Awareness about Sickle Cell Disease among General Population in Al-Ahsa, Saudi Arabia

Ghalib Al Ali, Mohammed Alshareet, Mohammed Abdullah Alsultan, Mohammed Al Wabari, Abdulhadi Al Ali, Ali Alshareet, Ahmad Essa Alhejji

Abstract— BACKGROUND AND OBJECTIVES: Sickle cell disease (SCD) is one of the most common hereditary hematological disorder. It is estimated that the number of SCD cases in the eastern region were (145 cases/100000) alone. Even though SCD in Saudi Arabia has huge health and socioeconomic burdens on the country especially in the prevalent areas, however, it is a highly preventable disease. Hence, people awareness of the disease and premarital screening are the golden stone in the prevention. Therefore, the aim of the study is to evaluate community knowledge, awareness and attitude toward SCD in Al-Ahsa region of Saudi Arabia. METHODS: A descriptive cross-sectional study was conducted among the general population of Al-Ahsa. Self-administrated questionnaires along with a consent form was answered by 221 Saudi subjects. RESULTS: The total respondents' number was (n=221). 94.6% have heard about sickle cell disease, and 87.3% know that SCD is an inherited disorder. Furthermore, 65% believed that premarital checking along with health education and enactment of laws collectively are the best preventive measures. However, only 28.1% knew that SCD can lead to life-threatening infections, 22.2% knew that SCD can lead to Kidney failure, and only 16.3% knew that stroke is a complication of SCD. Conclusion: The results depicted that people's awareness of SCD was acceptable. However, knowledge and awareness should be increased. Nevertheless, government laws and premarital obligatory tests should be kept.

Index Terms— Sickle cell disease; Public awareness; Public knowledge; Al-Ahsa; premarital screening; school performance; prevention.

INTRODUCTION

Sickle cell disease (SCD) is one of the most common hereditary hematological disorders worldwide, which prominently endemic in Sub-Saharan region, Mediterranean region, Saudi Arabia, and South-East Asia [1-3]. SCD is an autosomal recessive red cells disorder, which is characterized by production of abnormal hemoglobin (Hemoglobin S) [1-5]. Hemoglobin S has the tendency to polymerase and deforms the red cells from normal biconcave to a sickle or crescent shape, which consequently result in different types of attacks such as, acute chest syndrome, stroke, splenic sequestration, vase-occlusive crisis, hemolytic crisis, infectious crisis, and progressive organ damage leading to high morbidity and mortality [4-7].

Many studies have been conducted to determine the prevalence of SCD in Saudi Arabia, which showed that it is a very common disease in the country, especially in the eastern region followed by the southern region. It is estimated that the number of SCD cases in the eastern region were (145 cases/100000), (24 cases/100000) in the southern, (12 cases/100000) in the western, and (6 cases/100000) in the central region. Moreover, another study showed that 4.2% of the adult population has sickle cell trait, and 0.26% has SCD, with the highest prevalence seen in the Eastern region, with 17% of the population found to have sickle cell trait, and 1.7% having SCD [1,8]. Despite the fact the information regarding the morbidity and mortality pattern associated with SCD in Saudi Arabia are insufficient, there is some hospital-based studies from Eastern region depicted that 73% of deaths occur under the age of 30 years. The most commonly attributed causes of mortality found to be acute chest syndrome followed by infections [1].

Even though SCD in Saudi Arabia has huge health and socioeconomic burdens on the country especially in the prevalent areas, however, it is a highly preventable disease. Hence, people awareness of the disease and premarital screening are the golden stone in the prevention [8]. Therefore, the aim of the study is to evaluate community knowledge, awareness and attitude SCD in Al-Ahsa region of Saudi Arabia. According to recent literatures review, there is no single previous study has been conducted in this regard in Al-Ahsa region.

OBJECTIVES

1. To assess the knowledge of Al-Ahsa community about SCD in different aspects, such as: general knowledge, complications, transmission and treatment.

2. To detect community awareness regarding prevention and triggers of the disease.

3. To determine the perception toward the disease effect on school performance.

METHODS

Study Design:

A descriptive cross-sectional study was conducted among general population of Al-Ahsa region of Saudi Arabia, carried out between 1/6/2015 and 1/6/2016. The sample size was calculated using the following formula: $p(1-p)(\frac{1.96}{error})^2$. Sample size found to be 385, with 95% confidence interval.

Study population:

All Saudi population who lives in Al-Ahsa region were included in this study. The questionnaire was distributed through scattered manner to three hundred and eighty-six subjects.

Study Procedure:

The questionnaire was adapted from a Bahrain study [9], composed of six sections, each section consists of multiple-choice ques-

tions: the first section was about demographical data. The remaining sections were about general knowledge about the disease, how to live with the disease, how to treat the disease, how the disease be acquired, and the complications of the disease respectively. A bilingual expert translated the questionnaire to Arabic language. Along with a consent form declares that the collected data will be confidential and will be used for research purposes only. A pilot study was conducted to assess the validity of the questionnaire; those who participated were excluded from original study. Filling the questionnaire was voluntary.

