received the EBI compared to those who received routine healthcare. Such an empowerment program enriched the participants with a variety of strategies that enhanced their belief in having control over their unpleasant symptoms, suffering, and discomforts (Cheng et al., 2019). These strategies include, but are not limited to, disease management such as utilizing non-pharmacological

interventions to control pain episodes, e.g., the use of liquids, hot showers, the use of hot water bags, and massaging (Maniavi et al., 2019). Besides, educating them about the cognitive and behavioral techniques to deal with the pain, including relaxation, deep breathing, distraction techniques, and mental imagery, may also be helpful. The program also included instructions related to the importance of compliance with medication and blood transfusions. It's worth mentioning that the EPI is not only focused on the physical aspect but also promotes the participants' beliefs in their efficacy in many areas like mastery experiences, social persuasion, and emotional well-being. Therefore, high self-efficacy has been linked with numerous benefits to daily life, such as a healthy lifestyle, improved patient performance, and self-management capabilities (Crosby et al., 2020). As a result, it was not surprising that the majority of patients in the EBI group reported being able to reduce SCD pain through methods other than taking extra medication and doing most of the day-to-day activities, managing SCD symptoms so they enjoyed doing things, and dealing with the frustration of having SCD. These results are in harmony with the findings of a quasi-experimental study conducted by Ahmadi et al. (2015), who found that self-management interventions using the 5As model are effective in changing behaviors and promoting self-efficacy in patients with SCD. Further, similar findings were reported in a randomized controlled trial conducted by Al Nasiri et al. (2020) in Los Angeles, California, USA. The study highlighted the impact of smartphone technology in delivering an innovative family-based educational intervention program for improving knowledge and self-efficacy in SCD symptom management. Our findings are also compatible with those of Borimnejad et al. (2018), who conducted a randomized controlled clinical trial to investigate the effect of a family-centered empowerment program. They concluded that the implementation of such a program is practically feasible and can increase self-efficacy in patients with chronic blood disorders. On the contrary, the findings of Hamnes et al. (2012) were incongruent with the current

study findings. In the preceding research, they studied the effectiveness of a one-week multidisciplinary inpatient self-management program on self-efficacy among patients with chronic illnesses. The limitations of the Hamnes et al. (2012) study were attributable to an intensive intervention period, which hindered the researcher's capacity to focus on satisfying the participant's needs during the planning, intervention, and motivation of these patients.

Undoubtedly, self-care is crucial for the successful management of a chronic disease or condition, particularly SCD. It seems to be essential to improve general health status, physical functioning, emotional well-being, and social functioning, as well as minimize pain crises among patients with SCD (Zhang & Pan, 2021). From Orem's standpoint, all humans have the capacity for self-care unless the self-care demands exceed the self-care capabilities. So, Orem asserts that a self-care deficit delineates the need for nursing interventions as the patients are not capable of or have limited abilities for providing continuous, effective self-care activities. From this perspective, nurses may enable patients to meet their self-care needs and develop their self-care agency through health education, direct nursing actions, and supportive care. In investigating the impact of the EBI on the patients' self-management capacities, the result of the current study revealed that the application of the EBI enabled adults with SCD to develop their capacity for self-care as their scores improved after the intervention compared to the control group with significant statistical differences. This could be justified by the implementation of the EBI, the acquisition or modification of lifestyle, and effective coping strategies, which can lead to a reduction in symptoms, promote self-management behaviors and maximize the health outcomes among the EBI participants (Ahmadi et al., 2015). During the general discussion session, the patients were enriched with self-management strategies to prevent SCD complications, such as hydration, dietary regimens and supplements, sports and exercise, minimizing infections, medication compliance, and non-

pharmacological pain management. In their systematic review, Gyamfi et al. (2021) found many randomized controlled trials conducted in low- and middle-income countries for SCD management. The authors concluded that evidence-based interventions are effective for SCD management and recommended that medicinal therapies should be implemented in conjunction with non-pharmacological measures in order to reduce SCD-related morbidity and mortality.

Definitely, the developed self-care capacity can be linked to improved self-efficacy among the EBI group who declared their ability to manage day-to-day activities. These results are congruent with Nagshabandi & Abdulmutalib (2019), who found a positive correlation between self-efficacy and self-care management among patients with SCD. The authors of this study recommended a multifaceted program to improve self-management, inhibit problems associated with SCD, and promote the disease-controlling process. In their secondary data analysis, Matthie et al. (2015) also found that patients with SCD may benefit from self-care interventions that maximize SCD self-efficacy and facilitate access to crucial information. Along the same lines, an exploratory qualitative study was done by Tavares et al. (2017) at the haematology centre of an inland municipality in Ceará, Brazil. They found that educational actions aimed at guiding and supporting the patient with SCA enabled them to maintain self-care activities, reach proficiency, and succeed in applying what is recommended by Orem's self-care theory. Besides, Amertil et al. (2020), who performed a study in a sickle cell clinic in Ghana, found comparable results. They confirmed that self-efficacy was shown to have a strong and positive correlation with self-management. Thus, the results may enhance self-care measures and reduce uncertainty about sickness, resulting in improved health outcomes.

Since self-management instructions are a never-ending task for patients with SCD, the patients of the present study were followed up through social

networking applications to continuously monitor their self-care practices. Indeed, keeping in touch with the patients empowered them to carry on the application of the given instructions and minimize non-compliance (Homburg et al., 2022). A similar approach was adopted by Issom et al., (2021) in their mixed method study, which used chatbot messaging apps and virtually met patients to facilitate adoption and long-term engagement (Issom et al., 2021). The quantitative findings of this study revealed that chatbots for health coaching were user-friendly, entertaining, and supportive of patients' autonomy. Qualitatively, participants were enthusiastic about using the innovative method and affirmed its use in SCD knowledge acquisition. The majority of participants in Issom et al. (2021) research proclaimed the system's practicality in educating them about recommended self-care practices for symptom avoidance.

Health-related quality of life reflects how an individual feels about their current life situation. It includes their perception of their overall well-being, as well as goals, expectations, and concerns. Health-related quality of life (HRQoL) is a broad, multidimensional concept that usually includes subjective evaluations of both positive and negative aspects of life. Health-related quality of life does not only include the individual's general health but also encompasses different aspects such as emotional well-being, social dysfunction, fatigability, and pain frequency and severity. These multifaceted characteristics of the patient's HRQoL increase the challenge of its precise measurements (Bhagat et al., 2014). Badawy et al. (2021) proclaimed in their systematic review that SCD is a devastating hematologic disorder in which patients experience several complications across their lifespan that lead to HRQoL domain impairment. Al Saleh et al. (2021) measured HRQOL among patients with SCD from 27 primary healthcare centres in the Kingdom of Bahrain using the World Health Organization's quality of life BREF Questionnaire. They found that socioeconomic factors are mainly the determinants of HRQoL; however, the

patient's personality traits are the pain-catastrophizing agent. These findings advocate for a comprehensive approach to the management of patients with SCD. Bhagat et al. (2014) conducted a study at a tertiary healthcare facility in central India to compare HRQoL in SCD and other chronic non-communicable diseases. They reported that, besides merely pharmacotherapy and standard SCD management, including folic acid, hydroxyurea, vitamins, zinc, pneumococcal vaccination, and prophylactic antibiotics (penicillin), the overall HRQoL among patients with SCD was observed to be significantly lower as compared to other chronically ill patients. Therefore, Bhagat et al. (2014) recommended the mainstay of management for patients with SCD to restore their overall quality of life. These are consistent with the results of the present study, where the majority of patients in both the EBI and the control groups reported low scores in all HRQoL domains at the initial assessment. This could be attributed to the chronic pain crisis that limits their physical functioning, social roles, and emotional well-being as well. In this context, Nagshabandi & Abdulmutalib (2019) highlighted that sickle cell pain is complex and multifactorial, as patients who have a lower awareness of their abilities to alleviate extended pain develop a lower self-care capacity to perform daily activities and exhibit a lower HRQoL. Similarly, a study done in the UK concluded that patients with SCD and pain who are admitted to daycare seemed to have impaired HRQoL as a result of pain (Anie, 2012). Moreover, Thomas & Taylor (2002) conducted a qualitative study and asserted that patients with SCD expressed far worse HRQoL during the focus groups than when rating their responses on paper-based health surveys. Jebbin and Adotey (2011) also stated that, based on their 10-year experience managing SCD, the majority of SCD patients who presented to the emergency department complained of acute abdomen. Another study done by Goldstein-Leever et al. (2020) at a multidisciplinary SCD clinic indicated that patients' self-efficacy in controlling the SCD pain crisis strongly predicted HRQoL. Patients with a higher level of self-efficacy exhibited improved HRQoL. Bhagat et al. (2014) added that

many factors contributed to poor HRQoL among patients with SCD, which introduces a fourth dimension in the management of such a painful and debilitating chronic illness. In this respect, Ali et al. (2017) examined triggers for pain crises among patients with SCD in Bahrain and found that a sizable proportion of the patients reported that temperature changes were the main triggers for their pain crises. Other triggers identified by participants in this study were physical exertion and psychological stress. Al Hajeri et al. (2019) conducted a cross-sectional study to evaluate the satisfaction level of patients with SCD regarding healthcare services in Bahrain. They discovered that patients were generally satisfied. Furthermore, Ali et al. (2017) assessed the HRQoL of adults with SCD in the Kingdom of Bahrain. A large number of respondents from SMC and health centres outpatient clinics, the general public, and the SCD society completed the SF-36. One-quarter of the participants had SCD, one-third of them had other chronic illnesses, and the rest were disease-free. Ali et al. (2017) concluded that adults with SCD in Bahrain showed significant impairment in all domains of HRQoL, especially role-physical, role-emotional, and general health when compared to the general population.

Recently, there has been a paradigm shift from a palliative medical model grounded in pharmaceutical principles to a participatory prevention-based approach that fosters the patients' self-management behaviors and symptom control (Barakat et al., 2010). In the SCD situation, the acquisition of effective coping strategies can lead to a reduction in symptoms, prevent pain episodes, promote health outcomes, and achieve a better HRQoL. The results of the present study showed a significant improvement in the HRQoL mean scores, especially in the physical functioning and general health of the participants in the EBI group compared to those who received routine health care. After implementing the EBI, they reported a significant reduction in role limitations due to emotional problems, pain frequency, and severity. Similar results were reported in a study

conducted by Ahmadi et al. (2015) to assess the effectiveness of self-management programmes on HRQoL in SCD patients who received the programme for 12 weeks. The results of Ahmadi et al. (2015) revealed the efficacy of applying this supportive method in empowering the patients and enabling them to independently manage the disease and restore their HRQoL. The congruency between the results of the current study and Ahmadi et al. (2015) could be attributed to the detailed and well-designed self-management program at the five phases of individualized consultation and the personal face-to-face training, i.e., assess, advise, agree, assist, and arrange. Further, the interventions were tailored based on each patient's needs assessment and the agreed objectives. The group discussions were conducted to share experiences while patients were individually educated about practical skills and ongoing communication with them was established.

In order to achieve an acceptable level of HRQoL, patients need to learn how to manage and control the disease (Edwin 2011). It is clear that the EBI assisted the patients to control self-care at home, helping with personal pain regulation and, subsequently, the prevention of pain crises and achieving a better HRQoL. Lenoci (2002) illustrated that the learned strategies to cope with the disease increased the patients' skills in dealing with the disease at home and in the community.

Regarding physical functioning, the results of the present study showed that the vast majority of the patients in the EBI group reported that moderate activities, such as walking, climbing several flights of stairs, moving a table, pushing a vacuum cleaner, or lifting or carrying groceries, were not limited at all after applying the instructions provided to them throughout the program. Similarly, all the patients in the EBI expressed their ability to independently perform self-care activities such as bathing or dressing themselves. The application of the EBI may decrease the burden of the disease, especially on the

role of physical functioning, by using different strategies as non-pharmacological pain interventions. Moreover, using massages improves physical functioning and increases relaxation among those patients. Using these EBI approaches may decrease the unpredictability of SCD attacks and the difficulty of getting and keeping power. The results of the current study are congruent with Zhang et al. (2021), who reported that nursing intervention based on the Orem self-care theory can promote and speed up the recovery of patients and ultimately improve their level of hope and HRQoL. Likewise, a regional EBI program in Saudi Arabia done by Amr et al. (2011) showed significantly lower scores in physical functioning, the role of physical and bodily pain, and general health domains. It is observed that only a small proportion of patients in both the EBI and control groups reported good health at the initial assessment. Meanwhile, a notable increment in the percentage was observed among patients after the application of EBI, while the percentage remained the same among patients in the control group.

