



CODEN [USA]: IAJ PBB

ISSN: 2349-7750

**INDO AMERICAN JOURNAL OF  
PHARMACEUTICAL SCIENCES**Available online at: <http://www.iajps.com>

Research Article

**HEALTH CARE PROVIDER ATTITUDE DURING THE  
MANAGEMENT OF SICKLE CELL DISEASE PATIENTS, A  
MULTICENTER STUDY IN SAUDI ARABIA**

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**Abstract**

*Objective: To investigate the health care provider attitude during the management of sickle cell disease patients in Saudi Arabia.*

*Method: Data was collected using a questionnaire which was distributed to health care providers (physician and nurses) from both genders at King Fahad Hospital, Ohud Hospital and Maternity And Children Hospital in Madinah, Saudi Arabia. The questionnaire consists of three basic paragraphs: (1) attitudes, practices, and knowledge level; (2) the health care provider's believe; and (3) demographic information.*

*Results: Females were 52.3%, Nurse 42.1%, physicians 57.9%. 37.4% of the participants deal with Sickle cell disease patients always. 20.6% of the participants believe that more than 75% of sickle cell patients seek drug when they come to the hospital. 19.6% of the participants believe that more than 75% of sickle cell patients are frustrating to take care of them. 72% focus on the need to avoid addiction during treatment. And 69% believe that the self-report of patient about acute pain episodes is the most reliable. 60% were bothered by the way some nurses treat patients with sickle cell disease, while 59% were bothered by the way some physicians treat patients with sickle cell disease.*

*Conclusion: Health care providers in Saudi Arabia have a negative attitude towards sickle cell disease patients. But nurses are more negative towards this group of patients compared to physicians.*

**Keywords:** Sickle cell disease, Hemoglobin, Gene, Phenotypes, Pain management.

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Please cite this article in press Omar Mohammed Alawaji et al., *Health Care Provider Attitude During The Management Of Sickle Cell Disease Patients, A Multicenter Study In Saudi Arabia.*, Indo Am. J. P. Sci, 2019; 06(01).

**INTRODUCTION:**

Sickle cell disease (SCD) is an autosomal recessive disorder, this disease is characterized by abnormal hemoglobin S production and is associated with high mortality and morbidity [1]. SCD is expressed only when sickled hemoglobin (HbS) is inherited from both parents i.e. sufferer (SS), but when sickled hemoglobin (HbS) is inherited from one of parents, this become heterozygous state (AS) (a carrier of disease) and called sickle cell trait [2]. Sickle cell disease causes the Red Blood Cells to change from the normal biconcave disc form to an irregular sickled form [3]. Sickle cells also have a tendency to stick to the walls of the blood vessels. Consequently, sickled Red Blood Cells can clog blood vessels, and prevent normal blood flow and reduce oxygen delivery to organs and tissues [3].

WHO reported that about 5% of world's population carries the gene that responsible for disorders of hemoglobin, and about 300000 children around the world are born with sickle cell disease yearly [2]. SCD is common in Sub-Saharan Africa, Saudi Arabia and Mediterranean basin [4]. According to WHO, the highest prevalence of SCD is in Africa, which ranges from 10% to 40% [4].

SCD prevalence in Saudi Arabia differs significantly in different regions of the country, but the highest prevalence is in the Eastern province, followed by the southwestern provinces [1]. In 2007, it was reported that the highest rates of sickle cell disease at Al-Ahsa region of the country by 1.20%, followed by Qunfudah and Jazan [3]. while, other areas showed much lower prevalence rates [3]. Hematological and clinical variability exists in SCD in Saudi Arabia with two main phenotypes: a severe phenotype and a mild phenotype [1].

SCD patients exhibit multiple organ damage generally due to recurrent occlusion of blood vessels, which is superimposed on a background of failure to thrive and poor development. A lot of patients have repeated hospital admissions for their condition, and may suffer from chronic pain episodes, recurrent infections, fatigue, delayed growth, vision problems, and hand-foot syndrome [4].

