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Self-care Management and Self-efficacy among Adult Patients with Sickle Cell Disease

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Abstract An important specific management for patients with chronic disease is self-care. Patients who are diagnosed with sickle cell disease have home-care as a contribution to enduring their pain and therefore restraining a pain crisis. An improved interpretation of self-care can benefit the team of health care by preparing the sickle cell patients with required resources and abilities essential to aid in managing their disease. The aim of the study was to assess self-care management and self-efficacy among adult patients with sickle cell disease. A descriptive design was used in this study. The study was conducted at King Abdulaziz University Hospital in Jeddah, data collected from outpatients' clinic, medical wards and day care unit. A purposeful sample of 50 adult patients diagnosed with sickle cell disease male or female. Data was collected through the main two tools; Tool I: consists of two parts: Part 1. Structured interview questionnaire to assess patients' sociodemographic and clinical data; Part 2: Self-care management used to measure perceived self-care ability. Tool II: Sickle Cell Self-Efficacy Scale used to assess the perceived ability of patients with SCD to manage their disease. The study results showed that 58% were female and 42% male, their mean age was 36.75 years. There was statistically significant difference found regarding self-efficacy in relation to age, marital status, level of education, and patient years with sickle cell disease. However, there are statistically significant difference found regarding self-care management in relation to the level of education, living situation and patient years with sickle cell disease. It was concluded that there was a positive differed statistically correlation between self-efficacy and self-care management among sickle cell patients. It was a recommendation to developing patient education program aimed to successful self-care comprised in the disease controlling process. Undertake additional research efforts to plan interventions to achieve health outcomes of young adults' patients.

Keywords: *self-care management, self-efficacy, sickle cell disease*

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1. Introduction

The World Health Organization recognizes sickle cell anemia as a main concern for public health, because of problems with access to health services in several regions of the world. In general, 3.500 children/year are born with sickle cell anemia, and one child in a 1000 births has the disease [1].

Sickle cell disease (SCD) is the most common mono-hemoglobin disorder worldwide, affecting approximately 20 to 25 million people, most of whom live in sub-Saharan Africa [2, 3]. According to [4] who reported that by 2050, there will be a 30% increase in the number of people with sickle cell anemia, the most prevalent form and severity of SCD.

Sickle cell disease is a chronic genetic disease, which causes many complications through the patient's life. This may cause many physical complications such as painful crises and strokes and has many other effects such as depression, poor quality of life, coping issues and weak family relationships, and thus may cause a huge burden on both patients and their families, with frequent visits to hospitals. When SC patients have a better understanding of their illness, they manage their disease better and improve their quality of life [5].

Sickle cell disease is a lifelong, inherited disorder, which can cause a number of complications throughout an individual's life. It may cause a huge burden on both the patient and their family, including frequent visits to healthcare facilities. The illness causes not just physical complications such as painful crises and strokes but may have many other effects such as depression, poor quality of life, coping issues and poor family relationships. When people with a chronic illness have a better understanding of their illness, they manage their illness better and improve their quality of life.

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The majority of hospitalized SC patients suffers from pain as a common complication, which requires patients to establish active roles in disease management [6]. This The chronic pain is the most common reason for hospital visits, admissions, and readmissions, particularly in young adults aged 18–39 years [7]. According to [8] the other psychological factor was unemployment, which leads to low self-esteem, anxiety, stress, and depression in these patients.

To deal with this disease, patients with SCD must require a range of multifaceted performances that improve self-efficacy and self-management and inhibit problems associated with SCD. Self-efficacy is defined as a person's belief in his ability to accomplish daily life activities with symptom management, especially in individual beliefs that can be used to control emotions, performances, and the general mood. It is a significant factor for effective self-management and behavior changes [9,10].

1.1. Significant of the Study

An important specific management for patients with chronic disease is self-care. Patients diagnosed with sickle cell disease have home care as a contribution to their pain tolerance, thus reducing the pain crisis. Better self-care interpretation can benefit the health care team by preparing sickle cell patients with the resources and capacities to help manage their disease [7].

Individuals with sickle cell disease can be overstated by repeated acute complications and doubled due to progressive organ injury. When people with SCD learn to self-manage, their medical outcomes and quality of life recover; and they reduced the need for health care facilities [5].