Pain and suffering in patients with SCD may hinder their ability to be productive citizens, which impacts their HRQoL. Pain episodes are by far the most common cause of inpatient emergency department visits among persons with SCD (Zanoni et al., 2020). Fortunately, none of the participants in the EBI group complained of severe pain or fatigue after receiving the EBI, compared to a minority of patients in the control group. In the present study, the researcher trained the patients about non-pharmacological pain measures, which subsequently enabled them to control their pain and minimize the consumption of strong analgesics. The EBI program also highlighted the importance of practicing sports and exercises as well. According to Piel et al. (2017), SCD is a condition that results in varying degrees of acute, frequent ischemic pain episodes. Vaso-occlusive pain crises are caused by an accumulation of hemoglobin S in blood vessels, which results in intense, frequent, and excruciatingly painful sensations. These chronic crises have an array of serious

consequences. For that reason, Pinto et al. (2020) reported that practicing low-to-medium-intensity exercise is not only safe but also helpful for patients with SCD. Such exercises resulted in considerable growth of the tiny blood vessels, as well as increased endurance and oxygen content in the body. Pinto et al. (2020) also suggested certain exercises that help stimulate blood circulation and work to improve vital processes. Moreover, Zanoni et al. (2020) documented the effectiveness of a home-based exercise program for SCD incapacities in improving trunk-muscle strength and consequently reducing lower-back pain intensity.

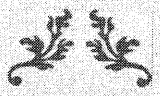
As a matter of fact, understanding the perception of HRQoL among individuals with chronic diseases makes it possible to provide the appropriate supportive interventions that inspire them to face the disease's chronicity and achieve indispensable adjustment. Zanoni et al. (2020). In addition to the medical symptoms, such patients encounter significant psychological and psychosocial disorders that influence all aspects of their lives, including depression, anxiety, a feeling of worthlessness, and social alienation, as well as the consequent impairment of their HRQoL index. An Egyptian cross-sectional study assessed the effects of depression and anxiety in sickle cell patients. They revealed that depression prevalence was related to the level of severity and complications of the illness. Moreover, both anxiety and depression had reduced the patients' HRQoL. Despite this, patients with SCD in the Kingdom of Bahrain frequently reported low self-esteem, depressive symptoms, and feelings of hopelessness as a result of frequent pain, hospitalizations, and lost working days (Ali et al. 2017).

It seemed that SCD pain and impaired emotional well-being among patients with SCD are interdependent, as both of them reciprocally cause, affect, intensify, and aggravate each other. Undoubtedly, pain causes emotional distress, while psychological stress exacerbates pain, leading inexorably to a worsening of the situation. In this regard, Adam et al. (2017) performed an analytic

epidemiologic prospective study at the Duke Adult Comprehensive Sickle Cell Center, Durham, North Carolina, USA. They found that depression is prevalent in adult patients with SCD and is associated with worse HRQoL. They suggested that efforts should focus on prevention, early diagnosis, and intervention for depression in those patients who suffer from chronic pain that persists for more than 3 months. Chronic pain is associated with depression and other psychological disorders that adversely impact the desired clinical outcomes. On the other hand, Ali et al. (2017) documented that psychological stress triggers pain crises among patients with SCD. A vicious cycle between pain and psychological distress could be explained in light of the biopsychosocial model developed by Engel (1978). This model illustrates the dynamic, interactional, and dualistic view of human experience in which there is the mutual influence of mind and body. Psychosocial variables are more important determinants of susceptibility, severity, and course of illness. So, nurses must attend simultaneously to the biological, psychological, and social dimensions of illness and build bridges between the two realms. Tsao et al. (2013) studied the psychological aspects and hospitalization for pain crises in youth with SCD and pointed to psychosomatics as a reason for experiencing such pain during emotional stress. Thus, patients communicate their psychological distress in the form of bodily and organic symptoms.

In the current study, it's worth mentioning that none of the patients in the EBI group reported feeling anxious after attending the program, in comparison to the control group. Moreover, the percentage of patients who expressed their feelings of happiness most of the time increased among patients in the EBI group compared to those in the control group. A remarkable decline in such emotional problems was noticed among patients in the EBI group after receiving the program, while the percentage was raised among those in the control group. The patients who received the EBI felt

calmer and more peaceful than those who received routine healthcare. These results could be justified by robust evidence suggesting that EBI can be effective in improving emotional well-being through training the patients to adopt different relaxation techniques such as deep breathing exercises, mental imagery, and yoga. The result of the current study is similar to that of Smith et al. (2021), who utilized a patient-centered approach to gather information on social determinants of health from patients with SCD in preparation for their transition to adult care. They highlighted the vital role of the clinic social worker in managing the patients' social problems.



Chapter VI

Conclusion, Recommendations, Limitations and Nursing Implications



CONCLUSION

The study findings demonstrated the practicality of using the EBI program to deliver high-quality, and effective educational interventions. The results of the present study provide empirical evidence for the value of applying the EBI program grounded on the 5A model in promoting self-efficacy, self-care capacity and health-related quality of life among adults with SCD.

RECOMMENDATIONS

Based on the findings of the current study, the following recommendations are suggested:

- Continuous monitoring and evaluating self-care practices for patients with SCD for early detection and problem solving.
- Because structural self-management programs based on the 5A model are straightforward and cost-effective, it is simple to apply this model to improve the functional conditions of these individuals. The 5A steps are thus recommended as a simple choice for nurses to assist patients.
- Health care practitioners, such as health educators, doctors, and nurses, will find it worthwhile to introduce counselling, which will be utilized to address the importance of SCD self-care management in reducing disease complications at each chronic diseases' clinic appointment.
- As an extension of their treatment plan, healthcare practitioners may inspire patients with SCD to join online support groups using best practices forum design to optimize their participation, deliver accurate medical information, and provide a variety of self-care management approaches.

For further study:

- Self-efficacy, social support, education levels and income are possibly essential factors for comprehending the self-care management of sickle cell disease in this group. Not only do these potentially significant associations align with prior studies, but they also have implications for the clinical management of patients with SCD and educational strategies that may be employed to enhance self-care practices.
- Evidence based-intervention that promote self-care management, SCD self-efficacy, and access to knowledge may be beneficial for individuals with SCD. Further research is required to guide the development of interventions based on the daily self-care behaviors of adults with SCD.
- Additional studies are required to determine the everyday pain prevention and pain management approaches used by patients with SCD prior to seeking treatment.
- Future studies might aim to recruit participants from a larger variety of backgrounds, and further in-depth assessment techniques could be used.
- Researchers should implement further educational programs for improving patients' self-care and self-efficacy skills.
- Action research that bridges the gap between healthcare professionals and patients provides a chance to support the community with sickle cell disease by providing comprehensive methods that fulfil the psychological, social, and physical needs of patients.

LIMITATIONS

Despite the representativeness of our sample, patients who are seeking treatment in secondary health care settings were not included in this research. Unfortunately, we were unable to cross-check some of the data accessible in the patients' prior medical records. The researchers also struggled with the frequent withdrawals from the study at different stages. The study also has limitations related to the sample size, as conducting the study with a larger sample size may result in more generalized findings. The researcher also faced a challenge in completing the follow-up of all the study participants.

It is important to note that while the inclusion and exclusion criteria for a study can help to ensure that the study is conducted in a controlled and standardized manner, it is not always possible to control participants' access to information sources such as the internet or books. This can be a limitation of the study, as participants may be exposed to information that could influence their behavior or responses.

Another limitation of the study is that patients who have other chronic illnesses in addition to SCD were not explicitly excluded from the study. This could potentially impact the study results, as patients with other chronic illnesses may have different healthcare needs and

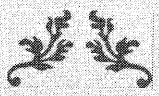
may respond differently to educational interventions. Therefore, it is important for researchers to consider the potential impact of other chronic illnesses on the study outcomes and to control for these factors in the study design and analysis. By acknowledging the potential impact of other chronic illnesses on the study outcomes, researchers can ensure that their findings are as accurate and reliable as possible.

NURSING IMPLICATIONS

In nursing education, practice, research and administration can be included to explain the significance of this finding towards nursing profession.

Nursing implications of the 5A model include the need for nurses to assess patients' self-care behaviors and readiness to change, provide personalized advice and information, work collaboratively with patients to set goals and develop a plan of action, provide support and resources to help patients achieve their goals, and schedule follow-up appointments and referrals as needed. By implementing the 5A model, nurses can promote self-efficacy, self-care capacity, and health-related quality of life in adults with chronic diseases.

Overall, the empowerment-based intervention program based on the 5A model has significant nursing implications for promoting self-efficacy, self-care capacity, and health-related quality of life in adults with sickle cell disease. By providing education, support, and ongoing care, nurses can help patients manage their condition and improve their overall well-being.



Chapter VII

Summary



SUMMARY

The occurrence of any SCD-associated complications profoundly impacts patients' ability to perform activities of daily living. Sickle cell pain is complex, highly individual, and influenced by patients' past and present experiences. These patients are often suffering needlessly from recurring pain crises or complications. Patients with SCD should exhibit an internal belief in their ability to control and manage the disease symptoms on a daily basis in order to achieve the desired outcomes through continuous education and empowerment.

Empowerment is an enabling process through which individuals exert control over their lives by being equipped with the necessary information and extending their awareness regarding the available alternatives. This will allow them to make better use of their own abilities rather than being passive recipients of professional care. As a result, using an empowerment-based intervention approach based on the 5A's model is especially important among SCD patients to improve self-efficacy, self-management capacity, and health-related quality of life. Utilizing EBI represents a shift from a focus on ameliorating deficits and addressing risks to the development of capacity.

In order to avoid the unfavorable consequences, such patients must take charge of their health by adopting self-care measures, including but not limited to maintaining adequate oxygenation, hydration, a healthy diet, rest, and avoiding extreme temperatures. These measures may help alleviate painful crises and reduce the need to seek health care intervention. Empowerment-based interventions based on the 5As model offer patients with SCD a healthier and happier quality of life.

The aim of the study is to investigate the effectiveness of EBI on the self-efficacy, self-management capacity and HRQoL among adults with SCD.

The study was conducted in two primary health care centers in the Kingdom of Bahrain: Shaikh Jaber Al-Ahmed Al-Subah Health Center (HC), which is one of the largest health centers and operates 24 hours a day, including weekends and holidays, and Budaiya HC. A convenience sampling of 70 patients with SCD who expressed their voluntary willingness to participate in the study comprised the study subjects. The patients were randomly assigned to two equal groups: the intervention group (35 patients received the empowerment-based intervention) and the control group (35 patients received the routine care of the health center).

Three tools were used to collect the necessary data: The sickle cell self-efficacy scale (SCSES) tool was designed by Edwards et al. (2000) to assess the self-appraisals of adult patients with sickle cell disease for their ability to engage in daily functional activities. The second tool was the appraisal of the revised self-care agency scale, which was originally developed by Kearney and Fleischer (1979) according to Orem's self-care theory and revised by Wang and Laffrey (2000) to assess the level of health-related self-care capacity. The third tool was the 36-item short form survey (SF-36) developed by RAND Corporation (1990) to measure patients' health status and outcomes. The SF-36 is a self-report questionnaire consisting of eight scales measuring two main dimensions: physical and mental health.

For both EBI and control groups, the researcher initially collected the baseline data by assessing the patients' demographic and clinical characteristics, self-efficacy, and self-management capacity using the three

tools. Empowerment based intervention was implemented through (a) structured small-group discussion sessions, (b) individualized consultations, and (c) follow-up sessions. The control group received routine health education delivered by nurses working at the health center. Finally, the patients in both the EBI and control groups were reassessed for self-efficacy and self-management capacity after one month using the three tools.

The main results of the present study revealed the following:

- Nearly one-half of the patients in both the study and control groups had 30 to less than 40 years (47.2% and 43.8% respectively). The mean age of the patients in the study group was 35.03±7.93 years and in the control, the group was 36.47±9.27 years and no statistically significant difference was found between the two groups.

- The majority of patients in the study and control group had a family member with SCD (80.6% and 96.9% respectively). Slightly more than half of the patients in both groups received blood transfusions in the preceding year (58.3% and 53.1% respectively).

- It is noticed that the mean score of the patients in the EBI group reported that their ability to keep doing most of the day-to-day activities was 2.83±1.36 compared to 2.94±1.24 in the control group before the program with no significant statistical differences.

- Regarding having the capacity for self-care, it was found that 3.61±1.18 of patients in EBI group made the needed adjustments to stay healthy before the application of the program compared to 3.53±1.29 for the control group. Moreover, it also showed that, 3.17±1.23 of patients among EBI Group evaluated the effectiveness

of things regularly that they did to stay healthy compared to3.47±1.02 among control group before application of the program.

- It was found that the mean score of the patients in the EBI group with regards to having the capacity for self-care before the EBI was 28±0.61 compared to 3.50±0.73 among patients in the control group with no significant statically differences. However, it was also been highlighted that the application of the EBI enabled adults with SCD to develop their capacity for self-care as their scores improved from 3.26±1.84 to 4.02±0.42 after the intervention compared to 2.90±0.54 and 3.02±0.52 for the control group, with significant statistical differences between the two groups.
- It is revealed that more than half of the patients who received the EBI reported their ability to perform vigorous activities compared to only 15.6% of those patients in the control one.
- It was revealed that 30.6 % of patients in the EBI group did not cut down the amount of time that they spent on work or other activities. This percentage increased to 80.6% after the application of the program. Meanwhile, the percentage of those patients in the control group remained almost the same (34.4 % at the pretest and 37.5% at the posttest) with a significant statistical difference. Moreover, a significant decline in the patients' accomplishment was noticed after receiving the EBI (8.3%). Whereas, the percent of patient in the control group showed a slight decline from 75.0% to 68.8% after receiving the routine health care
- It was observed that 27.8% and 18.8% of patients in EBI and control groups reported that physical health or emotional problems moderately interfered with their normal social activities with family, friends, neighbors, or groups before the application of the program.

