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Effect of Structured Education Booklet on Self-efficacy, Self-care practices and Health-Related Quality of Life in Adults with Sickle Cell Disease

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Abstract
Background: Sickle Cell Disease (SCD) is a chronic disorder that has an impact on a patient's quality of life. A structured education booklet has the potential to affect self-efficacy, self-care practices and subsequently better quality of life. **Aim:** To investigate the effect of structured education booklet on self-efficacy, self-care practices and health related quality of life in adult patients with sickle cell disease. **Design:** Pre experimental one group (pretest-posttest) design. **Setting:** Inpatient and outpatient clinic, Clinical Hematology Unit, Department of Internal Medicine Assiut University Hospital. **Study subjects:** Purposive sample of forty adult patients with sickle cell disease of both sexes were included in the study and followed up for 3 months. **Data collection tools: (I)** structured interviewing questionnaire, **(II)** Sickle Cell Self-Efficacy Scale, **(III)** Self-care practices assessment sheet (**a**-Jeanerette Self-care Assessment Tool, **b-** The 24-item Appraisal of Self-care Agency Scale) and **(IV)** Adult Sickle Cell Quality of Life Measurement Information System. **Results:** The mean score of self-efficacy (14.25±2.78Vs.30.22±3.37), self-care practices measured as self-care actions (20.2±1.4Vs. 27.55±1.65), perceived self-care ability (65.9±4.1 Vs. 97.25±11.3), and health-related quality of life improved significantly when compared to the pre-structured education ($p < 0.001$**). **Conclusion:** Structured education booklet improved patient's self-efficacy, self-care practices, hence improving QOL in SCD patients. **Recommendation:** The study findings underscore the significance of implementing structured education booklet as an integral component of management of individuals with sickle cell disease as a means of enhancing self-efficacy, care practices and health-related quality of life.

Keywords: Health-Related Quality of Life, Self-care practices, Self-efficacy, Sickle Cell Disease & Structured education booklet

Introduction
Sickle cell disease (SCD) is an inherited blood disorder. It includes various genotypes; it arises when sickle hemoglobin (HbS) substitutes the normal hemoglobin A (HbA). This is due to a genetic mutation that causes abnormal polymerization of deoxygenated hemoglobin and, consequently, defective hemoglobin and sickled-shape red blood cells, yielding a range of clinical conditions **(Bell et al., 2024).**

Sickle cell disease has a significant, increasing global public health impact, and considerable illness burden. Each year, about 300,000 to 400,000 affected infants are born. From 2000 to 2022, the number of SCD patients raised from 5.46 to 7.74 million. SCD is among the top 20 causes of death for patients aged 15 to 49 years. SCD is identified as the 12th leading cause of death in the 2023 Global Burden of Disease study **(Thomson et al., 2023).**

Sickle cell disease is a chronic disorder, which can cause various complications such as painful crises and strokes. It is better to prevent stroke than to treat it, Hydroxyurea therapy may lower and prevent the risk of primary stroke in SCD patients (**Moeen et al., 2018).** Sickle cell disease may cause a burden on the patient and his family; it requires frequent visits to healthcare providers; it greatly affects health and QOL of SCD patients. Therefore, it is important for patients, and their families to understand the causes, symptoms, and treatment options. Better understanding helps patients to better manage their health and improve quality of life (**Elendu et al., 2023).**

Self-efficacy (SC) refers to an individual's confidence in their ability to handle daily activities and manage symptoms, including their capacity to control emotions, performance, and overall mood. It plays a crucial role in effective self-management and behavior change **(Shorey & Lopez, 2021).** For SCD patients, SC includes knowing signs and symptoms of a sickle cell pain crisis, other potential complications, and managing their condition daily **(Chestnut, 2021).** Moreover**,** self-care refers to the perceived ability to involve in therapeutic activities to improve QOL and health, as well as application of these activities. Self-

care practice is important to prevent complications and improve QOL **(Agina-Obu, 2023).**

Patients with SCD need to participate in a variety of complex activities to improve self-efficacy and self-management **(Al Nagshabandi & Abdulmutalib, 2019).** Self-management is crucial, as patients handle over 90% of the daily challenges associated with their disease, and to prevent disease-related complications **(Druyeet al., 2024).** Self-care management involves active participation of SCD patients to maintain their health and well-being, and improve the ability to manage their chronic disease. When patients are educated about self-management principles and practice these skills, this leads to more efficient use of health resources, better health outcomes, and reduced healthcare costs **(Druyeet al., 2024).**