1.2. Study Aim

The present study aims to assess self-care management and self-efficacy among adult patients with sickle cell disease, through these objectives:

1. Assess the self-care management among adult patients with sickle cell disease.
2. Assess the self-efficacy among adult patients with sickle cell disease.
3. Assess the relationship between self-care management and self-efficacy among adult patients with sickle cell disease.

1.3. Research Question

What is the relationship between self-care management and self-efficacy among adult patients with sickle cell disease?

2. Subjects and Method

2.1. Research Design

Descriptive design was used to achieve the aim and objectives of the study.

2.2. Setting and Subjects

The study was conducted in the outpatient clinics, medical wards and day care unit at King Abdulaziz University Hospital (KAUH) in Jeddah, Saudi Arabia. A purposeful sample included 50 adult patients diagnosed with sickle cell disease. They were recruited according to the inclusion criteria of being adult patients > 18 years old either female or male. Those who were able to communicate and free from any psychological problems and agreed to participate voluntarily.

2.3. Tools of the Study

The researchers have used two tools for data collection:
Tool I. Structured interview questionnaire. It consists of two parts:

Part I. Socio-demographic and Clinical Data: It was designed by the researchers, written in simple Arabic language to assess patients' socio-demographic and clinical data; it includes; age, gender, marital status, level of education, working nature, living status, how many years had SCD, admission to the hospital for pain crises yearly, and disorders they have experienced because of having SCD.

Part II. Self-care Management: The self-care management adopted from [11] was used to measure perceived self-care ability and self-care actions. Self-care ability is defined as the ability to contribute to beneficial performance, which refers to improving and/or maintaining health status and life excellence. It consisted of 24-items are summed to get a total score and higher scores correspond to higher levels of self-care ability. Scoring system, range from one "disagree" to three "agree".

Tool III. Sickle Cell Self-Efficacy Scale (SCSES):

The Sickle Cell Self-Efficacy Scale adopted from [12] was used to assess the perceived ability of patients with SCD to control their disease, as well as to participate in well-designed daily activities. It is included in 9 questions related to patients' awareness about their ability to work daily and managing SCD symptoms (eg, pain crisis). Scoring system, are ranging from one (not sure) to 3 (sure). Scores on the SCSES range from 9 - 27. Responses to individual questions are collected for a total score, with higher values indicating increased self-efficacy and vice versa.

2.4. Ethical Consideration

Official permission was acquired from ethical committee Faculty of Nursing, King Abdulaziz University. Additional approval was written were recruited from the unit of biomedical ethics of King Abdulaziz University Hospital. After the aim, and objectives of the study methods were

explained. Each participant received a written informed consent with clear instruction. In addition, the patients have informed that contribution in the study as voluntary, and their decision would not harm them the treatment or service they are offered in the hospital. The researchers assure each participant read the consent carefully. Confidentiality and anonymity maintained for all participants.

2.5. Validity and Reliability

Five professionals from the Medical Surgical Nursing academic staff, Faculty of Nursing, King Abdulaziz University, to judge the appropriateness, accuracy, and representation of the tool, reviewed the research tools. They were selected to test the clearness, probability, and relevance of tools. Modifications were made because of their response. The reliability of Self-care management and Sickle Cell Self-Efficacy Scale were obtained from the tool designers as well as other used investigation studies. The alpha reliability of the scale was reported as 0.75, and 0.89 respectively, that indicating very high internal consistency.

2.6. Pilot Study

It was carried out on 10% of the subjects. Tools were tested in the earlier stated setting in order to be revised for clearness, thoughtful, comprehensiveness, practicability, applicability, viability and ease of application, noticing any difficulties and problems that may be met during data gathering. It also facilitated to guess the time wanted to complete the research tools. Data collected from the pilot study were analyzed. The researchers have omitted the piloted data from the sample size participating in the research.

