



## Survey on Sickle Cell Disease (SCD) Awareness amongst High School Students in AlQunfudah, KSA

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### ABSTRACT

*Introduction: Sickle Cell Disease (SCD) is one of the most common hereditary diseases in the world. The prevalence of SCD in Saudi Arabia varies greatly in different parts of the country, the highest prevalence in the eastern region, followed by the southwestern. The Saudi Ministry of Health (MOH) started a premarital national screening program for SCD in 2004. The main objective of this program is to reduce the prevalence of SCD in the population by reducing the number of at-risk marriages. Previous studies in Saudi Arabia have documented poor awareness in the population about the hereditary transmission of SCD, the associated complications, and the premarital screening services, despite their positive attitude towards the program. Objectives: We aimed to assess the awareness about SCD among the high school students in AlQunfudah city. This will help to understand if there is a gap in awareness and serve as a need assessment study for future awareness programs. Methods: A cross-sectional study based on an electronic questionnaire was distributed on social media to the high school students of AlQunfudah. The questionnaire consists of 13 questions to assess the patients' knowledge and awareness of SCD. Categorical were presented as frequency and percentages. A Chi-square test was used to test for association. Results: A total of 428 high school students have filled the survey. 320 (71.70%) have heard about sickle cell disease before. The majority of students knew what causes SCD and how it is diagnosed, (70.30%) and (55.10%) respectively. However, only 33.40% knew how much of the children would be affected by the disease if both parents are affected. When asked if participants are willing to marry a partner with SCD, only (23.10%) said yes. A significant difference in answering was found when comparing the pattern of answers across gender, age, and marital state. Conclusion: The knowledge of the disease varied from one aspect to another with an overall moderate level. However, there was an overall excellent attitude toward SCD. It showed a healthy behavior toward marriage decisions reflecting a high understanding of the SCD burden.*

**Keywords:** Sickle cell disease, SCD, Knowledge, Attitude, High school

### INTRODUCTION

Sickle Cell Disease (SCD) is one of the most common hereditary diseases in the world [1]. It is an autosomal recessive genetic disorder in which abnormal hemoglobin S is produced and associated with increased morbidity and mortality. The prevalence of SCD in Saudi Arabia varies greatly in different parts of the country, the highest prevalence is in the eastern region, followed by the southwestern region [1,2]. The main mechanism of the pathophysiology of SCD is hemoglobin polymerization as a result of the inherited genetic mutation, which leads to major changes in red blood cells. It converts its flexible, spherical biconcave disc-shaped cells into rigid, sickle-shaped cells. The abnormal (sickled) red blood cells block the blood vessels leading to a vaso-occlusive painful crisis which is the hallmark manifestation of SCD [3,4].

Clinical presentation of SCD is a result of recurrent vaso-occlusion and chronic hemolysis. Recurrent vaso-occlusion leads to acute and chronic pain attacks and organ dysfunction that can affect multi-organ systems, including bones,

spleen, liver, brain, lungs, kidneys, and joints. Chronic hemolysis leads to different complications including anemia, gallstone, and jaundice [5].

SCD is suspected based on specific features in the CBC and peripheral blood film. The diagnosis is then confirmed using hemoglobin electrophoresis [6-8].

The goal of treatment is to prevent the complications of SCD and the associated morbidity [9]. Hydroxyurea is one of the old and most effective therapies in decreasing the symptoms and complications of SCD. Folic acid supplementation is important because of the high demand for RBCs production with chronic hemolysis and the shortened life-span of the RBCs in patients with SCD. Blood transfusion is often required in perioperative settings and acute complications like stroke [6]. Vaccination for encapsulated bacteria is recommended to prevent life-threatening bacterial infections in patients with SCD [6]. So far, the only curative treatment for SCD is allogeneic stem cell transplantation [10].

The Saudi Ministry of Health (MOH) started a premarital national screening program for SCD in 2004. The main objective of this program is to reduce the prevalence of SCD in the population by reducing the number of at-risk marriages [11].

