Assessment of knowledge and attitude of caregivers toward the preventive measures of sickle cell crisis at-Dr Gaafar Ibnuof Pediatric Hospital, (2022)

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Abstract:

Introduction: Sickle cell disease (SCD) patients are at high risk of experiencing poor outcomes, which can develop organ damage. After a definitive diagnosis has been made, the parents should start a comprehensive educational program about their child's condition. This program should include practical information about the various complications and preventive measures of the sickle cell crisis. The role of the caregiver in the prevention of sickle cell crisis focuses on avoiding demanding physical activities, smoking, and environments with low oxygen pressure, such as non-pressurized airplane flights and high altitudes as well as avoiding exposure to the sun and enough hydration for a sickler child. The study aimed to assess the knowledge and attitude of caregivers toward the preventive measures of the sickle cell crisis.

Methods: A descriptive cross-sectional study design was conducted in the Sickle cell referral clinic, Dr. Gaafar Ibnauf Paediatric Hospital, Khartoum, Sudan, with a random sample of 286 caregivers who attended the referral clinic during the study period between September and December 2021. Data were collected using a pre-structured investigator-filled questionnaire. Proportion and binomial tests were used to investigate the statistical significance of the knowledge and attitude of caregivers toward the preventive measures of sickle cell crisis.

Results: The vast majority of participants were female from the second class with intermediate educational levels. The study findings showed that 59% of caregivers have satisfactory knowledge while 41% of caregivers have unsatisfactory knowledge about the preventive measures for sickle cell crisis. Negative attitude toward the preventive measures of sickle cell crisis have been observed in 85% of the studied group.

Keywords: Knowledge, Attitude, Caregivers, Preventive measures, Sickle cell, crisis.

المستخلص

المقدمة: ان مرضى فقر الدم المنجلي (SCD) معرضون بشكل كبير لخطر المعاناة من نتائج سيئة، والتي يمكن أن تتسبب في تلف أعضاء الجسم. بعد إجراء التشخيص النهائي، يجب على الوالدين البدء في برنامج تعليمي شامل حول حالة أطفالهم. كما يجب أن يتضمن هذا البرنامج معلومات عملية حول المضاعفات المختلفة والتدابير الوقائية لنوبات مرض فقر الدم المنجلي. ويركز دور مقدم الرعاية في الوقاية من هذا المرض على تجنب المصاب للأنشطة البدنية والتدخين والبيئات ذات ضغط الأكسجين المنخفض مثل الرحلات الجوية غير المضغوطة والارتفاعات العالية. بالإضافة إلى تجنب التعرض لأشعة الشمس والحصول على كمية كافية من الماء.

تهدف الدراسة الحالية الى تقييم معرفة وسلوك مقدمي الرعاية تجاه التدابير الوقائية لنوبات مرض فقر الدم المنجلي.
منهجية الدراسة: تم إجراء دراسة مقطعية وصفية في العيادة الخارجية لفقر الدم المنجلي التابعة لمستشفى الدكتور جعفر بن عوف التخصصي للأطفال، الخرطوم، السودان وذلك من خلال أخذ عينة عشوائية من ٢٨٦ من مقدمي الرعاية للأطفال المصابين بمرض فقر الدم المنجلي والذين حضروا العيادة خلال فترة الدراسة ما بين سبتمبر وديسمبر ٢٠٢١. تم جمع البيانات عن طريق الاستبانة المنظمة مسبقا وتم استخدام اختبار توزيع النسب واختبار ذو الحدين لفحص الدلالة الإحصائية لمعرفة وسلوك مقدمي الرعاية تجاه التدابير الوقائية لنوبات مرض فقر الدم المنجلي.
نتائج الدراسة: كانت الغالبية العظمى من المشاركين من الإناث ذوي حالة اقتصادية ومستويات تعليمية متوسطة. أظهرت نتائج الدراسة أن ٥٩٪ من مقدمي الرعاية لديهم معرفة كافية بينما ٤١٪ من مقدمي الرعاية لديهم معرفة غير كافية بالتدابير الوقائية لنوبات مرض فقر الدم المنجلي. لوحظ السلوك السلبي تجاه التدابير الوقائية للمرض في ٨٥٪ من عينة الدراسة.
الكلمات المفتاحية: المعرفة، السلوك، مقدمو الرعاية، التدابير الوقائية، نوبات، الخلايا المنجلية.