2.7. Procedure for Data Collection

1. The study was carried out from the beginning of September 2016 to the end of January 2017.
2. Before starting the questionnaire, the researchers explained the aim of the study simply to the patients who approved to contribute to the study prior to data collection and fulfill the inclusion criteria were selected.
3. The researchers collected data from the studied patients who agreed to participate. Administered tools were compiled from the above-mentioned resources and translated into Arabic to facilitate the data collection process.
4. The researchers were available in the morning shift at the clinical field for two days/week. Data were collected in single individual interviews; for each patient individually for 15-30 minutes and, then asked each one to fill in the previously mentioned tools.
5. Total scores for SC patient's self-efficacy and management of self-care were used for analyses and find the correlation.

2.8. Statistical Analysis

Data were collected, tabulated and analyzed using SPSS (Statistical Package for Social Science) version 21. Descriptive analysis mean and standard deviation were accustomed to describe the continuous variables, frequency and percentage characteristics of a studied sample, t-test pair was used as well as to test relation and correlation.

3. Results

Table 1 show the sociodemographic and clinical data distribution of the studied sample, most of the patients 58% were female and 42% male. The mean age was 36.75 years. Apropos of marital status 62% were single, 34% married and 4% divorced. In relation to the level of education, 48% of all patients were a secondary school, while 38% bachelor. As regards to working nature, it was found that 20% of the patients were working full time, 14% working part-time, 40% not working, and 56% receiving assistance. Regarding the living status, it was found that 94 % live with the family. About patient years diagnosed with sickle cell disease, 46% of the patients diagnosed more than 20 years, 26% between 15-20 years, while 8% between 1-5years.

Table 1. Socio-demographic and clinical data distribution of the studied sample (n=50)

Sociodemographic characteristics and clinical data		No.	%
Age	18 - 24	12	24
	25 - 34	24	48
	35 - 59	14	28
	Mean ±SD	36.75±4.98	
Gender	Male	21	42
	Female	29	58
Marital status	Single	31	62
	Married	17	34
	Divorced	2	4
Level of education	Primary	7	14
	Secondary	24	48
	Bachelor	19	38
Working nature	Full time	10	20
	Part-time	7	14
	Not working	20	40
	Not working (disable)	30	60
Living status	Living solo	3	6
	Living with the family	47	94
Patient years with sickle cell disease	1- 5	4	8
	5 - 10	6	12
	10 - 15	4	8
	15 - 20	13	26
	20 and more	23	46
Admission to the hospital for pain crises yearly	1-3	1	2
	3-6	37	74
	6-9	10	20
	and more	2	4
Common disorders with sickle cell disease	CNS	50	100
	Respiratory system	21	42
	CVS	41	82
	GIT	4	8
	Genitourinary	19	38
	Musculoskeletal	42	84

Concerning the admission to the hospital for pain crises yearly, the majority of the patients 74% reported that 3-6 per year that require being in the hospital, 20% had 6-9 crises per year and only 4% had 10 and more crises per year. The common disorders with sickle cell disease, it was found that central nervous system, respiratory system, cardiovascular system, gastrointestinal system, genitourinary, and musculoskeletal disorders' 100%, 42%, 82%, 8%, 38%, and 84% respectively.

Table 2 presented the distribution of the sickle cell patients according to self-care management. It was found that 94% of the patients agree in their response to look for better habits to care, regularly take actions to ensure the safety of my family and myself, and ask help when unable to care for me. In addition, around 92% agree to make the needed adjustment if any mobility is restricted, take adequate measures to keep the hygienic in my environment, and do the desired adjustment to stay well as circumstance change. Whereas, 88%, 86%, 82%, 78%, and 70% of the patients respectively agree in their response to maintain my hygiene, altered some of my old habits in order to improve my family, when needed manage by myself, regularly assess the effectiveness of anything to stay healthy, and set new priorities to manage my health to stay well.

Table 3 illustrated the distribution of the sickle cell patients according to self-efficacy. It was revealed that, 64%, 56%, 56%, 52%, and 50% of the studied patients sure in their responses that can do something to feel better if you feel unhappy, can control how often or when you get tired, deal with the frustration of having sickle cell disease, manage your life from day to day compared with other people suffering from sickle cell disease, and can do most of the things you do day after day.