Previous studies in Saudi Arabia have documented poor awareness in the population about the hereditary transmission of SCD, the associated complications, and the premarital screening services, despite their positive attitude towards the program [11,12].

We aimed to assess the awareness about SCD among the high school students in AlQunfudah city. This will help to understand if there is a gap in awareness and serve as a need assessment study for future awareness programs.

## MATERIALS AND METHODS

### Study Design, Settings, Area, and Population

A cross-sectional study based on an electronic self-administrated questionnaire was distributed on social media to the high school students of AlQunfudah from April 2020 to June 2020. A total number of 428 high school students filled the questionnaire.

### Study Tool

A tool was designed using the existing literature, practicing physicians, and hematologists to assess the awareness among high school students. The questionnaire was initially designed in English and then translated to the Arabic language. The questionnaire consists of 13 questions to assess the patients' knowledge and awareness of SCD.

### Data Analysis

The data was analyzed using Statistical Package for Social Sciences (SPSS) version 23. Categorical variables were presented as frequency and percentages. Chi-square test was utilized to test for association between demographic variables and knowledge and attitude about SCD. A p-value <0.05 was considered statistically significant.

### Ethical Considerations

The study was ethically approved by the Research Ethics Committee, Faculty of Medicine, King Abdul-Aziz University, Jeddah, Saudi Arabia (Reference No. 204-20). Before individual data collection, each participant was informed about the study and voluntarily filled the questionnaire.

## RESULTS

A total of 428 high school students have filled the survey. Table 1 shows the demographical data of the participants. 52 (12.1%) of the participants were male and 376 (87.9%) were female. The age group of the largest proportion of participants was 17-18; 202 (47.2%) then the group >18; 147 (34.3%) and the 15-16 group 79 (18.5%). As for the marital state, the majority were single 383 (89.5%), however, 34 (7.9%) were married, 9 (2.1%) were divorced and 2 (0.05%) were widows.

**Table 1 Demographic profile of the participants (n=428)**

Demographical Characteristics	n	%
<b>Gender</b>		
Male	52	12.1
Female	376	87.9
<b>Age</b>		
15-16	79	18.5
17-18	202	47.2
>18	147	34.3
<b>Marital Status</b>		
Single	383	89.5
Married	34	7.9
Divorced	9	2.1
Widow/er	2	0.05

Table 2 demonstrates the frequency and rates of responses to the questions asked. 320 (71.70%) have heard about sickle cell disease before. Most of them have heard about it from family 99 (23.10%), the second most common source of knowledge was internet/media 72 (16.80%). The majority of students knew what causes SCD and how it is diagnosed, (70.30%) and (55.10%) respectively. However, only 33.40% knew how much of the children would be affected by the disease if both parents are affected. When asked if participants are willing to marry a partner with SCD, only (23.10%) said yes.

**Table 2 Participants answers for the questions (n=428)**

Question	n	%
<b>Q1/Have you heard of SCD before?</b>		
Yes	320	71.7
No	108	28.3
<b>Q2/From where have you heard about SCD (n=320)?</b>		
Health care worker	61	14.3
Internet/media	72	16.8
Friends	37	8.6
Family	99	23.1
School	51	11.9
<b>Q3/What is the cause of SCD?</b>		
Acquired	19	4.4
Hereditary (correct answer)	301	70.3
I don't know	108	25.2
<b>Q4/How is SCD diagnosed?</b>		
By blood test (correct answer)	236	55.1
Urinary Test	46	10.7
I Don't Know	146	34.1
<b>Q5/What is the risk for children to become sickle cell patients if both parents are sickle cell patients?</b>		
All the children (correct answer)	143	33.4

