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Authors' Affiliation:
[1]Department of Pediatrics, Faculty of Medicine, Tabuk University, Tabuk, Saudi Arabia
[2]Medical Intern, Tabuk University, Tabuk, Saudi Arabia
[3]Medical Student, Tabuk University, Tabuk, Saudi Arabia
[4]Pediatric Neurology Resident, King Fahad Medical City, Riyadh, Saudi Arabia
[5]Consultant Pediatric Hematology and Oncology, King Salman Armed Forces Hospital, Tabuk, Saudi Arabia
[6]Registrar of Pediatric Hematology and Oncology, King Salman Armed Forces Hospital, Tabuk, Saudi Arabia
[7]General Practitioner, King Khalid Hospital, Tabuk, Saudi Arabia

[*]**Corresponding author**
Medical Intern, Tabuk University, Tabuk, Saudi Arabia
Email: Ziad.Saleh.Z46@gmail.com

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Knowledge, attitudes and practices of parents of children with sickle cell disease towards vaso occlusive crisis in Tabuk area, Saudi Arabia: A cross-sectional study

Sawsan Mohammed Al Blewi[1], Ziad Saleh D Albalwi[2*], Abdullah I Altidlawi[2], Lena Defallah G Alzahrani[3], Rawan Defallah G Alzahrani[4], Laila Abdullah S Al-Anazi[2], Mohand Basher Gahesh Albalawi[2], Abdulrahman Arshed N Alharfy[2], Naif Mohammed Al-Balawi[5], Ehab Hanafy[6], Yassmeen Hmoud Suliman Alblowi[7], Khaled Abdullah S Alasmari[3], Amal Abdullah Ayed Albalwi[3]

ABSTRACT

Our objective is to assess the knowledge, attitudes and practices of parents of children with sickle cell disease (SCD) towards vaso-occlusive crisis (VOC). Cross-sectional study, administered to patients following up in King Salman Armed Forces Hospital (KSAFH), Saudi Arabia. The study included 134 participants. Data analysis performed using Statistical Package for the Social Sciences. Regarding assessment of the participant's knowledge only 0.9% had a low knowledge level, 54.3% had a moderate level and 44.7% had a high level. Evaluation of the participants' practices, 7% had a low level and 77.2% had a high-level practice. Participant's attitudes level toward the VOC was good in 97.4% of participants, while 2.6% had a poor attitude. There was a good level of general knowledge among parents of SCD patients. However, their knowledge about the role of vaccines and hospital admission was inadequate. The adequate knowledge of the parents was transformed into good practices, where the highest percentage of the participants had high practices and attitude scores. We recommend establishing more education meetings with parents as this is the preferred source of information by the parents.

Keywords: Sickle, Cell, Knowledge, Attitudes, Practices

1. INTRODUCTION

Sickle Cell Disease (SCD) is an autosomal recessive disease inherited when both parents carry the defective gene in which the normal adult hemoglobin (Hg A) is replaced with the sickled one (Hg S). A patient with sickle cell anemia inherited two abnormal genes that code for hemoglobin S instead of hemoglobin A. SCD causes considerable morbidity and mortality among children in the world who are affected (Hebbel et al., 2020; Kuikel et al., 2021; Zolaly et al., 2019; Maqbul et al., 2022). In Saudi Arabia, it has been reported that we have a high prevalence of SCD due to high consanguinity marriage, as described that 75.8 % of SCA patients have a positive history of consanguinity. The prevalence for sickle-cell trait ranges greatly from 2% up to 27%, while sickle-cell disease reaches 2.6% in some areas of Saudi Arabia (Hazzazi et al., 2020; Jastaniah, 2011).

Patients with this disease are vulnerable to many complications, one of these is a vaso-occlusive crisis (VOC), which is the most common complication and causes great, recurrent pain to the patient. Many factors affect development of VOC, including dehydration, infection, high altitude and extremes of weather. VOC usually presents as pain and swelling in the fingers under 2 years of age and pain and swelling in the long bones above 2 years of age. The primary management of VOCs is pain control. Blood transfusion and antibiotics have specific indications in VOCs and aren't mainstays of treatment (Darbari et al., 2020; Zolaly et al., 2019).