SCD patients require comprehensive care including pain management, preventive interventions, blood transfusions, and hydroxyurea. Moreover, transfusions complications like iron overload are common and have significant consequences such as heart failure, cirrhosis, and death [5]. Because of disabling and complex nature of SCD, suitable ambulatory management is critical to prevent acute

pain, hospitalizations, and vasoocclusive episodes [5].

Healthcare providers' attitudes towards patients may be a participating factor to the quality of communication and care that received by patients [6,7]. Identifying and eliminating the negative attitudes of health care providers is of great importance because of their well-known association with poor patient outcomes [7]. Therefore, this study aimed to investigate the health care provider attitude during the management of sickle cell disease patients in Saudi Arabia.

**METHODOLOGY:**

Based on the nature of the study, and the objectives sought to be achieved, and the data to be obtained to study the health care provider attitude during the management of sickle cell disease patients, based on the questions that study sought to answer them, the study used descriptive analytical approach which is based on the study of the phenomenon, as it is in reality, and contribute to describe it accurately as it illustrates its characteristics through information gathering, analysis and interpretation, and then apply the results in the light.

**Population & sample of the study**

The study population consists of all health care providers who work in Adult and pediatric emergency departments and hematological units, and the study relied on the selection of a simple random sample of the study population consisting of (55) persons, and so we have a Random study sample composed of 55 Observations, 47.7 % of them were male, and 52.3 % were female, and this size is adequate to give accurate results on the subject under study.

**Tool of the study**

Study tool represented in a form of questionnaire to study the health care provider attitude during the management of sickle cell disease patients. it is formed of three components: (1) attitudes, practices, and knowledge level; (2) the health care provider's believe ; and (3) demographic information.

**Correct Tool of the study**

Questionnaire has been designed according to five-scale, where answers are given numerical weights that present the answer degree to every statement, so it would be as follows, (Strongly agree) = 5, (Agree) = 4, (Not sure) = 3, (disagree) = 2, (Strongly disagree) = 1.

**Table (1): Correct Tool of the Study.**

Mean	Relative Weight	Level
Less than 1.8	Less than 36%	Strongly disagree
From 1.8 to less than 2.6	From 36% to 51.9%	disagree
From 2.6 to less than 3.4	From 52% to 67.9%	Not sure
From 3.4 to less than 4.2	From 68% to 83.9%	Agree
More than 4.2	More than 84%	Strongly Agree

**RELIABILITY & VALIDITY:****A. Validity****1. Face validity**

The face validity was used in order to ascertain the validity of the questionnaire and its suitability for research purposes by presenting it to a group of academic and professional arbitrators to express an opinion regarding the validity and validity of each paragraph of the questionnaire.

**2. Internal Consistency**

Internal consistent Means consistency of each paragraph of the questionnaire with the axis that belong to that specific paragraph, so correlation coefficients has been calculated between the degree of each paragraph and the total score of the axis to which it belongs, in order to verify the validity of the questionnaire, the results indicate validity consistency of internal data in the study where values of correlation coefficient ranged for all phrases between 0.219 to 0.673 and these values were significant at 5% level.

**B. Reliability**

In general reliability means the degree to which an instrument measures the same way each time it is used under the same condition with the same subjects, There are many methods in which it can be measured in order to ascertain the extent of the Reliability to measure what it was designed for, but

in this study Cronbach's Alpha method have been used to calculate the reliability in the data. the total reliability coefficient reached to 0.536, which considered good value of the Cronbach's Alpha.

**STATISTICAL METHODS:**

The statistical analysis program (SPSS v.21) was been used in the study in data entry and analysis, with the use of necessary statistical methods to achieve the objectives of the study. The following statistical methods were used:

- 1.Frequencies & Percentages
- 2.Mean.
- 3.Standard Deviation
- 4.Cronbach's Alpha.
- 5.Pearson Correlation Coefficient.
- 6.Chi-square test.

**DATA ANALYSIS AND DISCUSSION:****Introduction**

This chapter addresses the results of the descriptive statistical analysis represented in the description of the study sample, as well as the results of inferential statistical analysis, as well as displaying the most important statistical results that have been reached about the problem of the study, which aims to study the health care provider attitude during the management of sickle cell disease patients, in addition this Chapter include hypothesis testing results, discuss and comment upon and interpreted in line with the reality of the study.