A quarter of the children	92	21.5
Half of the children	50	11.7
I Don't Know	143	33.4
<b>Q6/Which of the following is a preventive measure for SCD?</b>		
Medical advice	60	14
Pre-marital screening (correct answer)	307	71.7
I don't know	61	14.3
<b>Q7/Do you think it is necessary to do the pre-marital screening for SCD?</b>		
Yes (correct answer)	421	98.4
No	7	1.6
<b>Q8/Can your partner's genotype influences the decision to marry them?</b>		
Yes (correct answer)	379	88.6
No	49	11.4
<b>Q9/If your partner has SCD, are you going to marry them?</b>		
Yes	99	23.1
No	329	76.9
<b>Q10/What should a couple do if they discover that their genotypes predispose them to give birth to a child with SCD?</b>		
Separating	64	15
Continue with married life	11	2.6
Consult a doctor (Genetic Counselling) (Correct Answer)	316	73.8
I Don't Know	37	8.6

Table 3 shows the differences in answering based on gender. A significant difference in answering between males and females were observed when asked about: 1) hearing about SCD before, 2) the cause of SCD, 3) the risk for children to be affected with the disease if both parents are affected, 4) preventive measure for SCD, ( $p=0.001$ ,  $p=0.009$ ,  $p=0.004$ ,  $p<0.001$ ) respectively.

**Table 3 Gender Based Comparison of Answers (n=428)**

Question	Male (n=52)		Female (n=372)		p-value
	n	%	n	%	
<b>Q1/Have you heard of SCD before?</b>					
Yes	29	55.80%	291	77.40%	0.001*
No	23	44.20%	85	22.60%	
<b>Q2/What is the cause of SCD?</b>					
Acquired	1	1.90%	18	4.80%	0.009*
Hereditary (correct answer)	29	55.80%	272	72.30%	
I don't know	22	42.30%	86	22.90%	
<b>Q3/How is SCD diagnosed?</b>					
By blood test (correct answer)	25	48.10%	211	56.10%	0.11
Urinary test	3	5.80%	43	11.40%	
I don't know	24	46.20%	122	32.40%	
<b>Q4/What is the risk for children to become sickle cell patients if both parents are sickle cell patients?</b>					

All the children (correct answer)	16	30.80%	127	33.80%	0.004*
A quarter of the children	4	7.70%	88	23.40%	
Half of the children	4	7.70%	46	12.20%	
I Don't Know	28	53.80%	115	30.60%	
<b>Q5/Which of the following is a preventive measure for SCD?</b>					
Medical advices	4	7.70%	56	14.90%	<0.001*
Pre-marital screening (correct answer)	29	55.80%	278	73.90%	
I don't know	19	36.50%	42	11.20%	
<b>Q6/Do you think it is necessary to do the pre-marital screening for SCD?</b>					
Yes (correct answer)	50	96.20%	371	98.70%	0.18
No	2	3.80%	5	1.30%	
<b>Q7/Can your partner's genotype influence the decision to marry them?</b>					
Yes (correct answer)	45	86.50%	334	88.80%	0.627
No	7	13.50%	42	11.20%	
<b>Q8/If your partner has SCD, are you going to marry them?</b>					
Yes	14	26.90%	85	22.60%	0.489
No	38	73.10%	291	77.40%	
<b>Q9/What should a couple do if they discover that their genotypes predispose them to give birth to a child with SCD?</b>					
Separating	8	15.40%	56	14.90%	0.982
Continue with married life	1	1.90%	10	2.70%	
Consult a doctor (genetic counselling) (correct answer)	38	73.10%	278	73.90%	
I don't know	5	9.60%	32	8.50%	

\*: Significant at level 0.05

A demonstration of the differences in answering based on age group was shown in Table 4. There was a significant difference between age groups in answering the question related to 1) hearing about SCD before ( $p < 0.001$ ), 2) the cause of SCD ( $p = 0.011$ ), 3) how SCD is diagnosed ( $p < 0.001$ ), 4) the risk for children to be affected with the disease if both parents are affected ( $p = 0.005$ ), 5) preventive measure for SCD ( $p < 0.001$ ), 6) if partner's genotype can influence the decision to marry them ( $p < 0.001$ ), 7) what should be done if parents are at risk of having a child with SCD ( $p = 0.002$ ).