Internationally, a study by Okoko et al., (2017) aimed to measure parents' knowledge, attitudes and practices in Brazzaville, Congo. Total of 319 parents were interviewed, they found that parents knew SCD in 88.7% of cases, its genetic transmission in 78.1% cases. They also had a good knowledge of the VOC in 31.7% of cases. Their home practices were good in 31% of cases, fairly good 42.3% of cases (Okoko et al., 2017).

Nationally a study conducted to assess the awareness of parents about VOC among parents of sickle anemic patients in Almadinah Almunawwarah and its impact on the symptoms of the disease. The result demonstrated the average number of VOCs during the year before the study was 4 ± 5, while the numbers of attacks requiring admissions during that year were 1 ± 2. The average knowledge score was 79% for all parents; almost three fourths of parents had a good level of knowledge and one fourth had a fair level of knowledge. The study showed a notable association between the knowledge and the outcome of VOC (Zolaly et al., 2019). We couldn't find any studies regarding this research area in Tabuk district, Saudi Arabia.

2. MATERIALS AND METHODS

Questionnaire based cross-sectional study that aims to measure knowledge, attitudes and practices of parents of children affected by SCD in Tabuk city, Saudi Arabia. Our questionnaire was administered through an interview with the parents of patients following up in the clinics of King Salman Armed Forces Hospital (KSAFH). Our questionnaire included questions regarding the parent and the patient's demographic data, information including how many times the child had an attack in the last year, how many times they needed to present to the emergency room (ER) and if they needed admission to the hospital.

It was constructed to measure their knowledge about SCD, VOC risk factors, VOC development, how it presents, how to prevent it and what is used first to treat the pain crisis. We also aimed to assess the caregivers' practices regarding the prevention of VOCs including both pharmaceutical and non-pharmaceutical practices, harmful or ineffective practices, how they manage the VOC at the start and their practice when primary management doesn't work. Finally, parent's attitudes toward VOC prevention, education, in-hospital treatment and doctor advice.

The study used a questionnaire that was divided into four parts:

1. The child's socio-demographic characteristics and the child's relative
2. Knowledge related questions consisting of thirteen simple-choice (yes/ no) questions and one multiple-choice question.
3. Practice during VOC consisting of four simple-choice (yes/ no) questions and one multiple choice questions.
4. Attitude toward VOC consisting of five simple-choice (yes/ no) questions.

A score was calculated based on the respondent's answers to the knowledge-related items as follows:

For simple-choice questions (yes or no):

Incorrect responses receive a score of 0

Correct answers received a score of 1

For multiple choice questions:

0 if no correct option was given (inadequate knowledge)

1 for each correct answer given (adequate knowledge)

A score will be calculated for attitude, an adequate level is assumed for any respondent who adequately replies to at least half of the questions for knowledge and practices. A low-level score will be calculated for those answering less than 50% of the questions, a

moderate knowledge level is assumed for any respondent who adequately replies to at least half of the questions, high knowledge score will be assumed for those who answer more than 75% of questions.

The population size was 270 patients following-up in KSAFH pediatric haemato-oncology clinics; sample size was 136, with a 90% confidence level and a 5% margin of error. The study included 134 participants, 12 excluded as they were used in the pilot study.

The study included any children below 14 years of age diagnosed with SCD and following up regularly for at least 12 months. Excluding any children whose last appointment was outdated, who started following up less than 12 months or who are following for sickle-thalassemia disease or other haemoglobinopathies. Study period was between 2021 to 2022.

Data analysis was performed using the Statistical Package for the Social Sciences, SPSS 23rd version. Frequency and percentages were used to display categorical variables. Minimum, maximum, mean and standard deviation was all used to display numerical variables. Independent t-test and ANOVA test were used to test for association. ANOVA test was followed by a Tukey post-hoc test to determine where the exact difference between groups existed. The level of significance was set at 0.05.

