




Sickle Cell Illness Awareness among the General Public

Hassan Ahmed Alawlah , Abdulmajeed Ahmed Alsenani, Tarik Khaled A. AlTarky,
Allosh Hedaiwish Alazmi
Majmaah University, Saudi Arabia

Abdulkhalek Sulaiman I Almushaiqeh, Abdullah Saad Alwazan, Ibrahim Abdulaziz S. S. Alabdurahem,
Ahlam Hadi Khormi, Ibtihaj Ahmed Ali Omar, ALHanouf Tawfiq Alohal, Safiah Nasser Yaseen,
Rashed Salem Hadi Almuhamdhi, Abdullah Ayidh Sameer Almutairi, Elham Khalid Alshehri,
Norah Abdullah Al Nafisah
Ministry of Health, Saudi Arabia

Suggested Citation

Alawlah, H.A., Alsenani, A.A., AlTarky, T.K.A., Alazmi, A.H., Almushaiqeh, A.S.I., Alwazan, A.S., Alabdurahem, I.A.S.S., Khormi, A.H., Omar, I.A.A., Alohal, A.T., Yaseen, S.N., Almuhamdhi, R.S.H., Almutairi, A.A.S., Alshehri, E.K. & Al Nafisah N.A. (2023). Sickle Cell Illness Awareness among the General Public. *European Journal of Theoretical and Applied Sciences*, 1(6), 315-324.
DOI: [10.59324/ejtas.2023.1\(6\).31](https://doi.org/10.59324/ejtas.2023.1(6).31)

Abstract:

Background: Lifelong sickle cell disease (SCD), a group of inherited blood disorders, afflicts millions of individuals. Sickle cell disease (SCD), with a global prevalence of 112 cases per 100,000 individuals, frequently gives rise to this condition. Sickle Cell Disease (SCD) exhibits a high prevalence in various regions, including Sub-Saharan Africa, Saudi Arabia, India, South and Central America, as well as the Mediterranean. We conducted a study in Tabuk, Saudi Arabia to assess the level of public knowledge and awareness of Sickle Cell Disease (SCD). **Methods:** The present study employed a cross-sectional observational design, encompassing a sample of 386 individuals residing in Tabuk, who were over the age of 18 and represented both genders and various nationalities. Demographic data and sickle cell disease awareness were obtained through the utilization of a structured questionnaire that was developed from previous research. **Results:** The present study included a total of 386

adults residing in Tabuk, Saudi Arabia, who satisfied the predetermined inclusion criteria. Among the participants, 47.4% fell between the age range of 18 to 25 years. The majority of participants had a satisfactory level of knowledge, with 24.1% of individuals aged 18-25, 10.1% of those aged 26-35, 7.3% and 6.55% of individuals aged 36-45, and a significant proportion of participants aged over 45. **Conclusion:** The survey participants demonstrated a satisfactory degree of understanding on the prevalence of sickle cell disease (SCD) in the Kingdom of Saudi Arabia (KSA).

Keywords: *Sickle cell disease, Awareness, Tabuk, Saudi Arabia.*

Introduction

Sickle cell disease (SCD) is a hereditary hematological disorder characterized by a range of genetic blood abnormalities, which persist throughout an individual's lifespan and affect a substantial global population (Oluwole et al.,

2022). Sickle cell illness is attributed to the substitution of valine with glutamic acid at the sixth position in the beta chain of hemoglobin (Hb). The transmission of this disease occurs through an autosomal-recessive inheritance pattern. The production of sickle hemoglobin (HbS) occurs as a result of a specific point



mutation, leading to the formation of a kind of hemoglobin that exhibits lower solubility compared to the conventional fetal or adult hemoglobin (Uche et al., 2017). Sickle cell disease (SCD) exhibits a global prevalence of approximately 112 instances per 100,000 individuals, positioning it as one of the prevailing infectious ailments on a global scale (Hurissi et al., 2022).

Several studies have been conducted in Saudi Arabia to determine the prevalence of sickle cell disease (SCD). The conducted investigations have shown evidence of the prevalence of this ailment throughout the nation, particularly in the eastern and southern regions. The prevalence of sickle cell disease (SCD) is highest in the southern region. According to Alhejji et al. (2018), the prevalence of sudden cardiac death (SCD) was projected to be 145 cases per 100,000 individuals in the eastern area, 24 cases per 100,000 individuals in the southern region, 12 cases per 100,000 individuals in the western region, and 6 cases per 100,000 individuals in the central region.