**Table 4 Age Group Based Comparison of Answers (n=428)**

Question	15-16 (n=79)		17-18 (n=202)		>18 (n=147)		p-value
	n	%	n	%	n	%	
<b>Q1/Have you heard of SCD before?</b>							
Yes	50	63.30%	140	69.30%	130	88.40%	<0.001*
No	29	36.70%	62	30.70%	17	11.60%	
<b>Q2/What is the cause of SCD?</b>							
Acquired	2	2.50%	12	5.90%	5	3.40%	0.011*
Hereditary (correct answer)	50	63.30%	133	65.80%	118	80.30%	
I don't know	27	34.20%	57	28.20%	24	16.30%	
<b>Q3/How is SCD diagnosed?</b>							

By blood test (correct answer)	35	44.30%	90	44.60%	111	75.50%	<0.001*
Urinary test	11	13.90%	29	14.40%	6	4.10%	
I don't know	33	41.80%	83	41.10%	30	20.40%	
<b>Q4/What is the risk for children to become sickle cell patients if both parents are sickle cell patients?</b>							
All the children (correct answer)	22	27.80%	54	26.70%	67	45.60%	0.005*
A quarter of the children	22	27.80%	45	22.30%	25	17.00%	
Half of the children	6	7.60%	27	13.40%	17	11.60%	
I don't know	29	36.70%	76	37.60%	38	25.90%	
<b>Q5/Which of the following is a preventive measure for SCD?</b>							
Medical advices	13	16.50%	35	17.30%	12	8.20%	<0.001*
Pre-marital screening (correct answer)	48	60.80%	132	65.30%	127	86.40%	
I don't know	18	22.80%	35	17.30%	8	5.40%	
<b>Q6/Do you think it is necessary to do the pre-marital screening for SCD?</b>							
Yes (correct answer)	76	96.20%	199	98.50%	146	99.30%	0.206
No	3	42.90%	3	42.90%	1	14.30%	
<b>Q7/Can your partner's genotype influence the decision to marry them?</b>							
Yes (correct answer)	57	72.20%	184	91.10%	138	93.90%	<0.001*
No	22	27.80%	18	8.90%	9	6.10%	
<b>Q8/If your partner has SCD, are you going to marry them?</b>							
Yes	19	24.10%	47	23.30%	33	22.40%	0.962
No	60	75.90%	155	76.70%	114	77.60%	
<b>Q9/What should a couple do if they discover that their genotypes predispose them to give birth to a child with SCD?</b>							
Separating	8	10.10%	23	11.40%	33	22.40%	0.002*
Continue with married life	1	1.30%	7	3.50%	3	2.00%	
Consult a doctor (genetic counselling) (correct answer)	57	72.20%	153	75.70%	106	72.10%	
I don't know	13	16.50%	19	9.40%	5	3.40%	

\*: Significant at level 0.05

Table 5 displays the answers to questions based on the marital status and shows the difference in answering between groups. A significant difference was present only when asked about how SCD is diagnosed ( $p=0.03$ ) and when asked what to be done if both parents are at risk of having a child with SCD ( $p=0.006$ ).

**Table 5 Participants answers for The Questions (n=428)**

Question	Single (n=383)		Married (n=34)		Divorced (n=9)		Widow/er (n=2)		p-value
	n	%	n	%	n	%	n	%	
<b>Q1/Have you heard of SCD before?</b>									
Yes	281	73.37%	30	88.24%	7	77.78%	2	100.00%	0.223
No	102	26.63%	4	11.76%	2	22.22%	0	0.00%	
<b>Q2/What is the cause of SCD?</b>									
Acquired	19	4.96%	0	0.00%	0	0.00%	0	0.00%	0.135
Hereditary (correct answer)	266	69.45%	29	85.29%	4	44.44%	2	100.00%	
I don't know	98	25.59%	5	14.71%	5	55.56%	0	0.00%	
<b>Q3/How is SCD diagnosed?</b>									

