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Assessment of the Attitude, Knowledge, and Complications Related to Sickle Cell Disease in Al-Ahsa Region, Saudi Arabia

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Abstract: Sickle-cell disease (SCD) is one of the well-known hematological disorders that affects many people around the world. The risk of disease transmission increases with consanguineous marriage. SCD is considered a life-threatening condition, with mortality rates increasing annually because of the large number of comorbidities associated with this disease. The Al-Ahsa region carries the highest rate of SCD in Saudi Arabia. The aim of the study is to evaluate the attitude, knowledge, perceptions, and misunderstandings regarding SCD and its complications. An analytical cross-sectional study was conducted among 387 participants of the Al-Ahsa population. Data was collected using a structured, self-administered questionnaire. The questionnaire contains four important domains: socio-demographical information, knowledge, attitude, and complications of SCD. Of the 387 people sampled, 80% of the participants had heard about SCD, and the major source of information were their friends and families. More than half of the population knew that SCD is inherited, although 40% did not know about the treatment for SCD. Most of the participants showed a positive attitude, being sympathetic toward people with SCD, while half of the participants preferred not to have a child rather than have one with SCD. A high proportion of the population did not know that SCD is a leading cause of life-threatening infections, kidney failure, and stroke. The study indicates that there is a need for awareness programs to address some misconceptions and expand information regarding SCD, which could contribute to improving knowledge about SCD.

Keywords: sickle cell disease, knowledge, attitude, Saudi Arabia.

评估沙特阿拉伯哈萨地区与镰状细胞病相关的态度、知识和并发症

摘要：镰状细胞病(SCD)是众所周知的血液疾病之一，影响着世界各地的许多人。近亲结婚会增加疾病传播的风险。SCD被认为是一种危及生命的疾病，由于与该疾病相关的大量合并症，死亡率每年都在增加。哈萨地区的SCD发病率在沙特阿拉伯最高。该研究的目的是评估对SCD及其并发症的态度、知识、看法和误解。在哈萨人群的387名参与者中进行了一项横断面分析研究。使用结构化的自我管理问卷收集数据。问卷包含四个重要领域：社会人口学信息、知识、态度和SCD并发症。在抽样的387人中，80%的参与者听说过SCD，主要信息来源是他们的朋友和家人。超过一半的人知道SCD是遗传的，尽管40%的人不知道SCD的治疗方法。大多数参与者表现出积极的态度，对患有SCD的人表示同情，而一半的参与者宁愿不生孩子也不愿生孩子。很大一部分人不知道SCD是危及生命的感染、肾衰竭和中风的

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主要原因。该研究表明，有必要开展宣传计划来解决一些误解并扩大有关SCD的信息，这可能有助于提高对SCD的了解。

关键词：镰状细胞病，知识，态度，沙特阿拉伯。

1. Introduction

Sickle-cell disease (SCD) is one of the well-known hematological disorders that affects many people around the world. A point mutation in beta-globin gene leads to hemoglobin polymerization, by producing hemoglobin S (Hb S) instead of hemoglobin A (Hb A). The abnormal hemoglobin, Hb S, disturbs erythrocytes' normal shape, which is important for carrying oxygen to body tissues; the erythrocytes become crescent shaped, which affects red blood cells' ability to carry oxygen and carbon dioxide [1]. In addition, the sickle erythrocyte becomes rigid and less pliable than the normal erythrocyte. The mutant hemoglobin genes are transmitted from one generation to another by autosomal recessive inheritance that requires two affected or carried parents to pass the SCD to the offspring [17]. The disease risk increases with consanguineous marriage – when the two parents are considered relatives [2].