In the year 2022, a study was undertaken with the objective of stimulating interest in the assessment of knowledge, enhancing the understanding of sickle cell anemia (SCA) throughout various sectors of Saudi society, and facilitating the dissemination of further information pertaining to this medical disease. Furthermore, a study was conducted to assess the level of readiness among individuals and communities to undergo premarital testing as a preventive measure against genetic disorders. A total of 60.16 percent of individuals demonstrated awareness of the prevailing circumstances. A few 53 individuals, constituting 13.3 percent of the sample, demonstrated awareness regarding the impact of disease on children in cases where both parents were afflicted. According to Khalifa et al. (2022), a study involving 390 participants revealed a consensus rate of 97.5% on the importance of premarital counseling.

A descriptive cross-sectional survey was undertaken in 2019 to investigate the population of Al-Ahsa. A total of 221 individuals hailing

from Saudi Arabia actively engaged in the study by voluntarily completing self-administered questionnaires and providing their informed consent through a permission form. Based on the findings, there was a satisfactory degree of knowledge on Sickle Cell Disease (SCD) within the general community. Nevertheless, it is imperative to prioritize education and promote awareness. Nevertheless, it is imperative for the government to persist in implementing legislation and mandating premarital testing, as argued by Alhejji et al. (2018). The objective of this study was to assess the level of community knowledge and awareness regarding sickle cell disease (SCD) within the general population residing in the Tabuk region of Saudi Arabia. Based on a recent examination of the literature, it has been found that no prior research has been undertaken specifically addressing this matter within the Tabuk region.

Methodology

Study Design and Setting

The present investigation is a cross-sectional observational study conducted in Tabuk city, located in the Northwestern region of Saudi Arabia. The study was carried out during a duration spanning from July 2021 to October 2022.

Study Population

Tabuk city male and female residents from all nationalities

The Inclusion Criteria of this Study

All individuals, regardless of their gender or nationality, residing in Tabuk, Kingdom of Saudi Arabia, who are 18 years of age or older, and identify as male or female, express their consent to partake in the study.

Exclusion Criteria

Individuals who are below the age of 18 and citizens who dwell beyond the geographical boundaries of Tabuk city, who express their unwillingness to partake in the activity.

Sample Size

The Qualtrics calculator was utilized to estimate a sample size of 386, with a confidence level of 95%. In order to conduct a study with a 95% confidence interval, a 5% acceptable error margin, and a design effect factor of 2, a minimum of 386 participants is required. To enhance the precision of the study, the number of participants was subsequently raised by 45%. The determination of sample size is performed via the online tool available at <http://www.raosoft.com/samplesize.html>.

Rationale of Topic Selection

Sickle cell disease is a prevalent condition that can be mitigated by the dissemination of knowledge throughout the community. The prevalence of the sickle-cell trait in Saudi Arabia is estimated to range from 2% to 27%, with the highest occurrence observed in the Eastern region. Additionally, it is estimated that up to 2.6% of individuals in the population may have sickle-cell disease (SCD). Evaluating the level of awareness among the general population regarding this prevalent disease will facilitate the implementation of preventive measures.

Method for Data Collection and Instrument

The researchers employed a structured questionnaire as a tool for data collection in the study. The development of this instrument was informed by a comprehensive review of pertinent research undertaken both in Saudi Arabia and other locations. The questionnaire was ultimately comprised of a total of 20 questions, which were further categorized into two distinct sections. The initial portion encompasses demographic characteristics, encompassing variables such as age, gender, educational attainment, and marital status. The second component of this study examines the assessment of knowledge and awareness pertaining to sickle cell disease (SCD), encompassing factors such as the mode of heredity, diagnostic methods, and potential curative treatments. The data was gathered through the utilization of a questionnaire administered via a Google form. The structured questionnaire employed in this study was derived

from a previously completed study (Khalifa et al., 2022).