By blood test (correct answer)	204	53.26%	27	79.41%	4	44.44%	1	50.00%	0.03*
Urinary test	41	10.70%	2	5.88%	3	33.33%	0	0.00%	
I don't know	138	36.03%	5	14.71%	2	22.22%	1	50.00%	
<b>Q4/What is the risk for children to become sickle cell patients if both parents are sickle cell patients?</b>									
All the children (correct answer)	124	32.38%	16	47.06%	3	33.33%	0	0.00%	0.195
A quarter of the children	80	20.89%	8	23.53%	4	44.44%	0	0.00%	
Half of the children	45	11.75%	4	11.76%	0	0.00%	1	50.00%	
I don't know	134	34.99%	6	17.65%	2	22.22%	1	50.00%	
<b>Q5/Which of the following is a preventive measure for SCD?</b>									
Medical advices	59	15.40%	1	2.94%	0	0.00%	0	0.00%	0.224
Pre-marital screening (correct answer)	268	69.97%	30	88.24%	7	77.78%	2	100.00%	
I don't know	56	14.62%	3	8.82%	2	22.22%	0	0.00%	
<b>Q6/Do you think it is necessary to do the pre-marital screening for SCD?</b>									
Yes (correct answer)	378	98.69%	32	94.12%	9	100.00%	2	100.00%	0.235
No	5	1.31%	2	5.88%	0	0.00%	0	0.00%	
<b>Q7/Can your partner's genotype influence the decision to marry them?</b>									
Yes (correct answer)	339	88.51%	31	91.18%	7	77.78%	2	100.00%	0.677
No	44	11.49%	3	8.82%	2	22.22%	0	0.00%	
<b>Q8/If your partner has SCD, are you going to marry them?</b>									
Yes	95	24.80%	4	11.76%	0	0.00%	0	0.00%	0.094
No	288	75.20%	30	88.24%	9	100.00%	2	100.00%	
<b>Q9/What should a couple do if they discover that their genotypes predispose them to give birth to a child with SCD?</b>									
Separating	52	13.58%	9	26.47%	2	22.22%	1	50.00%	0.006*
Continue with married life	7	1.83%	4	11.76%	0	0.00%	0	0.00%	
Consult a doctor (genetic counselling) (correct answer)	290	75.72%	20	58.82%	5	55.56%	1	50.00%	
I don't know	34	8.88%	1	2.94%	2	22.22%	0	0.00%	
* Significant at level 0.05									

## DISCUSSION

This study aims to survey the level of knowledge toward SCD in high school students of AlQunfudah city to identify the need for awareness campaigns that target the young generation. Data analysis has shown a discrepancy in the contribution rate between males and females, where more females contributed and have accounted for 87.9% of all responses. A similar finding was observed in other studies, where more females have contributed than males [13-15]. This could have happened due to an error in distributing the survey where more females received requests to fill the survey than males. Another factor could be that more females were willing to fill it than males. As for the marital state, as it is expected for 89.5% were single, a few percentages of 7.9% were married which occasionally is observed in our society. However, an unusual presence of divorced and widows was detected with minimum rates.

In the knowledge assessment section, the majority of high school students said they have previously heard about the diseases (71.70%), which is not surprising since Saudi Arabia is a country prevalent with SCD and it is common to be acquaintance with people affected by SCD in schools. This is consistent with the finding of Albagshi M, et al. where high school students had a decent prior knowledge about SCD and inconsistent with Al Arrayed S, et al. where the overall knowledge of students before lecturing was poor [13,16]. As for the source of information, the most common sources are family, the internet, and health care workers. This is to be expected since family is considered a primary source of knowledge for people from this age group, the internet is an open and accessible wide source of information,