After application to the EBI program, it is noticed that 38.9% of patients in the EBI group did not report such social limitation at all compared to only 3.1% with a significant statistical difference between both groups where $P<0.001$.

- Prior to the implementation of the EBI, there was no statistically significant difference between the EBI and control groups in terms of physical health-related role limitations. After application of the EBI, the mean patient scores increased dramatically.

- Concerning energy/fatigue, patients who received EBI had a significantly higher posttest mean score (67.50±11.57) compared to the pre-test.

- The EBI enabled adults with SCD to improve their emotional well-being, as their scores increased from 41.74±31.13 to 61.25±14.91 following the intervention, compared to 43.00±16.11 and 44.42±10.67 for the control group.

- In a comparison between those who received the EBI and those who received routine care, the mean scores of health-related quality of life related to pain dimension increased to 76.44±10.93 versus 60.38±20.08 ($P<0.001$).

- Adult with SCD who received the EBI reported a better general health and the posttest 73.19±9.79 compared to 49.16±13.04 for those in the control one.

- The results show that 13.9% of patients in the EBI group complained of severe pain during the past 4 weeks at the initial assessment. Whereas, none of the participants reported such complaint after receiving the EBI (0.0%). On the other side, the percentage of

patients in the control group who suffered from severe pain during the past 4 weeks increased from 25% to 28.1%.

- It was found that 19.4% of the patients in the EBI group, compared to 25.0% of the patients in the control group, felt full of pep for a little of the time before the EBI. This percent increased to 47.2% and 37.5% among patients in EBI and control groups at the posttest, respectively, with a significant statistical difference.

- It was found that 11.1% of patients in the EBI group compared to 18.8% of patients in the control group had a good bit of energy at the initial assessment. These percentages showed a significant increase to 44.4% after the application compared to 21.9% among the control group who received the routine care.

- It is clear that more than one quarter of the patients who received the EBI reported that they had to be a very nervous person all of the time (25%), compared to only 6.2% of those patients in the control group.

- Regarding patients' feeling calm and peaceful, 22.2 % of the patients who received the EBI felt calm and peaceful a good bit of the time, compared to only 21.9 % among those who received routine healthcare. This percent showed an increase in the EBI to 38.9 % while the percentage remained the same (21.9%) among those who received routine care.

- A remarkable decline in such emotional problems was noticed among patients in the EBI group after receiving the program as the percentage decreased to 13.9%, while the percentage rose to 28.1% of those in the control group.

- It is observed that approximately one third of patients in both the EBI and control groups (30.6% and 31.2%, respectively) reported good health at initial assessment. Meanwhile, a notable increment in the percentage was noticed among patients in the EBI after application, while the percentage remained the same among patients in the control group. There was a significant statistical difference between both groups.

- It was also highlighted that 27.8% of the EBI group reported that their health was definitely excellent before the program compared to 25%. This percent decreased to 21.9% after the program and remained the same among the EBI group. A statistically significant difference was observed.

- The mean score for physical functioning among patients in the EBI group was 45.56±19.99 compared to 51.09±17.26 among patients in the control group, with no statistically significant differences.

The results of the present study provide empirical evidence for the value of applying the EBI program grounded on the 5A model in promoting self-efficacy, self-care capacity and health-related quality of life among adults with SCD.



References



REFERENCES

Adam, S. S., Flahiff, C. M., Kamble, S., Telen, M. J., Reed, S. D., & De Castro, L. M. (2017). Depression, quality of life, and medical resource utilization in sickle cell disease. Blood advances, 1(23), 1983–1992. https://doi.org/10.1182/bloodadvances.2017006940

Adegbola M. (2011). Spirituality, Self-Efficacy, and Quality of Life among Adults with Sickle Cell Disease. Southern online journal of nursing research, 11(1), 5. PMCID: PMC3137798

Agyekum, K. (2002). Menstruation as a Verbal Taboo among the Akan of Ghana. Journal of Anthropological Research, 58(3), 367–387. https://doi.org/10.1086/jar.58.3.3631182

Ahmadi, M., Jahani, S., Poormansouri, S., Shariati, A., & Tabesh, H. (2015). The Effectiveness of self-management program on quality of life in patients with sickle cell disease. Iranian journal of pediatric hematology and oncology, 5(1), 18–26. DOI:10.17795/jjcdc-21702

Ahmed, M. H., Ghatge, M. S., & Safo, M. K. (2020). Hemoglobin: Structure, Function and Allostery. Sub-cellular biochemistry, 94, 345–382. https://doi.org/10.1007/978-3-030-41769-7_14

Aich, A., Jones, M. K., & Gupta, K. (2019). Pain and sickle cell disease. Current Opinion in Hematology, 26(3), 131–138. https://doi.org/10.1097/moh.0000000000000491

Ajinkpang, S., Anim-Boamah, O., Bimpong, K. A., Kanton, F. J., Pwavra, J., & Abdul-Mumin, A. (2022). Sickle Cell Disease in Children: Knowledge and Home-Based Management Strategies among Caregivers at a Tertiary Facility in Northern Ghana. BioMed research international, 2022, 3384813. https://doi.org/10.1155/2022/3384813

Al Hajeri, A., Ali M., Saleh L., Alkowari, S., Al Saad ```A. (2019). Evaluation of Satisfaction Level of Sickle Cell Disease Patients Regarding the Healthcare Services in Bahrain: A Cross-sectional Study. Journal of the Bahrain Medical Society, 10–16. https://doi.org/10.26715/jbms.2019.1_13022019

Al Nasiri, Y., Jacob, E., Lee, E., Nyamathi, A., Brecht, M.-L., A Robbins, W., & Al Mawali, A. (2020). Parent Educational Intervention Program for Improving Parental Knowledge, Self-efficacy and Health Related quality of life in Children with Sickle Cell Disease using Smartphone Technology: A Randomized Controlled Trial. Hematology and Medical Oncology, 5(2). https://doi.org/10.15761/hmo.1000203

Al Raqaishi, H., Al Qadire, M., Alzaabi, O., & Al Omari, O. (2021). Health-Related Stigma, Social Support, Self-Efficacy, and Self-Care Actions Among Adults With Sickle Cell Disease in Oman. Clinical Nursing Research. https://doi.org/10.1177/10547738211046731.

Alao, A., Dewan, M., Jindal, S., & Effron, M. (2004). Psychopathology in Sickle Cell Disease. West African Journal of Medicine, 22(4). https://doi.org/10.4314/wajm.v22i4.28059

Ali E., AlHalwachi F., Khalil F., Hejab Z., AlMoalem Z. Mandil M . (2017). Health-Related quality of life in Adults with Sickle Cell Disease in the Kingdom of Bahrain (FPRP). Saudi J. Med., 2(1), 3-14. https://doi.org/10.36348/sjm.2017.v02i01.002

AlSaleh A., Elbarbary A., Al Qashar A., Alserdieh F., Alahmed F., Alhaddar H., Alsada L., Yosri M., Saeed M., Khudhair M., Salih M., Fuad N., Alghmadi M., Qarqoor F. Almarabheh A., Chlif S., Ben Salah A. (2021). Determinants of the quality of life of Patients with Sickle Cell Disease in Bahrain: Implications for a Patient-Centered Management Approach at the Primary Health Care. Bahrain Medical Bulletin, 43(2), 431- 437.

Amertil, N. P., Ayitey, E. K., Kpongboe, D. G., & Attafuah, P. Y. A. (2020). Exploring self-management in adult sickle cell disease patients' at a

Teaching Hospital in Ghana. Nursing Open, 8(3), 1336–1344. https://doi.org/10.1002/nop2.750

Amr, M., Amin, T., & Al-Omair, O. (2011). Health related quality of life among adolescents with sickle cell disease in Saudi Arabia. Pan African Medical Journal, 8(1). https://doi.org/10.4314/pamj.v8i1.71057

Anie, K. A., Grocott, H., White, L., Dzingina, M., Rogers, G., & Cho, G. (2012). Patient self-assessment of hospital pain, mood and health-related quality of life in adults with sickle cell disease. BMJ Open, 2(4), e001274. https://doi.org/10.1136/bmjopen-2012-001274

Aujla, A., Dutta, D., Amar, S., Frishman, W., & Lim, S. H. (2020). Cardiovascular Sequelae of Sickle Cell Disease. Cardiology in review, 28(1), 10–13. https://doi.org/10.1097/CRD.0000000000000264

Badawy, S. M., Cronin, R. M., Hankins, J., Crosby, L., DeBaun, M., Thompson, A. A., & Shah, N. (2018). Patient-centered eHealth interventions for children, adolescents, and adults with sickle cell disease: Systematic review. Journal of Medical Internet Research, 20(7), e10940. https://doi.org/10.2196/10940

Badawy, S. M., Cronin, R. M., Hankins, J., Crosby, L., DeBaun, M., Thompson, A. A., & Shah, N. (2018). Patient-Centered eHealth Interventions for Children, Adolescents, and Adults With Sickle Cell Disease: Systematic Review. Journal of medical Internet research, 20(7), e10940. https://doi.org/10.2196/10940

Badawy, S., Beg U, Liem, R., Chaudhury, S, Thompson A. A systematic review of quality of life in sickle cell disease and thalassemia after stem cell transplant or gene therapy. (2021). Blood Advances, 5(2), 570–583. https://doi.org/10.1182/bloodadvances.2020002948

Bandura, A. (1997). Self-Efficacy: The Exercise of Control. New York: Freeman.

Barakat, L. P., Schwartz, L. A., Salamon, K. S., & Radcliffe, J. (2010). A family-based randomized controlled trial of pain intervention for adolescents with

sickle cell disease. Journal of Pediatric Hematology/Oncology, 32(7), 540–547. https://doi.org/10.1097/MPH.0b013e3181e793f9

Bastos Ferreira Tavares, N., Monique Araújo do Nascimento, N., Tavares de Luna Neto, R., Gonçalves Junior, J., & Maria Christofolini, D. (2017). Self-care practice in people with sickle cell anemia. Revista Brasileira Em Promoção Da Saúde, 30(4), 1–7. https://doi.org/10.5020/18061230.2017.6212

Benenson, I., & Porter, S. (2018). Sickle cell disease: Bone, joint, muscle, and motor complications. Orthopedic Nursing, 37(4), 221–227. https://doi.org/10.1097/NOR.0000000000000464

Bernier, K. M., Strobel, M., & Lucas, R. (2018). Assessing the effect of an educational intervention on nurses' and patient care assistants' comprehension and documentation of functional ability in pediatric patients with sickle cell disease. Journal of Pediatric Nursing, 41, 117–122. https://doi.org/10.1016/j.pedn.2018.04.001

Bhagat, VijayM., Baviskar, ShubhangiR., Mudey, AbhayB., & Goyal, RamchandraC. (2014). Poor health related quality of life among patients of sickle cell disease. Indian Journal of Palliative Care, 20(2), 107. https://doi.org/10.4103/0973-1075.132622

Borimnejad, L., PhD, Parvizy, S., PhD, Haghaani, H., PhD, & Sheibani, B., MS (2018). The Effect of Family-Centered Empowerment Program on Self-Efficacy of Adolescents with Thalassemia Major: A Randomized Controlled Clinical Trial. International journal of community-based nursing and midwifery, 6(1), 29–38.

Brugnara, C. (2018). Sickle cell dehydration: Pathophysiology and therapeutic applications. Clinical Hemorheology and Microcirculation, 68(2-3), 187–204. https://doi.org/10.3233/ch-189007

Castro, Eva & Regenmortel, Tine & Vanhaecht, Kris & Sermeus, Walter & Hecke, Ann. (2016). Patient empowerment, patient participation and

patient-centeredness in hospital care: A concept analysis based on a literature review. Patient Education and Counseling. 99. 10.1016/j.pec.2016.07.026. DOI: 10.1016/j.pec.2016.07.026.

Chatterjee, A., Agrawal, A.K., Adapa, D., & Tk, S. (2018). Sickle Cell Anaemia-A Synopsis of the Inherited Ailment. Archives of Medicine, 10.

