

## **Effect of an Educational Program on Self-Care Management for Patients with Sickle Cell Disease**

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### **Abstract**

**Background:** Sickle cell disease (SCD) is a chronic genetic disease, which causes many complications through the patient's life; self-care is an important aspect of managing a chronic disease. In SCD, self-care contributes to patients' pain management and prevention of pain crisis. **The aim of this study** was to evaluate the effect of an educational program on self-care management for patients with sickle cell disease, **Design:** Quasi-experimental research design. **Setting:** this study was conducted in hematology departments at Benha University Hospital & Nasser Institute. **Study subjects:** A convenient sample of all available patients (n=50) were included in this study. **Data collection tools:** two interview questionnaires: 1) Patients assessment questionnaire includes (socio demographic data, medical history & patients' knowledge about SCD. 2) Routine Self- Care Questionnaire includes (A-Jenerette Self-care Assessment questionnaire & B-Sickle Cell Self-Efficacy Scale questionnaire). **Results of the study revealed that:** The majority of patients had unsatisfactory knowledge scores pre-program implementation, when more than two thirds of them had satisfactory knowledge score immediately post program implementation and nearly two thirds of them had satisfactory knowledge three months follow-up the program, concerning self-care, the majority of studied patients had unsatisfactory total self-care scores at pre-program implementation, while nearly three quarters of them had satisfactory total self-care scores one month post program implementation and nearly two thirds of them had satisfactory total self-care score three months follow-up program implementation and regarding self-efficacy, the majority of studied patients had unsatisfactory self-efficacy scores at pre-program implementation, while nearly three quarters of them had satisfactory scores one month post program implementation and more than two thirds of them had satisfactory self-efficacy follow-up program implementation. **Conclusion:** The study concluded that there were statistically significant improvement in patients' knowledge, self-care & self-efficacy post & follow-up educational program implementation. **Recommendations:** This study recommended that performing continuous monitoring, evaluating self-care practice for sickle cell disease patients for early detecting and solving problem. Researchers should implementing further educational programs for improving patients' self-care and self-efficacy skills.

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**Keywords:** Educational program, patients, Self-care, Sickle cell disease

## **Introduction**

Sickle cell disease (SCD) is a serious, inherited condition affecting blood and various organs in the body. SCD affects (RBCs), causing sickling, which produce pain and other symptoms. In between episodes of sickling, people with SCD are normally well. Certain conditions can trigger sickling as cold, infection, lack of fluid in the body (dehydration) or low oxygen. Good treatment can decrease incidence of complications, so that early diagnosis and treatment are advised for SCD patients (*Badawy et al., 2017*).

Patients with SCD must adhere to a complex set of behaviors that promote self-management and prevent complications associated with the disease. Self-care management refers to a process in which the patients participate in health and well-being, it involves skills, attitude and abilities required to cope with chronic disease. Self-management programs in chronic diseases are a combination of strategies that enhance self-efficacy and promote self-care behaviors. (*Labor et al., 2017*).

Self-efficacy is also important for successful self-management and behavior changes, self-efficacy is the belief of a person's ability to perform tasks that are associated with daily management of the disease manifestations, and it depends on the individual beliefs that used to control emotions, behaviors and social environment. Self-efficacy is the mechanism that affects the positive results of self-management programs. As a result, promoting self-efficacy is important for achieving self-management skills (*Poku et al., 2018*).

Nurses play a very important role in caring for patients with SCD, nursing management focus on assessment of factors causing previous crisis and measures that the

patient uses to prevent and manage the crisis, pain levels should always be monitored by using a pain intensity scale, the nurse should also assess characteristics of pain such as the quality, frequency, and factors that aggravate or alleviate the pain, nurse should also assess patients for early detection and prevention of any complications, after complete nursing assessment, nurses should take actions to alleviate symptoms, control pain, prevent pain crisis and avoid further complications (*Thein et al., (2016)*).

## **Significant of the Study**

Large number of adults with SCD died during acute sickle cell related complications such as pain, acute chest syndrome, pulmonary hypertension, sudden death of unknown etiology, renal failure, and infection, the mortality rate in developed country is estimated to be as low as 0.5-1.0 per 100,000 patients. This is in contrast to higher rates in developing countries which recently reported a mortality rate of 15.5 per 1,000 patient (or 1,550 per 100,000 patients) (*Smith et al., 2017*).

## **Aim of the study**

The aim of the current study was to evaluate the effect of an educational program on self-care management for patients with sickle cell disease.

## **Research Hypothesis**

The study hypothesized that:

- There will be positive improvement in sickle cell disease patients' knowledge & self-care and self-efficacy practice post implementing the educational program.
- The number, severity of attacks and number of hospitalization for SCD patients will be diminished.
- There will be positive relation between patients' demographic characteristics and (knowledge, self-care & self-efficacy)

post and follow-up program implementation.

- There will be positive correlation between patients' knowledge & (self-care & self-efficacy) post and follow-up program implementation.

### **Subjects and Methods**

#### **Study design: -**

##### **1-Setting:-**

This study was conducted in hematology departments at (Benha University & Nasser Institute hospitals).

- Hematology department at Benha university hospital located at fifth floor, it is a part of medical department consisted of three rooms, each room contain five beds.
  - Hematology department at Nasser institute hospital located at eighth floor consisted of four rooms, each room contain five beds.

##### **2-Subjects:-**

All available patients with sickle cell disease (50 patients) in the previously mentioned settings during the time of data collection (six months), aged from (18-55) years old and agreed to participate in this study.

##### **3-Tools of data collection:**

The following tools were constructed, tested and piloted by the researcher to collect data; it was used as a follow:

- **Patients' knowledge regarding sickle cell disease questionnaire**, it was used pre, immediately post and three months following the educational program.
- **Pain crisis assessment questionnaire**, it was used pre, immediately post and three months following the educational program.
- **Jeanerette Self-care Assessment Tool (JSAT)** was used pre, one month post and three months following the educational program.

