Original Article

Knowledge and Awareness Regarding β Thalassemia and Sickle Cell Disease in Saudi Arabia

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Abstract

Sickle cell disease and beta-thalassemia are two genetic disorders that are caused by a slip in the genes for hemoglobin. The study aims to assess the level of knowledge and awareness of beta-thalassemia and sickle cell disease among single adults and married with no children. This is a cross-sectional study design, targeting males and females who live in the Kingdom of Saudi Arabia. The sample size was estimated by using the sample size formula. A sample size of 384 was determined with a 95% confidence level. Also, Microsoft Office Excel (2016) was used to enter the data into the computer, then imported into the SPSS version 20 application to perform statistical analysis.

The study included 744 participants, 55.1% of them were females and 44.1% of them were males. 64.2% of participants aged between 18-25 years old. Only 4.7% of participants had good knowledge of SCD, 41.7% had moderate knowledge and 53.6% had poor knowledge. The level of knowledge of thalassemia was found to be good in only 45 (6%) of participants, 34% had moderate knowledge and 60% had poor knowledge. Participants' knowledge scores regarding SCD were not significantly associated with any of their demographic characteristics. However, knowledge of thalassemia was significantly associated with educational level and monthly income ($P< 0.05$). In conclusion, the current study demonstrates a low knowledge level regarding sickle cell disease and thalassemia among the Saudi general population.

Keywords: Sickle cell diseases, Beta thalassemia, Knowledge, Awareness

Introduction

Sickle cell disease (SCD) and (β-thalassemia) are the most prevalent health problems worldwide, caused by a genetic disorder that leads to destroying genes for hemoglobin. There is a substance consisting of a protein called globin and an iron molecule called heme, which is responsible for carrying oxygen into RBC [1]. Thalassemia is caused by a lack or decrease in the production of alpha and beta-globin chains in hemoglobin. It is classified as alpha or beta-thalassemia based on which globin chain is affected. In addition, beta-thalassemia is categorized as major or minor thalassemia [2]. Moreover, β-thalassemia is characterized by autosomal recessive inheritance and abnormalities in the hemoglobin beta chain [3]. The risk for a child to get hemoglobin disorder is 25% if both parents are thalassemia trait carriers. Therefore, both parents must be carriers of thalassemia for a child to have it [4]. Similarly, SCD is an autosomal recessive genetic disorder that is inherited in beta globulin genes (HbSs). As a result, for the child to get the disease, both parents must have defective hemoglobin (HbS). If only one parent has defective hemoglobin (HbS), the child would be a carrier and diagnosed with sickle cell trait [5].

The major features of SCD are related to hemolytic anemia and vaso-occlusion. Consequently, resulting in chronic anemia, stroke, eye complications, foot and hand syndrome, sickle cell pain, and splenic infarction leads to functional asplenia, and growth retardation [6].

SCD complications can make the lives of affected people incredibly difficult. It may cause persisting development difficulties and disabilities, and children with SCD display clear signs of stroke [7].

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Additionally, a thalassemia patient's child is often healthy at birth, but within the first year of life, symptoms and signs such as frontal bossing, maxillary prominence, hepatosplenomegaly, severe anemia, and many complications start to manifest [8]. Heart failure is a consequence of thalassemia that can ultimately lead to death [9].

In addition, SCD and β thalassemia are two of the most widely inherited diseases in the world. Moreover, sickle cell disease is mostly found in Africa and the Middle East. On the other hand, beta-thalassemia is more common in Asia, the Mediterranean basin, and the Middle East [10].

Hemoglobinopathies are common in the Kingdom of Saudi Arabia as a result of the rise in consanguineous unions across the country. Consequently, the prevalence of these diseases varied in different parts of Saudi Arabia. The country's eastern provinces have the highest prevalence, followed by the southwestern provinces [11].

Previous research has shown that the prevalence of SCD in Saudi Arabia has not changed noticeably over the past 15 years despite the legal application of pre-marital genetic counseling [12].