Statistical Analyses

A survey instrument comprising of 12 questions and socio-demographic variables was utilized to evaluate the level of knowledge and awareness among the participants in the sample population. Following the extraction of the data, a process of verification, coding, and inputting into analysis tools was undertaken. The software employed in this study was IBM SPSS version 22, developed by SPSS, Inc. in Chicago, IL. A descriptive analysis was conducted on all variables, encompassing demographic traits as well as measures of awareness and knowledge. This analysis involved examining the frequency and percentage distribution of the variables. A total of 11 survey items pertaining to awareness and knowledge were included in the study, out of a possible 17. One point is awarded for each accurate response. Subsequently, the cumulative sum of the individual scores for the diverse elements was computed. Incorrect responses are assigned a numerical value of 0, whereas correct responses are assigned a numerical value of 1. The level of awareness and knowledge among the participants was subsequently assessed. Participants who obtained scores ranging from 0 to 3 were categorized as having a low level of awareness and knowledge. Those who scored between 4 and 7 were classified as having a moderate level of awareness and knowledge. Participants who achieved scores of 8 and above were deemed to have a high level of awareness and knowledge.

Chi-Square tests were conducted to assess the association between demographic parameters and the levels of knowledge and awareness among participants on sickle cell disease and its factors. The methods were validated assuming a significance level of $p < 0.05$. The study's findings were presented using tables and graphs.

Results

This study encompassed a total of 386 adult participants from the Tabuk region in Saudi

Arabia who met the specified inclusion criteria. The largest proportion of participants (47.4%) fell between the age range of 18 to 25 years. Table 1 illustrates that a majority of the participants possess a commendable degree of awareness and information pertaining to sickle cell disease, encompassing its diagnosis, symptoms, risk factors, and management strategies.

In relation to age disparities, a significant proportion of the participants exhibited a commendable level of knowledge. Specifically, 24.1% of individuals aged 18 to 25 years, and 10.1% of those aged 26 to 35 years, demonstrated a satisfactory level of knowledge. Additionally, 7.3% and 6.55% of individuals aged 36 to 45 years and above 45 years, respectively, also exhibited a commendable level of knowledge. There was no statistically significant association found between the age of the participants and their level of awareness and knowledge ($p = .199$). The distribution of gender differences in levels of good awareness was ascertained, with 25.4% observed in males and 22.5% in females. There is a lack of statistically significant evidence to support the presence of disparities between the genders of the participants and their degree of knowledge ($P = .317$). According to the findings of the study, the majority of participants were Saudi citizens, while a small percentage of 0.3% consisted of non-Saudis. These findings were obtained in relation to the link between participant nationality and their degrees of awareness and knowledge ($P = .407$). Nevertheless, the study did not find any statistically significant disparities between the participants' nationalities and their levels of expertise.

The majority of individuals who exhibited a significant level of awareness and knowledge were found to be either single or married, albeit in somewhat varying proportions. Specifically,

23.8% of participants were identified as single, while 22.8% were classified as married, in relation to their socioeconomic situation. However, save from a small fraction of widows and divorcees ($p = .181$), there are no statistically significant differences seen between the participants' social status and their level of awareness and knowledge.

Regarding the correlation between participants' educational levels and their level of awareness and knowledge, the findings indicate that awareness and knowledge levels are generally high across various educational backgrounds, irrespective of participants' differing levels of education. The user's text will be rewritten to adhere to academic standards without adding any additional information. A total of 8% of individuals classified as illiterate and 5% of those in middle school. A proportion of 9.3% of those enrolled in high school, 34.5% of those enrolled in university, and an additional 2.8% of individuals enrolled in post-graduate programs constitute the student population. There is no statistically significant difference in the educational background and knowledge level of the participants ($P = .188$).

Upon examination of the outcomes pertaining to individuals who possess familiarity with an individual afflicted with sickle cell disease, a discernible correlation between this familiarity and their level of knowledge and awareness was observed. persons who have personal connections with individuals affected by sickle cell disease had a higher level of knowledge and awareness compared to persons who do not have such connections. Based on the available evidence, a significant statistical distinction was observed between the participants' level of knowledge and awareness and their personal acquaintance with individuals affected by sickle cell disease ($P = .000 *$).

Table 1. Selected Characteristic of the Sample and the Association with the Awareness and Knowledge Level Regarding Sickle Cell Anemia and its Factors, in Tabuk Region