Cheng, L., Sit, J., Choi, K. C., Chair, S. Y., Li, X., Wu, Y., Long, J., & Yang, H. (2019). The effects of an empowerment-based self-management intervention on empowerment level, psychological distress, and quality of life in patients with poorly controlled type 2 diabetes: A randomized controlled trial. International Journal of Nursing Studies, 103407. Advance Online Publication. https://doi.org/10.1016/j.ijnurstu.2019.103407

Crosby, L. E., Hood, A., Kidwell, K., Nwankwo, C., Peugh, J., Strong, H., Quinn, C., & Britto, M. T. (2020). Improving self-management in adolescents with sickle cell disease. Pediatric Blood & Cancer, 67(10). https://doi.org/10.1002/pbc.28492

Damásio, B. F., & Koller, S. H. (2013). The Appraisal of Self-Care Agency Scale-Revised (ASAS-R): adaptation and construct validity in the Brazilian context. Cadernos De Saude Publica, 29(10), 2071–2082. https://doi.org/10.1590/0102-311x00165312

Daniels S. (2015). Cognitive behavioral therapy in patients with sickle cell disease. Creative nursing, 21(1), 38–46. https://doi.org/10.1891/1078-4535.21.1.38

Data & Statistics on Sickle Cell Disease. (2016, August 31). Centers for Disease Control and Prevention; CDC. https://www.cdc.gov/ncbddd/sicklecell/data.html

Dequeker, S., Van Lancker, A., & Van Hecke, A. (2018). Hospitalized patients vs. nurses' assessments of pain intensity and barriers to pain management. Journal of advanced nursing, 74(1), 160–171. https://doi.org/10.1111/jan.13395

Druye, Andrews A., et al. "Self-Management Recommendations for Sickle Cell Disease: A Content Analysis of Websites." Nursing & Health Sciences, vol. 22, no. 4, 23 June 2020, 10.1111/nhs.12741.

Edwards LY. Behavioral and psycho-educational support for pain management in adults with sickle cell disease. [Dissertation] South Carolina: Clinical-Community Psychology College of Arts and Sciences University of South Carolina; 2008

Edwards, R., Telfair, J., Cecil, H., & Lenoci, J. (2000). Reliability and validity of a self-efficacy instrument specific to sickle cell disease. Behaviour Research And Therapy, 38(9), 951–963. https://doi.org/10.1016/s0005-7967(99)00140-0

Edwards, R., Telfair, J., Cecil, H., & Lenoci, J. (2001). Self-efficacy as a predictor of adult adjustment to sickle cell disease: one-year outcomes. Psychosomatic Medicine, 63(5), 850–858. https://doi.org/10.1097/00006842-200109000-00020

Edwin, A., Edwin, F., & Etwire, V. (2011). Controlling sickle cell disease in Ghana ethics and options. Pan African Medical Journal, 10(0). https://doi.org/10.4314/pamj.v10i0.72223

Elham Abduallah Al Nagshabandi and Iman Abdallah Mohammed Abdulmutalib. Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease. American Journal of Nursing Research. 2019; 7(1):51-57. doi: 10.12691/AJNR-7-1-7

El-Shinnawy H, Goueli T, Nasreldin M, et al. Anxiety, depressive disorders, and quality of life in adults with sickle cell disease. Middle East Current Psychiatry. 2013;20(2):80-6.

Engel G. L. (1978). The biopsychosocial model and the education of health professionals. Annals of the New York Academy of Sciences, 310, 169–187. https://doi.org/10.1111/j.1749-6632.1978.tb22070.x

Ezenwa, Miriam & Yao, Yingwei & Mandernach, Molly & Fedele, David & Lucero, Robert & Corless, Inge & Dyal, Brenda & Belkin, Mary & Wilkie, Diana & Rohatgi, Abhinav. (2021). A Stress and Pain Self-management m-Health App for Adult Outpatients with Sickle Cell Disease (RADIANCE Study): Protocol for a Randomized Controlled Study (Preprint). JMIR Research Protocols. 11. 10.2196/33818.

Farmani Anoosheh, N., & Keikhaei, B. (2022). The Effect of L-Glutamine on Pain Crisis Reduction in Patients with Sickle Cell Anemia and Sickle β°-Thalassemia. Iranian Journal of Pediatric Hematology & Oncology, 12. https://doi.org/10.18502/ijpho.v12i4.10917

Fortin, P. M., Hopewell, S., & Estcourt, L. J. (2018). Red blood cell transfusion to treat or prevent complications in sickle cell disease: an overview of Cochrane reviews. The Cochrane database of systematic reviews, 8(8), CD012082. https://doi.org/10.1002/14651858.CD012082.pub2

Foster, J. G. W., & Prevost, S. S. (2012). Advanced practice nursing of adults in acute care. Philadelphia: F.A. Davis.

Frömmel C. (2018). Newborn Screening for Sickle Cell Disease and Other Hemoglobinopathies: A Short Review on Classical Laboratory Methods-Isoelectric Focusing, HPLC, and Capillary Electrophoresis. International journal of neonatal screening, 4(4), 39. https://doi.org/10.3390/ijns4040039

Glasgow, R. E., Funnell, M. M., Bonomi, A. E., Davis, C., Beckham, V., & Wagner, E. H. (2002). Self-Management aspects of the improving chronic illness care breakthrough series: Implementation with diabetes and heart failure teams. Annals of Behavioral Medicine, 24(2), 80–87. https://doi.org/10.1207/s15324796abm2402_04

Goldstein-Leever, A., Peugh, J. L., Quinn, C. T., & Crosby, L. E. (2020). Disease Self-Efficacy and quality of life in Adolescents With Sickle Cell Disease.

Journal of Pediatric Hematology/Oncology, 42(2), 141–144. https://doi.org/10.1097/mph.0000000000001363

Grabowski D, Aagaard-Hansen J, Willaing I, Jensen BB. Principled Promotion of Health: Implementing Five Guiding Health Promotion Principles for Research-Based Prevention and Management of Diabetes. Societies. 2017; 7(2):10. https://doi.org/10.3390/soc7020010

Gyamfi, J., Ojo, T., Epou, S., Diawara, A., Dike, L., Adenikinju, D., Enechukwu, S., Vieira, D., Nnodu, O., Ogedegbe, G., & Peprah, E. (2021). Evidence-based interventions implemented in low-and middle-income countries for sickle cell disease management: A systematic review of randomized controlled trials. PLOS ONE, 16(2), e0246700. https://doi.org/10.1371/journal.pone.0246700

Hajeri et al. Evaluation of Satisfaction Level of Sickle Cell Disease Patients Regarding the Healthcare Services in Bahrain: A Cross-sectional Study, Journal of the Bahrain Medical Society 2019; 31 (1): 10-16. https://doi.org/10.26715/jbms.2019.1_13022019

Hamnes, B., Mowinckel, P., Kjeken, I., & Hagen, K. B. (2012). Effects of a one-week multidisciplinary inpatient self-management program for patients with fibromyalgia: a randomized controlled trial. BMC musculoskeletal disorders, 13, 189. https://doi.org/10.1186/1471-2474-13-189

Hartweg, D. L. (1991). Dorothea Orem: Self-care deficit theory. Newbury Park, Calif: Sage Publications.

Hebert, N., Rakotoson, M. G., Bodivit, G., Audureau, E., Bencheikh, L., Kiger, L., Oubaya, N., Pakdaman, S., Sakka, M., Di Liberto, G., Chadebech, P., Vingert, B., Pirenne, F., Galactéros, F., Cambot, M., & Bartolucci, P. (2020). Individual red blood cell fetal hemoglobin quantification allows to determine protective thresholds in sickle cell disease. American journal of hematology, 95(11), 1235–1245. https://doi.org/10.1002/ajh.25937

Hockenberry & Wilson. (2019). Wong's Nursing Care of Infant and Children, 11th edition Elsevier: USA.

Hockenberry, M. J. (2016). Wong's Essentials Of Pediatric Nursing.

Hoffman A. J. (2013). Enhancing self-efficacy for optimized patient outcomes through the theory of symptom self-management. Cancer nursing, 36(1), E16–E26. https://doi.org/10.1097/NCC.0b013e31824a730a

Homburg, I., Morreel, S., Verhoeven, V., Monsieurs, K. G., Meysman, J., Philips, H., & De Graeve, D. (2022). Non-compliance with a nurse's advice to visit the primary care provider: an exploratory secondary analysis of the TRIAGE-trial. BMC Health Services Research, 22(1). https://doi.org/10.1186/s12913-022-07904-8

Issom, D. Z., Hardy-Dessources, M. D., Romana, M., Hartvigsen, G., & Lovis, C. (2021). Toward a Conversational Agent to Support the Self-Management of Adults and Young Adults With Sickle Cell Disease: Usability and Usefulness Study. Frontiers in digital health, 3, 600333. https://doi.org/10.3389/fdgth.2021.600333

J Med Internet Res 2018 | vol. 20 | iss. 7 | e10940 | p. 1

Jebbin, N., & Adotey, J. (2011). Acute abdominal conditions in people with sickle cell disease: A 10-year experience in Port Harcourt, Nigeria. Annals of African Medicine, 10(2), 165. https://doi.org/10.4103/1596-3519.82072

Jefferson, J. M., Sims, W. M., Umeh, N., Byeon, Y., Abdallah, K. E., Bonham, V. L., Naik, R. P., & Smith-Whitley, K. (2021). Splenic infarction in sickle cell trait: A comprehensive systematic review of case studies. EJHaem, 2(3), 585–600. https://doi.org/10.1002/jha2.248

Jenerette, C. M., & Murdaugh, C. (2008). Testing the Theory of Self-care Management for sickle cell disease. Research in nursing & health, 31(4), 355–369. https://doi.org/10.1002/nur.20261

Jenerette, C. M., Brewer, C., & Leak, A. N. (2011). Self-care recommendations of middle-aged and older adults with sickle cell disease. Nursing research and practice, 2011, 270594. https://doi.org/10.1155/2011/270594.

Jenerette, C. M., Pierre-Louis, B. J., Matthie, N., & Girardeau, Y. (2015). Nurses' attitudes toward patients with sickle cell disease: a worksite comparison. Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 16(3), 173–181. https://doi.org/10.1016/j.pmn.2014.06.007

Kehinde, T. A., & Osundiji, M. A. (2020). Sickle cell trait and the potential risk of severe coronavirus disease 2019-A mini-review. European journal of haematology, 105(5), 519–523. https://doi.org/10.1111/ejh.13478

Kearney, B. Y., & Fleischer, B. J. (1979). Development of an Instrument to Measure Exercise of Self-care Agency. Research in Nursing & Health, 2(1), 25–34. https://doi.org/10.1002/nur.4770020105

Khademian, Z., Kazemi Ara, F., & Gholamzadeh, S. (2020). The Effect of Self Care Education Based on Orem's Nursing Theory on quality of life and Self-Efficacy in Patients with Hypertension: A Quasi-Experimental Study. International journal of community based nursing and midwifery, 8(2), 140–149. https://doi.org/10.30476/IJCBNM.2020.81690.0

Khandekar, A., Pareek, A., Acharya, S., Tidake, P., & Shukla, S. (2019). Correlation between nephropathy and ophthalmic complications in cases of sickle cell anemia: An entangled association. Indian Journal of Medical Specialities, 10(2), 72. https://doi.org/10.4103/injms.injms_4_19

Khudhair, S. H. (2019). Self-Efficacy of Sickle-Cell Anemic Adult Patients at Blood Disease Wards in Baghdad Teaching Hospitals. Indian Journal of Public Health Research & Development, 10(1), 883. https://doi.org/10.5958/0976-5506.2019.00171.2

Lacerda, Flávia Karine Leal, et al. "Self-Care Deficits in Women with Leg Ulcers and Sickle Cell Disease." Revista Brasileira de Enfermagem, vol. 72, no.

suppl 3, Dec. 2019, pp. 72–78, 10.1590/0034-7167-2018-0005. Accessed 5 Oct. 2020.

