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Sickle Cell Anemia Patients' Perception of Vaso-Occlusive Crisis Management

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Abstract: *Vaso occlusive crisis is the most common cause among sickle cell anemia patients for admission. However, some patients complain of unrecovered of pain and recurrent hospitalization.*
Aim: *The study aimed to assess sickle cell anemia patients' perception of vaso occlusive crisis management.*
Methodology: *Quantitative descriptive study.*
Setting*: The study conducted in medical units at King Abdulaziz Hospital.*
Subjects: *A convenience sample of 65 adult patients of both gender diagnosed with sickle cell anemia hospitalized for vaso occlusive crisis management.*
Tool: *Patients' perception was assessed via structured interview patients' perception questionnaire regarding vaso occlusive crisis management. The questionnaire developed by the researcher. It was divided into two parts, part I is patients'sociodemographic and clinical data and part II is assessment of sickle cell anemia patients' perception of vaso occlusive crisis management.*
Result: *Overall patients' perception of VOC management weighted mean was 3.65 which consider as agreement for the provided management. Highest weighted means were 4.29 for treating with trust and respect followed by fluid therapy 4.20 and 4.15 for medical management. The lowest weighted means were related to nursing care provided during hospitalization. Among patients, there was no significant difference in age, gender, educational qualification, length of stay and waiting time in ED related to patients' perception since the $p > 0.05$. In addition, there was no influence of patients' perception by their age, gender and educational qualification.*
Conclusion: *Nursing, medical and hospital administration services considered as an essential aspect in patients' perception of VOC management provided during hospitalization. Therefore, nurses need to be encouraged for promoting their nursing care.*
Keywords: *Sickle cell disease, Vaso occlusive crisis, Management, Patients' Perception, Pain*

I. Introduction

Sickle cell disease according to National Heart, Lung, and Blood Institute in 2016 define as a label to all inherited red blood cell diseases and characterized by present of abnormal hemoglobin S (HbS) in red blood cells (RBCs). Hemoglobin is a protein find in RBCs with function to provide oxygen to all parts of the body. The meaning of inherited disease mean that disease transmitted from parents to their children through gene. Diseased individuals have two abnormal genes from each parent, and even though having at least one abnormal gene can cause the production of Hb S. On the other hand when an individual has two Hb S (Hb SS) in this case he will be diseased with sickle cell anemia. SCD most commonly disease in Africa, India, Caribbean, Middle East, and the Mediterranean (Mousa et al., 2010a; Zaini, 2016). SCD is affecting between 72,000-98,000 African American in the United States population (Hassell, 2010). National Hospital Ambulatory Medical Care estimated the number of visits of SCD patients 197,000 visits yearly and 29% admissions (Yusuf, Atrash, Grosse, Parker, & Grant, 2010). 90% of SCD patients visiting the emergency department (ED) need for admission due to episodes of sickle cell crisis (Brown, 2012).

In Saudi Arabia first gene of the sickle cell had been recognizing in Eastern region in 1963 by Lehman and coworkers. In Saudi Arabia, the HbS carrier prevalence differs in the northern and central regions from 0 to 1%. Moreover, it is varying in western, southern and some parts of the east by 7%, 12% and 25% respectively. By 2007 highest rate of sickling reported from Al-Ahsa followed by Qunfudah and Jazan(Mousa et al., 2010a; Zaini, 2016). Vaso-occlusive crisis (VOC), also termed sickle cell pain crisis, results from the small blood vessels blocking by sickled cells, with pain resulting from localized ischemia. Additional contributing factors likely include associated vascular endothelial damage and inflammation. Over time, recurrent VOC with

intermittent ischemia may lead to chronic end-organ damage, which is also characteristic of SCD (Hunt & Alisky, 2013).

From the perspective of patients, acute vaso-occlusive pain is the most significant complication. The increase of pain hesitancy associated with early death among sickle cell anemia patients older than 20 years (Rees, Williams, & Gladwin, 2010). Moreover, VOC considers as the responsible reason for 78-91% emergency visits and 59-68% of hospital admission for SCA patients with average 8-11 days of hospitalization length (Oelschlaeger, 2016). It varies in severity from debilitating to tolerable, and in frequency from constant to hardly ever. Variation in the presentation is due to both essential factors such as genotype or phenotype and extrinsic factors such as infection, exposure to cold or stress (Augier et al., 2014).

The reason behind recurrent emergency department (ED) visiting and multiple hospitalizations with short interval in-between for sickle cell anemia (SCA) patients experience vaso-occlusive crisis (VOC) is often due to complaining of VOC management.Yet there is no report about vaso-occlusive management in Saudi Arabia. Most of the patients visiting ED are sickle cell disease patients due to the painful crisis. In addition, SCA patients complaining of ignorance or neglected from nurses or delivering management without any concern to patients' experience of pain (Jenerette, Brewer, & Ataga, 2014; Lanzkron, S., Carroll, C Patrick, & Haywood, 2010).