Structured education is essential for patients with SCD. It represents the proactive role patients take in managing their chronic illnesses. This active engagement includes daily activities, tasks, or behaviors designed to mitigate the effects of these conditions on their quality of life. This includes daily activities, or behaviors designed to lessen effects of disease on QOL. Key elements of this approach provide SCD patients with knowledge, skills, and confidence needed to manage their disease effectively, leading to better health outcomes and improved QOL. Additionally, structured education lower healthcare costs, optimize resource use, and enhance collaboration between patients and healthcare providers **(Kavanagh et al., 2022; & Akinsete, 2022).**

Nurses are crucial in the care of patients with SCD, requiring a range of specialized skills and meticulous attention to the various signs, symptoms, and complications of the disease **(Mercado, 2023).** They play a key role in the prevention and management of SCD, focusing on early detection, screening, pain management, monitoring, and providing health education. Nurses are central to delivering comprehensive care and promoting health throughout the course of SCD **(Ndirangu-Mugo, 2024).** Inadequate care can lead to significant mortality from SCD, and survivors face serious health challenges that impact every aspect of their quality of life and well-being **(Kaur et al., 2022).**

Significance of the Study:

The World Health Organization identifies sickle cell disease as a major public health issue. It is estimated that approximately 300 million people globally carry the sickle cell trait **(Ahmadi et al., 2023).** Effective self-management among individuals with SCD can enhance their medical outcomes and self-efficacy, reduce the adverse effects of the disease, and decrease the need for healthcare services. However, there is a noticeable lack of studies specifically addressing these aspects, and there is limited research focused on SCD, particularly in adult patients. In light of these gaps, this study aims to assess whether structured education booklet can improve self-efficacy, self-care practices, and health related quality of life for adult's patients with sickle cell disease.

Aim of the study

Was to investigate the effect of a structured education booklet on self-efficacy, self-care practices, and health-related quality of life in adult patients with sickle cell disease.

Hypothesis:

To fulfill the aim of the study, the following hypothesis was formulated.

The post mean score of self-efficacy, self-care practices and health related quality of life among adults patients with sickle cell disease will improve after structured educational booklet.

Subject and Method

Technical design

Study Design:

This study utilized a pre-experimental one group (pretest-posttest) design.

Setting:

The study was carried out in Inpatient and Outpatient Clinic, Clinical Hematology Unit, Department of Internal Medicine, Assiut University Hospital.

Subjects:

Purposeful sample of 40 adult patients with sickle cell disease their age ranged from 20 to 65 years, either male or female. Patients were on oral hydroxyurea 20 mg/kg per day or transfusion with variable time periods before the study. Patients with a history of pain crisis at the time of the study or have a history of any psychological issues or refused to participate were excluded.

The sample size for this study was determined through a statistical power analysis, which assesses the likelihood that the analytical tests would yield significant results given the study sample. Power analysis considers the effect size and alpha level. Typically, the power index is set at 80% (0.8) or higher. In this study, a medium effect size of 0.5 and an alpha level of 0.5 were used. Using the G*Power tool for analysis, the minimum required sample size was calculated to be 40.

Tools:

Four data collection tools were employed to accomplish the objectives of the study:

Tool I. Structured interview questionnaire:

The researchers developed a single section based on relevant literature, which included the following:

Demographic and Clinical Data (13 items) included details such as age, gender, occupation, marital status, place of residence, educational level, smoking habits, disease onset, family history of SCD, consanguinity between parents and degree of their relatedness,

presence of other chronic illnesses, duration of the disease, and history of previous hospitalizations.

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

The Sickle Cell Self-Efficacy Scale, adapted from **Edwards et al. (2001),** was used to assess patients' abilities to manage their SCD and carry out daily activities effectively. The researchers used this scale to assess patients' self-efficacy as it includes nine questions about self-care in relation to SCD. It addresses issues such as pain, fatigue and mood management, the need for behavioral change, making appropriate illness care decisions, and the ability to do everyday tasks. The scale employs interval measurement, with responses ranging from 1 ("not at all sure") to 5 ("very sure"). The overall score is calculated by adding responses, with higher scores indicating greater self-efficacy.

Scoring system

The scale's scores ranged from 9 to 45. The scores were divided into three categories: low self-efficacy (9-20), moderate self-efficacy (21-32), and high self-efficacy (33-45). The Cronbach's alpha coefficient for the SCD self-efficacy measure was 0.89.

Tool III: Self-care practices assessment sheet: Self-care practice was operationalized as perceived self-care ability and self-care actions. This was measured using two different scales.

Jeanerette Self-care Assessment Tool (JSAT): (Jenerette & Murdaugh, 2008).

The J-SAT was employed to assess self-care actions, specifically one's engagement in SCD-related therapeutic activities and the use of resources to improve health and quality of life. These actions include knowledge about health, understanding and adhering to medication regimens, attending medical appointments, following a prescribed diet, staying hydrated, dressing appropriately for warmth, and managing stress. The J-SAT comprises eight items and uses an interval scale, with scores ranging from 1 ("never") to 4 ("almost always"). The responses are summed to produce a total score, which ranges from 8 to 32. A higher total score reflects a greater frequency of self-care actions. The J-SAT demonstrated an internal consistency reliability of 0.80.