SCD is considered one of the life-threatening conditions with increasing mortality rates yearly because of the high number of comorbidities associated with this disease. One of SCD's major complications are stroke and acute chest syndrome due to microvascular obstruction of sickling erythrocytes. This leads to an important manifestation in SCD patients, a pain crisis [3]. Worldwide, the prevalence of sickle cell disorders is 2.28 cases per 1000 of the population. The incidence of SCD is about 275 000 cases per 332 000 of the population affected by hemoglobin disorders annually [4]. Saudi Arabia has a high prevalence and burden of SCD [5]. The prevalence of SCD in Saudi Arabia is variable in each region; the Eastern province in Saudi Arabia has the highest SCD prevalence rate of 145 cases per 10000 people [6]. Al-Ahsa region carries the highest rate of SCD in Saudi Arabia [7]. The reason for the high prevalence of SCD in Saudi Arabia is consanguineous marriages, which account for 42-67% of all marriages in the region [8].

The remarkable prevalence of SCD in the Al-Ahsa region of Saudi Arabia might be due to poor knowledge and misunderstanding of this disease [2]. There is a significantly low level of knowledge and misconceptions among the university students in Dammam, Kingdom of Saudi Arabia, regarding SCD [9]. This study aimed to evaluate the attitude, knowledge perception, and misunderstanding regarding SCD and its complications.

2. Material and Methods

2.1. Study Area

The study was carried out in Al-Ahsa city in Saudi Arabia, which is located in Southwest Asia. Al-Ahsa is considered to be the largest city in Saudi Arabia's Eastern Province.

2.2. Study Design

An analytical cross-sectional study was conducted among the Al-Ahsa population. The data was collected over two months, from November 2019 to December 2019.

2.3. Inclusion and Exclusion Criteria

The study included both males and females from all age groups, different educational levels, and residents of Al-Ahsa, Saudi Arabia.

2.4. Sample Size Estimation and Sampling Technique

A sample size was obtained from a formula for cross-sectional studies: n=Z2P(1−P)/d2, where n - the sample size; Z - level of confidence (1.96); P - expected prevalence ([10] found that 51.4% of the population showed a good knowledge of SCD in Jeddah city); and d - precision (5%) [10, 11]. The sample size was estimated to be around 386.2–387 participants. In this study, we used a convenience sampling technique to select the participants based on availability.

2.5. Data Collection and Management

Data was collected by using a structured self-administered questionnaire, which was obtained from previous literature reviews [10, 12, 13]. The questionnaire included 24 questions and contained four main sections: socio-demographical information, knowledge, attitude, and complication of SCD.

Participants' data on their age, gender, educational level, occupation, and marital status was covered in the socio-demographical section. As for assessing the participants' knowledge of SCD, questions regarding its etiology, disease features, diagnosis, preventive measures, treatment, and inheritance pattern were included in the questionnaire [13]. "Yes," "no," and "I don't know," were used as choices for the complication section [10]. A three-point Likert scale ranging from "agree" to "disagree" was used to assess participants' attitudes [12].

2.6. Ethical Considerations

Participation in this study was voluntary, and only those participants who agreed to fill out the questionnaire were included in the study. The study ensured the participants' confidentiality since no names were required for filling out the questionnaire. Additionally, prior to answering the questionnaire, the participants were informed that the answers would only be used for research purposes.

2.7. Data Analysis

After the data was collected, it was then revised, coded, and fed into the statistical software IBM SPSS version 22 (SPSS, Inc. Chicago, IL). All statistical analysis was done using two-tailed tests. A P value of less than 0.05 was statistically significant.

For knowledge and awareness items, each correct answer was worth one point, and the total summation of the discrete scores of the different items was calculated for each knowledge domain (general and complications knowledge) along with the overall knowledge score. A participant with a score of less than 60% was considered to have poor awareness, while good awareness was considered if they had a score of 60% or more.

Descriptive analysis based on frequency and percent distribution was done for all variables including participants' personal data, if they had children with SCD, hearing about the disease, and their source of information. Knowledge and awareness regarding SCD in general and its related complications, besides their attitude towards SCD cases, were assessed in frequency tables and graphs. Crosstabulation was used to assess the distribution of the participants' knowledge level according to their personal data and source of information. Furthermore, relations were tested using the Pearson chi-square test and exact probability test for small frequency distributions.