Introduction

Sickle cell disease (SCD) was first described by Herrick in 1910 even though reports suggest a prior description of the disorder [1]; it is the result of homozygous and compound heterozygote inheritance of a mutation in the β-globin gene. A single base-pair point mutation (GAG to GTG) results in the substitution of the amino acid glutamic acid (hydrophilic) to valine (hydrophobic) in the 6th position of the β-chain of haemoglobin referred to as haemoglobin S (HbS) [2]. Sickle cell disease patients are at high risk of experiencing poor outcomes, which can develop organ damage [3]. After a definitive diagnosis has been made, the parents should start a comprehensive educational program about their child's condition. This program should include practical information about the various complications and preventive measures of sickle cell crisis [4]. The role of the caregiver in the prevention of sickle cell crisis focuses on avoiding demanding physical activities, smoking, and environments with low oxygen pressure, such as non-pressurized airplane flights and high altitudes as well as avoiding exposure to the sun and enough hydration for a sickler child [5].

Research question:

1- What do care providers know about preventive measures of sickle cell crisis?

2- How do care providers behave toward the preventive measures of the sickle cell crisis?

Significance of the study:

The study conducted in Western Sudan revealed that the percentage of individuals who are homozygous for sickle cell disease is highest in children under five years old. The study also analyzed the data from the various age groups and found that the HbAS frequency varied depending on gender. furthermore, among the households that were screened, 11.9% of the families had lost a child to this condition. Out of all the causes of childhood mortality, the percentage of children dying due to SCD was 17.0%.[6]. Previous studies in Sudan have documented inadequate caregivers' level of knowledge regarding the care of a child with SCD in 42% of the respondents [7] and poor attitude in 30.7% of respondents towards sickle cell disease [6]. Based on the findings of previous studies and work experiences, it was concluded that SCD patients are at high risk of developing severe complications. They should be regularly monitored and treated. If they are able to prevent these issues, the SCD crises could be prevented.

The study objectives:

The study aimed to assess the knowledge and attitude of caregivers toward the preventive measures of sickle cell crisis

Methods

This was a descriptive cross-sectional study conducted in the Sickle cell referral clinic, Dr Gaafar Ibnuof Pediatric Hospital, Khartoum, Sudan. This hospital was selected because it is the largest pediatric hospital in Sudan. Being located in Khartoum, the referral clinic provides services to patients coming from all parts of Sudan. Approximately, 50 patients are seen weekly in a regular follow-up every 1-2 months.

The sample consisted of 286 out of 1000 caregivers of children with SCD who were on regular follow-up and attended the clinic during the period between September and December 2021. Caregivers of patients with other chronic diseases besides SCD were excluded from the study. By simple random sampling, subjects were assigned to groups completely at random. Each subject was labeled then tables of random numbers were used to select from labeled subjects. Interviews were used to collect the data. Data were collected by the researcher using a pre-structured investigator-filled questionnaire. A structured questionnaire was developed to assess socio-demographic data, the basic knowledge regarding the cause of the disease, mode of inheritance, symptoms, triggers of crisis, general measures for prevention, and possible complications of SCD. The Likert scale was used to assess the attitude of caregivers toward the preventive measures of sickle cell crisis.

The knowledge level of caregivers was classified into two clusters according to the class interval value (0.5) which was calculated by a class interval equation equal to range (1) divided by two hence when the mean is less than 0.5 were graded as unsatisfactory knowledge, the mean is greater than 0.5 were graded as a satisfactory knowledge. The attitude level of caregivers was classified into two clusters according to the class interval value (3.5) which was calculated by a class interval equation equal to range (7.1) divided by two hence when the mean is less than 3.5 were graded as a negative attitude, the mean is greater than 3.5 were graded as a positive attitude.

Ethical approval was obtained from the Institutional Review Board of Alnelain University and the Ethics Committee of the Ministry of Health, Khartoum state. Permission from the Sickle cell referral clinic, Dr Gaafar Ibnauf Paediatric Hospital was obtained. The researcher maintained the anonymity and confidentiality of the participants after informed consent was obtained. The researcher collected the data during the rest time of the study groups. The researcher maintained the preventive measures for COVID-19. The statistical analysis was performed by using Statistical Packages for Social Sciences (SPSS) version 25, Proportion and binomial tests were used to investigate the statistical significance of the variable of interest.

