Medical Science

pISSN 2321–7359; eISSN 2321–7367

Knowledge and awareness of sickle cell disease among general population in Tabuk, Saudi Arabia

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To Cite:
Mighani HO, Albuhairy AH, Aljohani KM, Alwakeel AA, Albalawi YA, Alrabiah NM, Alquayr SM, Alsharif MM, Albuhayri AH, Alruwaili AM, Aljifry LK. Knowledge and awareness of sickle cell disease among general population in Tabuk, Saudi Arabia. *Medical Science* 2023; 27: e7ms2673.
doi: https://doi.org/10.54905/disssi/v27i131/e7ms2673

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Peer-Review History
Received: 09 December 2022
Reviewed & Revised: 13/December/2022 to 26/December/2022
Accepted: 30 December 2022
Published: 03 January 2023

Peer-review Method
External peer-review was done through double-blind method.

URL: https://www.discoveryjournals.org/medicalscience

ABSTRACT

Background: A group of inherited blood disorders are known as (sickle cell disease, SCD) that are life-long and afflict millions of people worldwide. This is frequently triggered by factors such as SCD has a global frequency of around 112 per 100,000 people. SCD is most commonly recorded in Sub-Saharan African countries, Saudi Arabia, India, South and Central America and Mediterranean regions. We aimed to measure community SCD knowledge & awareness in the general public in Tabuk region of Saudi Arabia. *Methods:* This is a cross-sectional observational study was conducted during the period among general-public in Tabuk, involved a total of 386 persons from Tabuk older than 18 for both gender all nationalities. A structured questionnaire modified from previous literature was used to collect demographic data and the level of awareness regarding sickle cell disease. *Results:* The study included 386 adult participants in the Tabuk region, Saudi Arabia who fulfilled the inclusion criteria, the majority (47.4%) in the age range (18-25) years. Most of the participants had a good level of knowledge, 24.1% of (18 to 25 years old) and 10.1% of (26 to 35 years old), as well as 7.3% and 6.55% of (36 to 45 years old) and (more than 45 years old), had good knowledge. *Conclusion:* There was a good level of knowledge about SCD prevalence in KSA among the study participants.

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

1. INTRODUCTION

Sickle cell disease (SCD) is a series of genetic blood abnormalities that are life-long and afflict millions of people worldwide (Oluwole et al., 2022). A glutamic acid substitution for valine at the sixth position in the hemoglobin

(Hb) beta chain is the cause of sickle cell disease. This illness is passed down in an autosomal-recessive way. Because of this point mutation, sickle hemoglobin (HbS) is produced, a kind of hemoglobin that is less soluble than typical fetal or adult hemoglobin (Uche et al., 2017). SCD has a worldwide incidence of around 112 cases per 100,000 persons and is one of the most common infectious diseases in the world (Hurissi et al., 2022).

Numerous researches have been being out in Saudi Arabia to establish the frequency of SCD. These investigations have demonstrated that it is a widespread illness in the nation, notably in the eastern area, followed by the southern region. The southern region has the highest-frequency of SCD. It is anticipated that there were 145 instances of SCD for each 100000 individuals in the eastern area, 24 cases for each 100000 individuals in the southern region, 12 cases for each 100000 individuals in the western region and 6 cases for each 100000 individuals in the central region (Alhejji et al., 2018).

In 2022, this research was conducted to arouse interest in knowledge evaluation, raise awareness of sickle cell anemia (SCA) among different segments of Saudi society and disseminate further information about the condition. In addition, an investigation on the degree to which individuals and communities are prepared to submit to premarital testing to prevent genetic diseases. 60.16 percent of people were aware of the situation overall. Only 53 people (13.3 percent) were aware of the effect illness had on children when both of their parents suffered from it. There was a 97.5 percent consensus among 390 participants about the significance of premarital counseling (Khalifa et al., 2022).