Cross-sectional research conducted in Saudi Arabia found that 4,444 (2.14%) out of 207,333 examined couples who sought marriage licenses had discordant results and were labeled as high-risk marriages. Unfortunately, about 90% of those couples got married [13].

A study conducted by Abioye-Kuteyi *et al*. found that the information and attitudes among participants with high education were much better than others. The majority of respondents (86.7%) and their partners (74.0%) have undergone screening for sickle cell disease. One-third to two-thirds of research participants continued their connection with their partner if one or both of them had hemoglobinopathy [14].

A study was done to measure the prevalence of β-thalassemia and SCD in Saudi Arabia. There were about 18.5 couples with positive β-thalassemia test results per 1000 participants who underwent screening (18.5 for carriers and 0.5 for cases). Additionally, the eastern region had the highest prevalence (59), followed by the southern, western, and central regions (14.2, 10.2, and 10.1 per 1000 respectively). While the northern region had the lowest incidence (3.9) [10].

Based on reviewing previous studies, it shows that there are limited studies conducted in Saudi Arabia to measure awareness of the population regarding SCD and β-thalassemia. Therefore, this study is proposed to assess knowledge and awareness regarding SCD and β-thalassemia among single adults and married with no children in Saudi Arabia. The study aims to assess the level of knowledge and awareness of β thalassemia and sickle cell disease among single adults and married with no children.

Materials and Methods

Study Design

A cross-sectional survey was conducted in Saudi Arabia from July 2022 to May 2023.

Study Setting: Participants, Recruitment, and Sampling Procedure

The study included males and females, either single adults or married with no children who live in the Kingdom of Saudi Arabia.

Inclusion Criteria

Initially, inclusion criteria were defined as age groups of 18 years and above. Saudi male and female of all educational levels, single male and female, and married male and female with no children.

Exclusion Criteria

Participants under the age of 18 or who are unable to sign the written informed consent. Also, we excluded any known cases of thalassemia, sickle cell trait, sickle cell disease, or any other inherited hematological disorders to eliminate selection bias.

Sample Size

The sample size was calculated by the following formula: n=z^2 pq/e^2. Here, n=Sample size P=Estimate of prevalence (population proportion) =0.5 q=1- P=1- 50%=50%=0.5 e=Acceptance error =0.05 z=1.96 it corresponds to a 95% confidence limit. Thus, n= (1.96) ^2 x 0.5 x 0.5/ (0.05) ^2=384. According to this formula:

$n = (z)^2 p (1 – p) / d.$

n = Sample size
z = Confidence level, which was 1.96
p = Expected prevalence, which was 50%
d = Absolute error, which was 5%

Thus, the minimum sample size was 384.

Method for Data Collection and Instrument (Data Collection Technique and Tools)

A self-administered questionnaire was performed. Before that, written informed consent from participants is required. A validated questionnaire was used to collect data it includes three sections: 1) Sociodemographic data (age, Gender, Marital state, Education level, Region, Occupation). 2) A valid questionnaire was conducted by Ebrahim Miri-Moghaddam, *et al*. to assess awareness of thalassemia [15]. 3) A valid questionnaire was conducted by Mohammed M. Kotb, *et al*., to assess the knowledge of the participants about SCA [13].

Scoring System

For each correct answer, a score of 1 was considered. A score of "0" was provided for an incorrect response, and a response "I don't know" was similarly considered wrong and received a score of "0". Then the total score was calculated.

The second section is to determine the level of awareness regarding SCD. Subsequently, respondents' awareness was divided into three categories: low knowledge (0–4), average knowledge (5-7), and good knowledge (8-10).

The third section is to determine the level of awareness regarding Thalassemia. Subsequently, respondents' awareness was divided into three categories: low knowledge (0–8), average knowledge (9-12), and good knowledge (13-16).

Analyzes and Entry Method

Microsoft Office Excel Software (2016) was used as the data entry tool, and statistical analysis was performed by (IBM SPSS Statistics for Windows version 20).