3. Results

In total, 387 participants completed the study questionnaire. Participants' ages ranged from 18 to over 38 years, with a mean age of 23.9 ± 11.8 years. Of the respondents, 302 (78%) were women. Moreover, 311 (80.8%) had a pre-university level of education, 152 (39.3%) were employed, and 137 (35.4%) were students. Regarding marital status, 200 (51.7%) participants were married, whereas 173 (44.7%) were single. A total of 18 (8.4%) had a child with SCD, and 319 (82.4%) had heard about sickle cell disease (Table 1).

Table 1 Personal data of the study participants in Saudi Arabia

Personal data	No	%
Age in years		
< 18	33	8.5%
19-28	169	43.7%
29-38	78	20.2%
> 38	107	27.6%
Gender		
Female	302	78.0%
Male	85	22.0%
Education level		
Pre-university	311	80.8%
University	74	19.2%
Occupation		
Employee	152	39.3%
Student	137	35.4%
None	98	25.3%
Marital status		
Married	200	51.7%
Widow	4	1.0%
Divorced	10	2.6%
Single	173	44.7%
Do you have any children with sickle cell disease?		
Yes	18	8.4%
No	196	91.6%
Do you hear about sickle cell disease?		
Yes	319	82.4%
No	68	17.6%

In terms of general knowledge, 76.7% of the study participants knew that SCD is an inherited disease. In addition, 59.9% of the study participants knew that frequent illness is a feature present in patients with sickle cell disease, whereas 78% knew that blood tests are used as a diagnostic method. A total of 69% of the study participants knew that sickle cell disease can be prevented by premarital counseling. In addition, 33.1% of the participants reported that there was a near perfect chance of having a healthy baby even when both parents had sickle cell disease. (None of the children would have sickle cell disease). Moreover, 27.6% knew that drugs are the main treatment for SCD. In terms of knowledge about complications, 78% of the study participants reported that pain stemming from sickle cell disease requires hospitalization, 41.1% knew that sickle cell disease leads to poor school performance, 21.7% knew that sickle cell disease leads to kidney failure, 17.8% agreed that sickle cell disease leads to life-threatening infection, and 15.5% knew that sickle cell disease leads to stroke.

Table 2 Knowledge regarding SCD among study participants in Saudi Arabia

Domain	Awareness items		No	%
Overall knowledge	What are the causes of sickle cell disease	Acquired	26	6.7%
		Inherited	297	76.7%
		I do not know	64	16.5%
	What are the features present in patients with sickle cell disease?	Yellow eye	66	17.1%
		Frequent illness	232	59.9%
		I do not know	89	23.0%
	How is sickle cell disease found in a patient?	Urine test	18	4.7%

Continuation of Table 2

		Blood test	302	78.0%
		I do not know	67	17.3%
	Sickle cell disease can be prevented by	Genetic counseling	59	15.2%
		Testing before marriage	267	69.0%
		I do not know	61	15.8%
	What is the chance of delivering a healthy baby when all the parents have sickle cell disease?	None of the children	128	33.1%
		All the children will be healthy	18	4.7%
		Half of the children will be healthy	66	17.1%
		A quarter of the children will be healthy	50	12.9%
		I do not know	125	32.3%
	What is the treatment of sickle cell disease?	No treatment	156	40.3%
		Herbals	13	3.4%
		Drugs	107	27.6%
		I do not know	111	28.7%
Risk factors	Does pain in sickle cell disease require hospitalization?	Yes	302	78.0%
		No	22	5.7%
		I do not know	63	16.3%
	Does sickle cell disease lead to life-threatening infection?	Yes	69	17.8%
		No	183	47.3%
		I do not know	135	34.9%
	Does sickle cell disease lead to kidney failure?	Yes	84	21.7%
		No	59	15.2%
		I do not know	244	63.0%
	Does sickle cell disease lead to stroke?	Yes	60	15.5%
		No	100	25.8%
		I do not know	227	58.7%
	Does sickle cell disease lead to poor school performance?	Yes	159	41.1%
		No	114	29.5%
		I do not know	114	29.5%

A total of 56.8% of the study participants had a good general knowledge level regarding SCD, but only 24.5% had good knowledge regarding SCD complications. In total, 26.4% of the study participants had good overall knowledge regarding SCD.