Table 4 described the relationship between self-efficacy and sociodemographic clinical data of the studied sample. There were statistically significant differences in self-efficacy and clinical-demographic data in relation to age and marital status, level of education, and patient years with sickle cell disease with (p= 0.001, 0.001, 0.001, and 0.049) respectively. While there were no significant differences with the living status and admission to the hospital for pain crises yearly with (p= 0.968 and 0.092) respectively.

Table 5 presented the relation between self-care management and sociodemographic clinical data of the studied patients. It shows that the difference was significant regarding self-care management in relation to the level of education, living status and patient years with sickle cell disease with (p=0.043, 0.008, and 0.050) respectively. Whereas there were no significant differences in relation to age, marital status, and the Admission to the hospital for pain crises yearly regarding total mean scores of self-care management with (p=0.167, 0.505, and 0.322) respectively.

Table 6 revealed the correlations between self-efficacy and self-care management among sickle cell patients. There was a significant positive correlation at p< (0.01) level between self-efficacy and Self-care management among sickle cell patients.

Table 2. Distribution of the sickle cell patients according to self-care management (n=50)

Sickle Cell Self-care Management	Disagree		Neither disagree nor agree		Agree	
	No.	%	No.	%	No.	%
1- Do the desired adjustment to stay well as circumstance change	0		5	10	45	90
2- Seldom check whether the measurements I take to stay well	20	40	16	32	14	28
3- Making the needed adjustment if any mobility is restricted	0		4	8	46	92
4- Take adequate measures to keep the hygienic in my environment,	0		4	8	46	92
5- Set new priorities to manage my health to stay well	0		15	30	35	70
6- Frequently no energy to manage myself in the way that I know	8	16	11	22	31	62
7- Look for better habits to care.	0		3	6	47	94
8- The frequency of showering depends on conditions to maintain my hygiene	1	2	5	10	44	88
9- Eat healthy to control body weight at a normal level	2	4	24	48	24	48
10- When needed, manage by myself	0		9	18	41	82
11- Frequently think including exercise and rest in my daily routine but never going to do it.	3	6	18	36	29	58
12- Over the years, friends have developed that can help when needed	9	18	23	46	18	36
13- Infrequently get sufficient sleep to feel rested	22	44	19	38	9	18
14- When obtaining knowledge regarding my health, rarely inquire for an explanation of language that does not understand	29	58	14	28	7	14
15- Rarely inspect my body to discover the occurrence of any problems	25	50	9	18	16	32
16- If take a new drug prefer to get knowledge about the side effect	6	12	17	34	27	54
17- Changed some of my old habits in order to improve my family	0		7	14	43	86
18- Take regular actions to ensure the safety of my family and myself.	0		3	6	47	94
19- Regularly assess the effectiveness of anything to stay healthy	2	4	9	18	39	78
20- In daily activities' I rarely take time to care for myself	29	58	7	14	14	28
21- When my health is threatened, I able to get the knowledge to keep well	5	10	12	24	33	66
22- Ask help when unable to care for me.	2	4	1	2	47	94
23- Rarely have time for myself	30	60	13	26	7	14
24- Because of restricted movement, I cannot always take care of myself in a suitable way	22	44	10	20	18	36

Table 3. Distribution of the sickle cell patients according to self-efficacy (n=50)

Sickle Cell Self-Efficacy	Not Sure		Neither not sure nor sure		Sure	
	No.	%	No.	%	No.	%
1- Are you sure that can do something to relieve the pain	17	34	11	22	22	44
2- Are you sure you can do most of the things you do day after day	14	28	11	22	25	50
3- Are you sure that you can relieve the pain of sickle disease from interfering in your sleep	20	40	20	40	10	20
4- Are you sure that you can relieve sickle cell pain using nonpharmacological techniques	12	24	16	32	22	44
5- Are you sure that you can control how often or when you get tired	12	24	10	20	28	56
6- Are you sure you can do something to feel better if you feel unhappy	5	10	13	26	32	64
7- Are you sure to manage your life from day to day compared with other people suffering from sickle cell disease	8	16	16	32	26	52
8- Are you sure you can relieve symptoms of the sickle disease so you can do the things you enjoy	13	26	16	32	21	42
9- Are you sure you can deal with the frustration of having sickle cell disease	13	26	9	18	28	56

* p< (0.05), ** p< (0.01).