The 24-item Appraisal of Self-care Agency Scale (Jenerette & Murdaugh, 2008).

The scale was used to measure perceived self-care ability, specifically the perceived capacity to engage in general therapeutic behaviors that aim to improve or maintain health and quality of life. It consists of 24 items, responses that are added together to provide an overall score, with higher scores indicating greater self-care ability. This scale operates on an interval measurement, with scores ranging from 1 ("totally disagree") to 5 ("totally agree"). The content validity index for the scale was 0.88, and it had an internal consistency reliability of 0.75.

Tool IV: The Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me):

The ASCQ-Me was meticulously created by **Treadwell et al., (2014)** to assess health-related quality of life specifically for individuals with SCD. The researchers utilized this scale, which consists of five short forms: Pain Impact (5 items), Emotional Impact (5 items), Social Functioning Impact (5 items), Stiffness Impact (5 items), and Sleep Impact (5 items). Each of these five-item sections is scored on a scale from 5 (never) to 1 (always).

Scoring system

The raw scores on the scale range from 5 to 25. To standardize the scores, they are transformed into t-scores, with a mean of 50 and a standard deviation of 10 (T Score = 50 ± (10 * Z score)). Higher t-scores reflect a better health status on the subscale. The internal consistency reliability was 0.90.

Operational design

The study was conducted in the following phases:

Tools' Validity:

The validity of Tool I:

Five experts from the Faculty of Nursing, Medical-Surgical Nursing and Faculty of Medicine, Clinical Hematology& Internal Medicine assessed the structured interview questionnaire and structured education booklet for patients with SCD. The questionnaire was updated based on the experts' feedback and suggestions.

Tools' Reliability:

Cronbach's alpha coefficient was used to evaluate the reliability of the produced tools by determining their internal consistency. The reliability of the structured interview questionnaire and the structured education tools for SCD patients was assessed, resulting in a correlation coefficient of 0.91.

Pilot Study

Once the tools were developed, they underwent testing in a pilot study involving 10% of the SCD patients, which amounted to 4 patients from the previously selected settings. This pilot study took place over one month before the main fieldwork began. The final version of the tools was refined based on the findings from the pilot study. The patients who participated in the pilot study were also included in the main study.

Field Work:

The study was carried out in four phases: assessment, planning, execution, and evaluation. Data collection before and after the study, along with the implementation of sessions, spanned one-year period from July 10, 2023, to July 10, 2024.

Phase I: Assessment phase (pre-structured education phase)

The researcher approached the SCD patients, introduced herself, and outlined the study's objectives. She then sought their written consent to participate and requested their cooperation. Each patient meeting the inclusion criteria was interviewed individually. Following this, the researcher explained the

assessment tools to the participants, which included a structured interview questionnaire on SCD patient assessment, the Sickle Cell Self-Efficacy Scale, a self-care assessment, and the Adult Sickle Cell Quality of Life Measurement Information System. She asked them to complete these tools as part of a pre-structured educational assessment.

Phase II: Planning

In this phase, data collection tools were created. The study's structured educational content was produced following a comprehensive evaluation of literature, which included books, journals, and periodicals. All materials are provided in simplified Arabic and enhanced with visual illustrations. The researcher then defined the structured education goals and grouped the materials based on importance and the number of sessions required. The researcher also designed the major instructional approaches, which included brainstorming, presentations, idea exchange talks, and demonstrations.

Phase III: Structured education implementation:

The researchers prepared the structured education by reviewing relevant literature and validating its content with expert jury members. SCD instructional materials featured a power point presentation as well as a handout in the form of an illustrated, color booklet. The researchers created this booklet to help patients, and their families understand what to expect following discharge and to reinforce information that was previously delivered orally.

Once the planning stage was complete, the researcher began conducting the structured education sessions. The study was carried out in Inpatient and Outpatient Clinic, Clinical Hematology Unit, Department of Internal Medicine Assiut University Hospital.

The researchers present in the clinical field during the morning shift three days/week. Individual interviews were used to collect data, with each patient taking 15-30 minutes to complete the previously mentioned tools (Pretest).

The educational content was divided into both theoretical and practical sessions. **The structured education booklet covered the following topics:**

Session 1: The session began by introducing the patients, building rapport, and creating a casual mood. The researchers spoke directly with the participants to clarify the session's objectives, location, duration, and timetable.