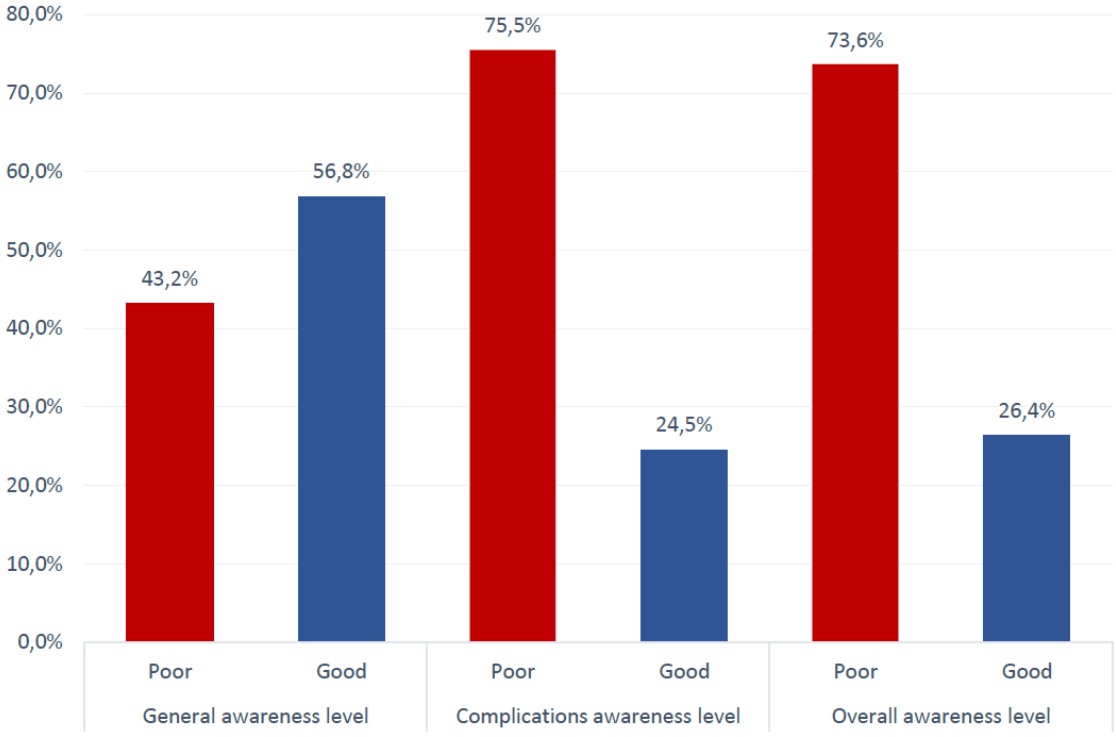

Fig. 1 Participants' knowledge level regarding SCD by domains and in total, Saudi Arabia

The most reported source of information was friends/family (38.5%), followed by health professionals (21.7%), the internet (14.7%), and mass media (7.5%). In contrast, 17.6% had no specific source.