- **Sickle Cell Self-Efficacy Scale (SCSES)** was used pre, one month post and three months following the educational program.

#### **Tool one: patient's Assessment Questionnaire:**

It was used to assess patients' socio-demographic characteristics, disease history, patients' knowledge regarding sickle cell disease and the effect of health educational program on pain crisis; it was used in simple Arabic language and consisted of four parts:

**1-Socio-demographic variables** including questions about (age, gender, marital status, level of education, employment status, number of family members and treatment costs).

**2- Medical history** including questions about (family history of SCD, history of chronic disease, inherited disease in the family, consanguinity relationship between the father and the mother and degree of this relativeness ...etc).

**3- Patient's knowledge regarding the disease:** It was adapted from (*Jenerette & Murdaugh, 2015*) & (*Edwards et al., 2001*) to assess patients' knowledge regarding SCD, it was used in simple Arabic language containing (**18 questions**) distributed into two parts:

1-knowledge about (blood, definition causes & manifestations of SCD) (8 questions)

2-Knowledge about (diagnosis, treatment, prevention & complication of SCD) (10 questions)

**-Scoring system:** The scores were distributed as (1) for correct answer & (0) for incorrect answer, 70% and above considered satisfactory while below 70% graded as unsatisfactory.

#### **4-Pain crisis assessment questionnaire:**

It was developed by the researcher after reviewing of related literatures to evaluate the number, severity of pain crisis and number of hospitalization of studied patients (**number of pain crisis, pain intensity according to pain rating scale, number of hospitalization due to pain crisis, number of hospitalization due to any SCD complication other than pain & number of pain crisis that require blood transfusion during last three months**) (5 questions).

#### **Second tool: Routine Self- Care Questionnaire:**

It was adapted from (*Edwards et al, 2001*), (*Sherbourne & Stewart, 2014*) & (*Jenerette & Murdaugh, 2015*) and modified by the researcher based on reviewing of the current literature, it was used to assess patient's self-care measures, it was written in simple English language and consists of two parts,

**1-Jeanerette Self-care Assessment Tool (JSAT):-** used to evaluate patients' participation in therapeutic activities (31 questions) distributed into three domains:-

- 1- Patients' adherence to **medication** (9 questions).
- 2- Patients' adherence to **diet** (9 questions).
- 3- Patients' adherence to **follow-up** (13 questions).

**-Scoring system:** The score was distributed as (2) for always done, (1) for sometimes done & (0) for never done, total score is 62 degrees.

- 70% and above considered as satisfactory ( $\geq 43$  degrees).
- Below 70% considered as unsatisfactory ( $< 43$  degrees).

**2'Sickle Cell Self-Efficacy Scale (SCSES):** to evaluate patients' perceived ability to participate in activities of daily living which distributed into 36 items distributed into 6 domains as following:-

- 1- Patients' self-efficacy about **hygiene** (7 questions).
- 2- Patients' self-efficacy about **ADLs** (5 questions).
- 3- Patients' self-efficacy about **sleep** (6 questions).
- 4- Patients' self-efficacy about **pain** (9 questions).
- 5- Patients' self-efficacy about **stress** (4 questions).
- 6- Patients' self-efficacy about **exercise** (5 questions).

**-Scoring system:** The score was distributed as (2) for always done, (1) for sometimes done & (0) for never done, total score is 72 degrees.

- 70% and above considered as satisfactory ( $\geq 50$  degrees).
- Below 70% considered as unsatisfactory ( $< 50$  degrees).

#### ***Educational program***

It was designed by the researcher according to the actual and potential needs assessment of the study patients after reviewing the related literature consisted of six sessions divided into two parts:

- Theoretical part includes four sessions.
  - Practical part includes two sessions.

#### **Preparatory Phase:**

- \*It included reviewing of related literature, and theoretical knowledge of various aspects of the study using books, articles, internet periodicals and magazines to develop tools for data collection and the educational program.
- \* Permission for data collection and implementation of educational program obtained from dean of Benha Faculty of Nursing and hospitals administrative personnel, Interviewing with available patients to explain the aim of the study, the effect of this study on their self- care practice and took their approval to

participate in the study prior to data collection

**Validity and reliability:**

- ❖ The revision of the tools was done by a panel of five medical surgical nursing experts to test the relevance and clarity of contents and minor modifications were done in the form of rephrasing and organization of some questions.
- ❖ Testing reliability of proposed tools was done by Cronbach's alpha test. It was used to test whether the questionnaire had internal consistency. The knowledge, self-care scale & self-efficacy scale had a good internal consistency and tests reached (0.636, 0.749, 0.785) respectively which indicates acceptable reliability.

**Pilot study:**

It was done on 10 % of the studied patients (5 patients) to assess the applicability of the study tools and estimate the proper time required for answering the required data. All participants in the pilot study were excluded from the main study.

**Field work:-**

**A-Assessment phase:-**

Assessment of patients' knowledge, self-care and self-efficacy practice was done .This assessment shed light on current knowledge and self-care practice level to detect the defect and help in developing the educational program according to results.

**B-Planning phase:**

The researcher made exploratory visit to study setting to put plan for carrying out the study. Educational program developed by the researcher according to patients' needs, moreover teaching materials such as (Discussion, demonstration and booklet) prepared to help in covering theoretical and practical information.

**C-Implementation phase:**

1. The study sample was 50 patients divided into 7 groups as a follow:
  - At Benha university hospital (21patients) divided into three groups each group includes 7 patients.
  - At Nasser institute hospital (29 patients) divided into four groups, three groups contain 7 patients and one group contains 8 patients.
2. The study was done during morning & Afternoon shifts three times weekly during the time of the study (9 months) started from beginning of June 2019 till February 2020.
  - Three months for pre-program data collection.
  - Three months for program implementation & data collection post implementing the program
  - Three months follow-up program implementation.

