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ORIGINAL ARTICLE

Level of awareness regarding sickle cell anemia among Riyadh residents

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ABSTRACT

Background: Sickle cell disease (SCD) is a common multisystem hereditary blood disorder in Saudi Arabia, with a variable prevalence from one area to another. Current epidemiological information about the condition focuses on some specific areas, with a lack of true incidence in the country. This study aimed to assess the awareness regarding sickle cell anemia, its risk factors (RF), symptoms, prevention, and its management among Riyadh residents.

Methodology: A cross-sectional study was conducted in primary healthcare centers, Riyadh, Saudi Arabia, employing a self-administered and a pretested questionnaire developed after considering the previously published reviews and opinions from epidemiological experts. Data were analyzed using the Statistical Package for the Social Sciences v23. A *p*-value of 0.05 or less was considered significant.

Result: We had 200 participants involved in this study; among them, 11.5% (n = 23) had SCD. We found that the general level of awareness was higher regarding RF, prevention, management, and lower symptom identification of SCD. We also found that the level of knowledge regarding SCD RF was high in 72% (n = 144), and was poor regarding the awareness of SCD symptoms (63%; n = 125). There was a statistically significant association between management and both genders (p = 0.03), while no significant association was found between different education levels and awareness of SCD (p > 0.1).

Conclusion: Overall, the level of awareness regarding SCD was low, with limited understanding of SCD; however, there was an association between gender and the level of awareness. We conclude that there is a need to increase public awareness about SCD which could address the misconceptions and increase knowledge among the general public.

Keywords: Sickle cell disease, sickle cell anemia, sickle cell trait, SCD, awareness, Riyadh.

Introduction

Sickle cell disease (SCD) is one of the common inherited blood disorders in the Kingdom of Saudi Arabia; it is a multisystem disorder, an autosomal recessive structural disease of hemoglobin (Hb) due to the substitution of valine for glutamic acid. Glutamic acid usually is present at the sixth position of the beta chain of Hb [1]. When the patient becomes stressed (e.g., deoxygenation) or exposed to environmental factors (e.g., cold weather or infections), the shape of the red blood cells (RBCs) changes into a sickle due to the Hb genetic alteration. The sickle-shaped RBCs are less deformable than the normal, round, biconcave ones; they are unstable with a shorter life span; therefore, they obstruct microcirculation causing local tissue hypoxia and appearance of clinical manifestations of SCD [2]. Sickle cell anemia is a multisystem disease with variable clinical presentation depending on the affected body system and type of complications. Some of the common presentations are

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the vaso-occlusive crisis, which is the most common presentation in SCD. Other presentations include acute chest syndrome (ACS), infections, pulmonary hypertension (PHTN), cerebrovascular accidents/ stroke pulmonary embolism, renal complications, eye complications, splenic sequestration, priapism, aplastic crisis, osteonecrosis, and cholelithiasis [3].

The information about SCD prevalence in Saudi Arabia is not very clear. Many studies about the prevalence have been conducted in specific areas of the country where the prevalence is higher. Studies have found that SCD is a common disorder in Saudi Arabia. In some areas, they also found that 2%-27% were carriers of sickle cell trait and 1.4% had SCD. According to the Saudi Premarital Screening Program, the prevalence of sickle cell trait was 4.2% and 0.26% for SCD. The prevalence was highest in the Eastern province, with 17% for sickle cell trait and 1.2% for SCD. Premarital screening may not be accurate because it depends on the incidence of SCD at the time of marriage, and survival of the patient until the time of marriage. Newborn screening in Eastern province showed a higher prevalence wherein premarital screening 21% were carriers for sickle cell trait and 2.6 for SCD [4]. In a systematic analysis study, the global burden of the disease showed that 3.2 million people live with SCD, 43 million people have sickle cell trait, with an annual mortality of 176.000 people due to SCD complications worldwide [5]. SCD can cause a wide range and variable complications. Common complications include chronic pain, ACS, priapism, aplastic crisis, splenic sequestration, and osteomyelitis. Other complication include delayed growth and development, hand and foot syndrome, cerebral hemorrhage, avascular necrosis, PHTN, cardiac disease, cholelithiasis, renal failure, and retinal complications [6].