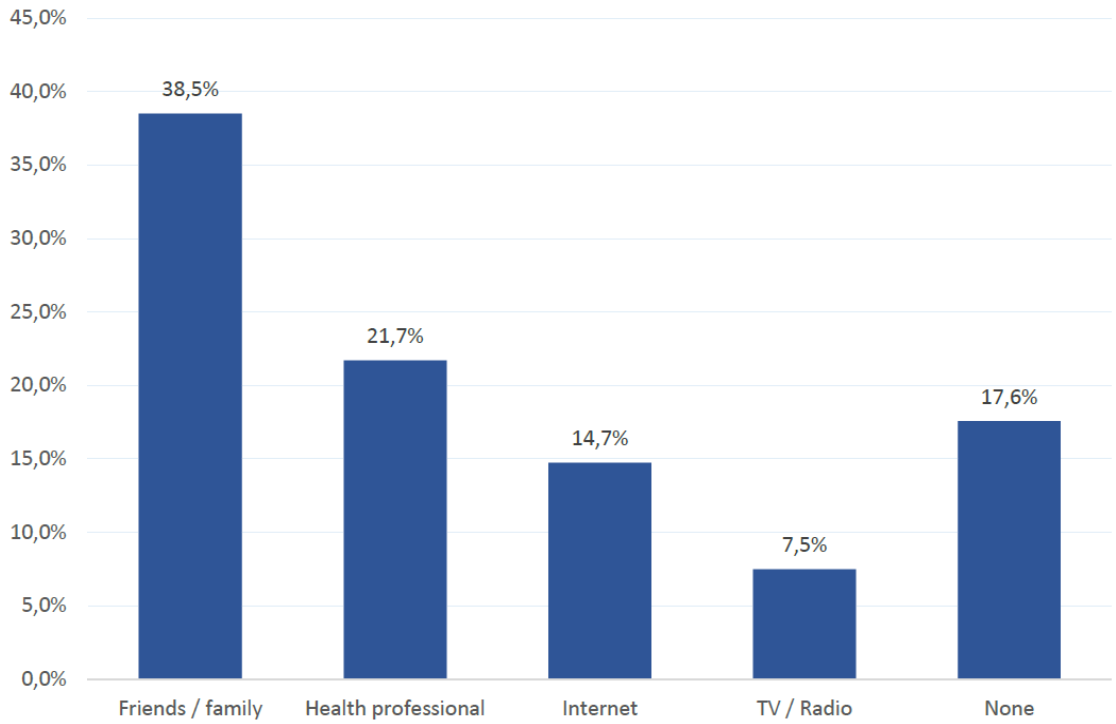

Fig. 2 Source of information regarding SCD among study participants

Of the participants, 54.3% felt sympathy for people with sickle cell disease. In contrast, 46.5% reported that they would never marry someone with sickle cell disease, and 42.1% stated that they would choose not to have a child rather than to have a child with sickle cell disease. At the same time, only 20.9% said they would end their relationship if they discovered that they had a chance of having children with sickle cell disease with their partner.

Table 3 Participants' attitudes toward SCD patients, Al-Ahsa, Saudi Arabia

Attitude items	**Agree**		**Neutral**		**Disagree**	
	No	**%**	**No**	**%**	**No**	**%**
I feel sympathetic for people with sickle cell disease.	210	54.3%	106	27.4%	71	18.3%
I will never marry someone with a sickle cell disease	180	46.5%	140	36.2%	67	17.3%
I will end my relationship if I discover that my partner and I have a chance to have children with sickle cell disease	81	20.9%	110	28.4%	196	50.6%
I will choose not to have a child than to have a child with sickle cell disease	163	42.1%	117	30.2%	107	27.6%

A good knowledge level regarding SCD was found to be significantly higher among older participants (41.1%) than among young participants (12.1%; $p = .001$). In addition, 29.1% of women had good knowledge regarding SCD compared with 16.5% of men ($p = .019$). A total of 29.2% of participants who had heard about sickle cell disease had good knowledge levels versus 13.2% of those who had not ($p = .007$). In addition, 32.2% of participants who received their information from family had good knowledge compared with 32.1% of those who received information from healthcare staff and 13.2% of those with no source of information ($p = .008$).

Table 4 Distribution of participants' overall knowledge regarding SCD by personal data

Personal data	**Overall awareness level**				**p-value**
	Poor		**Good**		
	No	**%**	**No**	**%**	
Age in years					.001*
< 18	29	87.9%	4	12.1%	
19-28	132	78.1%	37	21.9%	
29-38	61	78.2%	17	21.8%	
> 38	63	58.9%	44	41.1%	
Gender					.019*
Female	214	70.9%	88	29.1%	
Male	71	83.5%	14	16.5%	
Education level					.100
Pre-university	223	71.7%	88	28.3%	
University	60	81.1%	14	18.9%	
Occupation					.859
Employee	110	72.4%	42	27.6%	
Student	101	73.7%	36	26.3%	
None	74	75.5%	24	24.5%	
Do you have any children with sickle cell disease?					.794[$]
Yes	14	77.8%	4	22.2%	
No	147	75.0%	49	25.0%	
Do you hear about sickle cell disease?					.007*
Yes	226	70.8%	93	29.2%	
No	59	86.8%	9	13.2%	
If you heard about sickle cell disease, what is your source of information?					.008*