Lamoureux, L. M., Coda, K. A., & Halliday, L. C. (2021). Hemochromatosis in Two Female Olive Baboons (Papio anubis). Comparative medicine, 71(1), 99–105. https://doi.org/10.30802/AALAS-CM-20-000070

Lee, L., Askew, R., Walker, J., Stephen, J., & Robertson-Artwork, A. (2012). Adults with sickle cell disease: an interdisciplinary approach to home care and self-care management with a case study. *Home Healthcare Nurse*, *30*(3), 172–183; quiz 183-185. https://doi.org/10.1097/NHH.0b013e318246d83d

Lenoci, J. M., Telfair, J., Cecil, H., & Edwards, R. F. (2002). Self-care in adults with sickle cell disease. Western journal of nursing research, 24(3), 228–245. https://doi.org/10.1177/01939450222045879

Lianhong Zhang1, Wenyan Pan Effect of a nursing intervention strategy oriented by Orem's self-care theory on the recovery of gastrointestinal function in patients after colon cancer surgery .Am J Transl Res 2021;13(7):8010-8020

Loiselle, K., Lee, J., Szulczewski, L., Drake, S., Crosby, L. E., & Pai, A. (2016). Systematic and meta-analytic re-view: Medication adherence among pediatric patients with sickle cell disease. Journal of Pediatric Psychology, 41(4), 406–418. doi:10.1093/jpepsy/jsv084

Łuczyński, W., Głowińska-Olszewska, B., & Bossowski, A. (2016). Empowerment in the Treatment of Diabetes and Obesity. Journal Of Diabetes Research, 2016, 5671492. https://doi.org/10.1155/2016/5671492

Ludwig, N. N., Sil, S., Khowaja, M. K., Cohen, L. L., & Dampier, C. (2018). Executive Functioning Mediates the Relationship Between Pain Coping and quality of life in Youth with Sickle Cell Disease. Journal of pediatric psychology, 43(10), 1160–1169. https://doi.org/10.1093/jpepsy/jsy057

Mahdi, N., Al-Ola, K., Khalek, N. A., & Almawi, W. Y. (2010). Depression, anxiety, and stress comorbidities in sickle cell anemia patients with vaso-occlusive crisis. Journal of pediatric hematology/oncology, 32(5), 345–349. https://doi.org/10.1097/MPH.0b013e3181d869d5

Mandal, A. K., Mitra, A., & Das, R. (2020). Sickle Cell Hemoglobin. Sub-cellular biochemistry, 94, 297–322. https://doi.org/10.1007/978-3-030-41769-7_12

Maniavi F, Rostami Sh, Keikhaei Dehdezi B, Cheraghian B. The Effect of Non pharmacological Palliative Methods Training on Sickle Cell Anemia Outcomes. Int J Pediatr 2019; 7(7): 9729-39.DOI:10.22038/ijp.2019.39507.3370

Matsuda, A., Yamada, Y., Ishizuka, N., Matsushima, E., Kobayashi, K., Ohkubo, T., & Yamaoka, K. (2018). Effects of a Self-Monitoring quality of life Intervention for Patients with Cancer Receiving Palliative Care in Japan: Study Protocol for a Randomized Controlled Trial. Asian Pacific Journal of Cancer Prevention, 19(11), 3027–3032. https://doi.org/10.31557/apjcp.2018.19.11.3027

Matthie, N., Jenerette, C., & McMillan, S. (2015). Role of self-care in sickle cell disease. Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses, 16(3), 257–266. https://doi.org/10.1016/j.pmn.2014.07.003

McClafferty, H. (2017). Integrative Pediatrics: Art, Science, and Clinical Application (1st ed.). Routledge. https://doi.org/10.4324/9781315371108

Minkler, M. & Wallerstein, N. (2012). 3. Improving Health through Community Organization and Community Building: Perspectives from Health Education and Social Work. Ithaca, NY: Rutgers University Press. https://doi.org/10.36019/9780813553146-005.

Mogueo, A., Oga-Omenka, C., Hatem, M., & Kuate Defo, B. (2021). Effectiveness of interventions based on patient empowerment in the control

of type 2 diabetes in sub-Saharan Africa: A review of randomized controlled trials. Endocrinology, Diabetes & Metabolism, 4. DOI:10.1002/edm2.174.

Morrone, K. A., Kalluri, D., Davila, J. G., Edusei, G., Shoberu, B., Rosario, J., Figueiredo, L. M., Carullo, V. P., Weiss, M., Rinke, M., & Manwani, D. (2017). Decreased Hospital Readmissions for Vaso Occlusive Crisis with Implementation of a Sickle Cell Pain Action Plan (SPAP). Blood, 130(Suppl_1), 867–867. https://doi.org/10.1182/blood.v130.suppl_1.867.867

Nader, E., Grau, M., Fort, R., Collins, B., Cannas, G., Gauthier, A., Walpurgis, K., Martin, C., Bloch, W., Poutrel, S., Hot, A., Renoux, C., Thevis, M., Joly, P., Romana, M., Guillot, N., & Connes, P. (2018). Hydroxyurea therapy modulates sickle cell anemia red blood cell physiology: Impact on RBC deformability, oxidative stress, nitrite levels and nitric oxide synthase signalling pathway. Nitric Oxide, 81, 28–35. https://doi.org/10.1016/j.niox.2018.10.003

Nagshabandi, E. A. A., & Abdulmutalib, I. A. M. (2019). Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease. American Journal of Nursing Research, 7(1), 51-57.

Ogu, U. O., Badamosi, N. U., Camacho, P. E., Freire, A. X., & Adams-Graves, P. (2021). Management of Sickle Cell Disease Complications Beyond Acute Chest Syndrome. Journal of Blood Medicine, Volume 12, 101–114. https://doi.org/10.2147/jbm.s291394

Olubiyi, O. O., Olagunju, M. O., & Strodel, B. (2019). Rational Drug Design of Peptide-Based Therapies for Sickle Cell Disease. Molecules (Basel, Switzerland), 24(24), 4551. https://doi.org/10.3390/molecules24244551

Omolola, A. O., Adesuyi, A. B., Omolola, B. T., & Kosemani, T. (2020). Assessment of Knowledge of Nurses in Providing Psychosocial Care for

Mothers with Sickle Cell Child in Osun State Nigeria. Babali Nursing Research, 1(1), 7–17. https://doi.org/10.37363/bnr.2020.115

Osunkwo, I., Andemariam, B., Minniti, C. P., Inusa, B. P. D., El Rassi, F., Francis-Gibson, B., Nero, A., Trimnell, C., Abboud, M. R., Arlet, J., Colombatti, R., Montalembert, M., Jain, S., Jastaniah, W., Nur, E., Pita, M., DeBonnett, L., Ramscar, N., Bailey, T., & Rajkovic-Hooley, O. (2021). Impact of sickle cell disease on patients' daily lives, symptoms reported, and disease management strategies: Results from the international Sickle Cell World Assessment Survey (SWAY). American Journal of Hematology, 96(4), 404–417. https://doi.org/10.1002/ajh.26063

Piel, F. B., Steinberg, M. H., & Rees, D. C. (2017). Sickle cell disease. The New England Journal of Medicine, 376(16), 1561–1573. https://doi.org/10.1056/NEJMra1510865

Pinto, D. M. R., do Sacramento, M. de S., Santos, P. H. S., Silva, W. S., de Oliveira, E. C., Gardenghi, G., Ladeia, A. M. T., & Petto, J. (2020). Physical exercise in sickle cell anemia: a systematic review. Hematology, Transfusion and Cell Therapy. 43(3): 324–331. https://doi.org/10.1016/j.htct.2020.06.018

Quality of life in Adults with Sickle Cell Disease in the Kingdom of Bahrain (FPRP)

Rappaport, J. Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. Am J Commun Psychol 15, 121–148 (1987). https://doi.org/10.1007/BF00919275.

Riesch, S. K., & Hauck, M. R. (1988). The exercise of self-care agency: An analysis of construct and discriminant validity. Research in Nursing & Health, 11, 245-255.

Riley, T. R., & Riley, T. T. (2019). Profile of crizanlizumab and its potential in the prevention of pain crises in sickle cell disease: evidence to date. Journal of blood medicine, 10, 307–311. https://doi.org/10.2147/JBM.S191423

Santos, T., de Matos, M. G., Simões, C., Leal, I., & do Céu Machado, M. (2017). (Health-related) quality of life and psychosocial factors in adolescents with chronic disease: a systematic literature review. International journal of adolescent medicine and health, 31(4), 10.1515/ijamh-2017-0037. https://doi.org/10.1515/ijamh-2017-0037

Shojaeezadeh D, Tol A, Sharifirad G, et al. Evaluation of educational program based on empowerment model to promote self-efficacy and its relationship to diabetes control in patients with type 2 diabetes. Iranian Journal of Diabetes and Lipid Disorders. 2011;11:474–82

Shook, L. M., Mosley, C., Farrell, C. B., Connelly, A., & Jones, C. L. (2021). Educational needs of school nurses regarding the evidence-based management of sickle cell disease. International Journal of Environmental Research and Public Health, 18(21), 11641. https://doi.org/10.3390/ijerph182111641

Sickle Cell Disease Ontology Working Group. (2019). The Sickle Cell Disease Ontology: enabling universal sickle cell-based knowledge representation. Database: The Journal of Biological Databases and Curation, 2019. https://doi.org/10.1093/database/baz118

Singhal, D., Kutyna, M. M., Chhetri, R., Wee, L., Hague, S., Nath, L., Nath, S. V., Sinha, R., Wickham, N., Lewis, I. D., Ross, D. M., Bardy, P. G., To, L. B., Reynolds, J., Wood, E. M., Roxby, D. J., & Hiwase, D. K. (2017). Red cell alloimmunization is associated with development of autoantibodies and increased red cell transfusion requirements in myelodysplastic syndrome. Haematologica, 102(12), 2021–2029. https://doi.org/10.3324/haematol.2017.175752

Smith, K. E., Cox, J. R., Haynes, R. L., Bohnker, N. I., & Saving, K. L. (2021). A Patient-Centered Approach to Gathering Information on Social Determinants of Health from Patients with Sickle Cell Disease in

Preparation for Their Transition to Adult Care. Blood, 138(Supplement 1), 4943–4943. https://doi.org/10.1182/blood-2021-147963

Smith, M. B., Macieira, T., Bumbach, M. D., Garbutt, S. J., Citty, S. W., Stephen, A., Ansell, M., Glover, T. L., & Keenan, G. (2018). The Use of Simulation to Teach Nursing Students and Clinicians Palliative Care and End-of-Life Communication: A Systematic Review. The American journal of hospice & palliative care, 35(8), 1140–1154. https://doi.org/10.1177/1049909118761386

Sousa, V. D., Zauszniewski, J. A., Bergquist-Beringer, S., Musil, C. M., Neese, J. B., & Jaber, A. F. (2010). Reliability, validity, and factor structure of the Appraisal of Self-Care Agency Scale-Revised (ASAS-R). Journal of Evaluation in Clinical Practice, 16(6), 1031–1040. https://doi.org/10.1111/j.1365-2753.2009.01242.x

Tanabe, Paula, et al. "Understanding the Complications of Sickle Cell Disease." AJN, American Journal of Nursing, vol. 119, no. 6, June 2019, pp. 26–35, 10.1097/01.naj.0000559779.40570.2c.

Thomas, V. J., & Taylor, L. M. (2002). The psychosocial experience of people with sickle cell disease and its impact on quality of life: Qualitative findings from focus groups. British Journal of Health Psychology, 7(3), 345–363. https://doi.org/10.1348/135910702760213724

Tsao, J. C., Jacob, E., Seidman, L. C., Lewis, M. A., & Zeltzer, L. K. (2013). Psychological aspects and hospitalization for pain crises in youth with sickle-cell disease. Journal of Health Psychology, 19(3), 407–416. https://doi.org/10.1177/1359105312471570

Uvero C. Nursing Theries 2012. Available at URL: http://nursingtheories mtctfn2012012.blogspot.com/2012/03/dorothea-orem.html. Retrieved on 18 march 20143. ww.ajtr.org /ISSN:1943-8141/AJTR0128621

Wallerstein, N. B., & Duran, B. (2006). Using Community-Based Participatory Research to Address Health Disparities. Health Promotion Practice, 7(3), 312–323. https://doi.org/10.1177/1524839906289376.

Wang, H. H., & Laffrey, S. C. (2000). Preliminary development and testing of instruments to measure self-care agency and social support of women in Taiwan. The Kaohsiung journal of medical sciences, 16(9), 459–467. PMID: 11271731

Wastnedge, E., Waters, D., Patel, S., Morrison, K., Goh, M. Y., Adeloye, D., & Rudan, I. (2018). The global burden of sickle cell disease in children under five years of age: a systematic review and meta-analysis. Journal of Global Health, 8(2), 021103. doi:10.7189/jogh.08.021103

Weir, N. A., Conrey, A., Lewis, D., & Mehari, A. (2018). Riociguat use in sickle cell related chronic thromboembolic pulmonary hypertension: A case series. Pulmonary Circulation, 8(4), 204589401879180. https://doi.org/10.1177/2045894018791802

Whitlock, E. P., Orleans, C. T., Pender, N., & Allan, J. (2002). Evaluating primary care behavioral counseling interventions: an evidence-based approach. American Journal Of Preventive Medicine, 22(4), 267–284. https://doi.org/10.1016/s0749-3797(02)00415-4

Yacoub, M. I., Zaiton, H. I., Abdelghani, F. A., & Elshatarat, R. A. (2019). Effectiveness of an educational program on nurses' knowledge and practice in the management of acute painful crises in sickle cell disease. Journal of Continuing Education in Nursing, 50(2), 87–95. https://doi.org/10.3928/00220124-20190115-08

Yaqoob, Shafeeqa & Nasaif, Husain. (2015). Nurses' knowledge and attitudes toward pain assessment and management for adult sickle cell disease patients during sickling crisis. Clinical Nursing Studies. 3. 10.5430/cns. v3n4p36. DOI:10.5430/cns.v3n4p36

Yusra Al Nasiri, Jacob E, Lee E, Nyamathi A, Brecht ML, et al. (2020) Parent educational intervention program for improving parental knowledge, self-efficacy and health related quality of life in children with sickle cell disease using smartphone technology: A randomized controlled trial. Hematol Med Oncol 5: DOI: 10.15761/HMO.1000203

Zanoni, C. T., Galvão, F., Maria, R. M., Zulli, R., Ricciardi, J. B., Cliquet, A., Junior, & Saad, S. T. O. (2021). Effectiveness of a home-based therapeutic exercise program on lower back pain and functionality in Sickle Cell Disease (SCD) patients. Hematology, Transfusion and Cell Therapy, 43(3), 268–279. https://doi.org/10.1016/j.htct.2020.05.004

Zhang, L., & Pan, W. (2021). Effect of a nursing intervention strategy oriented by Orem's self-care theory on the recovery of gastrointestinal function in patients after colon cancer surgery. American Journal of Translational Research, 13(7), 8010–8020.