There are factors affecting of patients' perception about crisis management such as excess numbers of SCD patients visiting ED or hospitalized, staff shortage or negative attitude toward those patients (Porter et al., 2012). Appropriate treatment to SCA patients who visit the hospital with crisis pain can decrease the rate of hospitalizations and readmission.Management of vaso-occlusive crisis is a complex concern which needs more attention from health care providers, all patients with SCD experience VOC during their lifetime and they are at risk for acute complication in case of improper management such as acute chest syndrome (Yawn et al., 2014).

The highest number of patients visiting the emergency department or admitting to the hospital are sickle cell anemia patients complaining of vaso-occlusive crisis pain that cannot be manage at home. Despite crisis pain management provided during the long period of hospitalization, still, some SCA patients demonstrate a low level of satisfaction and complaining of unmanaged pain either normal discharged or against medical advice.The purpose is to measure the patients' perception regarding crisis pain management they receive during their visit to ED or hospitalized which can give us a hint to what the patients' need more than a painkiller and how the way of providing treatment can effect on patients' perception. Understanding patients' perception will promote communication related VOC pain management process between patients and health care providers. However, only few studies undertaken in this topic. Even though all the studies done in ED and assessing the management provided during visiting ED. VOC management is extend even for after discharge, health care providers role didn't stop when the patients receiving the treatment. Non-pharmacological approaches showed an important role in managing VOC pain along with pharmacological, despite the ignorance of this part during management from health care providers.

Aim of the study:

This study aimed to assess sickle cell anemia patients' perception of vaso-occlusive crisis management.

Research question

What is the sickle cell anemia patients' perception regarding vaso-occlusive crisis management?

II. Materials and Method

II.1.Study design: Quantitative descriptive design was used in this study.

II.2.Setting: The researcher conducted the study in female and male medical wards at King Abdulaziz Hospital (KAH) in Jeddah. Each ward with total capacity of 31 beds capacity, the average of SCA patients admitted to each ward 3-6 patients weekly according to medical records reports in medical wards. KAH located in the south regionof Jeddah. This hospital stated operating under the Ministry of Health (MOH) in 1990 with full bed capacity of 445 beds.

II.3.Subjects: A convenience sample of 65 adult patients of both gender diagnosed as SCA with VOC. The sample size was estimated by using the EPI info program with confidence coefficient at 90%.

Inclusion criteria:

- SCA patients at resolving phase of painful crisis (sixth day of attack).
- Patients with age 18 years and above.

Exclusion criteria:

- Patients with chronic diseases (diabetes mellitus and hypertension) or SCA complications (acute chest syndrome, leg ulcers, stroke, deep vein thrombosis and pulmonary embolism).

II.4.Tool: Patients' Perception regarding Vaso-Occlusive Crisis Management Questionnaire
Structured interview questionnaire to assess patients' perception of VOC management. It was developed by the researcher after thorough review of literature, it was divided into two parts:

Part I: Patients' Sociodemographic and Clinical Data:

It was developed by the researcher to elicit the following data: age, sex, years of diagnosis as SCA, education qualification, working status, marital status, smoking, alcohol consumption, number and the reason for visiting the emergency department, number of previous hospital admission during the last year, factor of crisis precipitating, and duration of last hospital admission.

Part II: Assessment of SCA Patients' Perception of VOC management Tool:

In this part patients will be asked how strongly do they agree or disagree with the 18 items regarding VOC management, these items rated on a 5-points Likert scale ranging from strongly agree = 5 to strongly disagree =

II.5.Written approval: The research proposal has been sent to the medical research and study department in directorate of health affairs at Jeddah with all required papers that filled up by the researcher student and ratified by the King Abdulaziz University nursing administration to obtain a written approval for the topic of study and get the right to conduct the study at king abdulaziz hospital.

II.6.Validity and reliability: The data collection tool was developed by the researcher in English language and translated into Arabic language, tool was reviewed by five academic experts in the medical surgical nursing department to test its clarity, relevance and no modifications were done accordingly. The reliability statistically measured by Cronbach's Alpha α, reliability score for instrument variables was 0.94.

II.7.Pilot study: Pilot study is important to assess feasibility of the study to be conducted on the setting areas, check each question if it measure what supposed to measure, if words and questions understandable, all participant's response in the same way, time needed to answer all questions. 10% of sample size, equivalent to 7 participants. Pilot study conducted at King Abdulaziz Hospital included medical wards over three weeks. After analyzing and reviewing the pilot study results. No changes were done.

II.8.Procedure: The study was conducted throughout a period of three months from October to December in 2016

- Researcher interviewed the patients after head nurse permission and explained the procedure of collecting data from patients.
- The researcher introduced herself; explain verbally the purpose of the study and patients have rights to participate or not.
- After patients verbally agreement to participate, the interview was started and each interview last for 15 minutes to complete the patents' perception questionnaire.