\*The period of data collection and program implementation was increased to nine months because of the effect of Covid 19 which influence patients' monitoring, education and evaluation

3. Interview with available patients to explain the aim of the study, the effect of this study on their self- care & self-efficacy practice and took their approval to participate in the study prior to data collection.
4. The researcher collected data about patient self-care and self-efficacy practice by using questionnaires before developing the educational program.
5. The researcher developed an educational program and booklet regarding self-care for patients with sickle cell disease according to their needs in simple Arabic language.
6. The educational program & booklet were reviewed by 5 experts in Medical Surgical

Nursing department at Benha University (two assistant professors and three lecturers).

7. The educational program & booklet were given by the researcher to patients and were asked to apply its contents.

8. Post-test was done after the educational program.

9. Follow up of the guidelines intervention was carried out after three months by using the same tools.

### **Educational program**

It was conducted by the researcher according to the actual needs' assessment of the study patients after reviewing the related literature consisted of two parts:

**1-Theoretical part:** - Knowledge booklet given to each patient group included four sessions.

**2-Practical part:** - Demonstration about self-care & self-efficacy was done for each patient group, it included two sessions.

### **D-Evaluation phase:**

This phase used to evaluate the effect of educational program on self-care measures for patients with sickle cell disease by comparing results pre, post and three months after implementation of educational program. It was done by using the same questionnaires to evaluate patients' knowledge, self-care and self-efficacy management measures.

### **-Statistical Analysis:**

Data entry and analysis were organized, categorized, analyzed using a personal computer using SPSS (statistical program for social science) version 21 by using Chi-square test & Pearson correlation coefficient (r) was used for correlation analysis and degree of significance. Data were presented using descriptive statistics in the form of frequencies and percentages; description of qualitative variables as mean, SD and range, statistical significant was considered highly

significant at  $p \leq 0.001^{**}$ , significant at  $P \leq 0.05^*$ , insignificant at  $P > 0.05$ .

### **Results:-**

**Table (1)** shows that nearly one half of studied patients (48.0%) aged between 40 to 50 years old also nearly three quarters of them (74.0%) were female, in addition more than one third of them (38.0%) were single, concerning educational level, nearly one half (48.0%) of studied patient had intermediate education, and more than one half of them (54.0%) weren't working also more than one third of studied patients (34.8%) changed their work nature due to disease, related to treatment costs, about two thirds of them (64.0%) treated at the expense of the state.

**Figure (1)** shows that the majority of studied patients (86.0%) have unsatisfactory knowledge pre-program implementation, while more than two thirds of them (68.0%) had satisfactory knowledge post program implementation and nearly two thirds of them (62.0%) had satisfactory knowledge follow-up the program.

**Figure (2)** shows that the majority of studied patients (88.0%) had unsatisfactory total self-care pre-program implementation, while about three quarters of them (72.0%) had satisfactory total self-care post program implementation and nearly two thirds of them (60.0%) had satisfactory total self-care follow-up program implementation.

**Figure (3)** shows that more than three quarters of studied patients (80.0%) had unsatisfactory total self-efficacy pre-program implementation, while about three quarters of them (74.0%) had satisfactory total self-efficacy post program implementation and more than two thirds of them (68.0%) had satisfactory total self-efficacy follow-up program implementation.

**Table (2)** reveals that, pre-program implementation, there was no statistically significant relation between total knowledge and socio-demographic characteristics in all items except for items related to age, level of education & working nature there was statistically significant relation ( $p < 0.05^*$ ).

Post & follow-up program implementation, there was no statistically significant relation between total knowledge and socio-demographic characteristics in all items except for item related to educational level there was highly statistically significant relation ( $p < 0.001^{**}$ ) and items related to age & working nature, there was statistically significant difference ( $p < 0.05^*$ ).

**Table (3)** reveals that: pre-program implementation, there was no statistically significant relation between total self-care and socio-demographic characteristics in all items except for items related to age & educational level of studied patients there was statistically significant relation ( $p < 0.05^*$ ).

Post & follow-up program implementation, there was no statistically significant relation between total self-care and all items of socio-demographic characteristics except items related to age, educational level & work nature there was statistically significant relation ( $p > 0.05^*$ ).

**Table (4)** shows that pre-program implementation, there was no statistically significant relation between total self-efficacy and socio-demographic characteristics in all items except for item related to level of education there was highly statistically significant relation ( $p < 0.001^{**}$ ).

Post program implementation, there was no statistically significant relation between total self-efficacy and socio-

demographic characteristics in all items except age, there was statistically significant relation ( $p < 0.05^*$ ) and educational level there was highly statistically significant relation ( $p < 0.001^{**}$ ).

Follow-up program implementation, there was no statistically significant relation between total self-efficacy and socio-demographic characteristics in all items except for items related to age & educational level, there was statistically significant relation ( $p < 0.05^*$ ).

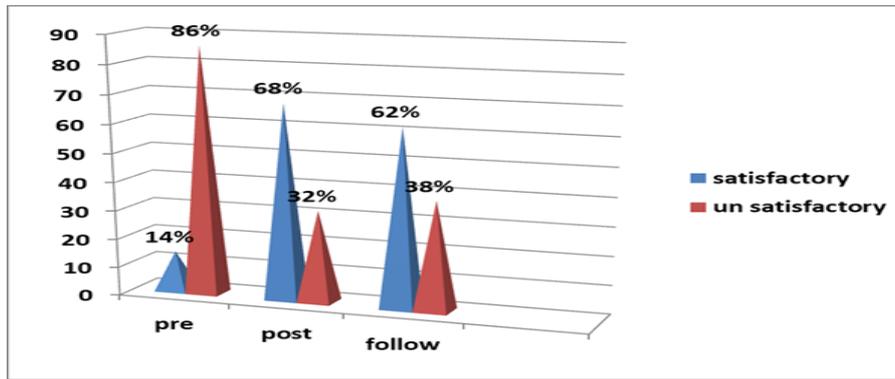
**Table (5)** shows that there was statistically significant positive correlation between total pre knowledge score regarding sickle cell disease and their total self-care at pre, post & follow-up program implementation, the current study also reveals that there was highly statistically significant positive correlation between total knowledge (post and follow-up) and total self-care at (pre, post & follow-up) program implementation.