				Awareness and Knowledge Level			
Characteristics of the sample		N=386	%	Good	Intermediate	Poor	P
Age in year	From 18 to 25	183	47.4	93(24.1)	68(17.6)	22(5.7)	.199
	From 26 to 35	77	19.9	39(10.1)	32(8.3)	6(1.6)	
	From 36 to 45	71	18.4	28(7.3)	39(10.1)	4(1)	
	More than 45	55	14.2	25(6.5)	26(6.7)	4(1)	
Gender	Female	172	44	87(22.5)	73(18.9)	12(3.1)	.317
	Male	214	55.4	98(25.4)	92(23.8)	24(6.2)	
Nationality	Saudi	381	98	184(47.7)	162(42)	35(9.1)	.407
	Non-Saudi	5	1.3	1(.3)	3(.8)	1(.3)	
Marital status	Single	198	51	92(23.8)	82(21.2)	24(6.2)	.181
	Married	177	45.9	88(22.8)	78(20.2)	11(2.8)	
	Divorced	8	2.1	3(.8)	5(1.3)	0(0)	
	Widow	3	.8	2(.5)	0(0)	1(.3)	
Education	Illiterate	5	1.3	3(.8)	1(.3)	1(.3)	.188
	Primary school	0	0	0(0)	0(0)	0(0)	
	Middle school	2	.5	2(.5)	0(0)	0(0)	
	Secondary school	66	17.1	36(9.3)	21(5.4)	9(2.3)	
	University	281	72.8	133(34.5)	124(32.1)	24(6.2)	
	Post-graduate	32	8.3	11(2.8)	19(4.9)	2(.5)	
Knowing someone who has sickle cell e?	Yes, I know	174	45.1	124(32.1)	50(13)	0(0)	.000*
	I do not know	212	4.9	61(15.8)	115(29.8)	36(9.3)	

Note: *Significant

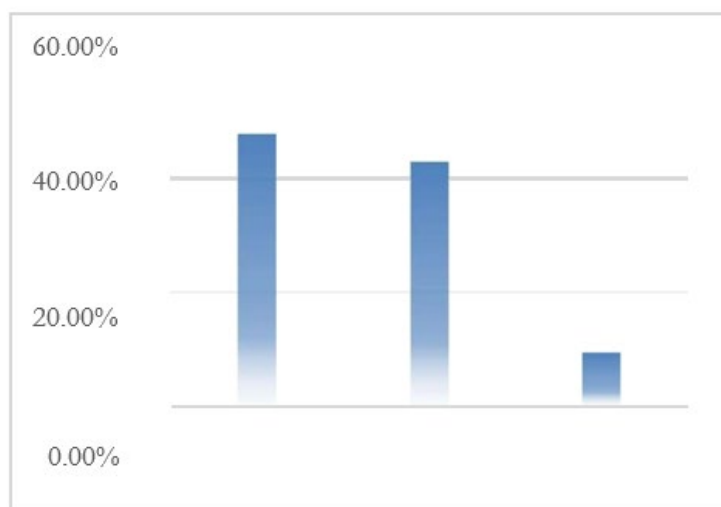


Figure 1. That most of the Participants Have a Good Level of Awareness and Knowledge of Sickle Cell Disease, Its Diagnosis, Symptoms, Risk Factors and Its Management

Table 2. The Questions by which Participants' Level of Awareness and Knowledge about Sickle Cell Disease and Its Factors was Measured

Awareness and knowledge about (sickle cell disease)		N	%
Have you ever heard of sickle cell disease (SCD)?	Yes	340	87.6
What kind of diseases are SCD classified?	Bone disease	8	2.1
	Gastrointestinal disease	3	.8
	Blood disease (correct answer)	337	86.9

	Lymphatic disease	0	0
	Nerve disease	1	.3
	I don't know	37	9.5
Do you know someone who has SCD?	Yes	174	44.8
If yes? How do you know them?	Mother/Father	7	1.8
	Brother/Sister	29	7.5
	Aunt/Uncle	10	2.6
	Cousin	1	.3
	Friend	100	25.8
	Other	35	9.0
Awareness and Knowledge about (SCD) Risk factors		N	%
How do you think people with SCD get affected?	Malnutrition	20	5.2
	By virus	3	.8
	By bacteria	3	.8
	Inherited (correct answer)	301	77.6
	Mineral deficiency	12	3.1
	Malnutrition	20	5.2
	I don't know	47	12.1
Awareness and Knowledge about (SCD) Clinical features		N	%
What are the symptoms of sickle cell anemia?	Pale skin (correct answer)	10	2.6
	Fatigue and tiredness (correct answer)	39	10.6
	A headache	9	2.6
	Chronic pain episodes (correct answer)	28	7.6
	Diarrhea	5	1.5
	Vision problems (correct answer)	7	2.0
	Recurring infection (correct answer)	16	4.3
	Vomiting	4	1.2
	I don't know	66	17.0
What do you think about the severity of SCD?	Very serious (correct answer)	179	46.1
	Moderate	100	25.8
	Not serious	18	4.6
	I do not know	89	22.9
Awareness and Knowledge about (SCD) diagnosis		N	%
Which one of those is the test to diagnose SCD?	Ultrasound	2	.5
	Blood test (correct answer)	332	85.6
	Urine / feces test	4	1.0
	I do not know	48	12.4
What is the probability for a child to get SCD? If both parents had SC trait?	All children	68	17.5
	50% of offspring	130	33.5
	25% of offspring (correct answer)	73	18.8
	I do not know	115	29.6
Do you think pre-marital examination is necessary?	Yes (correct answer)	348	90.2
	No	1	.2
	I do not know	37	9.6
If a married couple found out that their genetic test showed the chance of having a child with SCD, what do you think they should do?	Separate	100	25.9
	Continue their marriage	6	1.6
	Consult a doctor (correct answer)	241	62.4
	I do not know	39	10.1
Awareness and Knowledge about (SCD) management		N	%
Is SCD curable?	Yes	85	22
	No (correct answer)	138	35.8
	I do not know	163	42.2