Results

The data were grouped and analyzed to assess the knowledge and attitude of caregivers toward the preventive measures of sickle cell crisis

Table (1): Socio-demographic characteristics of the studied group

Socio-demographic characteristics				
	N	**Mean**	**Minimum**	**Maximum**
Age (years)	286	34.6	17.00	65.00
		N	**Frequency**	**Percent**
Gender	Male	286	41	14.3
	Female	286	245	85.7
Occupation	Not employed	286	202	70.6
	Workers	286	39	13.6
	Professional	286	8	2.8
	Self employed	286	25	8.7
	Student	286	12	4.2
Resident area	Slum	286	7	2.4
	Third class	286	25	8.7
	Second class	286	248	86.7
	First class	286	6	2.1

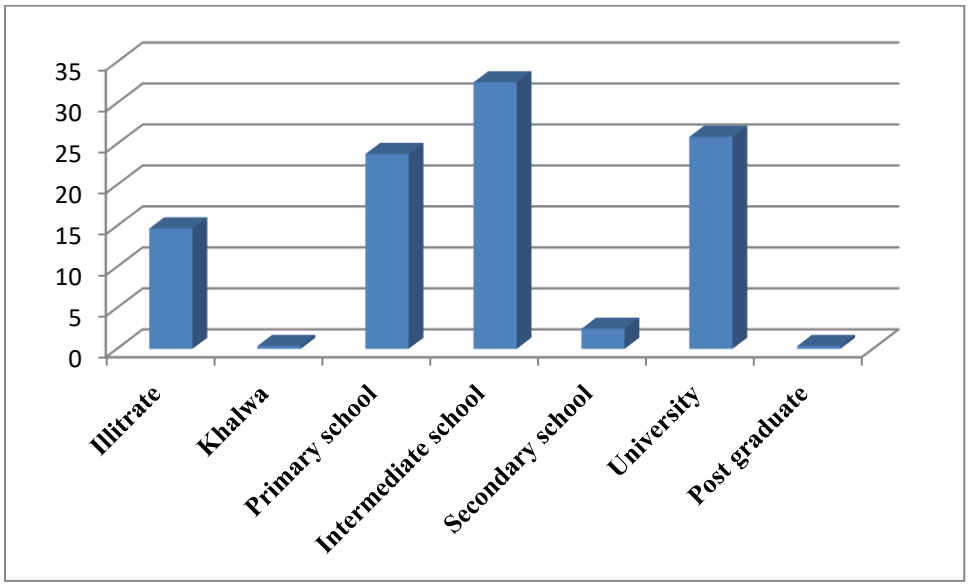

Figure I: The education level of caregivers

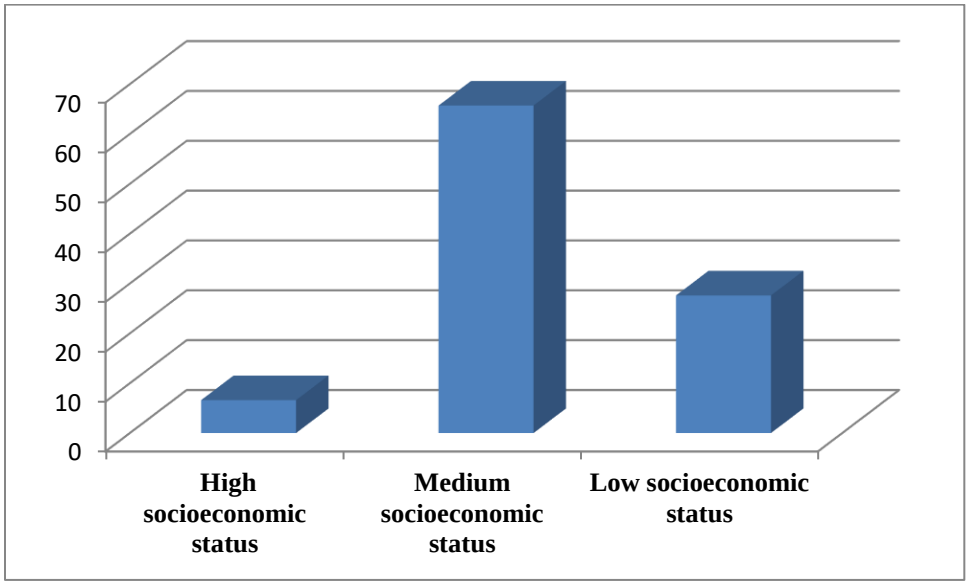