**Table (6)** reveals that there was statistically significant positive correlation between total pre and follow-up knowledge score regarding sickle cell disease and their self-efficacy at pre, post & follow-up program implementation.

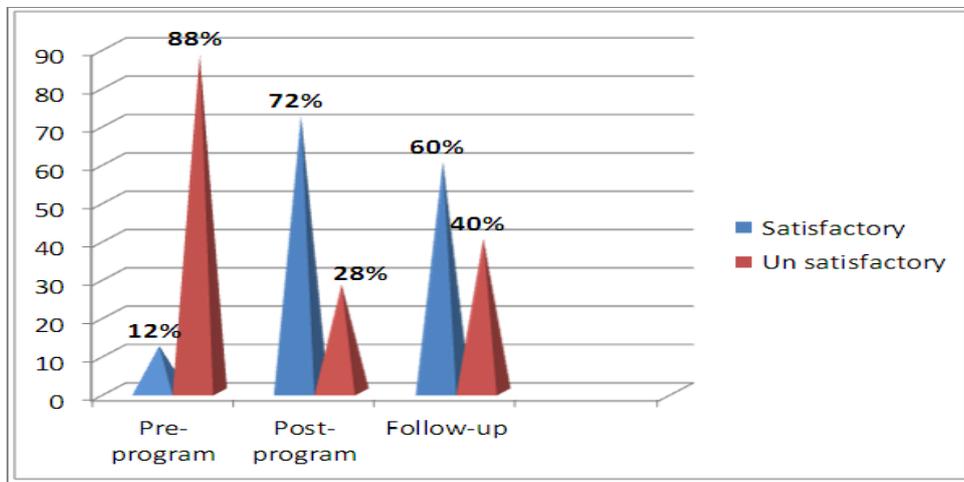
Regarding the correlation between total knowledge post and total self-efficacy pre, post & follow-up program, the current study reveals that there was statistically significant positive correlation between total post knowledge score regarding sickle cell disease and their self-efficacy at pre-program implementation however, there was highly statistically significant positive correlation, post & follow-up program implementation.

**Table (1): Frequency and percentage distribution of studied patients' according to their demographic characteristics (n=50).**

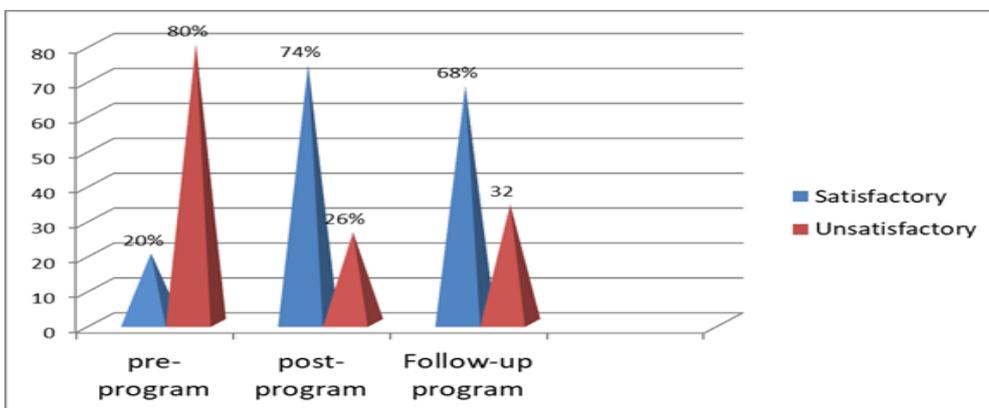
<b>Demographic characteristics</b>	<b>No</b>	<b>%</b>
<b>*Age</b>		
20<30	3	6.0
30<40	16	32.0
40<50	24	48.0
>50	7	14.0
<b>*Gender</b>		
Male	13	26.0
Female	37	74.0
<b>*Marital Status</b>		
Single	19	38.0
Married	31	62.0
Divorced	0	00.0
Widow	0	00.0
<b>*Educational level</b>		
Illiterate	5	10.0
Read &write	8	16.0
Intermediate learning	24	48.0
High education	13	26.0
<b>*Work nature</b>		
Working	23	46.0
Not working	27	54.0
<b>*Change in work nature due to disease(n=23)</b>		
Yes	8	34.8
No	15	64.2
<b>*Treatment costs</b>		
Treatment at the expense of the state	23	64.0
Health assurance	21	42.0
Private Treatment	6	12.0



**Figure (1): Distribution of SCD patients' according to their total knowledge pre, post & follow-up program implementation (n=50).**



**Figure (2): Distribution of SCD patients according to their total self-care adherence pre, post & follow-up program implementation (n=50)**



**Figure (3): Distribution of SCD according to their total self-efficacy pre, post & follow-up program implementation (n=50).**

**Table (2):- Relation between total knowledge & demographic characteristics of SCD patients' pre, post & follow-up program implementation (n=50).**