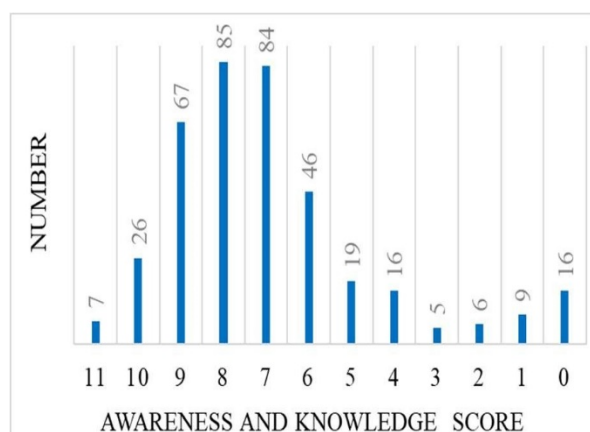


Figure 2. Distribution of Awareness and Knowledge Score about Sickle Cell Anemia among the Studied Population, in Tabuk Region

Discussion

The identification of genes affected by the disease in sickle transgenic mice and people is being facilitated through the utilization of expression microarrays in several organs. After the identification of these genes, it is possible to search for polymorphisms in order to identify genetic modifiers that contribute to the determination of individual risk. This knowledge can facilitate the development of rational treatments before the occurrence of organ damage.

Sickle Cell Disease (SCD) is a subject that is of significant public health interest. It is imperative to possess an adequate understanding of SCD and its associated ramifications in order to effectively manage this condition. Based on a recent review of scholarly literature, it has been found that there is a lack of study conducted on the assessment of SCD (Specific Carbohydrate Diet) in the region of Tabuk, Saudi Arabia. Hence, it is imperative to assess the Saudi Arabian public's impression of the Saudi Commission for Tourism and National Heritage (SCTH). Previous community-based surveys conducted in major urban areas found that African Americans have limited awareness of sickle cell disease (SCD), which contradicts the current research findings indicating a substantial improvement in their understanding (Vassiliou et al., 2001). Adewoyin et al. (year) demonstrated a considerable level of proficiency in the field of

public health pertaining to sickle cell disease (SCD) in Nigeria.

The populace of Bahrain in the Middle East shown a significant level of awareness and comprehension regarding sickle cell disease (SCD). The preventive activities implemented in Bahrain were positively received and aligned with the current research findings. According to Panter-Brick (1991), the population of Bahrain in the Middle East demonstrated a comprehensive comprehension of sickle cell disease (SCD), and the preventive actions implemented in the country were widely acknowledged and valued. According to Alfahl et al. (2022), the previous study reported that 98 percent of participants were familiar with Sudden Cardiac Arrest (SCA), however in our study, only 88 percent of individuals demonstrated awareness of SCA.