Table 4. Relation between self-efficacy and socio-demographic clinical data of the studied sample (n=50)

Sociodemographic and clinical data	Self-efficacy	Tests	
	Mean ± SD	f/t	P-value
Age (years)			
18 – 24	23.67 ± 4.81	13.756	<0.001**
25 – 34	29.54 ± 5.40		
35 – 59	34.36 ± 5.09		
Marital status			
Single	26.55 ± 5.48	12.685	<0.001**
Married	34.29 ± 4.88		
Divorced	34.00 ± 4.24		
Level of education			
Primary	25.29 ± 4.61	13.086	<0.001**
Secondary	26.92 ± 5.40		
Bachelor	34.26 ± 5.21		
living status			
Live solo	29.33 ± 4.62	0.041	0.968
Live with the family	29.49 ± 6.52		
Patient years with sickle cell disease			
1- 5	30.50 ± 7.33	2.597	0.049*
5 – 10	26.67 ± 5.47		
10 – 15	28.25 ± 2.87		
15 – 20	26.08 ± 6.93		
20 and more	32.17 ± 5.69		
Admission to the hospital for pain crises yearly			
1-3	19.00 ± 0.0		
3-6	30.68 ± 6.26	2.278	0.092
6-9	26.80 ± 5.90		
10 and more	26.00 ± 4.24		

Table 5. Relation between self-care management and socio-demographic clinical data in the studied patients (n=50)

Socio-demographic and clinical characteristics	Self- care management	Tests	
	Mean ± SD	f/t	P-value
Age			
18 – 24	84.25 ± 8.19	1.859	0.167
25 – 34	86.08 ± 6.14		
35 – 59	89.00 ± 4.98		
Marital status			
Single	85.77 ± 7.16	0.693	0.505
Married	87.94 ± 4.80		
Divorced	84.50 ± 10.61		
Level of education			
Primary	88.86 ± 7.65	3.376	0.043*
Secondary	84.08 ± 6.81		
Bachelor	88.58 ± 4.71		
Living status			
Live solo	92.43 ± 4.93	2.790	0.008*
Live with the family	85.49 ± 6.25		
Patient years with sickle cell disease			
(1- 5)	83.75 ± 5.91	2.553	0.050*
(5 – 10)	90.50 ± 9.12		
(10 – 15)	90.50 ± 4.36		
(15 – 20)	82.77 ± 6.34		
20 and more	87.26 ± 5.37		
Admission to the hospital for pain crises yearly			
1-3	75.00 ± 0.0	1.196	0.322
3-6	86.89 ± 6.54		
6-9	86.50 ± 6.59		
10 and more	84.00 ± 0.00		

Table 6. Correlations between Self-efficacy and Self-care Management among Sickle Cell patients

Variable		Self-efficacy	Self-care management
Self-efficacy	r	----------	0.207
	P-value	----------	<0.001**
Self-care management	r	0.834	----------
	P-value	<0.001**	----------

* p< (0.05), ** p< (0.01).

4. Discussion

The aim of this study was to assess self-care management and self-efficacy among adult patients with sickle cell disease. Regarding the sociodemographic clinical data of this study showed that more than half of the sample were female and less than half were male, their mean age was 36.75 years old, and most of the patients single, these findings are generally consistent with [13] which conducted study to examined the sociodemographic characteristics of SCD patients, and found that there was an even distribution of SCD across gender 42 % in males and 58 % in females. In addition, this finding agrees with the results of the study by [14] who informed that SCD affects males and females equally because the inheritance is autosomal recessive. That is the affected gene is on one of the first 22 pairs of chromosomes that do not determine gender; hence, the disease occurs in children of carrier parents in the same proportion across gender in a ratio of 1:1 between male and female.

As regard to the level of education, less than half of the patients had secondary education and slightly more than one third had a bachelor degree. A study by [15] reported that the majority of SCD patients had secondary and bachelor level of education.

According to patients working nature in this study, it was found that more than half-receiving assistance and live with their family. This is consistent with [16] who stated that inability to work has shown to have negative effect on disease severity as well as SC patient's quality of life.

The result of the present study shows almost half of the participants had more than 20 years with sickle cell disease, and a quarter of them between 15 – 20 years. This was in consistent with [17] testified that, median ages of patients with sickle cell disease were between 42 and 48 years, respectively, for male and female.