3. RESULTS

A total of 134 participants were included in the study. As for the relationship among the patients, 40.4% were fathers, 56.1% were mothers, 2.6% were brothers and 0.9% was a sister. As for the age of the caretaker, 2.6% were between 18 and 24 years old, 16.7% were between 25 and 34 years old, 56.1% were between 35 and 45 years old and 24.6% were older than 45 years. As for the marital status of the caretaker, 97.4% were married and 2.6% were separated. As for the caretaker's educational level, 5.3% had a primary school education, 10.5% had an intermediate school education, 51.8% had a high school education and 32.5% had a higher education/college education. As for the age of the child affected with SCD, 6.1% were younger than 2 years, 28.1% were between 2 and 5 years, 30.7% were between 5 and 10 years and 35.1% were between 10 and 14 years. The number of participant's kids affected by SCD was one kid in 60.5% of the, 29.8% had two kids affected by SCD, 5.3% had three kids affected by SCD and 4.4% had more than three kids affected by SCD. Table 1 displays the assessment of the participant's knowledge regarding the VOC.

Table 1 Assessment of the participant's knowledge about the vaso-occlusive crisis (n = 114)

Question	N	%
Q1/ Does sickle cell disease run in families?		
Yes (correct answer)	111	97.4
No	3	2.6
Q2/ Do you know the sickle cell status of your children?		
Yes (correct answer)	109	95.6
No	5	4.4
Q3/ Have you ever heard about the vaso-occlusive crisis (sickle cell pain crisis)?		
Yes (correct answer)	109	95.6
No	5	4.4
Q4/ Which of the following can precipitate a vaso-occlusive crisis?		
Dehydration (correct answer)	75	65.79
Infection (correct answer)	78	68.42
Extremes of weather, very cold or very hot (correct answer)	107	93.86
High altitude (correct answer)	63	55.26
Eating fava beans	10	8.77
Do children with SCD need extra vaccines?		
Yes (correct answer)	46	40.4
No	68	59.6
Does vaso-occlusive crisis cause bone pain?		

Yes (correct answer)	107	93.9
No	7	6.1
Does vaso-occlusive crisis cause bone swelling?		
Yes (correct answer)	97	85.1
No	17	14.9
Does VOC need a blood transfusion as initial management?		
Yes	30	26.3
No (correct answer)	84	73.7
Does VOC need antibiotics as initial management?		
Yes	72	63.2
No (correct answer)	42	36.8
Knowledge Score (lowest possible score = 0, highest possible score = 12)		
Minimum	5	
Maximum	12	
Mean	9.02	
Standard deviation	1.61	

Table 2 displays the assessment of the participant's practices regarding the VOC. 7% of the participants had a low-level score, 15.8% had a moderate and 77.2% had a high level.

Table 2 Assessment of the participant's practices toward vaso-occlusive crisis (n = 114)

Question	n	%
Q1/ Which of the following are you doing to protect your child from VOC?		
Give Hydroxyurea (correct answer)	105	92.11
Keep him warm (correct answer)	102	89.47
Hydration (correct answer)	95	83.33
Avoid protein diet	10	8.77
Q2/ What do you do if your child starts to have a vaso-occlusive crisis?		
Give Hydration (correct answer)	77	67.54
Give paracetamol (Acetaminophen) (correct answer)	77	67.54
Give Non-Steroidal Anti-inflammatory drugs (correct answer)	72	63.16
Give Steroid	1	0.88
If your child doesn't improve with the abovementioned measures (Q above), Would you continue to manage your child at home for 2 days before going to the hospital?		
Yes	40	35.1
No (correct answer)	74	64.9
Do you try to cautery your child to improve the VOC?		
Yes	1	0.90
No (correct answer)	113	99.10
Do you try to give your child myrrh to improve the VOC?		
Yes	7	6.1
No (correct answer)	107	93.9
Practice Score (lowest possible score = 0, highest possible score = 9)		
Minimum	3	

Maximum	9
Mean	7.21
Standard deviation	1.39

While evaluating the participant's attitudes regarding the VOC. We asked if protecting the child against the risk factors can reduce VOC, 96.5% answered with yes. When asked if educating the parents can protect children with SCD. 97.4% answered yes. When asked if the caretaker is afraid to take the child to the hospital because of painkiller medication addiction. 35.1% said yes, while 64.9% said they're not afraid. When asked if they have ever refused admission to the hospital due to VOC, 94.9% haven't. Finally, when asked if they've ever signed against medical advice. 90.4% haven't. Regarding the participant's attitudes levels toward the VOC. 2.6% had a poor attitude, while 97.4% had a good attitude.