Zimmerman, M. A. (1995). Psychological empowerment: Issues and illustrations. American Journal of Community Psychology, 23(5), 581–599. https://doi.org/10.1007/bf02506983

Zimmerman, M. A. (2000). Empowerment theory: Psychological, organizational, and community levels of analysis. In J. Rappaport, E. Seidman, J. (Ed) Rappaport, & E. (Ed) Seidman (Eds.), Handbook of community psychology. (2000-03855-002; pp. 43–63). Kluwer Academic Publishers.

Zimmerman, M. A., & Warschausky, S. (1998). Empowerment theory for rehabilitation research: Conceptual and methodological issues. Rehabilitation Psychology, 43(1), 3–16. https://doi.org/10.1037/0090-5550.43.1.3

Zoffmann, V., Kirkevold, M. (2012). Realizing empowerment in difficult diabetes care: a guided self-determination intervention. Qual. Health Res. 22 (1), 103–118. https://doi.org/10.1177/1049732311420735



Appendices



Appendices I

Tool I: Sickle Cell Self-Efficacy Scale (SCSES)

Sickle Cell Disease Self-Efficacy Scale (SCSES)

The following questions ask about how sure you are in dealing day-to-day with sickle cell disease. There are no right or wrong answers; we just want to know what you think. So, for each question, tell us how sure you are by circling the response that best tells how you feel. Please answer every question.

1. How sure are you that you can do something to cut down on most of the pain?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

2. How sure are you that you can keep doing most of the things you do day-to-day?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

3. How sure are you that you can keep sickle cell disease pain from interfering with your sleep?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

4. How sure are you that you can reduce your sickle cell disease pain by using methods other than taking medications?
[ ] 1 Not Sure at All
[ ] 2 Not Sure
[ ] 3 Neither
[ ] 4 Sure
[ ] 5 Very Sure

5. How sure are you that you can control how often or when you get tired?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

6. How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

7. As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

8. How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

9. How sure are you that you can deal with the frustration of having sickle cell disease?

[ ] 1 Not Sure at All

[ ] 2 Not Sure

[ ] 3 Neither

[ ] 4 Sure

[ ] 5 Very Sure

Scoring: Responses from individual items are summed to give an overall score, with higher scores indicating greater self-efficacy.



Appendices II

Tool II:The Appraisal of Self-Care Agency Scale-Revised (ASAS-R)



The Appraisal of Self-Care Agency Scale-Revised

Items	Content	Scores
Item 1	To make adjustments to stay healthy.	1 2 3 4 5
Item 3	To set new priorities to stay healthy.	1 2 3 4 5
Item 2	To make the needed adjustments to stay healthy.	1 2 3 4 5
Item 10	To evaluate the effectiveness of things to stay healthy.	1 2 3 4 5
Item 8	To have changed old habits to improve health.	1 2 3 4 5
Item 5	To look for better ways to take care of yourself.	1 2 3 4 5
Item 14	Lack of time to take care of yourself.	5 4 3 2 1
Item 15	Inability of taking care of yourself.	5 4 3 2 1
Item 4	Lack of energy to care of yourself.	5 4 3 2 1
Item 11	Seldom take time to care for yourself.	5 4 3 2 1
Item 6	Take time to care for yourself when necessary.	1 2 3 4 5
Item 15	Inability of taking care of yourself.	1 2 3 4 5
Item 12	Receive necessary information, when health is threatened.	1 2 3 4 5
Item 7	Obtain information about side effects of a new medication.	1 2 3 4 5
Item 9	Take measures to ensure safety of yourself and the family.	1 2 3 4 5
Item 13	Seek help when unable to care for yourself.	1 2 3 4 5

Note: 1 = Totally Disagree; 2 = Disagree; 3 = Neither Disagree or Nor Agree; 4 = Agree; 5 = Totally Agree

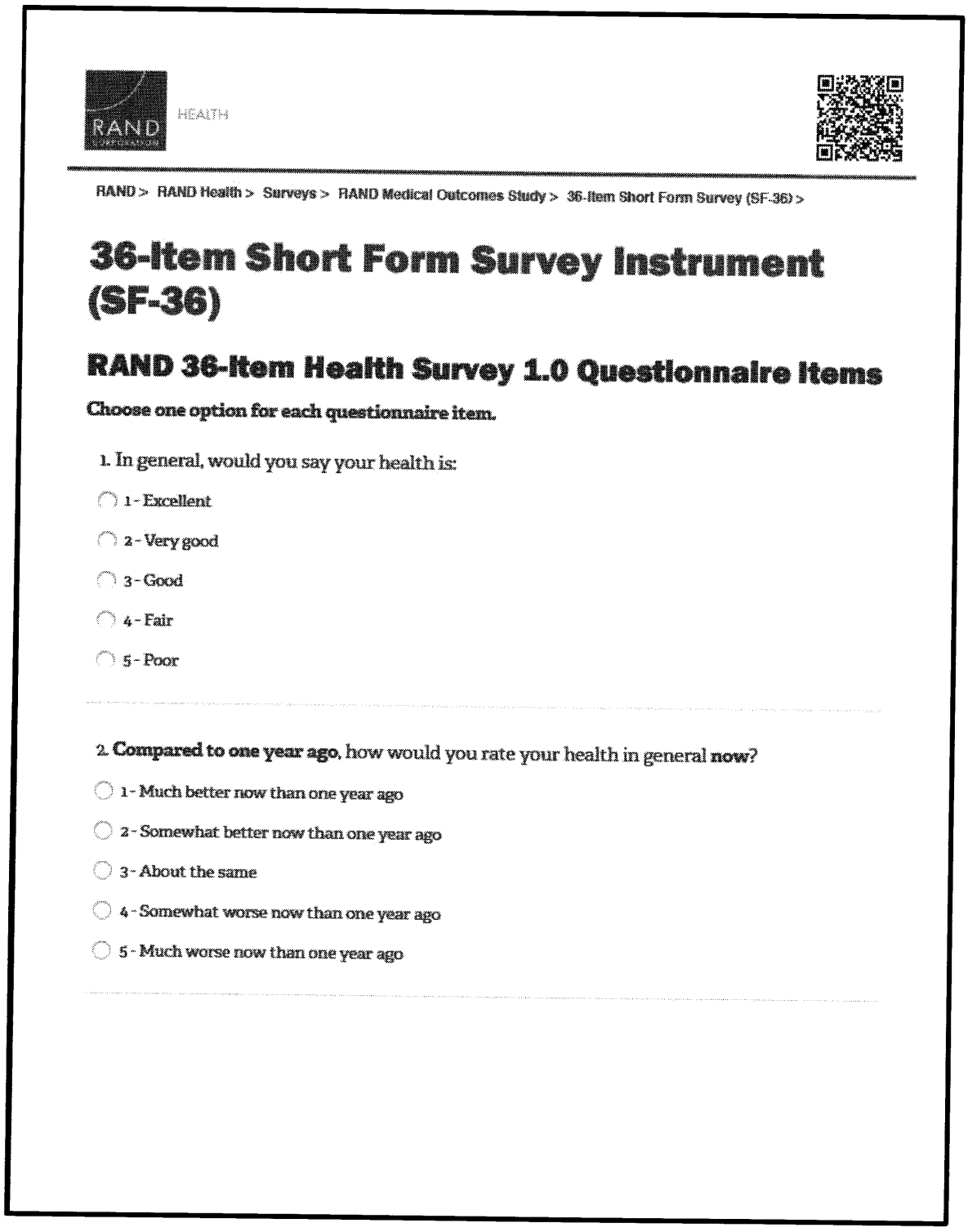


Appendices III

Tool III: 36-Item Short Form Survey Instrument (SF-36)



36-Item Short Form Survey Instrument (SF-36)



RAND HEALTH

RAND > RAND Health > Surveys > RAND Medical Outcomes Study > 36-Item Short Form Survey (SF-36) >

36-Item Short Form Survey Instrument (SF-36)

RAND 36-Item Health Survey 1.0 Questionnaire Items

Choose one option for each questionnaire item.

1. In general, would you say your health is:

- 1 - Excellent
- 2 - Very good
- 3 - Good
- 4 - Fair
- 5 - Poor

2. **Compared to one year ago**, how would you rate your health in general **now**?

- 1 - Much better now than one year ago
- 2 - Somewhat better now than one year ago
- 3 - About the same
- 4 - Somewhat worse now than one year ago
- 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	○ 1	○ 2	○ 3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○ 1	○ 2	○ 3
5. Lifting or carrying groceries	○ 1	○ 2	○ 3
6. Climbing **several** flights of stairs	○ 1	○ 2	○ 3
7. Climbing **one** flight of stairs	○ 1	○ 2	○ 3
8. Bending, kneeling, or stooping	○ 1	○ 2	○ 3
9. Walking **more than a mile**	○ 1	○ 2	○ 3
10. Walking **several blocks**	○ 1	○ 2	○ 3
11. Walking **one block**	○ 1	○ 2	○ 3
12. Bathing or dressing yourself	○ 1	○ 2	○ 3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
13. Cut down the **amount of time** you spent on work or other activities	◯ 1	◯ 2
14. **Accomplished less** than you would like	◯ 1	◯ 2
15. Were limited in the **kind** of work or other activities	◯ 1	◯ 2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	◯ 1	◯ 2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	◯ 1	◯ 2
18. **Accomplished less** than you would like	◯ 1	◯ 2
19. Didn't do work or other activities as **carefully** as usual	◯ 1	◯ 2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

◯ 1 - Not at all

◯ 2 - Slightly

◯ 3 - Moderately

◯ 4 - Quite a bit

◯ 5 - Extremely

21. How much **bodily** pain have you had during the **past 4 weeks**?

- 1 - None
- 2 - Very mild
- 3 - Mild
- 4 - Moderate
- 5 - Severe
- 6 - Very severe

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

- 1 - Not at all
- 2 - A little bit
- 3 - Moderately
- 4 - Quite a bit
- 5 - Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of pep?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
24. Have you been a very nervous person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
25. Have you felt so down in the dumps that nothing could cheer you up?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
26. Have you felt calm and peaceful?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
27. Did you have a lot of energy?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
28. Have you felt downhearted and blue?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
29. Did you feel worn out?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
30. Have you been a happy person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
31. Did you feel tired?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

○ 1 - All of the time

○ 2 - Most of the time

○ 3 - Some of the time

○ 4 - A little of the time

○ 5 - None of the time

How TRUE or FALSE is **each** of the following statements for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. I seem to get sick a little easier than other people	○ 1	○ 2	○ 3	○ 4	○ 5
34. I am as healthy as anybody I know	○ 1	○ 2	○ 3	○ 4	○ 5
35. I expect my health to get worse	○ 1	○ 2	○ 3	○ 4	○ 5
36. My health is excellent	○ 1	○ 2	○ 3	○ 4	○ 5

ABOUT

The RAND Corporation is a research organization that develops solutions to public policy challenges to help make communities throughout the world safer and more secure, healthier and more prosperous. RAND is nonprofit, nonpartisan, and committed to the public interest.



1776 Main Street
Santa Monica, California 90401-3208

RAND® is a registered trademark. Copyright © 1994-2016 RAND Corporation.



Appendices V

Consents



University of Bahrain
College of Health and Sport Sciences
Allied Health Department

Informed consent form

Name :

I hereby give my consent to participate in the sutdy titled: Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adult with Sickle Cell Disease.

Resercher Name : Hasan A.Ali Khalil Rashwan **Course Title :** Applied Reasearch Project

Student No : 20052138 **Supervisor Name :** Zohour Ibrahim

I, the undersigned, confirm that : (please tick as appropriate)

statment	yes	No
1. I have read and understood the information regarding the study procedures, requirements and possible side affects as provided in the information sheet		
2. I voluntarily agree to participate in the all stages of the project		
3. I understand that I have the right to withdraw in any time without being ask for clarifications.		
4. The procedures regarding confidentiality have been clearly explained to me (use of names, pictures, anonymisation of data, etc),		
5. The use of the data in research, publications, sharing and archiving has been explained to me.		
6. I understand that other researcher will be able to access the data only if they agree to preserve the confidentiality of the data and if they agree to the terms I have specified in this form.		
7. I understand that, if there is any concern about the appropriateness of my continuing in this research, I may be asked to withdraw my involvement at any stage.		
8. I have been given the opportunity to ask questions about the project and my participation. I have the right to ask further questions in the future		
9. All the information that I gave to the researcher are true and accurate to the best of my knowledge and I understand that I must notify if there are any changes to the information.		
10. I along with the Researcher agree to sign date this informed consent form		

Participant Name	Signature	Date
Investigator Name	Signature	Date

University of Bahrain

College of Health and Sport Sciences

Allied Health Department

Information sheet

Study Title:

Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adult with Sickle Cell Disease.