Regarding the admission to the hospital for pain crises yearly, the majority of the patients were admitted to hospital from 3 to 6 times per year. This finding is coherent with [18] who emphasized that most of the patients were admitted to the hospital from 3 to 6 times, with SCD often experience unpredictable painful crises or pain episodes requiring healthcare visits, which has been found to be associated with more serious health outcomes. However, [19] indicated that preventing painful episodes in SC patients, they might be able to prevent frequent visits to their providers, thereby allowing them to better focus on education and peer relationships during this critical period of development. From researcher's views in chronic disease as sickle cell disease, the patient's capability to do actions that will improve the pain experience is contributory in adjusting to pain extended period.

Regarding complications developed followed sickle cell disease it was found that all patients suffer from the central nervous system, while the majority suffer from musculoskeletal disorders and cardiovascular system. Although less than half of the patients suffer from respiratory system and genitourinary and few of them suffer from gastrointestinal disorders. This supported by [20] who clarify that sickle cell disease is associated with a high degree of morbidity. The cooperative society of sickle cell disease (CSSD) found that morbid event such as strokes that impaired functions often preceded death in childhood. Frequently patients surviving until adulthood experience significant organ system damage that may include pulmonary failure, pulmonary hypertension, renal failure, congestive heart failure, leg ulcer and osteonecrosis of the femoral or the head. Also [18] reported that SC patients having numerous problems through their life. Most patients with SCD have many years where their illness is more in control and other years where their complications and pain crisis are much more severe.

The results of the current study show that statistically significant difference among SC patient's self-efficacy with age, marital status, level of education and years with sickle cell disease. While there was no significant relation with the living status and Admission to the hospital for pain crises yearly. These could be due to patients were likely to be more knowledgeable and predicted perceived self-care capability and self-care activities about health do so may contribute in more health and wellness doings, thus may need fewer hospital appointments. These findings coincide with [7,11,21,22] who reported the SCD self-efficacy, and level of education was as essential in thoughtful the role of self-care in adults with SCD. Where advanced perceived self-care capacity and self-care activities have been related to higher SCD self-efficacy, and schooling in the overall SCD patients. This finding is consistent with [1] who reported that patients with SCD have bases of knowledge about the disease and know it; they become keener to face the challenges to self-care.

The current study showed that there were statistically significant differences between the self-care management of the SCD patient with the level of education, the living status and years of the patient with sickle cell disease. The researchers point out that SCD patients with a high level of education are more likely to have a stronger sense of self-care and regularly take care of self-care from less educated people. These results coincide with [7,23] who reported that in general SCD patients with the ability of advanced self-care and self-care work was associated with the advanced self-efficacy of SCD and education. The study [7] shows that clients with less education are less likely to have knowledge self-care values, have a weaker sense of self-care ability as a result, and are less likely to be confident in completing these self-care works than those with advanced education. Low levels of education may affect a person's ability to participate in appropriate self-care activities.

Finally, there was a statistically significant positive correlation between self-efficacy and self-care management among sickle cell patients. From the researchers' interpretation,

patients who are considered able to complete daily activities are more likely to have a greater awareness of their self-care, and therefore may have more self-care that will improve the extended pain. This finding was consistent with [9,20] which revealed that SCD patients with low levels of self-efficacy had increased pain and more physical and psychological symptoms associated with SCD than individuals who reported higher self-efficacy levels. According to [7] who pointed out that the self-efficacy of high SCD was associated with better self-care, so they could do their daily activities and thus may lead to more self-care work.

5. Conclusion

On the light of the present study, findings represent that there is a positive statistical association between self-efficacy and self-care management among SC patients. There is a statistically significant difference found regarding self-efficacy in relation to age, marital status, level of education, and patient years with sickle cell disease. However, there are a statistically significant difference found regarding self-care management in relation to the level of education, living status and patient years with sickle cell disease.

6. Recommendations

1. Developing patient education program aimed to successful self-care comprised in the disease controlling process.

2. Young adults with SCD need to undertake additional research efforts to plan interventions to achieve health outcomes while living with SCD.

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