Session 2: The goal of this session was to provide patients with information about sickle cell disease, including definitions of related terms, risk factors, clinical manifestations, complications, and management strategies. Additionally, it aimed to guide patients on when to seek medical care for symptoms such as fever, chest pain, severe pain, severe headache, dizziness or stiff neck, seizures, abdominal swelling, loss of sensation or movement, prolonged painful erection in men, breathing difficulties, or sudden vision loss **(Elendu et al., 2023; Kaur et al., 2022; Matthie et al., 2019; Moeen et al., 2018 & Kato et al., 2018).**

Session 3: This session focused on self-care practices that can help prevent or reduce pain crises. Self-care practices include drinking 8-10 glasses of fluids per day, getting 7-9 hours of sleep, eating a diet rich in fruits, vegetables, whole grains, and protein, engaging in moderate exercise such as walking or biking once a week, resting when tired, following prescription instructions, and undergoing recommended medical and lab tests. It also underlined the importance of immunizations, such as the annual flu shot, as well as pneumococcal and meningococcal vaccines. Patients were advised to avoid common illnesses like the flu, avoid extreme temperatures, limit alcohol consumption, stay away from of high-altitude environments, quit smoking, wash hands before eating and after using the bathroom, thoroughly wash fruits and vegetables, avoid raw meat, eggs, and unpasteurized milk, and effectively manage stress **(Mercado, 2023; & Riegel et al., 2021).**

Phase IV: Evaluation (post-structured education phase)

Following the implementation of the structured education booklet, patients were evaluated one and three months later to measure the impact of the education on self-efficacy, self-care practices, and health-related QOL, using the previously mentioned tools.

Ethical Considerations:

Approval for the study was obtained from the Faculty of Nursing at Assiut University's ethics committee, with the code number NUR (53) dated 29/5/2023. There were no risks associated with the study for the participants. The study adhered to standard ethical principles in clinical research. Each participant was provided with written consent forms detailing the study's nature and purpose. Confidentiality and anonymity were assured, and participants were informed that their involvement was entirely voluntary. They had the right to withdraw from the study at any time without providing a reason. Patient privacy was maintained throughout the data collection process.

Administrative design:

An official letter from the dean of the Faculty of Nursing, Assiut University was sent to the hospital administrator, outlining the study's objectives and requesting their cooperation throughout the study period. Following that, both the hospital director and the head of the Clinical Hematology Unit, Department of Internal Medicine, Assiut University Hospital, gave written permission to perform the study.

Statistical design:

Results were analyzed using IBM-SPSS 20.0

(IBM-SPSS Inc., Chicago, IL, USA). The data were sorted, organized, coded, and transferred into specialized formats for computer analysis. Normality was assessed using the Anderson-Darling test, and homogeneity of variances was checked before conducting further statistical analyses. Categorical variables were described using frequencies and percentages (N, %), while continuous variables were reported as means and standard deviations (Mean, SD). The Chi-square test and Fisher's exact test were employed for comparing categorical variables, while t-tests and ANOVA were used for comparing continuous variables. Pearson correlation was used to examine associations between scores. A p-value of < 0.05 was considered statistically significant.

Results

Table (1): Demographic and clinical data of the studied patients (n=40):

Table (1a): Demographic data of the studied patients

Variables	N	(%)
Age (in years):		
20 – 35	34	85%
36 – 55	6	15%
Mean ± SD	26.95± 7.6	
Gender:		
Male	19	47.5%
Female	21	52.5%
Marital status:		
Single	38	95%
Married	2	5%
Education:		
Illiterate	3	7.5%
secondary certificate	37	92.5%
Occupation		
Literal	2	5%
Student	17	42.5%
Don't work	21	52.5%

Table (1b): Clinical data of the studied patients

Smoking		
Yes	0	0
No	40	100.0%
Comorbid disease		
Yes	5	12.5%
No	35	87.5%
Duration of disease		
5-10 yrs.	12	30%
10-15 yrs.	16	40%
15-20 yrs.	11	27.5%
20 and more	1	2.5%
Previous hospitalization for pain crises yearly		
Yes	40	100%
No	0	0.0%
If yes how many times/ year		
2	3	7.5%
3	15	37.5%
4	14	35%
5 and more	8	20%

Family history:		
Yes	33	82.5%
No	7	17.5%
Consanguinity		
Yes	33	82.5%
No	7	17.5%
Degree of relativeness		
1st degree	33	82.5%
No relation	7	17.5%
Treatment		
Blood transfusion dependent	33	82.5%
Hydroxyurea	7	17.5%

Table (2): Follow-up of self-efficacy among SCD studied patients pre, after one and 3 months of the structured education booklet (n=40):

Sickle Cell Self-Efficacy Scale	Pre		After one month		After 3 months		P. value	P1	P2	P3
	No	%	No	%	No	%				
Low	40	100.0	0	0.0	1	2.5	<0.001**	<0.001**	<0.001**	0.602
Moderate	0	0.0	39	97.5	38	95.0				
High	0	0.0	1	2.5	1	2.5				
Mean+SD	14.25± 2.78		30.65± 1.350		30.22± 3.37		<0.001**	<0.001**	<0.001**	0.473