Demographic characteristics	Pre-program				Post-program				Follow-up			
	Satisfactory		Unsatisfactory		satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory	
	No	%	No	%	No	%	No	%	No	%	No	%
<b>Age</b>												
20<30	0	0.0	3	6.0	0	0.0	3	6.0	0	0.0	3	6.0
30<40	0	0.0	5	10.0	12	24.0	3	6.0	7	14.0	8	16.0
40<50	8	16.0	17	34.0	20	40.0	5	10.0	19	38.0	6	12.0
>50	2	4.0	5	10.0	6	12.0	1	2.0	6	12.0	1	2.0
<b>Chi-square &amp;P-value</b>	7.071 <0.05*				10.213 <0.05*				10.284 <0.05*			
<b>Gender</b>												
Male	3	6.0	11	22.0	12	24.0	2	4.0	11	22.0	3	6.0
Female	7	14.0	29	58.0	26	52.0	10	20.0	21	42.0	15	35.0
<b>Chi-square &amp;P-value</b>	.025 >0.05				.1.066 >0.05				1.792 >0.05			
<b>Marital Status</b>												
Married	7	14.0	24	48.0	24	48.0	7	14.0	21	42.0	10	20.0
Single	3	6.0	16	32.0	14	28.0	5	10.0	11	22.0	8	16.0
<b>Chi-square &amp;P-value</b>	.340 >0.05*				.090 >0.05				.496 >0.05			
<b>Level of education</b>												
Illiterate	0	0.0	5	10.0	1	2.0	4	8.0	1	2.0	4	8.0
Read &Write	0	0.0	8	16.0	3	6.0	5	10.0	3	6.0	5	10.0
Intermediate	4	8.0	20	40.0	21	42.0	3	6.0	15	30.0	9	18.0
Highly educated	6	12.0	7	14.0	13	26.0	0	0.0	13	26.0	0	0.0
<b>Chi-square &amp;P-value</b>	8.974 <0.05*				20.943 <0.001*				13.976 <0.001*			
<b>Working nature</b>												
Working	8	16.0	15	30.0	21	42.0	2	4.0	16	32.0	7	14.0
Not working	2	4.0	25	50.0	17	34.0	10	20.0	16	32.0	11	22.0
<b>Chi-square &amp;P-value</b>	5.817 <0.05*				5.469 <0.05*				4.354 <0.05*			
<b>Cost of treatment</b>												
On the expense of the state	4	8.0	19	38.0	15	30.0	8	16.0	13	26.0	10	20.0
Health insurance	5	10.0	16	32.0	18	36.0	3	6.0	15	30.0	6	12.0
Free treatment	1	2.0	5	10.0	5	10.0	1	2.0	4	8.0	2	4.0
<b>Chi-square &amp;P-value</b>	.330 >0.05				2.729 >0.05				1.080 >0.05			

Non sig. >0.05 Sig. <0.05\* High sig. <0.001\*\* X1= relation between pre& post program X2= relation between pre& follow-up program

**Table (3): Relation between total self-care & socio-demographic characteristics of SCD patients' pre, post & follow-up program implementation**

Demographic characteristics	Pre-program				Post-program				Follow-up			
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory	
	No	%	No	%	No	%	No	%	No	%	No	%
<b>Age</b>												
20<30	0	0.0	3	6.0	0	0.0	3	6.0	0	0.0	3	6.0
30<40	0	0.0	15	30.0	13	26.0	2	4.0	11	22.0	4	8.0
40<50	3	6.0	21	42.0	17	34.0	7	14.0	15	30.0	9	18.0
>50	3	6.0	4	8.0	6	12.0	1	2.0	4	8.0	3	6.0
<b>Chi-square &amp;P-value</b>	8.618		<0.05*		10.272		<0.05*		5.729		<0.05*	
<b>Gender</b>												
Male	1	2.0	13	26.0	12	24.0	2	4.0	8	16.0	6	12.0
Female	5	10.0	31	62.0	24	48.0	12	24.0	22	44.0	14	28.0
<b>Chi-square &amp;P-value</b>	.434		>.05		1.814		>.05		.066		>.05	
<b>Marital Status</b>												
Married	4	8.0	27	54.0	21	42.0	10	20.0	16	32.0	15	30.0
Single	2	4.0	17	34.0	15	30.0	4	8.0	14	28.0	5	10.0
<b>Chi-square &amp;P-value</b>	.663		>.05		.734		>.05		2.391		>.05	
<b>Level of education</b>												
Illiterate	1	2.0	4	8.0	1	2.0	4	8.0	1	2.0	4	8.0
Read & Write	1	2.0	7	14.0	4	8.0	4	8.0	3	6.0	5	10.0
Intermediate	0	0.0	24	48.0	21	42.0	3	6.0	19	38.0	5	10.0
Highly educated	4	8.0	9	18.0	10	20.0	3	6.0	7	14.0	6	12.0

<b>Chi-square &amp;P-value</b>	7.904 <0.05*				11.643 <0.05*				8.900 <0.05*			
<b>Working nature</b>												
working	2	4.0	21	42.0	21	42.0	2	4.0	16	32.0	7	14.0
Not working	4	8.0	23	46.0	15	30.0	12	24.0	14	28.0	3	6.0
<b>Chi-square &amp;P-value</b>	.440 >0.05				7.873 <0.05*				6.543 <0.05*			
<b>Treatment cost</b>												
Expense of the state	2	4.0	21	42.0	15	30.0	8	16.0	13	26.0	10	20.0
Health insurance	2	4.0	19	38.0	16	32.0	5	10.0	13	26.0	8	16.0
Private treatment	2	4.0	4	8.0	5	10.0	1	2.0	4	8.0	2	4.0
<b>Chi-square &amp;P-value</b>	2.946 >0.05				1.090 >0.05				.259 >0.05			

Non sig. >0.05 Sig. <0.05\* High sig. <0.001\*\* X1= relation between pre& post program

(Statistical significant difference)

X2= relation between pre& follow-up program

**Table (4): Relation between total self-efficacy & socio-demographic characteristics of SCD patients' pre, post & follow-up program implementation.**