**Analysis of results**

Table (2) shows the participants distribution according to demographic data, 47.7% of the participants were males, while 52.3% of them were females, their distribution according to their position 42.1% of them were Nurse, 28% of them were resident, 13.1% of them were specialist, and 9.3% of them were Consultant. And their distribution according to years of practice, 43% of them were between 5 to 10 years, and 23.4% of them were More than 10 years.

*Table (2): shows the participants distribution according to demographic data.*

		Frequency	Percent	P-value
<b>Gender</b>	Male	51	47.7	.629
	Female	56	52.3	
<b>Your Position:</b>	Nurse	45	42.1	.000
	Resident	30	28.0	
	Specialist	14	13.1	
	Consultant	10	9.3	
	Paramedic	4	3.7	
	Other	4	3.7	
<b>Years of practice:</b>	<1	10	9.3	.000
	1-3	13	12.1	
	3-5	13	12.1	
	5-10	46	43.0	
	>10	25	23.4	
<b>Total</b>		<b>107</b>	<b>100.0</b>	

The following table shows the participants distribution according to their deal with Sickle cell patients, 37.4 of them always deal with sickle cell patients, 28% of them usually deal with sickle cell patients, and 23.4% of them sometimes deal with sickle cell patients.

*Table(3): shows the participants distribution according to their deal with Sickle cell patients.*

	Frequency	Percent	P-value
Always	40	37.4	.000
Usually	30	28.0	
Sometimes	25	23.4	
Rarely	8	7.5	
Never	4	3.7	
Total	107	100.0	

The following table shows the percentage of patients with SCD as they seek drug when they come to the hospital, over-report (exaggerate) discomfort, and whether it is frustrating to take care. By assessing health care providers who work in Adult and pediatric emergency departments and hematological units. 20.6% of the participants believe that more than 75% of sickle cell patients seek drug when they come to the hospital, and 29.9% of the participants believe that 51% -75% of sickle cell patients seek drug when they come to the hospital.

27.1% of the participants believe that 51%-75% of sickle cell patients over-report (exaggerate) discomfort and 23.4% of the participants believe that 21% -50% of sickle cell patients over-report (exaggerate) discomfort.

19.6% of the participants believe that 21%-50% of sickle cell patients are frustrating to take care, and 19.6% of the participants believe that more than 75% of sickle cell patients are frustrating to take care.

*Table (4): shows the percentage of patients with SCD as they seek drug when they come to the hospital, over-report (exaggerate) discomfort, and whether it is frustrating to take care.*

What percentage of patients with SCD:		<5%	6% - 20%	21% - 50%	51% - 75%	>75%	P-value
Are drug seeking when they come to the hospital?	#	12	21	17	32	22	.033
	%	11.2	19.6	15.9	29.9	20.6	
over-report (exaggerate) discomfort?	#	9	18	25	29	17	.016
	%	8.4	16.8	23.4	27.1	15.9	
Are frustrating to take care of?	#	9	31	21	18	21	.015
	%	8.4	29	19.6	16.8	19.6	

The following table shows the mean, standard deviation, and relative weight By assessing health care providers who work in Adult and pediatric emergency departments and hematological units about the degree to which each of the following is a sign that the patient with SCD is inappropriately/unnecessarily drug-seeking.

**Table (5): shows the frequencies, percentages, mean, standard deviation, relative weight, of participants' answers on the first axis**

Dimensions		Strongly disagree	disagree	Not sure	Agree	Strongly Agree	Mean	Std.Dev	Relative weight
Patient requests specific narcotic drug and dose?	#	7	11	18	43	27	3.68	1.159	74%
	%	6.5	10.3	16.8	40.2	25.2			
Patient changes his/her behavior (e.g., appears in greater distress) when provider walks in room?	#	5	12	20	47	22	3.65	1.078	73%
	%	4.7	11.2	18.7	43.9	20.6			
Patient appears comfortable (e.g., talking on phone) while complaining of severe pain?	#	4	18	24	38	22	3.53	1.114	71%
	%	3.7	16.8	22.4	35.5	20.6			

The paragraph "Patient requests specific narcotic drug and dose" was ranked first with a relative weight 74%, while the paragraph "Patient changes his/her behavior (e.g., appears in greater distress) when provider walks in room" was ranked second with a relative weight 73%. and the paragraph "Patient appears comfortable (e.g., talking on phone) while

complaining of severe pain " was ranked third with a relative weight 71%.