Subjects and Methods

A cross-sectional study was conducted in Riyadh, Saudi Arabia. A sample size of 200 participants was selected from primary healthcare centers in Riyadh using a quota sampling method from 1/2/2018 until 22/2/2018. Data collection was done in the following primary healthcare centers: Alnaseem South Medical Center, Almounsiyah Medical Center, Almasif Medical Center, Irqah Medical Center, and Prince Sultan Medical Center in Al-Diriyah. The inclusion criteria were adults (18 years and above), males, and females. The exclusion criterion was medical staff. The data were collected using a self-administered, pre-coded, and pre-tested questionnaire, which was developed explicitly for this study after consulting the literature and epidemiology consultant. The survey we used comprised close-ended questions to assess the general awareness of sickle cell anemia and its risk factors (RF), signs and symptoms, management, and knowledge of its prevention. The questionnaire was subjected to a probe to test its validity and reliability. Data entry and analysis was done using the Statistical Package for the Social Sciences version 23, and Microsoft Excel was used to generate tables and figures. A *p*-value of 0.05 or less was considered significant. Before data collection, consent was obtained from all participants, emphasizing confidentiality and the right to withdraw from this study was assured.

Results

Table 1 shows that of 200 participants, 62.5% (n = 125) were aged between 18 and 30 years, while 24% (n = 48) of participant were aged between 31 and 40 years, 9.5% (19) of the participants were between 41 and 50 years, and the rest 4% (n = 8) of the participants were above 51 years old. The table also shows that females were more than the half with 59.5% (n = 119) participants compared to the 40.5% (n = 81) of male participants. In the nationality section, the majority of the participants (87%; n = 174) out of 200 were Saudis and 13% (n = 26) of them were not. In the level of education section, 2.5% (n = 5) of the participants were illiterate, 3% (n = 6) had elementary education, 29.5% (n = 59) of them had secondary level, and the majority (65%; n = 130) of the participants had a

Table 1. *Demographic data (n = 200).*

Variable	Number	%	Total
Age			
18-30	125	62.5	200
31-40	48	24	
41-50	19	9.5	
Above 51	8	4	
Gender			
Male	81	40.5	200
Female	119	59.5	
Nationality			
Saudi	174	87	200
Non-Saudi	26	13	
Education level			
Illiterate	5	2.5	200
Elementary	6	3	
Secondary	59	29.5	
University	130	65	
Marital status			
Single	111	55.5	200
Married	76	38	
Divorced	10	5	
Widowed	3	1.5	
Occupation			
Employed	78	39	200
Non-employed	46	23	
Self-employed	10	5	
Student	66	33	

university education. In the marital status section, almost half of the respondents were single (55.5%; *n* = 111), while 38% (*n* = 76) of the participants were married, 5% (*n* = 10) of them were divorced, and the rest 1.5% (*n* = 3) were widowed. Table 1 also measures the socioeconomic status and it shows that 39% (*n* = 78) of participants were employed, 23% (*n* = 46) of participants were not, 5% (*n* = 10) of participants were self-employed, and 33% (*n* = 66) of participants were students.

Table 2 demonstrates the general knowledge regarding SCD of the 200 participants. 11.5% (*n* = 23) reported that they have SCD. The majority of the participants believed that genetic factors increase the risk of having SCD (72%; *n* = 144), while 28% (*n* = 56) believed the opposite. 69.5% (*n* = 139) and 82.5% (*n* = 165) thought that fatigue and pallor are symptom and sign of SCD, respectively. The majority (82.5%; *n* = 165) believed that premarital screening is a preventive method for SCD. Furthermore, 39% (*n* = 78) believed that daily folic acid supplementation is involved in the management of SCD. Less than one-third (28.5%; *n* = 57) thought avoiding extreme cold or hot weather is a part of SCD management. Finally, almost two-thirds (64.5%) believed that daily exercise is a part of management in SCD.

Figure 1 shows the general participants' level of awareness regarding SCD in four significant aspects. First, it shows that 72% (*n* = 144) have a high level of knowledge regarding SCD RF, while the rest 28% (*n* = 56) showed the opposite. Almost two-thirds of participants have a low level of awareness regarding the symptoms of SCD (63%; *n* = 125) and 37% (*n* = 74) have high levels. Nonetheless, 82.5% (*n* = 165) of the participants have a high level of awareness regarding the prevention of SCD, which was the highest score in this figure, and the remainder 17.5% (*n* = 35) have low levels. Finally, there was no significant difference between the participants in the awareness of SCD management, 54.5% (*n* = 109) have high levels of knowledge compared to the 45.5% (*n* = 91) who showed the opposite. In general, Figure 1 shows that most of the participants have a high level of awareness in RF, prevention, and management of SCD, and a low level of the knowledge of the symptoms.