Total Self-efficacy	Pre-program				Post-program				Follow-up			
	Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory		Satisfactory		Unsatisfactory	
	No	%	No	%	No	%	No	%	No	%	No	%
<b>Age</b>												
20<30	0	0.0	3	6.0	0	0.0	3	6.0	0	0.0	3	6.0
30<40	4	8.0	12	24.0	13	26.0	3	6.0	12	24.0	4	8.0
40<50	3	6.0	21	44.0	19	38.0	5	10.0	17	34.0	7	14.0
>50	3	6.0	4	8.0	5	10.0	2	4.0	5	10.0	2	4.0
<b>Chi-square &amp;P-value</b>	4.129		>.05		9.333		<0.05*		6.862		<0.05*	
<b>Gender</b>												
Male	7	14.0	24	48.0	22	44.0	9	18.0	20	40.0	11	22.0
Female	3	6.0	16	32.0	15	30.0	4	8.0	14	28.0	5	10.0
<b>Chi-square &amp;P-value</b>	.340		>.05		.390		>.05		.455		>0.05	
<b>Marital Status</b>												
Married	4	8.0	27	54.0	21	42.0	10	20.0	16	32.0	15	30.0
Single	2	4.0	17	34.0	15	30.0	4	8.0	14	28.0	5	10.0
<b>Chi-square &amp;P-value</b>	.063		>0.05		.734		>.05		2.684		>.05	
<b>Level of education</b>												
Illiterate	1	2.0	4	8.0	3	6.0	2	4.0	3	6.0	2	4.0
Read&Write	3	6.0	5	10.0	5	10.0	3	6.0	5	10.0	3	6.0
Intermediate	3	6.0	21	42.0	18	36.0	6	12.0	16	32.0	8	16.0
Highly educated	3	6.0	10	20.0	11	22.0	2	4.0	10	20.0	3	6.0
<b>Chi-square &amp;P-value</b>	18.000		<0.001**		11.520		<0.001**		6.480		<.05*	
<b>Work nature</b>												
Working	6	12.0	17	34.0	19	38.0	4	8.0	17	34.0	17	34.0

Not working	4	8.0	23	46.0	18	36.0	9	18.0	6	12.0	10	20.0
<b>Chi-square &amp;P-value</b>	.986 >0.05				1.641 >0.05				.684 >0.05			
<b>Treatment cost</b>												
Expense of the state	4	8.0	19	38.0	18	36.0	5	10.0	16	32.0	7	14.0
Health insurance	5	10.0	16	32.0	14	28.0	7	14.0	13	26.0	8	16.0
Private treatment	1	2.0	5	10.0	5	10.0	1	2.0	5	10.0	1	2.0
<b>Chi-square &amp;P-value</b>	.330 >0.05				1.076 >0.05				1.033 >0.05			

**Non sig. >0.05 Sig. <0.05\* High sig. <0.001\*\* X1= relation between pre& post program  
(Statistical significant difference) X2= relation between pre& follow-up program**

**Table (5):-Correlation between sickle cell disease patients' total knowledge regarding to SCD and their self-care adherence pre, post & follow-up program implementation (n=50).**

Total knowledge	Total self-care					
	Pre program		Post program		Follow-up	
	R	p-value	R	p-value	R	p-value
Total knowledge pre	0.330*	0.021	0.310*	0.000	0.294*	0.050
Total knowledge post	0.552**	0.000	0.631**	0.000	0.641**	0.000
Total knowledge follow-up	0.430**	0.000	0.541**	0.000	0.586**	0.000

**Non sig. >0.05 Sig. <0.05\* High sig. <0.001\*\* X1= relation between pre& post program  
(Statistical significant difference) X2= relation between pre& follow-up program**

**Table (6):- Correlation between sickle cell disease patients' total knowledge regarding to SCD and their self-efficacy adherence pre, post & follow-up program implementation (n=50).**

Total knowledge	Total self-efficacy					
	Pre program		Post program		Follow-up	
	r	p-value	R	p-value	r	p-value
Total knowledge pre	0.296*	0.021	0.281*	0.04	0.343*	0.015
Total` knowledge post	0.343*	0.028	0.884 **	0.000	0.854**	0.000
Total knowledge follow-up	0.322*	0.023	0.269*	0.037	0.300*	0.034

**Non sig. >0.05 Sig. <0.05\* High sig. <0.001\*\* X1= relation between pre& post program  
(Statistical significant difference) X2= relation between pre& follow-up program**

## **Discussion**

Sickle cell disease (SCD) is a serious inherited condition which affects the RBCs that become sickle-shaped (like a crescent moon) instead of normal disc shape, abnormal shape can cause various problems in the blood which result in a complex set of complications such as severe pain crisis, anemia, stroke, cholestasis, musculoskeletal abnormalities and even death (**Labore &Mawn (2017)**).

**As regards to age of studied patients**, the current study revealed that nearly half of patients aged from (40-50) years old and nearly three quarters of patients were female. The study was congruent with **Nagshabandi& Abdulmutalib., (2019)** who study entitled 'Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease' and showed that the mean age of their study sample was (36.75) years old and about three quarters of the sample were females.

The results were inconsistent with the results of the study by **Thein et al., (2016)** entitled (Sickle Cell Disease in the Older Adult)' who reported that SCD affects males and females equally because the inheritance is autosomal recessive and affected genes equally so that the disease occurs in patients of carrier parents in the same proportion across gender in a ratio of 1:1 between male and female.

**Regarding marital status**, the current study revealed that more than one third of studied patients were single, this may be related to the disease and their bad physical and psychological effect on health status because frequent pain crisis, unstable income and they were always afraid from marriage and bringing child affected with SCD. The

study results was agreed with **Adzika et al., (2017)** whose study entitled 'Socio-demographic characteristics and psychosocial consequences of SCD: the case of patients in a public hospital in Ghana' whose study revealed that the majority of the study sample were single.

As regards to the level of education, the current study revealed that nearly half of studied patients had intermediate education, this may be interpreted that low level of education may be related to the effect of SCD on school learning as recurrent pain crisis require frequent hospitalization and frequent absenteeism from the school which also results in short attention span and learning difficulties. The study agreed with **Adzika et al., (2017)** who study .entitled (Socio-demographic characteristics and psychosocial consequences of sickle cell disease) who reported that about three quarters of SCD patients graduated from secondary school.