Results and Discussion

The study included 744 participants, 55.1% of them were females and 44.1% of them were males. As for age, 64.2% of participants were aged between 18- 25 years old, 15.7% were 26- 30 years old and 10.2% of participants were 31- 40 years old. 72.4% of participants were single. 69.9% were university educated. One-third of participants live in the western region of the kingdom and almost another third in the eastern region. 55.4% of participants were students while 28% were employees **Table 1**.

Table 1. Sociodemographic characteristics of participants (n=744)

Parameter		No.	%
Age	18 - 25	478	64.2
	26 - 30	117	15.7
	31 - 40	76	10.2
	41 - 50	49	6.6
	51 - 65	24	3.2
Gender	Male	334	44.9
	Female	410	55.1
Marital status	single	539	72.4
	married	181	24.3
	widow	18	2.4
	divorced	6	.8
Educational level	primary	4	.5
	middle	5	.7
	secondary	139	18.7
	collegiate	520	69.9
	diploma	32	4.3
	Postgraduate	44	5.9
Residence place	Southern area	103	13.8
	Eastern Province	210	28.2
	The northern area	117	15.7
	Western Region	230	30.9
	Central Region	84	11.3
Functional status	Employee	208	28.0
	Unemployed/unemployed	109	14.7
	Student	412	55.4
	Retired / Retired	15	2.0

As illustrated in **Table 2**, 76.5% of participants think that consanguineous marriage increases the risk of sickle cell anemia. 48.1% think that a carrier of sickle cell disease has symptoms. 83.1% think there is a risk of sickle cell anemia in children of affected couples while 80.5% think there is a risk of sickle cell anemia in the children of carriers. 52% think that a child can develop sickle cell disease if one of his parents is healthy and the other is a carrier of the disease. 25.8% think there is a definitive cure for sickle cell anemia.

Table 2. Knowledge of participants of Sickle cell disease (n=744).

Parameter	Yes	No	I don't know
Do you think that consanguineous marriage increases the risk of sickle cell anemia?	569 76.5%	70 9.4%	105 14.1%
Do you think that a carrier of sickle cell disease has symptoms?	358 48.1%	267 35.9%	119 16.0%
Do you think there is a risk of sickle cell anemia in children of affected couples?	618 83.1%	47 6.3%	79 10.6%
Do you think there is a risk of sickle cell anemia in the children of carriers?	599 80.5%	55 7.4%	90 12.1%
Do you think that a child can develop sickle cell disease if one of his parents is healthy and the other is a carrier of the disease?	387 52.0%	235 31.6%	122 16.4%
Do you think that a person with sickle cell anemia should never marry in order not to have a child with sickle cell disease?	99 13.3%	540 72.6%	105 14.1%
Do you think that a person with sickle cell anemia should abstain from marriage so as not to have a child with sickle cell disease?	104 14.0%	521 70.0%	119 16.0%
Do you think a blood transfusion completely cures a patient with sickle cell anemia?	108 14.5%	424 57.0%	212 28.5%
Do you think there is a definitive cure for sickle cell anemia?	192 25.8%	324 43.5%	228 30.6%
Can a carrier of sickle cell anemia become infected?	252 33.9%	250 33.6%	242 32.5%

Regarding knowledge of SCD, only 35 (4.7%) of participants had good knowledge of SCD, 41.7% had moderate knowledge and 53.6% had poor knowledge **Figure 1**.

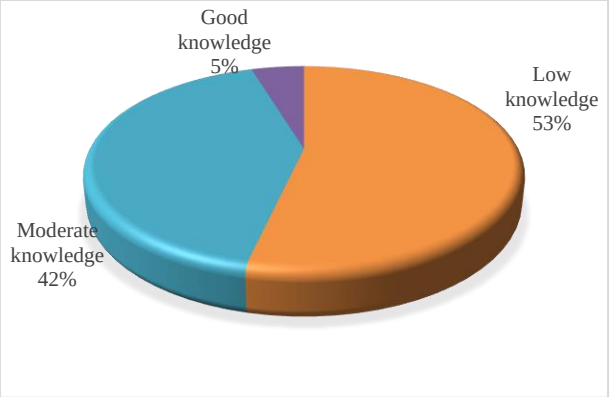

Figure 1. Knowledge scores of SCD among study participants.