In 2019, the population of Al-Ahsa was the subject of this descriptive cross-sectional survey that was conducted. 221 people from Saudi Arabia participated in the study by filling out self-administered questionnaires and a permission form. According to the results, an appropriate level of SCD knowledge existed among the general population. However, there should be a greater emphasis placed on education and awareness. Despite this, the government must continue to enact laws and make premarital testing obligatory (Alhejji et al., 2018). The aim of this study was to measure community knowledge and awareness of SCD among the general population in Tabuk region of Saudi Arabia. According to a recent literatures review, there is no single previous study has been conducted in this regard in Tabuk region.

2. METHODOLOGY

Study design and setting

This is a cross-sectional observational study in Tabuk city, the Northwestern Saudi Arabia during the period July 2021 - October 2022.

Study population

Tabuk city male and female residents from all nationalities

The Inclusion criteria of this study

All residents of both genders of all nationalities in Tabuk, Kingdom of Saudi Arabia, age ≥18 years, male and female sex, agree to participate

Exclusion criteria

Residents younger than 18 years, all residents outside the city of Tabuk, refusing to participate

Sample size

A sample size of 386 was estimated using the Qualtrics calculator, with a confidence level of 95%. For the study with 95% confidence interval, 5% acceptable error margin and design effect factor of 2, we need at least 386 participants and we increased the number by 45% to have greater precision. The calculation of sample-size is done by using http://www.raosoft.com/samplesize.html.

Rationale of topic selection

Sickle cell disease in common and can be prevented by community education. The estimated incidence of the sickle-cell trait in Saudi Arabia ranges from (2-27%) with the highest prevalence reported in the Eastern region and up to 2.6 percent of individuals could have SCD, assessing the awareness of the general population regarding this common disease will help implementation of preventive measures.

Sampling technique

Simple random sampling method

Method for data collection and instrument

A structured-questionnaire was used as a study tool. This tool was developed after consulting relevant studies conducted in Saudi Arabia and elsewhere. The final version of the questionnaire consisted of 20 questions divided into two sections. The first section includes demographic features such as age, gender, education level and marital status. The second section includes asses the knowledge and the awareness about SCD like the mood of inheritance, how it's diagnosed, is it curable. We collected the information using a Google form questionnaire. This structured questionnaire used in this study was taken from previous conducted study (Khalifa et al., 2022).

Ethical consideration

Ethical approval was obtained from the Tabuk Institutional Review Board (TU-077/022/160). The consent to participate was obtained from all the participants.

Statistical analyses

An electronic questionnaire consisting of 12 questions and socio-demographic characteristics was employed to assess the sample population's level of knowledge and awareness. After the data was extracted, it was verified, coded and input using analysis software. The software utilized was IBM SPSS version 22 (SPSS, Inc. Chicago, IL). All variables were subjected to a descriptive analysis based on frequency and percentage distribution, including demographic characteristics and measures of awareness and knowledge. 11 out of 17 awareness and knowledge-related survey questions were surveyed. There is a point given for each correct answer. The total of the individual scores for the various items was then calculated. Incorrect answers receive a value of 0, whereas correct answers receive a value of 1. The participants' awareness and knowledge were then calculated; those with overall scores between 0 and 3 were considered to have a poor level of awareness and knowledge, those with scores between 4 and 7 were considered to have an intermediate level of awareness and knowledge and participants with scores of 8 and above were considered to have a good level of awareness and knowledge.

Chi-Square tests were performed to evaluate the correlate demographic characteristics with the levels of knowledge and awareness of participants about sickle cell disease and its factors. Methods were verified under the assumption that p 0.05 was a significant level. Finally, tables and graphs were used to present the study's findings.

3. RESULTS

In this study included 386 adult participants in the Tabuk region, Saudi Arabia who fulfilled the inclusion criteria, the majority (47.4%) in the age range (18-25) years. Table 1 show 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.

Regarding age differences, most of the participants had a good level of knowledge, 24.1% of (18 to 25 years old) and 10.1% of (26 to 35 years old), as well as 7.3% and 6.55% of (36 to 45 years old) and (More than 45 years old), had good knowledge. There are no-significant differences between the participants' age and their level of awareness and knowledge (P=.199). While the distribution of gender difference for levels of good awareness was as follows: 25.4% in male and 22.5% in female. There are no statistically significant differences between the participants' gender differences and their level of knowledge (P=.317). The majority of participants were Saudi nationals, with 0.3% being non-Saudis, according to the study's findings on the association between participant nationality and awareness and knowledge levels (P =.407). However, there were (no-statistically significant differences) between the nationalities of the participants and their levels of knowledge.