Chi square test for qualitative data, One-way Anova T-test quantitative data (with LCD Method)
P: value: Comparison between 3 times, P1: Comparison between pre& after one month
P2: Comparison between pre& after 3 months, P3: Comparison between after one month & 3 months
**Significant level at P < 0.05, **Significant level at P < 0.01*

Table (3): Jeanerette Self-care Assessment Tool among studied patients pre, after one and 3 months of the structured education booklet (n=40):

Jeanerette Self-care Assessment Tool	Mean±SD	Range	P.value	P1	P2	P3
Pre	20.2±1.4	17-22	<0.001**	<0.001**	<0.001**	0.274
After one month	27.95±1.81	24-30				
After 3months	27.55±1.65	24-30				

One-way Anova T-test (with LCD Method), P. value: - Comparison between 3 times
P1: Comparison between pre& after one month, P2: Comparison between pre& after 3 months P3: Comparison between after one month & 3 months
**Significant level at P value < 0.05, **Significant level at P value < 0.01*

Table (4): Mean±SD of the 24-item Appraisal of Self-care Agency Scale among studied patients pre, after one and 3 months of the structured education booklet (n=40):

24-item Appraisal of Self-care Agency Scale	Mean±SD	range	P. value	P1	P2	P3
Pre	65.9±4.1	59-73	<0.001**	<0.001**	<0.001**	0.477
After one month	95.65±12.55	82-120				
After 3months	97.25±11.3	85-120				

One-way Anova T-test (with LCD Method)
P. value: - Comparison between 3 times, P1: Comparison between pre& post one month
*P2: Comparison between pre& after 3 months, P3: Comparison between after one month & 3 months, *Significant level at P value < 0.05, **Significant level at P value < 0.01*

Table (5): Adult Sickle Cell QOL Measurement Information System (ASCQ-Me) subscales among studied patients pre, after one and 3 months of the structured education booklet (n=40):

Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me) subscales		Mean±SD	Std. Error	Range	F	P.value
Emotional Impact	Pre	37.15±4.04	0.64	32.21-44.23	412.23	<0.001**
	After one month	53.89±2.88	0.45	52.82-61.41		
	After 3months	58.96±3.65	0.58	52.82-61.41		
Pain Impact	Pre	38.06±3.81	0.60	32.63-40.67	168.53	<0.001**
	After one month	54.12±3.81	0.60	48.7-56.74		
	After 3months	57.82±7.04	1.11	48.7-64.77		
Sleep Impact	Pre	37±2.24	0.35	33.81-38.53	1312.39	<0.001**
	After one month	52.55±0.75	0.12	47.96-52.67		
	After 3months	60.45±2.73	0.43	52.67-62.1		
Stiffness Impact	Pre	37.12±4.95	0.78	30.08-40.51	324.50	<0.001**
	After one month	55.16±2.97	0.47	50.94-57.2		
	After 3months	57.72±3.65	0.58	50.94-61.37		
Social Functioning Impact	Pre	37.34±4.65	0.74	30.72-40.53	323.48	<0.001**
	After one month	53.93±3.52	0.56	40.53-56.23		
	After 3months	58.73±3.56	0.56	40.53-60.16		

*One-way Anova T-test *Significant level at P value < 0.05, **Significant level at P value < 0.01*

Table (6): Correlations between Self-efficacy, Self-care practice and adult sickle cell quality of life measurement information system subscales among patients pre, after one and 3 months of the structured education booklet (n=40)

Scales	SCSES	JSAT	24-item Scale	Emotional Impact	Pain Impact	Sleep Impact	Social Impact
Before structured education booklet							
Sickle Cell Self-Efficacy Scale (SCSES)	1						
Jeanerette Self-care Assessment Tool (JSAT)	0.211	1					
The 24-item Appraisal of Self-care Agency Scale	-0.061	.473**	1				
ASCQ-Me quality of life subscales							
Emotional Impact	.416**	-.404-**	-.758-**	1			
Pain Impact	-0.151	0.100	0.049	-0.198	1		
Sleep Impact	-0.112	0.101	0.023	-0.106	.772**	1	
Stiffness Impact	0.199	0.023	0.181	0.054	.430**	.658**	1
Social Functioning Impact	0.160	0.255	0.194	-0.221	.772**	.772**	.658**
After one month							
Sickle Cell Self-Efficacy Scale (SCSES)	1						
Jeanerette Self-care Assessment Tool (JSAT)	.328*	1					
The 24-item Appraisal of Self-care Agency Scale	.533**	.319*	1				
ASCQ-Me quality of life subscales							
Emotional Impact	.439**	0.307	.468**	1			
Pain Impact	.378*	.399*	.493**	0.101	1		
Sleep Impact	.318*	0.264	0.176	0.061	0.231	1	
Stiffness Impact	.579**	0.100	.381*	0.263	.316*	0.231	1
Social Functioning Impact	.482**	.344*	0.148	0.250	.353*	0.165	.443**