When asked about the number of visits to the emergency department for an attack of VOC during the last year; 35.1% never did during the last year, 36% 1-2 times, 21.1% visited 3-4 times and 7.9% reported more than 5 times. As for what method the participants preferred to increase awareness about SCD, 81.6% of the parents preferred a discussing with the doctor, 7% said they'd prefer pamphlets to take with them and 11.4% preferred educational lectures.

Table 3 displays the factors associated with the participant's practices toward the VOC. A significant association was found between caretaker gender and practices toward the VOC ($p = 0.035$), fathers had a significantly higher practice score compared to mothers (7.59 ± 1.15 vs 7.03 ± 1.47). Age was also significant as older age groups had a notably higher score compared to the younger age groups ($p = 0.019$). Tukey's posthoc test revealed that those aged 35 – 45 years had significantly higher practice scores than those aged older than 45 years ($p < 0.05$).

Table 3 Factors associated with the participant's practices for vaso-occlusive crisis

Factor	Practice Score		P-Value
	Mean	Standard deviation	
Relation to the patient			
Father	7.59	1.15	0.035*
Mother	7.03	1.47	
Age of caretaker			
18-24 year	6	1.00	
25-34 year	6.47	1.58	0.019*
35-45 year	7.45	1.33	
> 45 years	7.29	1.21	
The educational level of caretaker			
Primary school	6.33	2.25	
Intermediate school	7.00	1.60	0.367
Secondary school	7.34	1.15	
Higher education–collage	7.22	1.49	
Age of the child affected by SCD?			
Younger than 2 years	7.57	0.79	
2-5 years	7.19	1.47	0.791
5-10 years	7.31	1.47	
10-14 years	7.08	1.35	
Number of Participants' Kids Affected by SCD			
One	7.45	1.24	
Two	6.74	1.33	0.078
Three	7.50	2.35	
More than three	6.80	1.79	

*Significant at level 0.05

Table 4 demonstrates the factors associated with the participant's attitudes toward the VOC. A worthy of attention association was found between caretaker gender and attitude score toward the VOC (p = 0.027), fathers had a significantly higher score compared to mothers (4.65 ± 0.64 vs 4.33 ± 0.82). The age of the caretaker was significantly associated with attitude toward VOC (p = 0.027), where the youngest age group (18-24 years) had the lowest score. The Tukey posthoc test revealed that those aged 18–24 years had a significantly lower attitude score when comparing all the other age groups (P < 0.05). The number of kids affected was also significant, where a higher number of affected kids had a lower attitude score compared to those with a lower number of affected kids (p = 0.023). Tukey posthoc test did not reveal any significant difference when each pair of groups was compared respectively.

Table 4 Factors associated with the participant's attitudes toward vaso-occlusive crisis

Factor	Attitude Score		P-Value
	Mean	Standard deviation	
Relation to the patient			
Father	4.65	0.64	0.027*
Mother	4.33	0.82	
Age of caretaker			
18-24 year	3	1.73	
25-34 year	4.53	0.61	0.011*
35-45 year	4.39	0.81	
> 45 years	4.61	0.74	
The educational level of caretaker			
Primary school	4.50	0.84	
Intermediate school	4.33	0.78	0.441
Secondary school	4.54	0.82	
Higher education–collage	4.27	0.84	
Age of the child affected by SCD?			
Younger than 2 years	4.29	0.76	
2-5 years	4.41	0.88	0.689
5-10 years	4.34	0.94	
10-14 years	4.55	0.68	
Number of Participants' Kids Affected by SCD?			
One	4.54	0.85	
Two	4.44	0.71	0.023*
Three	3.67	0.82	
More than three	3.80	0.45	

*Significant at level 0.05

4. DISCUSSION

A previous Saudi study has found that good knowledge of the risk factors, clinical manifestations and preventive measures of VOC is significantly associated with fewer attacks and hospital admissions for VOC and improved quality of life of sickle-cell children (Zolaly et al., 2019). The assessment of the participant's knowledge revealed a total knowledge score ranging from 5 to 12 with a mean (SD) score of 9.02 (1.61). Moreover, 44.7% participants had a high knowledge level about VOC, while more than half (54.3%) had a moderate level and only one participant (0.9%) had a low knowledge level (Figure 1).