Table 3 shows that 64.2% of participants think that thalassemia is a genetic disease. Moreover, 71.1% think that thalassemia is considered a blood disease. Additionally, 61.8% think that consanguineous marriage plays a role in thalassemia and 61.3% think that thalassemia be diagnosed by blood test. Finally, 74.3% reported that premarital examination is useful in reducing the birth of a child with thalassemia and 32.9% think that thalassemia patients need blood transfusions throughout their lives.

Table 3. Knowledge of participants of thalassemia (n=744).

Parameter	Yes	No	I don't know
Is thalassemia a genetic disease?	478 64.2%	39 5.2%	227 30.5%
Is thalassemia considered a blood disease?	529 71.1%	28 3.8%	187 25.1%
Does thalassemia occur after malnutrition?	148 19.9%	272 36.6%	324 43.5%
Does the face and shape of a person with thalassemia major change?	339 45.6%	59 7.9%	346 46.5%
Can consanguineous marriage play a role in thalassemia?	460 61.8%	52 7.0%	232 31.2%
Can thalassemia be diagnosed by blood test?	456 61.3%	63 8.5%	225 30.2%
Can thalassemia be predicted before infection?	265 35.6%	125 16.8%	354 47.6%
Is premarital examination useful to reduce the birth of a child with thalassemia?	553 74.3%	29 3.9%	162 21.8%
Is premarital examination the only way to prevent thalassemia?	307 41.3%	188 25.3%	249 33.5%
Is there any way to detect thalassemia major in the fetus?	266 35.8%	49 6.6%	429 57.7%
Does the diagnosis of thalassemia minor have any role in the prevention of thalassemia major?	305 41.0%	79 10.6%	360 48.4%
Does thalassemia minor have any special signs or symptoms?	233 31.3%	115 15.5%	396 53.2%
Is thalassemia minor disease curable?	206 27.7%	135 18.1%	403 54.2%
Can two people with thalassemia minor marry?	157 21.1%	210 28.2%	377 50.7%
Does marriage between a healthy person and a carrier of the disease lead to having a child with thalassemia major?	203 27.3%	212 28.5%	329 44.2%
Do thalassemia patients need blood transfusions throughout their lives?	245 32.9%	96 12.9%	403 54.2%

The level of knowledge of thalassemia was found to be good in only 45 (6%) of participants, 34% had moderate knowledge and 60% had poor knowledge as illustrated in **Figure 2**.

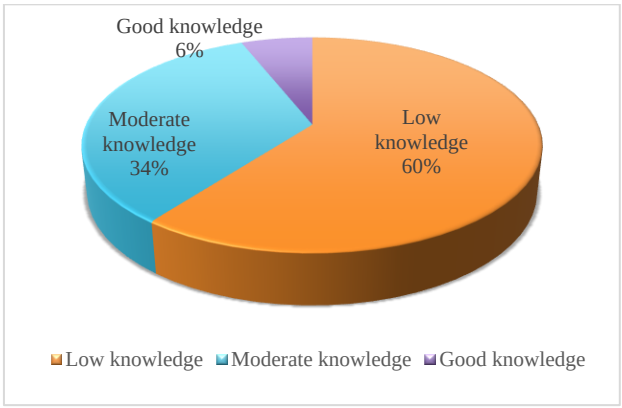

Figure 2. Knowledge scores of SCD among study participants.

As shown in **Table 4**, participants' knowledge scores regarding SCD were not significantly associated with any of their demographic characteristics. However, knowledge of thalassemia was significantly associated with educational level and monthly income (P< 0.05).

Table 4. Association between knowledge of SCD with sociodemographic character of participants (n=744).