In relation to the classification of sickle cell disease (SCD), it was found that 98% (n=2836) of the participants possessed knowledge that SCD is a hematological disorder. Conversely, a small proportion of participants, comprising 2% (n=59), were uninformed of the nature of SCD, while an even smaller percentage, constituting 0.2% (n=6), mistakenly believed it to be an infectious disease. Additionally, 0.1% (n=3) of the remaining participants erroneously saw SCD as a cardiovascular ailment. In relation to the classification of sickle cell disease (SCD), a significant majority of the participants (87%) demonstrated awareness that it is a

hematological problem. Conversely, a minority of the remaining participants (9%) expressed uncertainty regarding their knowledge of SCD, while a small proportion (2%) mistakenly believed it to be a condition affecting the skeletal system. In a prior study conducted by Alfahl et al. (2022), it was found that 98% of the participants were aware that the condition under investigation is a blood problem. The remaining 2% of participants either expressed uncertainty about their knowledge or held misconceptions about the nature of the ailment. Specifically, 0.2% of participants believed it to be an infectious disease, while 0.1% mistakenly considered it to be a cardio-vascular disease. The participants were surveyed regarding their awareness and understanding of risk factors associated with Sickle Cell Disease (SCD). The majority of respondents (77%) correctly identified SCD as a hereditary disorder. A smaller proportion (12%) indicated uncertainty, while a minority believed that malnutrition (5%) or mineral deficiency (3%) may lead to the development of SCD. The increase in community awareness and inclusion of thorough information in school curriculums regarding this matter can be attributed to the efforts of the Saudi Ministry of Health (Panter-Brick, 1991). This study examines the level of awareness regarding sickle cell disease among the general population residing in Al-Ahsa, Saudi Arabia.

A significant proportion of the study population (46%) expressed agreement regarding the profound impact of sickle cell disease (SCD) on health status and clinical manifestations, in contrast to a minority (22%) who lacked awareness on this matter. This finding suggests that the majority of participants possessed knowledge regarding the influence of SCD on overall well-being and cognitive functioning. Based on the findings of a recent survey, it was observed that a significant proportion, specifically 60.0%, of individuals diagnosed with sickle cell disease (SCD) in Saudi Arabia expressed the belief that this condition had a negative influence on their academic achievements. Furthermore, according to Kanter and Kruse-Jarres (2013), a study conducted on Saudi Sickler patients revealed that

37.5% of them received support from specialized after-school activities. Furthermore, a notable association exists between marital status and the awareness of the impact of sickle cell disease (SCD) on academic achievement. This finding aligns with our own research, which revealed that 18.8% of participants possessed knowledge of the 25% likelihood of offspring inheriting SCD when both parents carry the sickle cell trait. A significant majority, around 99% of the population, holds the belief that premarital examination is an essential practice. This observation can potentially be ascribed to the heightened level of care exhibited by parents of individuals with sickle cell disease (SCD) about the overall welfare of their children (Memish et al., 2011). In relation to the diagnosis of sickle cell disease (SCD), a majority of the participants (85%) correctly said that it is determined using a blood test. This response aligns with existing literature, since a blood test is capable of detecting the specific kind of hemoglobin associated with sickle cell anemia (Onimoe & Rotz, 2020).

The participants were also queried regarding their beliefs on the curability of SCD with medicine. Of the respondents, 35% expressed a negative viewpoint, 22% held an affirmative stance, and 42% indicated uncertainty on the matter. In a comparative analysis, Alfahl et al. (2022) found that a majority of participants (87%) expressed the belief that the condition under investigation was not curable. Conversely, a small percentage (2%) indicated that it was indeed curable, while 11% reported uncertainty regarding its curability.

Limitations

One primary constraint of this study pertained to the lack of validation of the questionnaire prior to its implementation. Additionally, the study's internal consistency, as indicated by an acceptable coefficient of 0.739, was found to be limited. Another weakness of the study was the exclusion of an examination of the most effective strategies for raising awareness among the population being assessed on the major

complications of sickle cell disease, such as renal failure, stroke, and hospitalization.

Conclusions

The study contributors shown a satisfactory degree of understanding on the prevalence of sickle cell disease (SCD) in Tabuk. The individuals possessed knowledge of Saudi Arabia's status as one of the countries with the greatest prevalence of sickle cell disease (SCD) globally. Furthermore, a notable degree of understanding was observed regarding the classification of diseases, methods of diagnosis, and a majority of participants in the survey demonstrated awareness of the clinical characteristics associated with Sickle Cell Disease (SCD). However, there appeared to be a lack of comprehensive understanding regarding the patterns of disease transmission, as well as a limited knowledge among participants on the likelihood of a child developing sickle cell disease (SCD) when both parents had the sickle cell (SC) trait. Additionally, the majority of participants shown a lack of knowledge in these areas.

Recommendations

It is recommended that additional educational programs be initiated in order to enhance awareness and information regarding sickle cell disease among the general public in Tabuk, Saudi Arabia.

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