and health workers are more likely to provide the community with medical information. Alghamdi, A has reported similar sources of information in their study [17]. When asked about the cause of SCD, 70.30% correctly identified the cause as hereditary. This reflects an overall appropriate understanding of the nature of the disease. This is similar to the findings of studies that assessed the knowledge about SCD in university students of Saudi Arabia done by Awad, L and Al Meslet A, et al. which showed that most students could identify the cause of SCD [18,19]. When asked about the method by which SCD is diagnosed, 55.10% managed to answer correctly. A reasonable number of students identified this correctly; those who did not answer correctly might not have been able to answer due to unfamiliarity with medical investigations. Awad, L reported a higher percentage (89.3%) of correct answering in their study [18]. When asked about how many children can be affected by the disease if both parents are affected only 33.40% answered correctly. Even though this information is taught to students, not many answered this which reveals a knowledge gap in the pattern of inheritance of SCD in high school students. Other studies in the literature have not reported this aspect of knowledge. As for the questions about the preventive measure, most students answered premarital screening right (71.70%). This could be attributed to the implemented program by the Saudi government that mandates universal premarital screening. This finding is consistent with what was reported by Albagshi M, et al., Kotb, M, et al., Alhowiti A, et al., and Kotb M, et al. [13,14,20,21].

In the attitude assessment section, there was an overall positive attitude toward all the questions. When asked if it is important to do the premarital screening, 98.4% agreed and when asked if the genotype of the partner can influence the decision to marry him/her, 88.6% agreed. Furthermore, 76.9% said they would refrain from marrying a spouse affected with SCD. 73.80% stated that they would consult a doctor if they discovered they are predisposed to have a child with SCD. This positive attitude can be attributed to the recognition of SCD complications and what difficulties await families affected by it. Similar positive attitudes were observed in Saudi Arabia by Albagshi M, et al. in Al-Ahsa Melaibari, et al. in Taif, Ibrahim, et al. in Jeddah, Al Sulaiman, et al. in Riyadh [13,22-24]. However, a study was done by Kotb M, et al. in Jazan shown a different attitude toward SCD which may indicate a variation in attitude among different cities and populations inside Saudi Arabia [14].

In the demographics-based comparison of knowledge and attitude, females were significantly more knowledgeable than males in questions asking if they heard about SCD before, the cause of SCD, how many children can be affected if both parents have SCD, and the preventive measures of SCD. Other studies showed that females were significantly more knowledgeable about SCD [20,25]. This may reflect a higher need for focus toward males in an awareness campaign about SCD. As for the age-based comparison, a significant difference in knowledge was present in almost all questions with higher knowledge found in older groups. Also, a more positive attitude toward behaviors of marriage and management of the risk of having a child affected with SCD were found in older groups. Higher knowledge can be explained by the natural increase in social experience with age and it is expected to have a better attitude with higher knowledge. Awad L has found a similar relationship between age and knowledge, where those above 20 had better knowledge than those younger than 20 [18]. As for the marital state, a significant difference was present only in knowing the method of diagnosing SCD to the favor of married people and the reaction to the risk of having a child affected with SCD to the favor of single people. Other studies revealed an overall better knowledge in married people [20,25].

### **Strengths and Limitations**

The strength of this study includes exploring the knowledge and attitude from different angles in high school students which is the period before marriage for most. The strength of the study is that it was done in AlQunfudah, which to our knowledge is the first that assess knowledge and attitude in the city. The limitations of this study include having a low number of males compared to females which may bias the results to some degree. Another limitation is that it does not cover the assessment of knowledge and attitude in high school students in other places in Saudi Arabia, which can provide a nation-wide understanding of the current state of knowledge and attitude and the need for national awareness programs.

### **Recommendation for Future Researches**

We recommend a nation-wide screening program for knowledge and attitude about SCD in Saudi Arabia. This will help to address the current level of knowledge and attitude in different areas as well as identifying the places in need of intervention. A program of increasing awareness in the area with poor attitudes will help to reduce the burden of SCD.



## CONCLUSION

In conclusion, this study has examined the level of knowledge and attitude among high school students toward SCD in AlQunfudah. The knowledge of the disease varied from one aspect to another with an overall moderate level. However, there was an overall excellent attitude toward SCD. It showed a healthy behavior toward marriage decisions reflecting a high understanding of the disease.

## DECLARATIONS

### Conflicts of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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