		Knowledge of SCD			Total (N=744)	P value
		Low	Moderate	Good		
Gender	Male	183 24.6%	133 17.9%	18 2.4%	334 44.9%	0.535
	Female	216 29.0%	177 23.8%	17 2.3%	410 55.1%	
Age	18 - 25	256 34.4%	198 26.6%	24 3.2%	478 64.2%	0.497
	26- 30	63 8.5%	50 6.7%	4 0.5%	117 15.7%	
	31 - 40	35 4.7%	36 4.8%	5 0.7%	76 10.2%	
	41 - 50	27 3.6%	20 2.7%	2 0.3%	49 6.6%	
	51- 65	18	6	0	24	

		2.4%	0.8%	0.0%	3.2%	
Marital status	single	291	223	25	539	
		39.1%	30.0%	3.4%	72.4%	
	married	96	77	8	181	
		12.9%	10.3%	1.1%	24.3%	
	widow	3	2	1	6	**0.905**
		0.4%	0.3%	0.1%	0.8%	
	divorced	9	8	1	18	
		1.2%	1.1%	0.1%	2.4%	
Educational level	primary	3	0	1	4	
		0.4%	0.0%	0.1%	0.5%	
	Middle	2	3	0	5	
		0.3%	0.4%	0.0%	0.7%	
	secondary	74	60	5	139	
		9.9%	8.1%	0.7%	18.7%	
	collegiate	283	213	24	520	**0.200**
		38.0%	28.6%	3.2%	69.9%	
	diploma	16	16	0	32	
		2.2%	2.2%	0.0%	4.3%	
	Postgraduate	21	18	5	44	
		2.8%	2.4%	0.7%	5.9%	
	Southern area	46	48	9	103	
		6.2%	6.5%	1.2%	13.8%	
	Eastern Province	121	81	8	210	
		16.3%	10.9%	1.1%	28.2%	
Monthly income	The northern area	57	52	8	117	**0.117**
		7.7%	7.0%	1.1%	15.7%	
	Western Region	129	96	5	230	
		17.3%	12.9%	0.7%	30.9%	
	Central Region	46	33	5	84	
		6.2%	4.4%	0.7%	11.3%	
	Employee	116	81	11	208	
		15.6%	10.9%	1.5%	28.0%	
Functional status	Unemployed	54	52	3	109	
		7.3%	7.0%	0.4%	14.7%	**0.697**
	Student	220	171	21	412	
		29.6%	23.0%	2.8%	55.4%	
	Retired	9	6	0	15	
		1.2%	0.8%	0.0%	2.0%	

SCD is an autosomal illness that affects hemoglobin, a protein found in red blood cells that transports oxygen to cells throughout the body. Atypical hemoglobin S, which can distort RBCs into a crescent or a sickle shape, is present in people with this condition. Recent studies have revealed an increase in the prevalence of SCD, with the Eastern Province bearing the brunt of the burden [5].

According to our study results, participants exhibited a poor knowledge level regarding SCD, which was inconsistent with previous studies. A previous Saudi study reported that most of the studied sample heard about SCD, which implies a good level of knowledge [16]. According to other studies [17], a substantial number of respondents had heard about SCD. Several studies [12, 18, 19] have found that more than half of the population has a poor general knowledge of SCD, contradicting the current study findings.

According to our study results, 76.5% of participants think that consanguineous marriage increases the risk of sickle cell anemia. 83.1% think there is a risk of sickle cell anemia in children of affected couples while 80.5% think there is a risk of sickle cell anemia in the children of carriers. A prior study found that respondents' perceptions of SCD were influenced by a lack of understanding of the disease's route of inheritance and treatment. Respondents expressed a negative attitude towards never marrying someone with SCD and preferring not to have children over having a child with SCD [16]. A comparable study conducted in Ghana [20] discovered that more than half of the populace had a favorable attitude towards SCD patients, which is like our findings.