Most of the participants who had a high degree of awareness and knowledge were single and married in slightly variable proportions, with 23.8% being single and 22.8% being married, when it came to socioeconomic status. However, other from a small percentage of widows and divorcees, (p=.181) there are no statistically significant variations between the participants' social standing and their degree of awareness and knowledge.

As for the association between the differences in the educational levels of the participants and their level of awareness and knowledge, it was revealed that the levels of awareness and knowledge are generally good at different educational levels, regardless of the difference in the educational levels of the participants. As follows: 8% of the illiterate, 5% of middle school

students, 9.3% of high school students, 34.5% of university students, in addition to 2.8% of post-graduate students. The participants' educational background and knowledge level do not different statistically significantly (P =.188).

When inspecting the results of the participants who knowing someone who has sickle cell disease and their level of knowledge and awareness, it was found that there is an association. The participants who knowing someone who has sickle cell disease, their level of knowledge and awareness was higher than the level of knowledge and awareness of participants who do not know. In light of this, there was a statistically-significant difference between the knowing someone who has sickle cell disease and the participants' level of knowledge and awareness (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	655.4	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	71.3	1(.3)	3(.8)	1(.3)	
Marital status	Single	198	51	92(23.8)	82(21.2)	24(6.2)	.181
	Married	177	345.9	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 disease?	Yes, I know	174	45.1	124(32.1)	50(13)	0(0)	.000*
	I do not know	212	54.9	61(15.8)	115(29.8)	36(9.3)	

*Significant

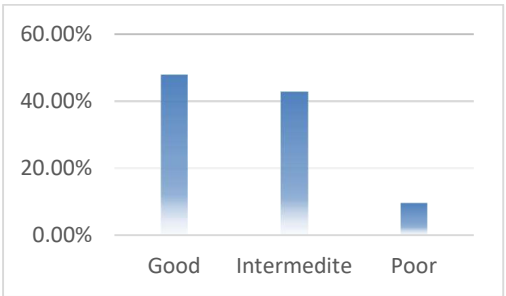

Figure 1 Shows that most of the participants have a good level of awareness and knowledge of sickle cell disease, its diagnosis, symptoms, risk factors and its management

Table 2 Shows the questions by which participants' level of awareness and knowledge about sickle cell disease and its factors was measured. The results are detailed below:

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	All children	68	17.5
	50% of offspring	130	33.5

trait?	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

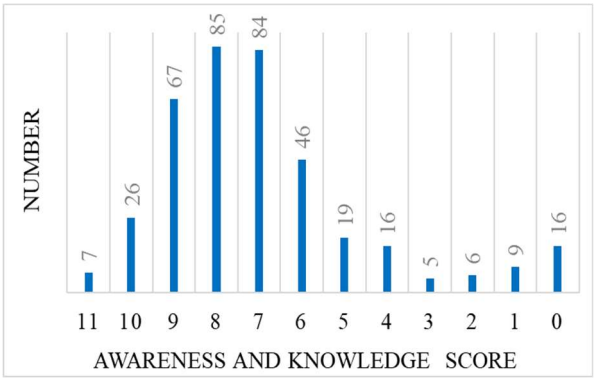

Figure 2 Distribution of awareness and knowledge score about sickle cell anemia among the studied population, in Tabuk Region

4. DISCUSSION

Genes in several organs impacted by the disease in sickle transgenic mice and humans are being found using expression microarrays. Following the identification of these genes, polymorphisms can be looked for to find genetic modifiers that help define individual risk, enabling reasoned treatments prior to the onset of organ damage.

SCD is a topic of public health concern, maintaining sufficient public health knowledge of SCD and its consequences is crucial to its management. According to a recent examination of the literature, no researchers have assessed SCD in Tabuk, Saudi Arabia. Thus, the Saudi Arabian public's perception of the SCD must therefore be evaluated. Early community-based surveys on African Americans in large urban locations revealed that these populations had little knowledge of SCD in contradiction to the present findings in which the knowledge was good (Vassiliou et al., 2001). Adewoyin and associates additionally showed a moderate-level of public-health expertise on SCD in Nigeria.