II.9.Ethical consideration: Study summary given to the patients include title, aim and benefits of participating. Patients allowed to ask questions before participating. Privacy and confidentiality of the collected data assured. Each participant informed about his right to withdraw participating in the study without consequences or harm.

Statistical analysis

Statistical Package for the Social Sciences (SPSS, version 22), was used to analyze the collected data from the study instruments. Descriptive statistics were used to examine the sociodemographic and clinical data. Frequency distributions were used to examine demographic and clinical data variables.Multiple response was used for frequency distribution to examine question 11, question 14 and question 15. Coded were done for all questions and statements of Likert scale. After coding all data entered in the SPSS. No missing values or data noticed. To measure the associations between SCA patients' perception of VOC management and some of demographic data, researcher used a statistic test called chi-square and is denoted by χ^2 . All statistical significance was based on a p-value less than or equal 0.05.

III. Result

Table 1 illustrate the characteristics regarding the sociodemographic data of the study. Males filled the ranks of patients at 64.6%. In addition, 96.9% of patients diagnosed as SCA patients since more than 15 years, and those aged 18-29 dominated the study, totaling 63.1% of the participants. Over half of the sample (63.1%) were single, with 40% of patients having completed secondary level of education. The unemployment rate among patients was prevailing at 46.2%. Finally, a majority of patients (76.9%) were non-smokers.

Table 1 Illustration of Sickle Cell Anemia Patients' Sociodemographic Data (n=65)

Sociodemographic Data	n	%
Age		
8- 29 years	41	63.1
30 - 39 years	22	33.8
40 - 49 years	2	3.1
Gender		
Male	42	64.6
Female	23	35.4
Years since diagnosed as SCD patient		
11 - 15 years	2	3.1
> 15 years	63	96.9
Educational Qualification		
Illiterate	2	3.1
Primary	19	29.2
Intermediate	8	12.3
Secondary	26	40
Bachelor degree	10	15.4
Working condition		
Full time	15	23.1
Part time	5	7.7
Receiving subvention	15	23.1
Not working	30	46.2
Marital status		
Single	41	63.1
Married	22	33.8
Divorced	2	3.1
Smoking		
Smoker	15	23.1
Non-smoker	50	76.9

Table 2 reveals that 67.7% admitted to the hospital due to VOC did so 1-4 times in the last year. In response to precipitating factors of VOC, 46.5% of patients chose cold exposure as the dominant factor in precipitating a crisis, with physical exertion next at 26.7%. Only 1.2% listed smoking and fever as precipitating factors.Over a third of patients who completed the questionnaire had experienced a crisis level of pain that lasted between 4-6 days. Furthermore, about two-third of patients (66%) indicated using oral analgesics (such as paracetamol) and anti-inflammatory medicines (such as Brufen) when experiencing VOC pain at home. Additionally, 33% of patients used massage to reduce pain in affected areas as nonpharmacological management, with 25.8% using warm compression.Interestingly, 96.9% of patients waiting in the ED for more than 1 hour before admission, with 76.9% waiting more than 1 hour in the ED just to receive the first dose of analgesic. In regards to the length of hospitalization, 44.6% were admitted for 1 week and 32.3% for 2 weeks. Only 12.3% indicated their last hospitalization lasted more than 4 weeks.

Table 2 Illustrate Sickle Cell Anemia Patients' Clinical Data (n=65)

Clinical data	**n**	**%**
Number of Hospital Admissions Due to Crisis in Last Year		
1-4 times	44	67.7
5-8 times	9	13.8
9-12 times	6	9.2
More than 12 times	6	9.2
Precipitating Factors of VOC		
Cold exposure	40	46.5
Physical exertion	23	26.7
Stress	6	7
Smoking	1	1.2
Infection	3	3.5
Hypoxia	10	11.6
Fever	1	1.2
Menstruation	2	2.3

The Average Length of Crisis Period		
1-3 days	16	24.6
4-6 days	26	40
7-9 days	17	26.2
10-11 days	6	9.2
Pharmacological Management Intervention to Relieve Pain at Home		
Paracetamol tab	32	33
Brufen tab	32	33
Tramal tab	28	28.9
Others	5	5.2
Non-Pharmacological Management Intervention to Relieve Pain at Home		
Heat generating ointment	18	18.6
Massage to affected area	32	33
Distraction	2	2.1
Relaxation	5	5.2
Bandaging affected area	9	9.3
Warm compression	25	25.8
Prayers	3	3.1
Herbal medicine	1	1
Music therapy	1	1
Others	1	1
Waiting time in emergency department before admission		
30 -< 60 mins.	2	3.1
> 1 hr.	63	96.9
Waiting Time Before Receiving First Dose of Analgesics in Emergency Department Before Admission		
15-< 30 mins.	2	3.1
30-< 60 mins.	13	20
> 1 hr.	50	76.9
Length of Last Hospitalization		
1 week	29	44.6
2 weeks	21	32.3
3 weeks	7	10.8
More than 4 weeks	8	12.3

Table 3 summarized the overall mean result of the patients' perception of VOC management. The overall total score mean for patients' perception is 73% (3.65 ± 0.71) on a 5-point Likert scale. High score of mean signifies that SCA patients' perception agree with VOC management. However, patients treated by health-care providers with trust and respect showed the highest mean (4.29) among SCA patients, while patients encouraged by nurses to try nonpharmacological interventions showed the lowest mean 2.80.A look into the details reveals that 85.5% of patients strongly agree that health-care providers treated them with trust and respect. 73.4% of patients reported agree for the effectiveness of overall crisis interventions received during hospitalization.