Figure II: The socioeconomic status categories of the studied group

Table (2): Samples Statistics of Caregivers' Knowledge toward SCD

Items of SCD	Mean	N	Std. Deviation	Std. Error Mean
Effect of SCD	.6394	286	.33661	.02133
Advice for SCD patient	.8343	286	.21631	.01371
Precautions of SCD	.6054	286	.28957	.01835
Trigger of SCD crisis	.7316	286	.27501	.01743
Preventive measures	.6837	286	.21608	.01369
Complications of SCD	.5417	286	.30577	.01938

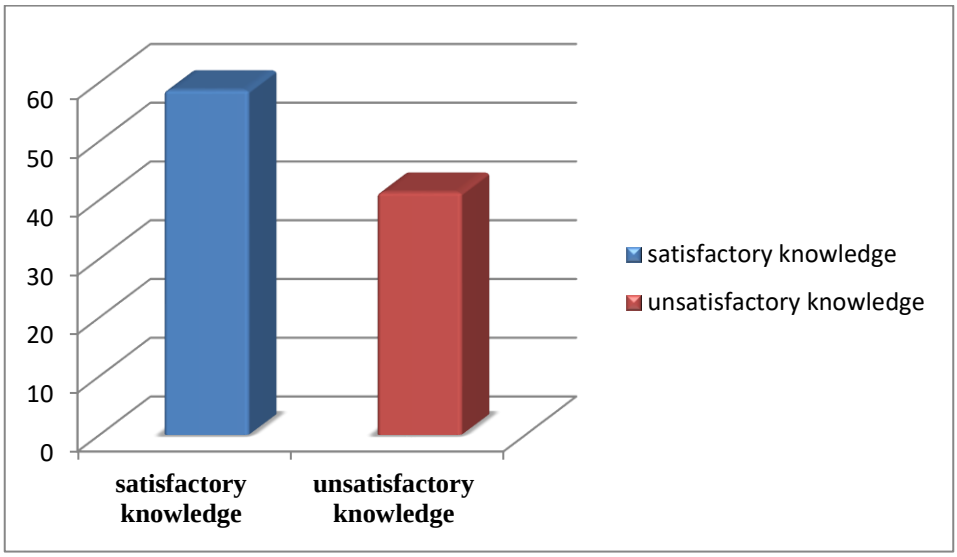

Figure III: Statistics of caregivers' level of knowledge about preventive measures of sickle cell crisis

The data depicted in Figure III shows that 59% of caregivers have satisfactory knowledge while 41% of caregivers have unsatisfactory knowledge about preventive measures for sickle cell crisis.