**Regarding patients working nature**, the study indicated that more than half of studied patients weren't working and more than one third of them changed their work nature related to disease process. From the researcher's point of view patients' inability to work and changing work nature may be related to frequent pain crisis that result in frequent hospitalization and missing work also, lack of power because the disease results in changing work nature to simple and clerical works. These results was consistent with the results of **Freitas et al.,( 2018)** whose study was about 'Quality of life in adults with sickle cell disease' and stated that more than one half of studied patients had inability to work because the negative effect of disease severity on patients ability to work.

**Related to treatment costs**, the current study showed that nearly two thirds of studied patients treated at the expense of the state, from the researcher's point of view, this may be related to the high cost of treatments so that patients can't afford it. The current study agreed with **Kotb et al., (2019)** entitled (Effect of Health Educational Program on the Knowledge of Adults and Attitude about Sickle Cell Anaemia in the Jazan Region of Saudi Arabia) and revealed that more than one half of studied patients received governmental treatment including blood transfusion and certain diagnostic measure periodically.

**Concerning patients' total knowledge about SCD** pre, post and follow-up program, the pre-program assessment revealed that the majority of the patients had un-satisfactory total knowledge pre-program implementation but more than two thirds of them had satisfactory knowledge immediately post program implementation and nearly two thirds had significant improvement three months follow-up program implementation, there was statistically significant improvement in patients' knowledge post & follow-up implementation of the program, from the researcher's point of view, this may be related to lack of exposure to such knowledge pre-program implementation or due to effective, clear, demonstration and re-demonstration, the impact of the program conducted by the researcher and patient interesting with gaining information about SCD.

These results agreed with the results of **Kotb et al., (2019)** whose study was about (Effect of Health Education Programm on the Knowledge and Attitude about Sickle Cell Anemia among Adult in the Jazan Region of Saudi Arabia) and found that there was a

marked increase in the level of knowledge on all knowledge items from the pretest to the posttest, that There were statistically significant differences observed between knowledge pre-program, immediately post and three month follow-up program implementation.

**Regarding patients' adherence to total self-care practice pre, post and three months follow-up program implementation**, the current study illustrated that about three quarters of studied patients adhered to self-care practice post-program implementation and about two thirds adhere to self-care practice three months follow-up program implementation, there were statistically significant differences observed between self-care practice pre-program, post and follow-up program implementation. This may be related to lack of exposure to self-care practice instructions pre-program which result in unsatisfactory self-care, the patient self-care was satisfactory post and three months follow-up implementation, this may be due to effective, clear and understandable program.

The findings agreed with **Calhoun et al., (2019)** whose study entitled (Implementation of an Educational Intervention to Optimize Self-Management and Transition Readiness in Young Adults with Sickle Cell Disease), the intervention resulted in improved skills in tasks, most notably those related to healthcare skills.

**Regarding total patients' adherence to self- efficacy practice**, the current study revealed that the majority of studied patients had unsatisfactory level of self-efficacy pre-program implementation, while about three quarters of them had satisfactory self-efficacy post program implementation and more than two thirds of

them had satisfactory self-efficacy three months follow-up program implementation.

These findings were congruent with **Ahmadi et al., (2015)**, whose study entitled (Health-Related Quality of Life and Predictive Role of Self-Efficacy in Iranian Patients with SCD) and revealed that the majority of studied patients had high self-efficacy post & follow-up program implementation as there was highly statistically significant difference post and follow-up program regarding performing measures to decrease pain, performing most daily activities, continue to sleep despite pain and controlling stress, discomfort & boredom.

The findings also agreed with **Nagshabandi& Abdulmutalib, (2019)** whose study entitled 'Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease' and reported that there was statically significant difference between self-efficacy items related to performing daily hygiene and performing exercise at least three times every week pre, post & follow-up program implementation.

**Concerning relation between total knowledge & demographic characteristics pre, immediately post & three months follow-up program implementation,** our study revealed that there was statistically significant relation between age and patients' knowledge. This may be related to previous exposure to such information as when age increase this increased years of experiencing of SCD which results in frequent hospitalization and more exposure to such knowledge from doctors and nurses.

These results were congruent with **Smith& Brownill, (2018)** whose study entitled (Knowledge, beliefs, attitudes, and behaviors regarding SCD: Implications for

prevention), and revealed that there was highly statistically significant positive relation between age and patients knowledge about SCD as when age increases patients' knowledge regarding disease, precipitating factors for pain crisis, complications and treatment improve due to increasing their interest for such knowledge.

**Regarding the relation between total knowledge score and patients' educational level,** the present study illustrated that there was a highly statistically significant relation between total knowledge score and patients' educational level pre, post and follow-up program implementation. This may be explained as with high education there were increased in patients' knowledge, understanding, interpretation and reading about the disease. There was also statistically significant relation between work nature and patients' knowledge post and follow-up program implementation this may be explained that clerical works means that patients had high level of education which increase their understanding and interpretation.

These findings agreed with **Hussain et al., (2015)** whose study entitled "Knowledge and misconception about sickle cell anemia and glucose-6-phosphate dehydrogenase deficiency among adult sickle cell anemia patients in Qatitf area (eastern KSA)" and reported that there was statistically significant relation between total knowledge score and educational level & job among there sample, as educational levels were significantly and positively associated with accurate knowledge of SCD in the study; this positive association is to be expected, as education is an essential component in promoting health, screening behaviors and healthier lifestyles.

**Concerning relation between total self-care & demographic characteristics pre, post & follow-up program implementation** the current study revealed that there was statistically significant relation between age and patients self-care practice, from the researcher's point of view this may be related to the adult people prefer to depend on themselves and not to rely on others in meeting their essential needs as they prefer to solve their health problems without affording their families their fatigues.

These findings agreed with *Labore & Mawn (2017)*, whose study entitled (Exploring Transition to Self-Management Within the Culture of Sickle Cell Disease ) the participants recognized a need to take control; to assume responsibility for disease management as family caregivers' decrease their authority, however the results of the present study disagreed with *Nagshabandi & Abdulmutalib., (2019)* whose study entitled 'Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease', and indicated that when age increase patients' depends on others on caring for them. This may be related to their fatigue, inability to care for themselves due to pain and other complications.