The following table shows the mean, standard deviation, and relative weight by assessing health care providers who work in Adult and pediatric emergency departments and hematological units about the second axis statements

**Table (6): shows the frequencies, percentages, mean, standard deviation, relative weight, of participants' answers on the second axis**

Dimensions		Strongly disagree	disagree	Not sure	Agree	Strongly Agree	Mean	Std.Dev	Relative weight
The most reliable indicator of the existence and intensity of acute pain episodes in sickle cell disease is patient self-report.	#	5	18	14	60	9	3.47	1.025	69%
	%	4.7	16.8	13.1	56.1	8.4			
An important focus of the health care provider in treating acute pain episodes in sickle cell disease is prevention of drug addiction	#	9	10	18	48	21	3.58	1.162	72%
	%	8.4	9.3	16.8	44.9	19.6			
A patient with sickle cell disease can present with crisis in the absence of any objective measures (e.g., baseline hemoglobin, normal reticulocyte count, normal physical examination)	#	4	18	20	47	17	3.52	1.071	70%
	%	3.7	16.8	18.7	43.9	15.9			

The paragraph " An important focus of the health care provider in treating acute pain episodes in sickle cell disease is prevention of drug addiction " was ranked first with a relative weight 72%, while the paragraph " A patient with sickle cell disease can present with crisis in the absence of any objective measures (e.g., baseline hemoglobin, normal reticulocyte count, normal physical examination)" was ranked second with a relative weight 70%. and the paragraph " The most reliable indicator of the

existence and intensity of acute pain episodes in sickle cell disease is patient self-report." was ranked third with a relative weight 69%.

The following table shows the mean, standard deviation, and relative weight By opinion health care providers who work in Adult and pediatric emergency departments and hematological units of SCD patients who exaggerate pain.

**Table (7): shows the frequencies, percentages, mean, standard deviation, relative weight, of participants' answers on the third axis**

Dimensions		Strongly disagree	disagree	Not sure	Agree	Strongly Agree	Mean	Std.Dev	Relative weight
Inadequate pain management by doctors and nurses	#	21	19.6	21	19.6	21	2.69	1.247	54%
	%	33	30.8	33	30.8	33			
Previous poor pain management in the health care system	#	19	26	13	42	3	2.84	1.227	57%
	%	17.8	24.3	12.1	39.3	2.8			

The paragraph " Previous poor pain management in the health care system " was ranked first with a relative weight 57%, while the paragraph " Inadequate pain management by doctors and nurses " was ranked second with a relative weight 54%.

The following table shows the mean, standard deviation, and relative weight by assessing health care providers who work in Adult and pediatric emergency departments and hematological units about the fourth axis statements

**Table (8): shows the frequencies, percentages, mean, standard deviation, relative weight, of participants' answers on the fourth axis**

Dimensions		Strongly disagree	disagree	Not sure	Agree	Strongly Agree	Mean	Std.Dev	Relative weight
I am bothered by the way some nurses treat patients with sickle cell disease	#	13	31	18	28	14	2.99	1.273	60%
	%	12.1	29	16.8	26.2	13.1			
I am bothered by the way some doctors treat patients with sickle cell disease	#	13	29	19	34	8	2.95	1.199	59%
	%	12.1	27.1	17.8	31.8	7.5			

The paragraph "I am bothered by the way some nurses treat patients with sickle cell disease" was ranked first with a relative weight 60%, while the paragraph "I am bothered by the way some doctors treat patients with sickle cell disease " was ranked second with a relative weight 59%.