Scales	SCSES	JSAT	24-item Scale	Emotional Impact	Pain Impact	Sleep Impact	Social Impact
After 3 months							
Sickle Cell Self-Efficacy Scale (SCSES)	1						
Jeanerette Self-care Assessment Tool (JSAT)	.393*	1					
The 24-item Appraisal of Self-care Agency Scale	.330*	.327*	1				
ASCQ-Me quality of life subscales							
Emotional Impact	.322*	0.076	0.129	1			
Pain Impact	0.015	0.054	0.037	0.120	1		
Sleep Impact	.435**	0.207	0.225	0.272	.378*	1	
Stiffness Impact	0.186	0.040	.395*	.443**	.435**	0.114	1
Social Functioning Impact	.779**	0.309	0.075	.391*	0.299	.509**	0.180

**Statistically Significant Correlation at P. value <0.05*
***Statistically Significant Correlation at P. value <0.01*

Table (1a): As regards the demographic data of the studied patients this table shows that, majority of them 85% were ranged in their age between 20-35 years with Mean±SD 26.95± 7.6 with slight female predominance (52.5%) who does not work, regarding marital status majority (95% were single). 92.5% have completed their secondary education.

Table (1b): All studied patients didn't smoke. Regarding the presence of concomitant conditions, the majority of patients (87.5%) had no history. Approximately 40% of them had SCD 10-15 years ago. All of the patients in the study had previously been hospitalized due to disease, with the majority (37.5%) being hospitalized three times annually. The majority of patients (82.5%) had a family history of disease, a first-degree consanguinity relationship, and required blood transfusions for treatment.

Table (2): A comparison between the scores of self-efficacy level in patients with sickle cell disease before and after the structured education booklet indicates that before the structured education booklet, the entire sample (100 %) had low self-efficacy whereas after one and three months of structured education booklet, the majority of patients (97.5% & 95%) respectively had moderate self-efficacy; the mean score of post-structured education self-efficacy increased compared to those before the structured education booklet, and this increase was statistically significant (P < 0.001**).

Table (3): Statistical analysis shows that the mean score of post-structured education patient's self-care action based on Jeanerette Self-care Assessment Tool was increased compared to those before the structured education booklet and this increase was statistically significant (P < 0.001**).

Table (4): Illustrates that noticeably the mean score of 24-item Appraisal of Self-care Agency Scale was increased post-structured education booklet compared to this before the structured education booklet and this increase was statistically significant (P < 0.001**).

Table (5): Shows highly statistically significant difference between adult sickle cell quality of life measurement information system subscales pre-structured education booklet and post follow up (P < 0.001**).

Table (6): Shows a statistically significant positive correlation between sickle cell self-efficacy, self-care practice and quality of life.

Discussion

Sickle cell disease is a genetic hemoglobin disorder that affects millions of people worldwide, with the majority living in developing countries. In these regions, public health initiatives and medical care often fail to reduce the disease's morbidity and mortality. Research has also revealed a link between SCD and increased anxiety and discomfort and decreased HR- QOL **(Omoregie, 2024).**

Self-care is the ability to engage in a variety of health-related activities to improve QOL and overall health, as well as the actual implementation of these actions **(Agina-Obu, 2023).** Many patients frequently lack self-efficacy, or the ability to manage SCD, as evidenced by the physical, psychological, and social challenges they face as a result of difficulties controlling their disease and preventing complications **(Amertil et al., 2021).**

Sickle cell disease has a significant impact on a patient's QOL, affecting their physiological, psychological, and social needs **(Kilonzi et al., 2022).** Given the chronic nature of SCD and the difficulties of self-management, it is crucial to assess each patient's individual needs, such as Self-care activities,

self-efficacy, and QOL to help mitigate negative impacts and improve overall well-being. Therefore, we aim to explore how structured education booklet affects efficacy, self-care practices, and QOL in SCD patients.

The results of this study highlight the efficacy of the structured education booklet in improving self-efficacy, self-care practices and health related quality of life in patients with SCD. The significant improvements observed in various outcome measures underscore the importance of integrating structured education into routine care for patients with SCD.

The study's demographic data revealed that most SCD patients were aged between twenty and thirty-five years, with a mean age of 26.95 ± 7.6 years. This coincides with an Egyptian study, "Impact of Nursing Instructions Protocol on Health Promotion Lifestyle for Patients with Sickle Cell Anemia at The New Valley" by **Khalaf et al., (2020),** which found that over half of the patients were between eighteen and thirty-eight years old suggesting that SCD is increasingly affecting adults rather than just children.