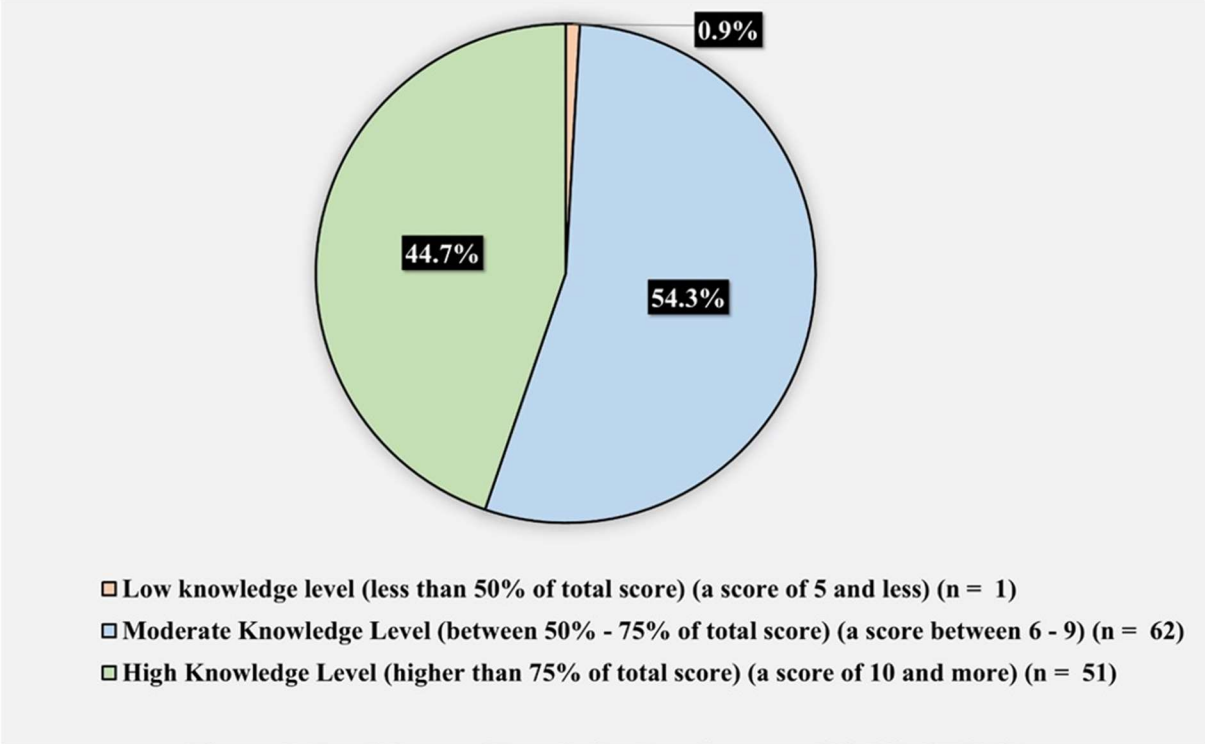

Figure 1 Participants knowledge levels toward sickle cell disease

This study didn't reveal any noteworthy association between the level of the participants' knowledge of VOC and the characteristics of the participants including the relation of the caretaker to the patient, the age and education of the caretaker, the age of the child affected with SCD and the number of kids affected with SCD. A corresponding questionnaire-based, cross-sectional survey included 123 parents of children with Sickle-cell disease, ages range between 2 up to 18 years old who reside in Almadinah Almunawwarah. The study revealed a mean (SD) total knowledge score of 30 (4) and 74% of the caregivers had a good knowledge score. There were no significant associations between the total knowledge score and the parents' level of education or the family income (Zolaly et al., 2019).