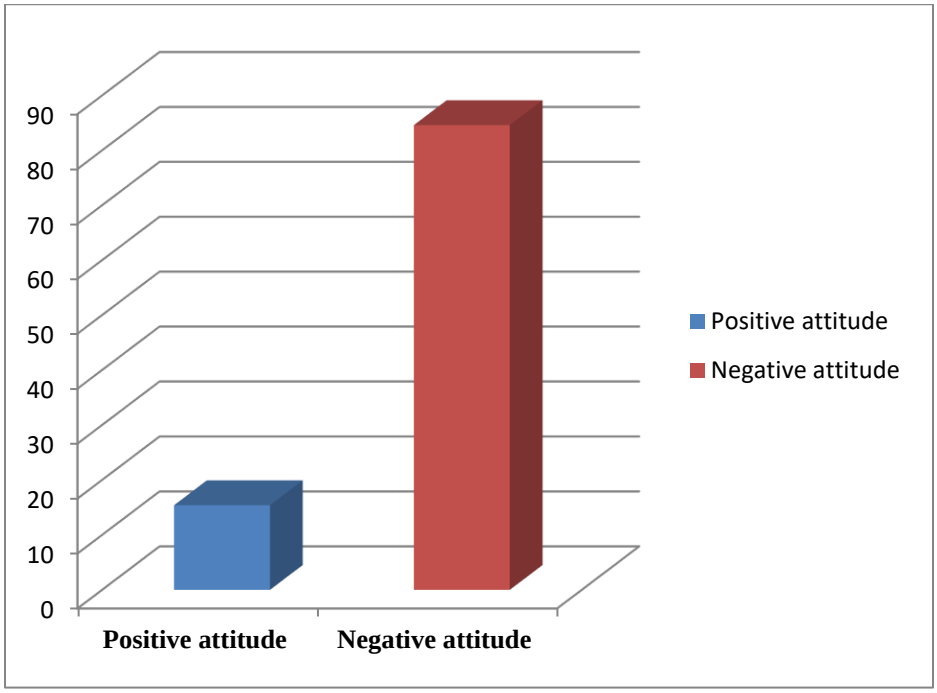

Figure IV: Statistics of caregivers' attitude toward the preventive measures of sickle cell crisis

The data depicted in Figure IV shows that 85% of caregivers have a negative attitude while 15 % of caregivers have a positive attitude toward the preventive measures of sickle cell crisis.

Table (3): Binomial test to investigate the significant differences between proportions

Binomial Test						
Variables		**Category**	**N**	**Observed Prop.**	**Test Prop.**	**Sig. (2-tailed)**
Knowledge	**Group 1**	**satisfactory**	168	0.59	0.50	0.006
	Group 2	**unsatisfactory**	118	0.41		
	Total		286	1.00		
Attitude	**Group 1**	**Negative**	243	0.85	0.50	0.000
	Group 2	**Positive**	43	0.15		
	Total		286	1.00		

The data depicted in Table 3 reveals that 59% of caregivers have significant satisfactory knowledge and 85% of caregivers have a negative attitude toward the preventive measures of sickle cell crisis at the confidence level of 95%.

Discussion

The study analyzed the attitude and knowledge of the caregivers toward the preventive measures of the sickle cell crisis. It was conducted to determine the extent of their knowledge and attitude toward the preventive measures of the sickle cell crisis.

The level of overall knowledge of caregivers about the preventive measures of sickle cell crisis was satisfactory. The finding indicated that 59% of caregivers have satisfactory knowledge while 41% of caregivers have unsatisfactory knowledge about the preventive measures of sickle cell crisis it could be due to some negative cultural beliefs and lack of social awareness so health education, guidelines, and counseling to patients and their guardians should be provided to increase awareness and reinforce knowledge of patient toward the preventive measure of sickle cell crisis. This study result was consistent with a result of the study, which has been noted that the majority of subjects 64.2% were labeled as moderately knowledgeable, and 13% of cases were labeled as poorly knowledgeable [8]. Furthermore, this study result was incongruent with a result of a recent study conducted in Western Kordofan State, Sudan which reported that about 46.9% of the households had poor knowledge, 26.1% had satisfactory knowledge, and 26.9% had good knowledge about sickle cell disease [6].

The level of attitude of caregivers toward the preventive measures of sickle cell crisis was negative. It revealed that 85 % of caregivers have a negative attitude while 15 % of caregivers have a positive attitude toward the preventive measures of sickle cell crisis. It could be related to the reflection of poor knowledge and some negative beliefs and customs in the attitude of the studied group therefore it is required to sensitize communities and policymakers about the prevention, screening, and management of SCD. This study result was similar to a recent study result which observed negative attitude toward SCD in 70-88% of patients [9]. This study result was different from Al daak study which concluded that about 48.0% had a satisfactory attitude towards sickle cell disease while 30.7% had a poor attitude and only 21.3 showed a good attitude [6]. Another study observed poor attitude among 15.4% of participants. And good attitude among 56% of the respondents [8].

Based on the previously mentioned findings the following can be concluded, this study indicated that the level of overall knowledge was satisfactory and the attitude of caregivers toward the preventive measures of sickle cell crisis was negative.

Recommendations:

Further research studies should be undertaken on a caregiver to investigate the factors affecting knowledge and attitude regarding preventive measures of the sickle cell crisis.

Conflict of interest: The authors have no relevant financial or non-financial interest to disclose to declare

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