Overview:

This study aims to investigate the effectiveness of Empowerment-Based Interventions (EBI) on the self-efficacy and self-management capacity among adults with sickle cell disease (SCD). The eligible patients will be divided into two groups at random and will give baseline data by utilizing three instruments to measure their demographic and clinical features, self-efficacy, and self-management capacity. After assessing self-efficacy and self-management capacity, the EBI will be implanted, and its effectiveness will be measured.

Why we are doing this research?

This research will address the needs of patients with SCD, exploring the effectiveness of different interventions to help promote their self-management capacity.

What will happened if I agreed to participate in this study?

You will be asked to sign a consent form, then you will be asked to complete a paper-based questionnaire which we estimate will take you 15 minutes. You may also wish to agree to a follow-up interview to find out more about your approach. You might join a small group discussion and follow-up sessions with individualized consultations that will focus on topics relevant to SCD management.

What are the possible benefits of taking part in this study?

It is hoped that this work will have a beneficial impact on how adults with sickle cell disease who will receive EBI to exhibit higher self-efficacy to have the ability to perform activities of daily living and self-management capacity. Results will be shared with participants in order to inform their professional work. Results will be shared with participants in order to inform their professional work.

What are the possible disadvantages and risks of taking part?

Participating in the research is not anticipated to induce any disadvantages or discomfort. The potential physical and/or psychological harm or distress will be the same as any experienced in everyday life.

Who is eligible to participate?

Adult patients with SCD who are treated at primary health care centres and are between the ages of 20 and 60 will be included in the study. Patients with physical or mental difficulties, on the other hand, will be excluded.

Will my taking part in this project be kept confidential?

All of the data gathered for this study will be kept as private as possible. To ensure participant privacy, names and contact information will not be disclosed; nevertheless, photographic and videotape records will be collected as needed. The researcher will keep your identity hidden by not exposing your face; nonetheless, the photos and video recordings may be published in a relevant article or shown in a lecture.

What will happened if I don't want to continue participating in this study?

Your decision to join or not engage in this study is entirely voluntary, and it will have no impact on your connection with the University of Bahrain or the researcher. You also have the right to withdraw from the study at any time; simply notify the researcher; no reason or explanation is required.

What happens if something was not right?

If you have any concerns regarding the project, you should contact Hasan Abdali as soon as possible so that he can address and resolve the problem. If you don't think your issue has been handled properly, you can contact Dr. Zohour Rashwan. All of the specifics are included here.

Contact details:

For further information, please do not hesitate to contact with any one of the researchers below:

Principal researcher

Hasan Abdali Khalil

Master student, College of Health and sport Sciences, University of Bahrain

Mobile: +00973 33302077

Email: hasali8@hotmail.com

Course supervisor

Dr Zohour Ibrahim Rashwan

Assistant Professor, Nursing Department, College of Health and sport Sciences, University of Bahrain

Mobile: +973 35094573

Email: zrashwan@uob.edu.bh

إقرار الموافقة المستنيرة على الإشتراك فى دراسة علمية

اقر انا / ..... الموقع ادناة بإن الباحث / حســـن عبدعلي خليل

قد قامت بإحاطتى تفصيلا بالآتى:

1- أهداف البحث:

تحديد تأثير التدخل القائم على التمكين على الكفاءة الذاتية والقدرة على الرعاية الذاتية وجودة الحياة المتعلقة بالصحة لدى المرضى البالغين المصابين بمرض.

2- الإجراءات التى سيتعرض لها المفحوص تفصيلا:

تنظيم محاضرات تثقيفية عامة لمجموعات صغيرة من المرضى بالاضافة الى بعض الجلسات الفردية التي تتضمن استراتجيات لتمكين المرضـــى من تقليل حدة الألم و القيام بالأعمال اليومية بالإضـــافة الى تقديم معلومات عامة عن مرض خلايا فقر الدم المنجلي مثل التعريف بالمرض، التغيرات الفيسولوجية، المضـاعفات، و طرق التشـخيص والعلاج. تتضـمن الإجراءات ايضـا إتباع خمس خطوات أساسية في الجلسات فردية وهم كالأتي: التقييم ، تقديم المشورة ، الاتفاق ، المساعدة ، والترتيب. إجراء جلسـات متابعة إسـبوعية للمرضـى للتأكد من التزامهم بإتباع الأرشـادات والتحقق من تقدم المريض ، أما بالنسـبة للمجموعة الضابطة تلقى المرضى الرعاية التمريضية الروتينية المتبعة من قبل المركز الصحي.

3- أى أضـرار أو مخاطر محتملة (إن وجدت) من البحث قد تعود على المريض بشـكل مباشـر أو غير مباشر وهى:-

لا يوجد أى أضرار أو مخاطر محتملة مباشرة أو غير مباشرة تعود على المريض.

4- الفوائد العائدة على المشترك فى البحث بشكل مباشر أو غير مباشر وهى:

المتابعة الدورية والمسـتمره للمرضـى المصـابين بمرض خلايا فقر الدم المنجلي وتقييم ممارسـات الرعاية الذاتية لديهم وذلك للكشـف المبكر وحل المشـكلات الصـحية التي قد تواجههم. تطبيق برنامج التدخل القائم على التمكين باسـتخدام نموذج الخمس خطوات لدى المرضى المصابين بالأمراض المزمنة المختلفة يحسن قدرتهم على الرعاية الذاتية وجودة الحياه لديهم.

5- إمكانية قبول أو رفض المشاركة:

تم التأكيد على عدم إجبارى للمشـاركة فى الدراسـة وكذلك لدى حق الإ نسـحاب من الدارسـة وقتما أشـاء دون أن يؤثر قراري على الرعاية الطبية المقدمة لي.

6- من سيعلم بمشاركتك فى البحث:

المسـئولون عن البحث وكذلك الممرضـات المعاونون لهم كما أن المعلومات الخاصـة بحالتى المرضـية وعلاجها سـتكون محفوظة بطريقة آمنة غيرمسموح بالإطلاع عليها إلا للمسئولين عن البحث.

7- البدائل المتاحة في حالة رفضـك للمشـاركة: تلقي الرعاية التمريضـية الروتينية المتبعة من قبل المركز الصحي.

هل لديك أى إستفسارات أخرى ؟

فى حالة رغبتك فى طرح أى سؤال أثناء الدراسة يمكنك توجيهه إلى الباحثة الرئيسية

تليفون: 0097333302077

توقيع الباحث **توقيع *المريض*** ***الرقم الشخصي*** ***التاريخ***



Appendices VI

Permissions



University of Bahrain
College of Health and Sports Sciences
Scientific Research and Publication Committee

Dec. 12, 2021

To: The Chairperson of the Research Technical Support Team
Ministry of Health
Kingdom of Bahrain

Dear Madam/Sir,

Greetings from the College of Health and Sport Sciences, University of Bahrain!

RE: Research study on "Empowerment-Based Intervention: Promoting Self-Efficacy and Self- Management Capacity among Adult with Sickle Cell Disease"- CHSS SRPC Recommendation No: 25/2021-22 dt. Dec. 12,2021.

The Scientific Research and Publication Committee, College of Health and Sport Sciences (CHSS), University of Bahrain (UOB), has reviewed and recommended the research proposal (CHSS SRPC Recommendation No: 25/2021-22 dt. Dec. 12, 2021) entitled "Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adult with Sickle Cell Disease" to the MoH RTST. Mr. Hasan A. Ali Khalil, a student enrolled in M.Sc Adult Health Nursing -Nursing Program of CHSS, UoB would be carrying out the study under the supervision of Dr. Zohour Rashwan, Assistant Professor, Nursing Department, CHSS, UoB as Master's Thesis. Notably, the outcome of the research is expected to benefit Sickle Cell Patients in the Kingdom of Bahrain. Therefore, I request to do the needful considering the paucity of time to complete the Master's Thesis.

Thank you for supporting scientific research at the CHSS, UOB.

Kind Regards,

Bekhit

Chairperson, Scientific Research and Publication Committee
College of Health and Sport Sciences
University of Bahrain

Kingdom of Bahrain
Primary Healthcare Centres

مملكة البحرين
مراكز الرعاية الصحية الأولية

Date :	10th February 2022
Proposal Title:	**Empowerment-Based Intervention: Promoting Self-Efficacy and Self-Management Capacity among Adult with Sickle Cell Disease**
Type of Study	**Master Research**
Name of Researcher submitting proposal:	**Hassan Ali**

Reviewer's recommendation:

Accept	☑
Request modifications	☐
Reject	☐

Reviewer's Comments:

Committee's recommendation:
Thank you for the efforts. Best of luck.

Signature: **Head of the Research Committee Primary Health Care**	Dr. Reham Ahmed Al-Garf

Signature: Core team Member	Dr. Adel Al-Sayyad

Appendices IV

Arabic Versions of The Three Instruments

الأداة الاولى: مقياس تقييم القدرة على الرعاية الذاتية

رقم السؤال	البنود	موافق جدا	موافق	لا أعرف	غير موافق	لست موافق على الاطلاق
إمتلاك السعة على العناية الذاتية						
1	مع تغير الظروف ، أقوم بإجراء التعديلات اللازمة للبقاء بصحة جيدة.					
2	إذا قلت قدرتي على الحركة، أقوم بإجراء التعديلات اللازمة.					
3	عند الحاجة ، أضع أولويات جديدة في التدابير التي أتخذها للبقاء بصحة جيدة.					
5	أبحث عن طرق أفضل للعناية بنفسي.					
6	عند الحاجة ، أتمكن من ادارة بعض الوقت للأعتناء بنفسي.					
10	أقوم بانتظام بتقييم فاعلية الأشياء التي تساعدني للبقاء بصحة جيدة.					
تنمية السعة على العناية الذاتية						
7	إذا تناولت دواءا جديدا ، أحصل على معلومات حول الآثار الجانبية لرعاية نفسي بشكل أفضل.					
8	في الماضي ، قمت بتغيير عاداتي القديمة من أجل تحسين صحتي.					
9	أتخذ بشكل روتيني تدابير للتأكد من ضمان سلامة نفسي وعائلتي.					
12	لدي القدرة للحصول على المعلومات التي أحتاجها عندما تكون صحتي مهددة.					
13	أطلب المساعدة عندما لا أستطيع الاعتناء بنفسي.					
إفتقار السعة على العناية الذاتية						
4	غالبا ما أفتقر إلى الطاقة اللازمة لرعاية نفسي بالطريقة المتوجبة علي.					
11	في أنشطتي اليومية ، نادرا ما أستغرق وقتا لرعاية نفسي.					
14	نادرا ما يكون لدي وقت لنفسي.					
15	لست دائما قادرا على رعاية نفسي بالطريقة التي أفضلها.					

الأداة الثانية: مقياس الكفاءة الذاتية

البنود	لست متأكدا على الاطلاق	غير متأكد	لا أعرف	متأكد	متأكد جدا
1- ما مدى تأكدك من قدرتك على تخفيف الألم الذي تشعر به عند إصابتك بنوبة ؟					
2- ما مدى تأكدك من الاستمرارية في القيام بمعظم الأمور التي تقوم بها يوميا ؟					
3- ما مدى تأكدك من قدرتك على منع آلام الفقر المنجلي من التدخل في نومك؟					
4- ما مدى تأكدك من قدرتك على تخفيف آلام النوبات بطرق بديلة عن تناول أدوية إضافية ؟					
5- ما مدى تأكدك من التحكم و السيطرة على عدد مرات النوبات أو الإصابة بالتعب ؟					
6- ما مدى تأكدك من القدرة على القيام بشيء لتخفيف عن نفسك عند شعورك بالحزن أو الاكتئاب ؟					
7- بالمقارنة مع الأشخاص المصابين بمرض الدم المنجلي ، ما مدى تأكدك من قدرتك على إدارة حياتك من يوم لآخر ؟					
8- ما مدى تأكدك من قدرتك على التحكم في أعراض فقر الدم المنجلي حتى تتمكن من القيام بالأشياء التي تستمتع بفعلها ؟					
9- ما مدى تأكدك من القدرة على التعامل مع الإحباط الناتج من مرض فقر الدم المنجلي؟					

الأداة الثالثة: الإستطلاع الصحي ذو النموذج القصير المكون من 36 عنصرا

الجنس

- ذكر
- انثى

العمر ------- سنة

المؤهل العلمي :

- ابتدائي
- اعدادي
- ثانوي
- بكالوريوس
- ماجستير
- دكتوراه

من فضلك، أجب على كل الأسئلة الموجودة في هذا الاستبيان. في حالة عدم وضوح أي سؤال، أرجو اختيار أقرب إجابة لمفهومك للسؤال.