Similarly, **Ahmadi et al., (2023)** reported a mean age of 26.34 ± 8.19 years for their SCD patients, supporting our results. Also, a study by **Azar et al., (2022),** showed that the mean age was 27.56 ± 9.14 years, which is consistent with the current study's findings. Similarly, **Alkindi et al., (2024)** identified a median age of 27 years, with a range from 21 to 35 years, among their participants. Moreover, **Nwabuko et al., (2022)** reported that the mean age was 27.8 ± 5.5 years for adults SCD patients,

The current study found that slightly over half of the patients were female, and most were single. This could be linked to the impact of the disease on physical and psychological health, including frequent pain crises.

The results of this study were consistent with the previous studies results by

Efobi et al., (2022), who studied 154 SCD patients, they reported a slightly higher number of females compared to males, with a male-to-female ratio of 1:1.1, they observed that the majority of patients were single. Also, **Kazak & Ozkaraman, (2021)** stated that more than two-thirds were single, and slightly more than half were female. Also, studies by **Ahmadi et al., (2023)** and **Nagshabandi & Abdulmutalib, (2019)** demonstrated that most SCD patients were single, with females slightly more than half of the patients.

Regarding the educational level, the current study revealed that most SCD patients had secondary education, and nearly more than half were unemployed. This was consistent with **Mohammed et al., (2021)**, who stated that more than half of their participants were unemployed, with more than a third changing jobs due to the disease, and that the majority had intermediate education. Moreover, **Waris et al., (2022)** reported a higher proportion of female participants, many of whom had secondary education and approximately half of whom were unemployed. Females outnumbered males and approximately, half of them were unemployed these findings reported by **Al Sayigh et al., (2023)** which were in line with current study finding.

The current study stated that neither of the patients smoked. The majority had no other health concerns, although a higher percentage had a family history of the disease and were related through first-degree consanguinity. In agreement with the current study, **Al Raqaishi et al., (2022)** showed that the majority of SCD patients did not smoke, and more than half had a family history of the disease.

Al Saad et al., (2022) reported that consanguineous marriages, especially between first cousins, were prevalent in Saudi Arabia, which contributed to the high incidence of genetic disorders such as SCD. **Kamal et al., (2021)** stated that the majority of patients had consanguineous parents, and more than one family member with SCD.

The current study found that two-fifths of the patients had SCD for 10–15 years. All participants had a history of hospitalization related to the disease; with more than one-third had been hospitalized three times per year. In agreement with the current study **Amertil et al., (2021),** reported an average of three emergency hospital visits per year. **Matthie et al., (2015),** demonstrated an average of three annual hospital visits for SCD pain crises. In contrast, **Al Nagshabandi & Abdulmutalib, (2019)** revealed that nearly half of their patients had SCD for over 20 years, with a quarter having it for 15-20 years, and the majority had been hospitalized 3 to 6 times per year.

Regarding treatment methods, the current study highlighted that the majority of patients received blood transfusions, with others being treated with hydroxyurea. This finding aligns with the literature, which underscores that RBC transfusion is a key component in managing patients with SCD **Sharma et al., (2024).**

In agreement with the current study **Ishwori et al., (2022)** postulated that SCD therapy options are essentially confined to transfusions and hydroxyurea. **Kamal et al., (2021)** reported that the majority of patients received blood transfusions at least three times a year. In contrast, **Esham et al. (2020)** stated that 64% of SCD patients were on hydroxyurea as part of their treatment plan.

The current study revealed that, prior to using the structured education booklet; all SCD patients had low self-efficacy, feeling either unsure or sure about their ability to manage daily life. However, one and

three months after using the booklet, the majority of patients exhibited a moderate level of self-efficacy. The mean self-efficacy score significantly increased post-intervention (P < 0.001**), indicating a statistically significant improvement. According to the researchers, this improvement is most likely due to the effective, clear, and understandable instruction provided to patients, which helped them better manage their disease. This finding validates the initial research hypothesis.

The findings of the current study align with those of **Ahmadi et al., (2014)** who demonstrated that just over half of the participants exhibited moderate self-efficacy prior to the intervention. However, following the intervention, a significant majority of participants exhibited high self-efficacy. They concluded that the self-management program improved both overall scores and self-efficacy sub-groups among SCD patients. Also, **Mohammed et al. (2021)** reported that most SCD patients had low levels of self-efficacy before the program. However, after the program was implemented, around three-quarters of the patients achieved satisfactory levels of self-efficacy, and over two-thirds maintained these satisfactory levels three months later.