Nurses perform frequent pain assessments and check vital signs. 75.6% of those surveyed agree that nurses do their role. 62.4% of patients uncertain that nurses responded fast enough when they were in pain. 75.6% of patients agreed that painkillers were always given to them when needed. In a related question regarding the adequacy of painkiller dosage, 69.8% agreed the doses were adequate. 73.2% of patients agreed that the nurses took their pain needs seriously. A majority of patients 77.6% agreed with the effectiveness of VOC drugs. 84% of patients strongly agreed that they received adequate intravenous fluids during hospitalization. 73.2% of patients agreed with administration of oxygen therapy when they needed it. 67.4% of patients were uncertain that close monitoring of oxygen saturation and respiratory rate was completed. 56% of patients uncertain with the nurses encouraging them to try nonpharmacological intervention during moderate pain.

In regards to the statement titled number 13 "Psychological support provided to you during hospitalization," 56.4% of patients uncertain with the statement. However, 70.8% of patients agreed that all their concerns related to VOC management were answered. In response to the statement "Received full information regarding your crisis management" 70.2% were agree. Majority of sample 83% agree that doctor did a good job in treating pain. "Discharge plan and follow-up discussed with you" 72.6% agree with this statement. In the last statement in the questionnaire, "Satisfied with overall care provided at hospital," 69.8% of patients agreed.

Table 3 Overall sickle cell anemia patients' perception of vaso occlusive crisis management

Statements	Total (%)	W.M. ± S.D	Overall Response (in Mean)
1- Health-care provider treated you with trust and respect	85.8	4.29 ± 1.00	Strongly Agree
2- Overall crisis intervention you received was effective	73.4	3.67 ± 0.56	Agree
3- Nurse performs frequently pain assessment and vital signs checking (blood pressure-temperature-pulse-respiration rate) during your crisis	75.6	3.78 ± 1.26	Agree
4- Nurse responded fast when you are in pain	62.4	3.12 ± 1.40	Uncertain
5- Painkiller always given to you when needed	75.6	3.78 ± 1.29	Agree
6- Painkiller dose was adequate	69.8	3.49 ± 1.34	Agree
7- Nurses taking your pain needs seriously	73.2	3.66 ±1.27	Agree
8- The Vaso-Occlusive crisis drugs were effective	77.6	3.88 ± 1.11	Agree
9- Adequate intravenous fluids administered during hospitalization	84	4.20 ± 1.06	Strongly Agree
10- Oxygen therapy was administer when needed	73.2	3.66 ± 1.19	Agree
11- Close monitoring of oxygen saturation and respiratory status	67.4	3.37 ± 1.27	Uncertain
12- Nurses encourage you to try nondrug intervention (heat, prayers etc.) in case of moderate pain	56	2.80 ± 1.43	Uncertain
13- Psychological support provided to you during hospitalization	56.4	2.82 ± 1.38	Uncertain
14- You been answered regarding your concerns related Vaso-Occlusive crisis management	70.8	3.54 ± 1.20	Agree
15- Received full information regarding your crisis management	70.2	3.51 ± 1.29	Agree
16- Doctor did a good job in treating pain	83	4.15 ± 0.96	Agree
17- Discharge plan and follow-up discussed with you	72.6	3.63 ± 1.33	Agree
18-Satisfied with overall care provided at hospital	69.8	3.49 ± 1.29	Agree
Total	**73**	**3.65 ± 0.71**	Agree

Table 4 shows the ranking of patients' perception items of Vaso-Occlusive crisis management according to the weighted mean. Those in Vaso-occlusive crisis management marking agree with the statement "health-care provider treated you with trust and respect" represented the highest item scored with a weighted mean of 4.29 ± 1.00, while those marking uncertain in the statement "nurses encourage you to try nondrug intervention (heat, prayers, etc.) in case of moderate pain" registered the lowest mean seen at 2.80 ± 1.43.

Table 4.4 Ranking of perception items for vaso occlusive crisis management according to weighted mean score

Study rank	Statements
1	Health care provider treated you with trust and respect.
2	Adequate intravenous fluids administered during hospitalization.
3	Doctor did a good job in treating pain.
4	The Vaso-occlusive crisis drugs were effective
5	Painkiller always given to you when needed.
6	Nurse perform frequently pain assessment and vital signs checking (blood pressure-temperature-pulse-respiration rate) during your crisis.
7	Overall crisis intervention you received was effective
8	Nurses taking your pain needs seriously.
9	Oxygen therapy was administer when needed.
10	Discharge plan and follow-up discussed with you
11	You been answered regarding your concerns related vaso-occlusive crisis management
12	Received full information regarding your crisis management.
13	Painkiller dose was adequate.