Table 3 shows the relationship between the awareness of SCD management and both gender. Ninety-one participants, 34.56% (*n* = 28) male and 52.94% (*n* = 63) female, have a low level of awareness regarding the management questions of sickle cell anemia. The table also shows that 88 participants have a moderate level of awareness regarding SCD management, 51.85% (*n*

Table 2. *Level of awareness regarding SCD for every question (n = 200).*

Variant	Answer/Number/%	Answer/Number/%	Total
1. Are you suffering from SCD?	Yes	No	200
	23	177	
	11.5%	88.5%	100%
2. Do you think genetic factors are risks of SCD?	Yes	No	200
	144	56	
	72%	28%	100%
3. Do you think fatigability is one of the symptoms of SCD?	Yes	No	200
	139	61	
	69.5%	30.5%	100%
4. Do you think pallor is a sign of SCD?	Yes	No	200
	165	35	
	82.5%	17.5%	100%
5. Do you think premarital screening is important in the prevention of SCD?	Yes	No	200
	165	35	
	82.5%	17.5%	100%
6. Do you think daily folic acid is part of the management of SCD?	Yes	No	200
	78	122	
	39%	61%	100%
7. Do you think avoiding too cold /hot weather is part of the management of SCD?	Yes	No	200
	57	143	
	71.5%	28.5%	100%
8- Do you think daily exercise is part of the management of SCD?	Yes	No	200
	129	71	
	64.5%	35.5%	100%

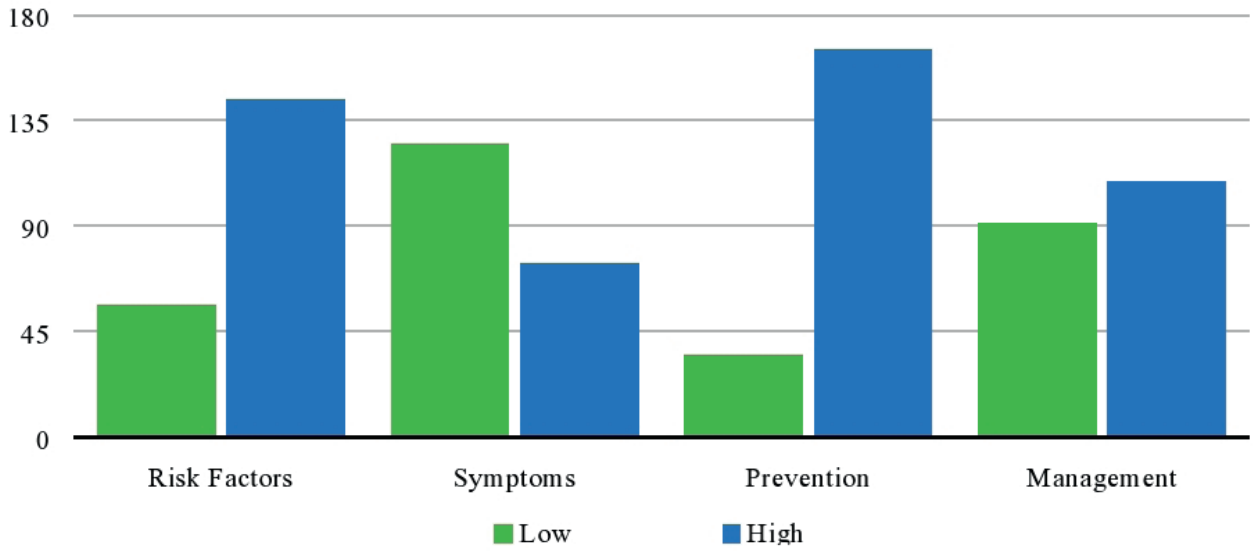

Figure 1. *Level of awareness regarding RF, symptoms, prevention, and management of SCD.*

Table 3. *Relationship between male and female levels of awareness about the management of sickle cell anemia in Riyadh.*

Management	Gender		Total
	Male	Female	
Low	28 (34.56%)	63 (52.94%)	91
Moderate	42 (51.85%)	46 (38.65%)	88
High	11 (13.58%)	10 (8.4%)	21
Total	81	119	200

p-value = 0.035.

Table 4. *The relationship between the level of education and awareness of SCD.*

Level of education	Awareness			Total
	Low	Moderate	High	
Illiterate	3	2	0	5
primary	5	1	0	6
secondary	38	19	2	59
university	108	21	1	130
Total	154	43	3	200

p-value = 0.132.

= 42) male and 38.65% (n = 46) female. Twenty-one participants' answers showed a high level of awareness regarding the management of SCD, of which 13.58% (n = 11) were male and 8.4% (n = 10) were female. There is a statistically significant association between management questions and both genders (p = 0.03).

Table 4 shows that out of the 5 illiterate participants, 3 participants showed a low level and 2 participants showed a moderate level of awareness regarding SCD. There were 6 participants with primary education level, of which five have a low level, and 1 had a moderate level of awareness of SCD. Neither illiterate nor primary educated participants showed a high level of awareness. Out of 59 participants with secondary education levels, 38 have low, 19 have moderate, and 2 have a high level of awareness regarding SCD. On the other hand, the majority of the participants had a university-level education (n = 130), 108 showed low, 21 moderate, and 1 showed a high level of awareness regarding SCD. In general, 154 participants out of the total 200 in this study have shown a low level of awareness of SCD, 43 out of 200 have shown moderate level, and the remaining three have shown high levels of SCD awareness in all education levels. There was no statistically significant association between education levels and awareness of SCD ($p > 0.1$), and this could be due to the sample size.