In our study, participants' knowledge scores regarding SCD were not significantly associated with any of their demographic characteristics. This was inconsistent with results reported in previous literature. According to a study conducted in the Albaha region, most of the population with a low level of knowledge were young men; however, according to another study [16], the majority of the respondents in this group were young women with pre-university education [19]. However, another study conducted in Saudi Arabia found that older individuals had little knowledge of SCD. According to a study conducted in the city of Jeddah [21], a relatively high percentage of the community agreed that SCD necessitates hospitalization and results in poor academic performance. Females were much more educated about SCD in other studies [18, 22]. This could indicate that a greater emphasis on males is required in an SCD knowledge program. In terms of the age-based comparison, there was a substantial difference in knowledge in almost all questions, with older groups having better knowledge. In addition, elder groups had a more favorable attitude toward marriage activities and risk management of having a kid with SCD. Increased knowledge can be explained by the natural increase in social experience with age, and higher knowledge is predicted to result in a better attitude. Awad L discovered a similar association between age and knowledge, with individuals over the age of 20 having more knowledge than those under the age of 20 [23]. In terms of marital status, there was only a significant difference in knowing the method of diagnosing SCD in favor of married individuals and the reaction to the risk of having a child affected with SCD in favor of single people. Other research has found that married adults had greater general knowledge [18, 22].

Thalassemia is among the most prevalent genetic illnesses globally, and it is caused by a failure in the production of hemoglobin chains. Clinical symptoms range from mild hypochromia and microcytosis to severe anemia [24].

According to our study results, the level of knowledge of thalassemia was found to be good in only 6% of participants, 34% had moderate knowledge and 60% had poor knowledge. This was lower than reported in studies reported previously. A study in Saudi Arabia showed that 53% of those polled had heard of thalassemia [24]. Armeli *et al*. found that 85% of their respondents were aware of thalassemia, compared to 65% in Bahrain research [25, 26]. This, together with a mean knowledge score of 5.8 out of a possible 12, demonstrates the urban population's general lack of understanding. These findings are concerning because Pakistan is located in the thalassemia belt, with 9.8 million carriers and about 5,000 thalassemia babies every year. Another study found that the majority of respondents (60%) were uninformed of the hereditary aspect of illness transmission and the significance of consanguineous marriages in disease transmission [24]. This is consistent with research conducted in Lahore by Ishaq *et al*. [27]. However, in a study conducted by Basu, 60% of participants were aware of their inherited nature [28]. It may be difficult to communicate this to the less educated public due to the complex inheritance pattern [29]. According to the research, using clear visuals, multimedia aids, and personal experience sharing can aid in conveying this critical information [30, 31]. This finding could be explained by a lack of health education and health programs among the general population.

Regarding the diagnosis by blood tests, 61.3% had correct knowledge compared to 89% had the correct knowledge in another study [24]. This is higher than in the Thailand study (45%) and the Lahore study (33%), which could be attributed to increased awareness programs over the last decade [32, 33]. Surprisingly, only 9.4% of those polled were aware that blood transfusions are used to treat thalassemia major. This is significantly lower than other research, notably the Kolkata study, in which two-thirds of the sample population correctly answered [28]. A study of parents' understanding of thalassemia gave a 100% favorable response to this question, most likely because they are the primary carers for a thalassemia child [34].

According to our study results, 74.3% of participants' premarital examination was useful in reducing the birth of a child with thalassemia. A study conducted in the Al-Madinah community by Bedaiwi *et al*. [1] discovered that a great majority (92.8%) believed in the importance of PMS, whereas 0.3% were unaware of it or refused to recognize its significance. Binshihon *et al*. [35] discovered that participants in their study had varying levels of understanding about the PMS program. Half of the participants had inadequate knowledge. These findings are consistent with prior KSA investigations [36-38].

Studies have shown that community health education and outreach programs are beneficial in reducing illness prevalence. As a result, the implementation of a comprehensive prevention program that includes premarital counseling, genetic testing, prenatal screening, and community-based awareness campaigns may help to minimize the disease burden.

Conclusion

The current study demonstrates a low knowledge level regarding sickle cell disease and thalassemia among the Saudi general population. Rather than depending simply on community seminars and information booklets, we believe that television has the potential to be the most effective medium for educating the public about SCD and thalassemia. We advocate for the inclusion of important information on prevalent blood illnesses in school curricula. Informational programs should target the general population, educate the public through TV broadcasts, life lectures, and seminars, emphasize the nature of inheritance of common blood diseases, emphasize preventive measures, and emphasize the distinctions between a carrier and an affected individual. More assistance should be granted to projects that have demonstrated their efficiency.

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