14	Satisfied with overall care provided at hospital.
15	Close monitoring of oxygen saturation and respiratory status.
16	Nurse was responding fast when you are in pain.
17	Psychological support provided to you during hospitalization.
18	Nurses encourage you to try nondrug intervention (heat, prayers etc.) in case of moderate pain.

For studying the relation between patients' perception of VOC management and their age, gender, and educational qualification, the chi-square test used a p-value < 0.05 as presented in Table 5 The patients' age, gender, and educational qualification showed no significant relation on perception since p-value > 0.05.

Table 5 Relation between the sickle cell anemia patients' perception of VOC management and the patients' age, gender and educational qualification

Sociodemographic data	**Assessment of Patients' perception**					2	Sig. (p-value)
	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree		
	no.	no.	no.	no.	no.		
Age							
18 -< 30	1	1	8	26	5		
30 - < 40	0	1	4	12	5	3.368	0.909
40- < 50	0	0	1	1	0		
Gender							
Male	1	0	10	24	7	5.349	0.253
Female	0	2	3	15	3		
Educational qualification							
Illiterate	0	0	0	2	2		
Primary	0	1	1	13	4		
Intermediate	0	0	1	6	1		
Secondary	0	0	8	14	4	15.981	0.454
Bachelor degree	1	1	3	4	1		

IV. Discussion

This research studied the SCA patients' perception of VOC management in medical wards within KAH at Jeddah city. This study used a descriptive design utilizing a tool developed by the researcher to assess the SCA patients' perception of VOC management. This study is the first to provide data on the scale of perception of VOC management for SCA patients in medical wards at KAH. patients' perception assessed through a Likert scale developed by the researcher. The first item covered whether they were treated with trust and respect. 85.8% of patients stated they strongly agreed with being treated with trust and respect by health-care either the nurses or doctors in medical units. It seems possible that the result stems from frequent readmission of patients to medical units which leads to them making a relationship with health-care provider. In agreement with this result, a previous study has demonstrated that 83 - 86% of SCD patients reported that the triage nurse, the ED nurse, and the ED physician had treated them with trust and respect (Porter et al., 2012).

In the current study, 73.4% reported that they agreed on the overall effectiveness of the VOC intervention they received during hospitalization. When specifically asked about overall management interventions, blood transfusion reported a mean of 4.35 and painkillers with a mean of 4.32, distinguishing themselves as the most effective in the eyes of the patients.

The results of this item will now be compared to the findings of previous works. A pilot randomized trial conducted to determine if RBC transfusion of approximately 10 ml/kg given within 24 hours of a VOC related admission might decrease the hospitalization time (HT) and cumulative opioid requirements. It found that the mean time of disconnection from IV pain medications in the subjects that received transfusion was 3.5 ± 1 d compared to 5.5 ± 3.9 d with those receiving standard care. Patients in the transfusion group had a 51% decrease in mean daily pain score in the 48 hours' post-transfusion compared to a 17% decrease in pain scores in the standard care group over the same time frame (Kelly, Deng, Hoppe, & Styles, 2015).

In the present study, 75.6% of those sampled agreed that the nurses performed frequent pain assessments and vital signs checks. A possible explanation for this result is that nurses know that any changes in pain levels and vital signs are related to the patients' status. This finding was supported by Yaqoob & Nasaif (2015) which demonstrated that 90% of the nurses agreed that vital signs are indicators for the pain intensity of patients'.

Additionally, 62.4% of patients were uncertain when asked about the speed with which nurses responded when patients were in pain. This result may indicate that nurses' have inadequate knowledge in VOC

management. This finding is consistent with the findings of Yaqoob & Nasaif (2015) which showed that staff nurses in SCD wards possessed poor knowledge of pain assessment and management.

In this study, 73.2% of patients agreed that nurses took their pain needs seriously. This result may be related to the positive attitude of medical nurses concerning SCA patients. Moreover, this contradicts a previous study by Jenerette et al., in 2015 that assessed nurses' attitude toward SCD patients. 55.5% of the respondents reported that nurses working in medical units or surgical units were more likely to show a negative attitude. According to the theory of self-care management for SCD, poor health outcome can be associated with negative nurse attitudes toward SCD patients, which affects the nurse-patient relationship (Jenerette, Pierre-Louis, Matthie, & Girardeau, 2015).

This study found that 86.4% of surveyed patients agreed regarding the effectiveness of painkiller, with 75.6% saying that painkillers were always given when needed and 69.8% stating the dose was adequate, . This result may be explained by the fact that a patient receives proper pharmacological management results that reduce pain level. This finding agrees with Feliu et al. (2011) which found that patients with oxycontin, oxycodone, methadone, and morphine reported their current pain intensity rating to be 3.06 ± 2.63 out of 10, with a reported 4.63 ± 2.83 average pain rating over the previous week and 5.34 ± 3.16 over the past month.