**Pertaining to the relation between total self-care & educational level**, the results also indicated that there was statistically significant relation between the educational level and total self-care, this may be interpreted that SCD patients with a high level of education are more likely knowledgeable, having a high sense of self-care, autonomy and regularly take care of themselves from less educated people.

These findings were congruent with *Robin & Leger, (2016)* whose study entitled

(Education Needs of Adults Living With SCD in The U.S. and Jamaica) who showed that less educated patients are more likely to diminish self-care skills, have a decreased sense of self-care ability and are less likely to complete these self-care practice than those with advanced education. Low levels of education may affect patients' participation in appropriate self-care activities whenever highly educated respondents offered suggestions in improving the educational interaction between educator and individual with SCD.

**Regarding the relation between total self-care & working nature**, the current study revealed that there was a statistically significant relation between self-care and working nature post and three month follow-up program implementation, this may be interpreted that working patients had self-autonomy and high self-esteem to care for themselves, the study is consistent with *Ahmadi et al, (2015)* whose study entitled (Health-Related Quality of Life and Predictive Role of Self-Efficacy in Iranian Patients with SCD) who revealed that, there was statically significant relation between working nature and patients' self-care practice.

Concerning the relation between total self-efficacy & demographic characteristics pre, post & follow-up program, the current study showed that there was statistically significant relation between age and patients' self-efficacy practice post and follow-up program implementation, this may interpreted that as age increases this result in increasing person experience and capability in controlling his life through managing pain, stress, sleep and performing ADLs which increase his self-efficacy and promote health.

The results of the present study agreed with *Calhon et al* ,(2019) whose study entitled (Implementation of an educational intervention to optimize self-management and transition readiness in young adults with sickle cell disease) and showed that adult patients adhere to self- efficacy practices more than younger patients due to their experience, self-care skills, and increased knowledge.

**Regarding the relation between total self-efficacy and educational level**, the current study indicated that there was highly statistically significant relation pre, one month post & three months follow-up program implementation this may be related to reading, understanding and following of new strategies to control pain, stress and preventing complications so that promoting self-efficacy. This finding agreed with *Nagshabandi& Abdulmutalib., (2019)* whose study entitled 'Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease' and revealed that patients with SCD have basics of knowledge about the disease; they become keener to face the challenges to self-care and self-efficacy.

Regarding the correlation between patients' knowledge & self-care, the current study showed that there were statically positive correlations between patients' knowledge and self-care practice. The study agreed with *Asnani et al., (2016)* whose study entitled (Interventions for patients and caregivers to improve knowledge of sickle cell disease and recognition of its related complications) and revealed that there were highly statically significant correlation as adequate patients knowledge improve patient understanding and adherence to self-care measures such as adherence to medical

appointments and follow-up to improve patients health status.

Regarding the correlation between patients' knowledge & self-efficacy, the current study revealed that there were statistically and highly statistically positive correlations between patients total knowledge regarding SCD and their self-efficacy practice at pre, post & follow-up program implementation, the study agreed with *Freitas et al., (2018)* whose study entitled (Quality of life in adults with sickle cell disease) who revealed that there was statistically significant positive correlation between studied patients' knowledge at pre, post and follow-up program implementation and their self-efficacy adherence may be related to that when patients' knowledge improve , this result in improvement in self-efficacy skills.

#### **Conclusion**

- Based on the findings of the current study, it could be concluded that, there was significant improvement in patients' knowledge immediately post and three months following educational program implementation moreover, there was significant improvement in patients' self-care & self-efficacy practice one month post and three months following educational program implementation. Regarding assessment of pain crisis, the study also concluded that, there were significant decrease in number, severity of pain crisis and number of hospitalization due to the effect of educational program.

#### **Recommendation:**

**The current study recommends the following**

#### **Researchers Recommendations:**

- Researchers should continuously create educational programs for SCD patients and their families about the

disease, management, complication, pain crisis, precipitating factors and preventing measures for early detecting and solving problems.

- Encourage researchers to implement the program on a large sample size and a different areas to evaluate its impact on health out-comes among patients with SCD.
- Conduct educational program for nurses to improve their knowledge and skills in caring for patients with SCD.

#### **Patients Recommendations:**

- Patients should perform self-care practice to decrease pain crisis.
- Recommend patients for frequent follow-up appointments for early detection and prevention of complications.
- Instruct patients to avoid activities that may precipitate SCD such as extreme cold and hot weather, stress, anxiety and infection.

#### **Nurses Recommendations:-**

- Recommend nurses to improve patients' care in out-patients clinics to provide more comfort and decreasing number of pain crisis by improving self-care measures.
- Nurses should provide additional program for in-home pain management with the training of cognitive and behavioral techniques to deal with the pain

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## تأثير برنامج تعليمي على الرعاية الذاتية لمرضى أنيميا الخلايا المنجلية

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يعد مرض فقر الدم المنجلي من الأمراض الخطيرة التي تؤدي إلي مضاعفات جسيمة مما يؤثر علي الرعاية الذاتية وكذلك الكفاءة الذاتية للمرضي. لذلك هدفت هذه الدراسة إلى تقييم تأثير برنامج تعليمي على الرعاية الذاتية لمرضى أنيميا الخلايا المنجلية. وقد أجريت الدراسة في أقسام أمراض الدم في مستشفى بنها الجامعي ومستشفى معهد ناصر علي ٥٠ مريض من مرضي فقر الدم المنجلي . حيث كشفت النتائج عن تحسن معلومات المرضي والرعاية الذاتية وكذلك الكفاءة الذاتية بعد تنفيذ البرنامج وفي خلال فترة المتابعة. كما أوصت الدراسة بأهمية إجراء برامج تعليمية علي عدد أكبر وأماكن مختلفة لتحسين الرعاية الذاتية وتقليل المضاعفات الناتجة عن المرض