The findings also agreed with **Al Nagshabandi & Abdulmutalib, (2019)** whose study entitled 'Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease' and reported that there was statistically significant difference between self-efficacy items pre, post & follow-up program implementation.

The current study demonstrated a significant increase in patients' self-care actions, as measured by the Jeanerette Self-care Assessment Tool, following structured education booklet compared to before education (P < 0.001**). Furthermore, the mean score of 24-item Appraisal of Self-care Agency Scale enhanced post- education compared to pre- education (P < 0.001**). This improvement could be attributed to the clear and straightforward information provided to SCD patients, which enhanced their understanding of their illness and subsequently improved their ability to manage it.

This finding aligns with the results of **Mohammed et al., (2021),** who reported that approximately three-quarters of SCD patients adhered to self-care practices, and about two-thirds continued to adhere to these practices three months later. A significant difference was observed in self-care practices across pre, post, and follow-up education. Also, **Hassan & Qalawa., (2021)** stated a significant difference regarding patient's self- care management before and after three months of the program (P< 0.01).

The current study highlighted that there was highly statistically significant difference between adult sickle cell quality of life measurement information system subscales pre-structured education booklet and post follow up (P < 0.001).

Researchers view the improvement in self-management of the disease that were resulted from teaching played a pivotal role in enabling patients to change their behaviors, improve their lifestyle and quality of life, and promote their health. These results go in one way with **Azar et al., (2022)** who reported that the higher the patients' knowledge level, the higher their ability in disease management, self-care, and quality of life would be.

Furthermore, **O'Brien et al. (2023)** stated the significance of self-care management skills in enhancing HR-QOL among SCD patients. Similarly, **Mahdy et al. (2021)** reported a significant difference in total QOL scores for sickle cell anemia patients, comparing post- and follow-up scores to those obtained prior to the implementation of self-learning guidelines.

In this study, a positive association was shown between self-efficacy and self-care practices, implying that higher self-efficacy in managing SCD leads to better self-care. Patients who believe that they can perform daily SCD-related tasks are more likely to practice better self-management.

According to the researchers, patients who are confident in their ability to perform daily SCD-related tasks tend to have a higher perception of their self-care capabilities, leading them to engage in more self-care activities. Those who believe in their ability to effectively carry out specific tasks and manage their illness daily are likely to have better self-management.

This finding aligns with previous research, such as the study by **Amertil (2021)** titled "Exploring Self-Management in Adult Sickle Cell Disease Patients at a Teaching Hospital in Ghana," which reported a positive and significant association between self-efficacy and self-management.

This finding supports earlier research by **Matthie et al. (2015)**, who indicated that high self-efficacy in managing sickle cell disease (SCD) is associated with improved self-care, enabling patients to perform daily activities more effectively and engage in more self-care tasks. Their study found that higher self-efficacy was linked to greater perceived self-care ability (p =.001) and more self-care actions (p =.002). Similarly, **Treadwell et al., (2016) & de Sousa et al., (2022)** reported a positive correlation between self-efficacy and self-care behavior, highlighting that individuals with higher self-efficacy are more likely to engage in care activities to manage their disease or chronic condition.

Additionally, **Al Nagshabandi & Abdulmutalib (2019)** documented a significant correlation between self-efficacy and self-management.

The current study also found a positive correlation between self-efficacy, self-care practices, and various subdomains of HR-QOL. This aligns with **Amertil et al. (2021)**, who reported improved self-care in SCD patients enhances health, QOL, and reduces healthcare costs. **Goldstein et al. (2020)** stated that self-efficacy was a key factor in improving QOL for SCD patients, with higher self-efficacy was associated with better HR-QoL. **Eberhardt et al. (2024)** demonstrated the critical role of self-efficacy in managing SCD. **O'Brien (2021)** reported that self-efficacy positively affects health outcomes for SCD patients, with HR-QOL was influenced by both self-efficacy and self-care actions. **Adegbola (2011)** postulated that patients with higher self-efficacy had greater levels of spirituality and QOL. **Molter & Abrahamson (2015)** reviewed academic literature on the relationship between self-efficacy and SCD health outcomes, revealed that most studies highlighted a positive association between self-efficacy and health quality in the SCD patients.

Conclusion:

The findings of the current study indicate a significant enhancement in self-efficacy, self - care practices, and health-related quality of life (HRQoL) following the structured education booklet, with improvements being statistically significant ($P < 0.001$) compared to measurements taken before the implementation.

Recommendations:

1. Integrate structured patient education designed to enhance self-care and boosting SCD self-efficacy into the overall management of sickle cell disease and healthcare providers should take the time to thoroughly explain it to patients and their families.
2. Explore the evolution of HRQoL across different stages of the disease and identify key factors influencing it in a further research.
3. Conduct further research with larger sample sizes and longer follow-up and across various settings.

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