On the statement regarding administration of oxygen therapy when needed, more than half of the patients (73.2%) reported they agreed with the statement. This result indicates the importance of demanding oxygen therapy for SCA patients during VOC management. In the line with this finding, Rowley et al. (2014) examined the microvascular oxygen consumption during sickle cell pain crisis and found that the median level of microvascular oxygen consumption for SCD patients during the crisis was 1.10 greater than the median level of healthy people at 0.75. This indicates that limitation of delivering oxygen increases the oxygen consumption level which affects the local oxygen saturation of hemoglobin.

Surprisingly, patients reported positively regarding oxygen administration, even though 67.4% reported uncertain when asked about close monitoring of oxygen saturation and respiratory status. A possible explanation for this result may be due to staff shortage or extended shifts which lead to work overload on nurses and improper care delivery to patients. An earlier study examined the relationship between nurses' shift length and patient/nurse outcomes. They found that patients were less satisfied with their care when there was higher percent of nurses working shifts of thirteen or more hours, and that higher satisfaction levels corresponded with a higher percentage of nurses working eleven or fewer hours (Stimpfel, Sloane, & Aiken, 2012).

In the current study, 84% of patients reported strongly agreed with the adequacy of intravenous fluids administered during hospitalization, indicating the importance of fluid therapy for VOC management plan. This matches previous findings conducted by Carden et al. (2017) which assessed stiffness of sickle RBCs after exposure to different IVFs. They found that the stiffness of sickle cells in normal saline (NS) was higher than those exposed to iso-osmolar fluids and hypo-osmolar fluids.

Furthermore, more than half of patients (56%) reported uncertainty regarding nurses' encouragement of the patient to pursue non-pharmacological therapies in the case of moderate pain events. The possible explanation for this result is inadequate nurses' knowledge regarding the importance of using non-pharmacological therapies and encourage patients to use non-pharmacological therapies. This result is supported by another study in Hong Kong which showed that nurses possess inadequate knowledge about both pharmacological and non-pharmacological interventions for pain (Lui, So, & Fong, 2008). Nonpharmacological therapies are effective in managing psychological and social complications of SCD, such as decreasing feelings of anxiety and depression, enhancing coping skills, and improving the quality of life (Williams & Tanabe, 2015).

In a disappointing result, 56.4% of patients surveyed reported being uncertain regarding whether or not they were provided psychological support during hospitalization. This result may stem from a lack of importance placed by the hospital on psychiatric consultations as a part of SCA patient management. In 2015, a study examined the role of spirituality and religiosity in adolescents and adults living with SCD as reported in research conducted from 2001-2013. The study found the use of spirituality and religiosity was ranked as important in increasing the ability to cope with SCD pain and decreasing reports of pain (Clayton-Jones & Haglund, 2015).

In this study, 70.8% patients agreed that health-care providers answered their concerns regarding VOC management and 70.2% of patients agreed that they received complete information about VOC management. The possible explanation for this result is a hospital focus on patient involvement in a pain management plan. This result is similar to the conclusion of Vahdat et al (2014) which concluded that patients' participation is considered a public right, one that guarantees the patient has complete information related to diagnosis and treatment. This resulted in increased satisfaction levels among patients', improve quality of life, decreased stress and anxiety, and enhanced professional relationships between patients and health-care providers.

Although this result differs from some published studies, Lattimer et al. (2010) used a cohort study to measure the hospital encounters of 45 patients using a standard research tool (The Picker Patient Experience Questionnaire, PPE-15). The results indicated that 86% of these patients were not involved in their care decisions and 64% received unclear information, including vague answers to treatment questions.

From the patients' perspective, 83% reported they agreed that the doctor did a good job in treating and managing their pain. In the study done by Porter. et.al., (2012) they found that 35% of 209 SCD patients surveyed reported the ED clinician did a good job managing pain. This result reflects the importance of which physician is treating the patient since he is the one leading the treatment plan and ordering medication. A high percent of agreement indicates a high level of trust between patients and their physicians.

Patients' perception is an indicator of adequate pain management. In a 2009 study done to assess patient perception of pain care in hospitals in the United States, they found a high rating (63%) of global satisfaction reported by patients regarding pain care. This high level of satisfaction was associated with high-level of pain control (Gupta, Daigle, Mojica, & Hurley, 2009). Importantly, 69.8% of patients surveyed reported being satisfied regarding overall care provided at the hospital. Oelschlaeger (2016) explored the perception of pain management in sickle cell crisis on three different sickle cell disease patients admitted to the same hospital at the same time, each with different histories and lab works. Upon discharge, pain management of crisis was assessed by asking questions of those three patients about their perceptions. The two most important questions dealt with their satisfaction levels with the pain management and what one thing they would change about the hospital stay as it related to pain management. All three patients stated they were satisfied regarding the management during their hospital stay, but, when asked to describe in more detail they showed some dissatisfaction regarding the management in regards to wait time to receive their pain medication, early discharge, a lack of understanding by the nursing staff concerning their condition, and the attitudes of health-care providers toward each of them, specifically that they were accused by the staff of faking the pain to receive painkillers.