Another study including 319 parents of children with SCD in Brazzaville, Congo concluded that the knowledge level concerning localization, clinical expression, triggering factors and preventive measures for VOC was poor in 66.6% of the participants. Only 31.7% of parents showed a good knowledge score. However, the study demonstrated several factors that were associated with a significant knowledge of VOC including parents' age between 25 and 34 years (OR: 1.8, 95% CI: 1 - 3), secondary education (OR: 1.7, 95% CI: 1 - 2.7) and having good practices for VOC (OR: 4.5, 95% CI: 2.7 - 7.5) (Okoko et al., 2017).

The current survey disclosed that the parents knew many important precipitating factors leading to VOC, as most of the parents answered that extremes of weather (93.86%), infection (68.42%), dehydration (65.79%) and high altitude (55.26%) were risk factors. In comparison with our findings, the participants in Almadinah Almunawwarah study showed a higher level of awareness concerning the role of infection (76.42%) and high altitude (69.91%) but lower awareness about hot weather (54.47%) as triggering factors for VOC. Furthermore, in our study, the parents were well informed that eating fava beans is not a triggering factor for VOC. In contrast to previous studies among the general population in the Al-Baha region, Saudi Arabia and Al-Bahrain country study that revealed high percentages of false beliefs about the role of Fava bean and other dietary factors in aggravating the disease. Earlier studies in Saudi Arabia and in Bahrain reported poor knowledge of the preventive measures among their patients (Zolaly et al., 2019; Alghamdi et al., 2018; Al-Arrayed and Al-Hajeri, 2010; Al-Nasir and Niazi, 1998; Jaffer et al., 2009).

In the present study, 46 (40.4%) respondents realized that children with SCD need extra vaccines. This number is much lower than that reported by Zolaly et al., (2019) in which 110 (89.43%) respondents recorded that vaccinations have an important role in preventing VOC. More than half of the children of those respondents did not receive the recommended vaccines. This was attributed to a lack of adherence to treatment, which is another commonly confronted problem. These observations require more attention from educators to raise awareness among SCD patients and their parents about the preventive role, indications and timing of the recommended vaccines. Also, it has been suggested that greater use of child routines and open family communication were

associated with better child and parent-reported adherence (Zolaly et al., 2019; Beverung et al., 2014; Sobota et al., 2015; Klitzman et al., 2018).

This study analyzed different aspects of the parents' practices to prevent and treat VOC. The participants recorded that they give hydroxyurea (92.11%), keep their children warm (89.47%) and hydrated (83.33%) to protect them from VOC. Furthermore, about two-thirds of the respondents correctly behaved when their children started experiencing the VOC, where they gave plenty of fluids and analgesics like paracetamol or nonsteroidal anti-inflammatory drugs. However, 40 (35.1%) subjects did not know the necessity of going to the hospital if the previous measures were not effective for two days. This is another warning that should be considered during parent health education. Fortunately, above 90% of the studied parents did not cauterize their children or give them myrrh to improve VOC. Hydroxyureas have been approved to reduce the occurrence of VOC through their role in inducing fetal hemoglobin and preventing the sickling of RBCs (Osunkwo et al., 2020; Almeida et al., 2012).

The assessment of the participants' practices regarding VOC showed a total score ranging from 3 to 9 with a mean (SD) of 7.21 (1.39). The highest percentage of participants (77.2%) had a high level, while 18 (15.8%) had a moderate level and 8 (7%) had a low level. Furthermore, fathers and participants aged 25 to 45-year-old showed significantly better practices toward VOC than mothers or other age groups. The high levels of parent practices recorded in our study are much higher than those reported by Okoko et al., (2017) in Brazzaville, Congo (31%). A recent study in Nigeria recorded that 38.3% of SCD patients had good practice of preventive measures toward VOC, while 61.7% of patients showed fair practices. Furthermore, this highlighted the role of good preventive practices for turning down the frequency of VOC in a year (Okoko et al., 2017; Efobi et al., 2022).