Discussion

In this study, the general level of awareness regarding SCD was low. We found that the level of knowledge was high regarding the RF of sickle cell anemia, as illustrated in Figure 1. This finding goes in line with a study carried out by Harrison, 2016, in the USA [7]. The high level could be attributed to widespread national campaigns encouraging the public for genetic counseling. Figure 1 also shows that the highest percentage of awareness was in SCD prevention. The majority of our respondents (82.5%; n = 165), had a high level of knowledge regarding its prevention; this finding goes in line with a study by Ugwu, 2016, in Nigeria [8]. This could be due to the high prevalence and the endemic of SCD in Nigeria.

Almost two-thirds of the participants have a low level of awareness regarding the symptoms of SCD (63%; n = 125), which was the lowest in the level of awareness. This low level is in contradiction with a study by Al Arrayed,

2010, in Bahrain [9]. His research found that there is good knowledge among the public. Also, he found that more than two-thirds of the respondents included in the study were aware that severe pain was one of the most common symptoms of SCD, which could be attributed to a higher level of prevalence and awareness in Bahrain. In general, Table 2 shows that most of the respondents in this study had a good knowledge of SCD. In agreement with this finding, a study in Southern province, Saudi Arabia, by Alghamdi, 2018 [10], showed that more than two-thirds of the respondents have a high level of knowledge about the basics of SCD. This finding could be attributed to the higher prevalence of SCD in the Southern province in Saudi Arabia. On the contrary, a lower level of knowledge was reported in Al-Qatif, eastern region, by Al-Suwaid, 2015, Saudi Arabia [11].

The majority of our respondents had a low level of awareness of sickle cell anemia between different educational levels. Table 4 shows no statistically significant association between education levels and knowledge of sickle cell anemia (p = 132). Interestingly, Table 1 shows that 130 participants had a university education and 59 had a secondary school level, of which 108 and 38 participants showed a low level of knowledge regarding SCD, as illustrated in Table 4. This finding does not support our hypothesis that state university-educated participants would show a much higher level of knowledge than the secondary, primary, and illiterate levels. A similar finding was also found in a study conducted by Osbourne CJ, 2011, in the USA [12], which found a low level of awareness among university students in both genders and different ethnic groups. Also, Boadu I, 2018, in Ghana [13], found that 45.1% of university students scored low in the SCD awareness questionnaire.

In contrast with our finding, Treadwell, 2006, in the USA [12], found that a high level of awareness is consistently correlating with a high level of education. Moreover, another study done by Olakunle, 2013, in Nigeria [14], found that 97.4% of secondary school students had a high level of knowledge about SCD, and he also mentioned that the majority of the participant's source of information was from health professionals, followed by the internet. We think the low level of knowledge in the university-level participants could be due to the hastiness of reading and answering the questions without proper comprehension.

Figure 1 shows that 45.5% (n = 91) of the participants had a low level of knowledge about SCD management. This finding is similar to two studies done by Boadu I, 2018, in Ghana [13], and Isah BA, 2016, in Nigeria [15]. Both studies found a lack of knowledge about the management and knowledge about SCD in general. The low level of knowledge attributed to the low socioeconomic class, lack of education, and attention. Table 3 shows that 34.56% (n = 28) male and 52.94% (n = 63) female participants had a low awareness level of SCD management. There is a statistically significant association between management questions in both genders (p = 0.03). This result implies that Ministry of Health should facilitate and continue giving more effective educational programs about SCD and promote other effective methods to increase awareness like using public figures and social media. Also, we recommend other researchers to investigate the areas of attitude and practice related to this study.

Conclusion

In general, the majority of participants showed a limited understanding and inadequate comprehensive knowledge of sickle cell anemia. Almost two-thirds of the participants scored low in the awareness questions of SCD symptoms, and nearly half of them scored low in management questions. The RF and prevention knowledge was high in 72% and 82.5%, respectively. There was a statistically significant association between the knowledge of SCD management in both genders. And we found no statistically significant association between education and awareness of SCD. Results from this study highlight the need for effective public health education on sickle cell anemia in trusted sources such as schools, media (radio/Television), and health centers. It is necessary to address misconceptions and increase the knowledge level.

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List of Abbreviations

ACS	Acute chest syndrome
PHTN	Pulmonary hypertension
RF	Risk factors
RBCs	Red blood cells
SCD	Sickle cell disease

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Conflict of interest
The authors declare that there is no conflict of interest regarding the publication of this article.

Consent for publication
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