Previous research found that a patient's age and gender could potentially influence a patient's perceptions of care, safety, participation, and levels of trust (Mollon, 2015). Suhonen and colleagues observed a trend whereby orthopedic or trauma patients from five different countries (Finland, Greece, Sweden, the UK, and the USA) perceived their care as less individualized the higher their educational level was. Moreover, the patients in older than 65 gave a higher evaluation of their care (Suhonen et al., 2010). The findings from this study do not support the findings of Suhonen et al. since no significant relationships were found. The possible explanation for this could be the lower percent of patients with an age 40 - 49 (2%) and the highest percentage of educational qualification fell in the secondary levels.

V. Conclusion

Numerous elements related to nursing, medical and hospital administrationexist to improve VOC management provided to SCA patients. Therefore, nursing, medical, and hospital administration services should be recognized as an essential aspect in the patients' perceptions of VOC management provided during hospitalization.Nurses should not consider their role limited to carrying out the doctors' orders only as they play a significant role in providing care. Their role toward SCA patients expands to the home through education, advocating for patients' right, and helping patients to gain access to all aspects of hospital care.This study showed that patients strongly agreed that trust and being treated with respect are paramount. This could be due to frequent admissions to the hospital and repeated meetings with the same health-care providers. Some aspects of nursing care identified were met with uncertain levels of perception. This could be due to negative attitudes of nurses toward SCA patients or due to a lack in the nurses' knowledge on the care needed. Despite the uncertainty reported regarding the nursing aspects, patients still reported being satisfied with their overall hospital care.

References

[1]. What Is Sickle Cell Disease? (2016, August 2). Retrieved May 15, 2017, from https://www.nhlbi.nih.gov/health/health-topics/topics/sca

[2]. Mousa, S. A., Alabdullatif, A., Al Sayegh, M., Artz, F., Al Zahrani, H., Hegazi, M., … Al Kindi, S. (2010a). Management of Painful VasoOcclusive Crisis of SickleCell Anemia: Consensus Opinion, 16(4), 365–376. http://doi.org/10.1177/1076029609352661.

[3]. Hassell, K. L. (2010). Population Estimates of Sickle Cell Disease in the U.S. AMEPRE, 38(4), S512–S521. http://doi.org/10.1016/j.amepre.2009.12.022

[4]. Zaini, R. G. (2016). Sickle-cell Anemia and Consanguinity among the Saudi Arabian Population. iMedPub Journals, 8, 2–4.

[5]. Yusuf, H. R., Atrash, H. K., Grosse, S. D., Parker, C. S., & Grant, A. M. (2010). Emergency Department Visits Made by Patients with Sickle Cell Disease A Descriptive Study, 1999–2007. AMEPRE, 38(4), S536–S541.

]6.[Brown, M. (2012). Managing the acutely ill adult with sickle cell disease. British Journal of Nursing (Mark Allen Publishing). http://doi.org/10.12968/bjon.2012.21.2.90

[7]. Hunt, S., & Alisky, J. (2013). Inpatient Management of Sickle Cell Disease. Hospital Medicine Clinics, 2(2), e247–e262. http://doi.org/10.1016/j.ehmc.2012.11.001