Our study showed that the adequate knowledge of the studied parents was transformed into good practices for preventing or treating VOC. The participants documented that the number of VOC during the last year was none (21.1%), 1–2 times (36.8%), 3–4 times (28.1%) and 5 or more (14%). As well, the recorded need for hospital admission due to VOC during the last year was never (49.1%) 1–2 times (41.2%), 3–4 times (6.1%), and 5 times or more (3.5%). This is different from the finding in a Nigerian SCD study by Amoran et al., (2017) who reported an increased frequency of painful crises among Nigerian SCD patients despite adequate knowledge of the preventive measures.

In this study, the evaluation of the participants' attitudes toward VOC revealed a minimum score of 1, a maximum score of 5 and a mean (SD) score of 4.43 (0.82). A high percentage (97.4%) of the study participants showed a good attitude toward VOC. These include their appreciation of the role of protective measures and the parents' education in reducing the incidence of VOC, besides their recognition of the need for hospital admission for the management of VOC. Furthermore, mothers, participants aged 18-24 years and those with a higher number of affected children were found to be significantly associated with a low attitude score. In Congo, Okoko et al., (2017) reported that 64.8% of the participants preferred the use of a health facility in the case of VOC; however, 14.5% practiced self-medication and the use of traditional medicine. It is important to note that the acquisition of good knowledge about the disease has a positive impact on the patient's attitudes as well as on their health (Okoko et al., 2017; Meints et al., 2016).

The participants' source of information about VOC was doctors and hospital personnel (66.7%), while 22.8% of participants reported that it was an experience with SCD. Other sources were the internet (9.6%) and family and friends (0.9%). This coincides with Zolaly et al., (2019) who reported that 69.23% of participants knew about VOC from their doctors, 17.94% from written information and 15.38% had seen it on the internet or heard about it from family and/or friends. In Brazzaville, Congo, healthcare workers (66.1%), the media (22.3%), the family (15.7%) and the school (11%) have been reported as sources of the parents' information (Okoko et al., 2017). The role of healthcare workers in the health education of SCD patients and their caregivers is highly warranted and a high percentage (81.6%) of our participants have preferred discussion with their doctors to increase awareness (Zolaly et al., 2019; Okoko et al., 2017).

Limitations

This study is limited by the small sample size and recall bias, which may have affected the answers of the participants.

5. CONCLUSIONS AND RECOMMENDATIONS

There was a good level of knowledge among parents of SCD patients about the precipitating factors, clinical manifestations and initial management of VOC. However, their knowledge about the preventive role of vaccines and the necessity of hospital admission was inadequate. The adequate knowledge of the studied parents was transformed into good practices for preventing or treating VOC where the highest percentage of the participants had high practices and attitude scores toward VOC. The SCD patients and their parents still need more development of their awareness; hence, it is crucial to establish regular health education

meetings with parents and their diseased children as this is the most preferred source of information by the parents. The parents would greatly benefit if more time is allocated to educate them about the triggering factors and preventative measures against VOC, which can be done by health care personnel. A national health education program is also recommended to raise awareness of SCD and its complications.

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Authors' contributions

Doctor Sawsan Al-Belwi supervised the manuscript writing as well as rewriting and editing, Lena Alzahrani and Rawan Alzahrani wrote the introduction, Khalid Alasmari and Laila Al-Anzi wrote materials and methods, Abdulrahman Alharfy, Yasmeen Alblowi and Amal Albalwi wrote the results, Ziad Albalwi, Abdullah Altidlawi and Mohand Basher wrote the discussion and conclusion. All the research team collected data, while doctor Sawsan trained the data collectors, Naif Albalawi and Ehab Hanafy supervised the team while in the clinics. All the research team fulfilled similar roles during proposal writing, doctor Sawsan, Naif and Ehab validated the questionnaire and research method.

Ethical approval

This study was approved by the medical ethics committee of King Salman Armed Forces Hospital (Ethical approval ID number: KSAFH-REC-2021-412).

Informed consent

Documented and oral informed consent was obtained from all individual participants included in the study.

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This study has not received any external funding.

Conflict of interest

The authors declare that there is no conflict of interests.

Data and materials availability

All data sets collected during this study are available upon reasonable request from the corresponding author.

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