1- بصورة عامة، كيف ترى حالتك الصحية؟ (اختر إجابة واحدة وضع علامة ✓ أمام الإجابة المناسبة)

- ممتازة
- جيد جدا
- جيدة
- لا بأس بها
- سيئة

2- مقارنة بما مضى، كيف تقيم حالتك الصحية الآن بصورة عامة؟ (اختر إجابة واحدة وضع علامة ✓ أمام الإجابة المناسبة)

- أفضل بكثير مما كانت عليه قبل عام
- أفضل نوعا ما من العام الماضي
- تقريبا على ما هي عليه
- أسوأ نوعا ما من العام الماضي
- أسوأ بكثير مما كانت عليه قبل عام

3- تتعلق البنود التالية بأنشطة يمكن ان تقوم بها خلال يومك العادي، في الوقت الحالي، الى أي مدى تقيدك حالتك الصحية:	نعم تقيدني كثيرا	نعم تقيدني قليلا	لا تقيدني اطلاقا
أ) من ممارسة الأنشطة الشاقة مثل: الجري، حمل الأشياء الثقيلة او مزاولة الأنشطة الرياضية المجهدة جدا؟	○	○	○
ب) من ممارسة الأنشطة متوسطة الجهد، كتحريك الطاولة او التنظيف باستخدام المكنسة الكهربائية او تنظيف حديقة المنزل و العناية بها؟	○	○	○
ج) من حمل المشتريات من البقالة او السوق المركزي (السوبرماركت)؟	○	○	○
د) من صعود الدرج لعدة أدوار؟	○	○	○
هـ) من صعود الدرج لدور واحد فقط؟	○	○	○
و) من الانحناء او الركوع او السجود؟	○	○	○
ز) من المشي لأكثر من كيلو متر ونصف؟	○	○	○
ح) من المشي لمسافة نصف كيلو متر؟	○	○	○
ط) من المشي لمسافة مئة متر؟	○	○	○
ي) من الاستحمام او ارتداء الملابس بنفسك؟	○	○	○

الصحة الجسمية

4- تتعلق البنود التالية (أ، ب، ج، د) بالمشاكل التي يمكن ان تواجهك خلال تأديتك لعملك او للأنشطة اليومية المعتادة نتيجة لحالتك الصحية الجسمية. خلال الأسابيع الأربعة الماضية، هل تسببت حالتك الصحية الجسمية في:	نعم	لا
أ) التقليل من الوقت الذي تقضيه في العمل او أي أنشطة أخرى؟	○	○
ب) التقليل مما تود إنجازه من العمل أو أي أنشطة أخرى؟	○	○
ج) تقييدك في أداء نوع معين من الأعمال أو أي أنشطة أخرى؟	○	○
د) أن تجد صعوبة في تأدية العمل أو أي أنشطة أخرى؟ (على سبيل المثال، احتجت الى جهد إضافي لتأديتها)	○	○

الصحة النفسية

5- تتعلق البنود التالية (أ، ب، ج) بالمشاكل التي يمكن ان تواجهك خلال تأديتك لعملك او للأنشطة اليومية المعتادة نتيجة لحالتك الصحية النفسية. خلال الأسابيع الأربعة الماضية، هل تسببت حالتك الصحية النفسية في:	نعم	لا
د) التقليل من الوقت الذي تقضيه في العمل او أي أنشطة أخرى؟	○	○
ذ) التقليل مما تود إنجازه من العمل أو أي أنشطة أخرى؟	○	○
ر) عدم انجاز العمل او أي أنشطة أخرى بالحرص المعتاد؟	○	○

الصحة الجسمية او النفسية

٦- خلال الأسابيع الأربعة الماضية، الى أي مدى تعارضت صحتك الجسمية او النفسية مع تأديتك لنشاطاتك الاجتماعية المعتادة مع عائلتك او اصدقائك او جيرانك او أي من المناسبات الاجتماعية الأخرى؟

(اختر إجابة واحدة وضع علامة ✓ أمام الإجابة المناسبة)

- o لم يكن هناك أي تعارض اطلاقا
- o كان هناك تعارض قليل
- o كان هناك تعارض متوسط
- o كان هناك تعارض كبير
- o كان هناك تعارض كبير جدا

شدة الألم

٧ – ما شدة الألم الجسمي الذي عانيت منه خلال الأسابيع الأربعة الماضية؟

(اختر إجابة واحدة وضع علامة ✓ أمام الإجابة المناسبة)

- o لم يكن هناك أي ألم
- o كان هناك ألم خفيف جدا
- o كان هناك ألم خفيف
- o كان هناك ألم متوسط
- o كان هناك ألم شديد
- o كان هناك ألم شديد جدا

8- خلال الأسابيع الأربعة الماضية، الى أي مدى أدى الألم الجسمي الى تعارض مع تأديتك لأعمالك المعتادة (سواء داخل المنزل او خارجه)؟

(اختر إجابة واحدة وضع علامة ✓ أمام الإجابة المناسبة)

- o لم يكن هناك أي تعارض
- o كان هناك تعارض قليل جدا
- o كان هناك تعارض متوسط
- o كان هناك تعارض كبير
- o كان هناك تعارض كبير جدا

٩- الأسئلة التالية تتعلق بكيفية شعورك وطبيعة سير الأمور معك خلال الأسابيع الماضية، الرجاء إعطاء إجابة واحدة لكل سؤال بحيث تكون هذه الإجابة هي الأقرب الى الحالة التي كنت تشعر بها.

خلال الأسابيع الأربعة الماضية، كم من الوقت:

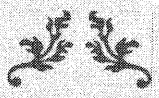
	في كل الاوقات	في معظم الاوقات	في كثير من الاوقات	في بعض الاوقات	في قليل من الاوقات	لم اشعر في أي وقت من الاوقات
أ) شعرت بأنك ملئ بالحيوية والنشاط؟	○	○	○	○	○	○
ب) كنت شخصا عصبيا جدا؟	○	○	○	○	○	○
ج) شعرت بأنك في حالة اكتئاب الى درجة لم يكن معها ادخال السرور اليك؟	○	○	○	○	○	○
د) شعرت بالهدوء والطمأنينة؟	○	○	○	○	○	○
هـ) كانت لديك طاقة كبيرة؟	○	○	○	○	○	○
و) شعرت بالإحباط واليأس؟	○	○	○	○	○	○
ز) شعرت بأنك منهمك (استنفذت قواك)؟	○	○	○	○	○	○
ح) شعرت بأنك شخص سعيد؟	○	○	○	○	○	○
ط) شعرت بأنك تعبان؟	○	○	○	○	○	○

١٠- خلال الأسابيع الأربعة الماضية، ما مقدار الوقت الذي تعارضت فيه صحتك الجسمية او مشاكلك النفسية مع نشاطاتك الاجتماعية (مثل زيارة الأصدقاء و الأقارب وغير ذلك)؟

(اختر إجابة واحدة وضع علامة ✓ أمام الإجابة المناسبة)

- ○ كان التعارض في كل الأوقات
- ○ كان التعارض في معظم الأوقات
- ○ كان التعارض في بعض الأوقات
- ○ كان التعارض في قليل من الأوقات
- ○ لم يكن هنالك تعارض في أي وقت من الأوقات

١١- ما مدى صحة او خطأ كل من العبارات التالية (أ، ب، ج، د) بالنسبة الى حالتك الصحية؟					
	صحيحة بلا شك	صحيحة غالبا	لا اعلم	خطأ غالبا	خطأ بلا شك
أ) يبدو أنني أصاب بالمرض أسهل من الآخرين.	○	○	○	○	○
ب) حالتي الصحية مساوية لأي شخص أعرفه.	○	○	○	○	○
ج) أتوقع أن تسوء حالتي الصحية.	○	○	○	○	○
د) حالتي الصحية ممتازة.	○	○	○	○	○



الخلاصة



المقدمة: على الصعيد العالمي، يتأثر ملايين الأشخاص بمرض خلايا فقر الدم المنجلي. تؤثر نوبات الألم المزمن والمضاعفات المرتبطة بالمرض بشكل عميق على قدرة الرعاية الذاتية للمرضى.

هدف البحث: الهدف من هذه الدراسة هو تحديد تأثير التدخل القائم على التمكين على الكفاءة الذاتية والقدرة على الرعاية الذاتية وجودة الحياة المتعلقة بالصحة لدى المرضى البالغين المصابين بمرض.

مكان الدراسة: أجريت الدراسة في اثنين من مراكز الرعاية الصحية الأولية في البحرين. تم اختيار هذين المركزين عشوائيا باستخدام الطريقة العنقودية.

عينة الدراسة: اشتملت عينة الدراسة على 68 مريضا بالغا مصابا بمرض خلايا فقر الدم المنجلي بشكل عشوائي حيث تم تقسيمهم إلى مجموعتين وهما مجموعة الدراسة و المجموعة الضابطة.

طريقة اجراء الدراسة: تم تطبيق التدخل القائم على التمكين من خلال تنظيم محاضرات تثقيفية عامة لمجموعات صغيرة من المرضى بالاضافة الى بعض الجلسات الفردية التي تضمنت استراتجيات لتمكين المرضى من تقليل حدة الألم و القيام بالأعمال اليومية. هدفت المحاضرات تثقيفية الى تقديم معلومات عامة عن مرض خلايا فقر الدم المنجلي مثل التعريف بالمرض، التغيرات الفيسولوجية، المضاعفات، و طرق التشخيص والعلاج. كما تم إتباع خمس خطوات أساسية في الجلسات فردية وهم كالأتي: التقييم ، تقديم المشورة ، الاتفاق ، المساعدة ، والترتيب. تم أيضا إجراء جلسات متابعة إسبوعية للمرضى للتأكد من التزامهم بإتباع الأرشادات والتحقق من تقدم المريض ، أما بالنسبة للمجموعة الضابطة تلقى المرضى الرعاية التمريضية الروتينية المتبعة من قبل المركز الصحي. تم إعادة تقييم كلتا المجموعتين من حيث الكفاءة الذاتية والقدرة على الرعاية الذاتية بعد شهر واحد.

أدوات البحث: تم استخدام ثلاث ادوات لجمع البيانات اللازمة وهم كالاتي: (أ) الكفاءة الذاتية لدى مرضى خلايا فقر الدم المنجلي، (ب) القدرة على الرعاية الذاتية، (ج) جودة الحياة المتعلقه بالصحة.

النتائج: تشير النتائج الى ظهور تحسن كبير في مجموعة التدخل القائم على التمكين فيما يتعلق بقدرتهم على الاستمرار في القيام بمعظم الأنشطة اليومية ، حيث كان المتوسط 4.31±0.79 مقارنة بالمجموعة الضابطة 3.47±0.89 ($P<0.001$). وكذلك ، ساهم تطبيق التدخل القائم على التمكين البالغين المصابين بمرض خلايا فقر الدم المنجلي من تقليل الألم باستخدام الطرق الغير دوائية ($P<0.001$). فيما يتعلق بالرعاية الذاتية ، أظهر المرضى الذين تلقوا برنامج التدخل القائم على التمكين قدرة أعلى على الرعاية الذاتية ، حيث كان المتوسط 4.32±0.35 مقارنة ب 3.49±0.48 في المجموعة الضابطة ($P<0.001$). كما مكنهم البرنامج من تطوير القدرة على الرعاية الذاتية 4.02±0.42 لمجموعة الدراسة مقارنة ب 3.02±0.52 للمجموعة الضابطة.

الخلاصة: يمكن ان نستخلص من نتائج الدراسة إن تطبيق برنامج التدخل القائم على التمكين باستخدام نموذج الخمس خطوات كان فعالا في تحسين الكفاءة الذاتية والقدرة على الرعاية الذاتية لدى المرضى البالغين المصابين بمرض خلايا فقر الدم المنجلي.

التوصيات: توصي الدراسة بالمتابعة الدورية والمستمره للمرضى المصابين بمرض خلايا فقر الدم المنجلي وتقييم ممارسات الرعاية الذاتية لديهم وذلك للكشف المبكر وحل المشكلات الصحية التي قد تواجههم. كما توصي الدراسة بتطبيق برنامج التدخل القائم على التمكين باستخدام نموذج الخمس خطوات لدى المرضى المصابين بالأمراض المزمنة المختلفة لتحسين قدرتهم على الرعاية الذاتية وجودة الحياه لديهم.

أدوات الدراسة

جامعة البحرين

قسم التمريض

كلية العلوم الصحية والرياضية

التدخل القائم على التمكين: تعزيز الكفاءة الذاتية والقدرة على الإدارة الذاتية لدى البالغين المصابين بمرض فقر الدم المنجلي

رسالة علمية

ايفاءا جزئيا لشروط الحصول على درجة الماجستير في علوم تمريض صحة البالغين

مقدمة من

حسن عبدعلي خليل إبراهيم

الرقم الجامعي: 20052138

تحت إشراف

د. زهور إبراهيم محمود رشوان

(أستاذ مساعد)

جامعة البحرين

مملكة البحرين

أبريل، 2023