### DISCUSSION:

We conducted a study to investigate Saudi health care provider attitude during the management of sickle cell disease patients. This study included 55

participants, the majority of them were females by 52.3 %. The proportions of nurses and physicians were close in this study, nurses constituted about 42.1% of health care providers in this study. Most of the participants in this study showed that they treat with SCD patients continuously, demonstrating the importance of knowing their attitude towards this category of patients and their ability to deal properly with those patients.

Its known that the attitudes of health care provider

towards certain groups of patients are affect the quality of care delivered to patients. Our findings showed that the attitude of health care providers was generally negative during the management of sickle cell disease patients. Yaqoob et al. found similar results in their study among staff nurses in Bahrain (8), and Freiermuth et al. in their study among emergency department providers (9).

About half of the participants in this study believe that the majority of patients exaggerate the expression of pain. As well as, the majority of our participants don't frustrating to take care of SCD patients. This corresponds to Freiermuth et al. who found that their Sample of Emergency Department Providers showed Unease with care of sickle cell patients (9), as well as Mainous et al. who found that only 20.4% of academic family physicians respondents felt comfortable with treatment of SCD (5), Etienne also pointed out that nurses experience uneasiness ,frustration and anger when they are required to care for SCD patients (10).

In general, participants in this study showed good knowledge of the signs that denotes that the patient with SCD is inappropriate / unnecessary drug solicitation. More than half of the participants agreed to consider the patient's behavior to determine if he needed drug or not. This is agree with what has been found in several previous studies that the nurses rely on the patient's behavior and vital signs to identify pain intensity (8, 11, 12).

But with regard to the patient's relaxed behavior such as talking or using the phone while claiming a severe pain. More than half of the participants thought that this group of patients with SCD are inappropriately/unnecessarily drug-seeking. This is a misconception that needs to be modified, SCD patients may not exhibit the expected signs of pain, because of coping mechanisms which have developed during the day-to-day SCD management. Patients who live with chronic and/or acute pain experiences psychological and physiological changes which affect pain behaviors and causes lack of visible signs of pain. So, when a health care provider perceives that SCD patients are not in pain because they can talk on the telephone, this could cause delays and stigmatization in treatment. It is necessary to know that, untreated acute SCD pain can cause morbidity and mortality (13).

There are potential objective indicators of pain such as grimacing, increased heart rate, etc., however, pain still subjective (14). The most reliable indicator of pain is Self-report (8). The majority of our

participants thought that the most reliable indicator of the existence and intensity of acute pain episodes in sickle cell disease is patient self-report.

addiction is a behavioral and psychological syndrome in which there is craving for a drug, compulsive use of a drug, and strong tendency to relapse if the drug is withdrawn (15). It was reported that, many physicians believe that SCD patients are more likely to become addicted to pain medication than other patients categories (16). Nearly half of the participants in our study believe that, they should focus on prevention of addiction during treating acute pain episodes. Studies show that providers are overestimate the risk of narcotics addiction and drug abuse among SCD patients (17-19).

Based on the opinion of our participants, physicians were better than nurses in the management of sickle cell disease patients. this is consistent with Freiermuth, Caroline et al. (9) and Singh et al. (20). This may be due to the better scientific level and broader experience of physicians compared to nurses, making them better able to understand the extent of the disease and how to deal with it. As well as, nurses usually have more longer and frequent interactions with the patient than physicians, so this "greater exposure" may explain higher levels of negative attitudes among nurses compared to physicians.

This study has some limitations including the number of participants in the study is small and therefore cannot be representative of all health care providers in Saudi Arabia, and the limitation of study time.

### CONCLUSION:

The results of this study showed that health care providers in Saudi Arabia have shown a negative attitude towards sickle cell disease patients. But the nurses were more negative towards this group of patients compared to physicians. Therefore, health care providers need to provide them with awareness programs and specialized people to teach them about sickle cell disease and about addiction to pain medication.

### ACKNOWLEDGEMENT:

We send our huge thanks to King Fahd Hospital in medina city, and all of Dr. Fatimah Saleh Alshammari, Miss. Imtinan Ibrahim Alhejaili, Miss. Walaa Jamil Masudi and Mrs. Hala Hashim Alsharif as they were our best data collectors, and it is rare to never to found someone like them, we hope for them the best life in their feature and may Allah bless them.

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