In the Middle East, Bahrain's population had a high degree of understanding regarding SCD and that the SCD preventive initiatives there were well-received and in line with the present findings. In the Middle East, Bahrain's population had a solid understanding of SCD and that the country's SCD preventive initiatives were well-received and appreciated (Panter-Brick, 1991). While 98 percent of participants in the prior study had heard of SCA, just 88 percent of our participants had (Alfahl et al., 2022).

Regarding the type of SCD, 2836 (98%) of the participants were aware that it is a blood problem, while 59 (2%), 6 (0.2%) and 3 (0.1%) of the remaining participants were unaware, thought it was an infectious disease and thought it was a cardio-vascular disease. Regarding to type of SCD, most of the participants (87%) knew that it is a blood disorder while (9%) of the remaining participants said they do not know, (2%) thought it is a bone disease. In another previous study: 98% knew that it is a blood disorder while 2% of the remaining participants said they do not know, (0.2%) thought it is an infectious disease and (0.1%) considered it is a cardio-vascular disease (Alfahl et al., 2022). The contributors were-asked about awareness and knowledge about "(SCD) risk factors, most of them 77% thought it is a hereditary disorder, while 12% said they do not know, 5% expected that one can get it from malnutrition and 3% mentioned that it is due to mineral deficiency. This can be explained by the role of Saudi MOH

in increasing community awareness as well as school curriculums that contain detailed information in this regard (Panter-Brick, 1991) Awareness about sickle cell disease among general population in Al-Ahsa, Saudi Arabia.

The majority of the study population (46%) agreed that SCD has dramatic effects on health status and clinical features and serious illness comparing to only 22 % who didn't know about that, which means that the majority were aware about the impact of SCD on the wellbeing and mental activity. According to a recent survey, 60.0% of Saudi Sickler patients thought that SCD had a detrimental impact on their ability to succeed in school. Additionally, of Saudi Sickler patients, 37.5% received assistance from special after-school programs (Kanter and Kruse-Jarres, 2013). Additionally, there is a strong correlation between marital-status and having the insight that SCD affects school performance and this is similar to our results that 18.8 % of participants know that 25% offspring will get SCD if both parents had SC trait. 99 % of population thinks that premarital examination is necessary. This is may be attributed to the fact that parents of SCD patients are more concerned about their child well-being (Memish et al., 2011). Regarding the diagnose of SCD, most of the participants 85%) answered that it is diagnosed by a blood test, this is right answer as a blood test can check for the form of hemoglobin that underlies sickle cell anemia (Onimoe and Rotz, 2020).

The participants were also asked: (Do you think that SCD can be a curable by using medication?), 35% said No while 22% said Yes and 42% said they do not know. Comparing to another study as regard it is curable or not: 87% of their participants said No while 2% said yes and 11% said they do not know (Alfahl et al., 2022).

Limitations

The main limitation of this study was that the questionnaire hadn't been validated before conducting the study and acceptable internal consistency was 0.739 which is limited. Another limitation was that study didn't include best way to increase awareness about SCD assessment population knowledge as regard serious complication of SCD such as renal failure, stroke and hospitalization.

5. CONCLUSIONS

There was a good level of knowledge about SCD prevalence in Tabuk among the study contributors. They were aware that Saudi Arabia is one of the highest prevalence countries in the world having SCD. Also, there was a good level of knowledge about type of disease, its way of diagnosis and most of people included in the study knew about clinical features of SCD. However, in depth knowledge about pattern of disease transmission seemed to be poor and participants showed poor knowledge of the probability for a child to get SCD, if both parents had SC trait moreover, the majority of participants.

Recommendations

We recommend that further educational campaigns should be inaugurated to raise awareness and knowledge about sickle cell disease among general population in Tabuk, Saudi Arabia.

Ethical approval

Ethical approval was obtained from the Tabuk Institutional Review Board (TU-077/022/160). The consent to participate was obtained from all the participants.

Funding

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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