Continuation of Table 4				
None	59	86.8%	9	13.2%
Health professional	57	67.9%	27	32.1%
TV/Radio	20	69.0%	9	31.0%
Internet	48	84.2%	9	15.8%
Friends/family	101	67.8%	48	32.2%

Notes: P - Pearson X^2 test; $ - exact probability test; * P < 0.05 (significant)

4. Discussion

In this study, most of the participants ranged in age from 19 to 28 years, and a high proportion were in the level of pre-university education, which may have affected the participants' knowledge regarding SCD. Women were found to have a good knowledge level regarding SCD, which was consistent with other studies [10]. Nearly half the participants were single, so the sample was considered a good target population based on previous studies [10, 12, 13]; connecting with this population might help individuals make proper decisions regarding their future partners who might carry SCD genes.

Regarding the participants' knowledge of SCD, most had heard about SCD, which implies a good level of knowledge. Consistent with other studies [13], a large proportion of the respondents had heard about SCD from their families and friends, whereas only 7.5% of the respondents had heard about it from the TV/radio. This indicates a need for more efforts by the media to carry out community campaigns related to SCD.

More than half the population knew the causes, features, and diagnostic criteria of SCD. In addition, 69% of the population identified that testing before marriage can prevent SCD, representing a good level of awareness about premarital testing. In contrast, there was a low level of knowledge regarding the inheritance mode and treatment of SCD, exhibiting a high need for improved SCD knowledge. The general awareness level was considered high in our study; specifically, 56.8% of the population had a good general awareness level. In opposition to the present study findings, multiple studies have shown that more than half of the population has a poor general knowledge of SCD [14-16]. A study conducted in the Albaha region found that most of the population with a poor level of knowledge comprised young men; in contrast, in our study, most of the respondents in this group were young women with pre-university education [16]. However, another study conducted in Saudi Arabia reported a poor knowledge level regarding SCD among older participants.

Consistent with a study conducted in the city of Jeddah [10], a relatively high percentage of the population agreed that SCD requires hospitalization and leads to poor school performance. In our study, a low percentage of the population was aware that SCD leads to life-threatening infection, kidney failure, and stroke. Since the complication awareness level was considered poor in our study, in opposition to the study conducted in Jeddah, this highlights the need to increase the level of awareness regarding SCD and its complications in the Al-Ahsa region.

The present study showed that the lack of information on SCD's mode of inheritance and treatment affected the respondents' attitudes toward SCD. Respondents raised a negative attitude regarding never marrying someone with SCD and choosing not to have a child rather than to have a child with SCD. A similar study conducted in Ghana [12] found that more than half of the population had a positive attitude regarding sympathy for SCD patients, which is analogous to our study.

This study recommends community campaigns and social media as the best ways to increase awareness about SCD based on the participants' opinions, in contrast to [12]. In addition, few articles in the literature address the level of knowledge of SCD, its impact on their attitude and adherence, and misunderstandings about SCD and its complications in Saudi Arabia. However, the small sampling size may not be large enough to represent the entire SCD community in Saudi Arabia, which could influence the study's findings.

5. Conclusion

This study aimed to assess people's attitudes, knowledge perceptions, and misunderstandings about SCD and related complications. There was a reasonable awareness of the causes and diagnosis of SCD, although the respondents did not recognize some SCD complications. The majority of respondents had a negative attitude toward those who have SCD. Therefore, there is a need for awareness programs to correct some misconceptions and increase knowledge about SCD. The study suggests that future research expand the survey to larger geographical areas to establish a documented epidemiology of SCD in Saudi Arabia.

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