[8]. Rees, D. C., Williams, T. N., & Gladwin, M. T. (2010). Sickle-cell disease. The Lancet, 376(9757), 2018–2031. http://doi.org/10.1016/S0140-6736(10)61029-X
[9]. Oelschlaeger, L. M. (2016). MOJ Public Health A Brief Look at the Perception of Pain Management in Sickle Cell Crisis, 4(4). http://doi.org/10.15406/mojph.2016.04.00082
[10]. Augier, R., Jenkins, S., Bortolusso Ali, S., Tennant, I., Williams-Johnson, J., & Reid, M. (2014). A Survey of the Pain Management of Acute Painful Crisis among Patients with Sickle Cell Disease at Two Centres in Jamaica. The West Indian Medical Journal, 63(3), 252–257. http://doi.org/10.7727/wimj.2013.333
[11]. Jenerette, C. M., Brewer, C. A., & Ataga, K. I. (2014). Care seeking for pain in young adults with sickle cell disease. Pain Management Nursing : Official Journal of the American Society of Pain Management Nurses, 15(1), 324–30. http://doi.org/10.1016/j.pmn.2012.10.007
[12]. Lanzkron, S., Carroll, C Patrick, Haywood, C. (2010). The Burden of Emergency Department Use for Sickle Cell Disease: An Analysis of the National Emergency Department Sample Database, 85(10), 797–799. http://doi.org/10.1002/ajh.21807.The
[13]. Porter, J., Feinglass, J., Artz, N., Hafner, J., Tanabe, P., Hospital, N., … Survey, C. (2012). Sickle Cell Disease Patients' Perceptions of Emergency Department Pain Management, 104(October).
[14]. Yawn, B. P., Buchanan, G. R., Afenyi-Annan, A. N., Ballas, S. K., Hassell, K. L., James, A. H., … John-Sowah, J. (2014). Management of Sickle Cell Disease. Jama, 312(10), 1033. http://doi.org/10.1001/jama.2014.10517
[15]. Kelly, S., Deng, X., Hoppe, C., & Styles, L. (2015). A pilot randomized trial of red blood cell transfusion for acute treatment of vaso-occlusive pain episodes in sickle cell anaemia. British Journal of Haematology, 171(2), 288–290. http://doi.org/10.1111/bjh.13390
[16]. Yaqoob, S. H., & Nasaif, H. A. (2015). Nurses' knowledge and attitudes toward pain assessment and management for adult sickle cell disease patients during sickling crisis. Clinical Nursing Studies, 3(4). http://doi.org/10.5430/cns.v3n4p36
[17]. Jenerette, C. M., Pierre-Louis, B. J., Matthie, N., & Girardeau, Y. (2015). Nurses' Attitudes Toward Patients with Sickle Cell Disease: A Worksite Comparison. Pain Management Nursing, 16(3), 173–181. http://doi.org/10.1016/j.pmn.2014.06.007
[18]. Feliu, M. H., Wellington, C., Crawford, R. D., Wood, M., Edwards, L., Byrd, G., & Edwards, C. L. (2011). Opioid management and dependency among adult patients with sickle cell disease. Hemoglobin, 35(5–6), 485–94. http://doi.org/10.3109/03630269.2011.610914
[19]. Rowley, C. A., Ikeda, A. K., Seidel, M., Anaebere, T. C., Antalek, M. D., Seamon, C., … Ackerman, H. (2014). Microvascular oxygen consumption during sickle cell pain crisis, 123(20), 3101–3105. http://doi.org/10.1182/blood-2013-11-533406.The
[20]. Stimpfel, A. W., Sloane, D. M., & Aiken, L. H. (2012). The longer the shifts for hospital nurses, the higher the levels of burnout and patient dissatisfaction. Health Affairs, 31(11), 2501–2509. http://doi.org/10.1377/hlthaff.2011.1377
[21]. Carden, M. A., Fay, M., Sakurai, Y., McFarland, B., Blanche, S., Diprete, C., … Lam, W. A. (2017). Normal Saline is Associated with Increased Sickle Red Cell Stiffness and Prolonged Transit Times in a Microfluidic Model of the Capillary System. Microcirculation. http://doi.org/10.1111/micc.12353
[22]. Lui, L. Y. Y., So, W. K. W., & Fong, D. Y. T. (2008). Knowledge and attitudes regarding pain management among nurses in Hong Kong medical units. Journal of Clinical Nursing, 17(15), 2014–2021. http://doi.org/10.1111/j.1365-2702.2007.02183.x
[23]. Williams, H., & Tanabe, P. (2015). Sickle Cell Disease: A Review of Non-Pharmacological Approaches for Pain. Journal of Pain and Symptom Management, 51(2), 163–177. http://doi.org/10.1016/j.jpainsymman.2015.10.017
[24]. Clayton-Jones, D., & Haglund, K. (2015). The Role of Spirituality and Religiosity in Persons Living With Sickle Cell Disease. Journal of Holistic Nursing, 1–10. http://doi.org/10.1177/0898010115619055
[25]. Vahdat, S., Hamzehgardeshi, L., Hessam, S., &Hamzehgardeshi, Z. (2014). Patient involvement in health care decision making: a review. Iranian Red Crescent Medical Journal, 16(1), e12454. http://doi.org/10.5812/ircmj.12454
[26]. Lattimer, L., Haywood, C., Lanzkron, S., Ratanawongsa, N., Bediako, S. M., & Beach, M. C. (2010). Problematic hospital experiences among adult patients with sickle cell disease. Journal of Health Care for the Poor and Underserved, 21(4), 1114–23. http://doi.org/10.1353/hpu.2010.0940
[27]. Gupta, A., Daigle, S., Mojica, J., & Hurley, R. W. (2009). Patient perception of pain care in hospitals in the United States. Journal of Pain Research, 2, 157–164. http://doi.org/10.2147/JPR.S7903
[28]. Mollon, D. L. (2015). Patients â€™ Perception of Feeling Known by Their Nurses and the Nurse Practice Envrionment.
[29]. Suhonen, R., Land, L., Välimäki, M., Berg, A., Idvall, E., Kalafati, M., … Leino-Kilpi, H. (2010). Impact of patient characteristics on orthopaedic and trauma patients' perceptions of individualised nursing care. International Journal of Evidence-Based Healthcare, 8(4), 259–67. http://doi.org/10.1111/j.1744-1609.2010.00185.x