Data Analysis:

The collected data was entered and analyzed by using SPSS software, version 21. The collected results of the study were expressed in a form of frequency table, pie chart. A chi-square and ANOVA were used to determine the significance between two variables or more (P value < 0.05).

RESULTS

The response rate was 57.25%. A total of 221 were collected, there were 131 females (59.3%) and 90 (40.7%) males in the study population. While 39 (17.6%) of the respondents were in the age group of < 18 years, 89 (40.3%) were in age group of 18-25 years, and 93 (42%) were in age group older than 25 years. Of the respondents, 35 (15.8%) were teacher, 112 (50.7%) were students, 1 (.5%) was doctor, 8 (3.6%) were engineer, 10 (4.5%) were businessman, and 55 (24.9) other. 112 (50.7%) were single, 107 married (48,4%), and 2 (0.9%) were separated. (Table 1).

Out of total 221 respondents, 94.6% have heard about sickle cell disease and 92.3% knew that it is a blood disease. 65.2% of subjects believed that there are different types of SCD and 87.3% know that SCD is an inherited disorder. Only 29% of subjects knew that not both parents need to have SCT for a baby to be born with SCD, and 58.9 believe that if they have SCD there is a chance to have a brother or sister with SCD. 13.1% of subjects are SCD carrier and 8.2% didn't know wither they are carrier or not. (Table 2)

The data shows that 44.8% of the participants agreed that sickle cell disease could impact a child's school performance, 37.6% strongly agree and only 2.3 are strongly disagreed. (Table 3)

80.5% of the participants believed that cold weather may worsen SCD and 86.4% believed that best ways to increase awareness of SCD are television and internet, health campaigns, education meetings, written information collectively. Furthermore, 28.9% believed that Premarital checking is the best preventive measures of SCD. However, 65% believed that premarital checking along with health education and enactment of laws are the best preventive measures. (Table 4)

According to the treatment modalities for sickle cell disease, 84.2% of subjects chose bed rest as a modality of treatment and 60.6% chose Intravenous saline. Furthermore, 61.5% believed of Injected analgesia and 53.8% believed of blood transfusion as modalities of treatment. However, only 7.7% of the subjects believed that oral fluids and 10.9% believed that oral analgesia are not modalities of treatment. (Table 5)

86% of the participant believed that sickle cell disease is an inherited disease, 5% thought that it can be transmitted through blood transfusion, and 7.7% didn't know how to get sickle cell disease. (Table 6)

According to complications of SCD, 89.6% knew that SCD can lead to pain requiring hospitalization, However, only 28.1% knew that SCD can lead to life-threatening infections, 22.2% knew that SCD can lead to Kidney failure, and only 16.3% knew that stroke is a complication of SCD. (Table 7)

There is a significant relationship between marital status and perception of SCD effect on school performance (p value = 0.034). Moreover, in comparison of believing there is a cure of SCD between Sickler patients and those who are SCT was significant, in favor of Sickler patients.

DISCUSSION

The goal of the presented study is to evaluate Al-Ahsa community awareness and perception regarding SCD since it is an area of public health concerns. Generally, the study showed that people had the least essential knowledge regarding sickle cell disease, which is similar to previous studies conducted in Bahrain [9].

Although most of the participants knew that SCD is an inherited disorder. Only (58.9%) had the correct knowledge regarding mode of inheritance, which seems better compared to Bahrain study (43%) [9]. 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 [10, 11].

The majority of the study population (82.4%) agreed that SCD has dramatic effects on child school performance, comparing to only 9.5% who disagreed, which means that the majority aware about the impact of SCD on the child wellbeing and mental activity. A recent study showed that 60.0% of Saudi Sickler patients believed that SCD affecting school performance in a negative manner. Furthermore, 37.5% of Saudi Sickler patients got help from special extra-educational services [12]. Moreover, there is a significant relationship between marital status and having the perception that SCD affects school performance (p value = 0.034). This is may be attributed to the fact that parents of SCD patients are more concerned about their child well-being [13].

The community believes that the best way to increase awareness about SCD is through the Internet and Television. This may have great influential aspects since most of Saudi public use Internet as the main source for health information [14]

65% of subjects saw that Premarital Screening program, health education, and law enforcement collectively are the best preventive measures against SCD. Saudi Arabia was one of the countries who has started premarital screening program since 2003 as a part of the steps to prevent the increase in the number of patient who suffer from common hemoglobinopathies in Saudi Arabia, including SCD, in which marriage certificate is not given to those who have high risk to have children with any of the diseases on the screening program

such as, SCD, however people with high-risk marriage has the right to marry [1,8].

Most of the subjects knew that bed rest and oral fluids are one of the best methods in treating Sickler patients (84.2%, 63.8%), respectively. Comparing to Bahrain study, which depicted that bed rest (74.8%) and Injected Saline (73.1%) [9]. Both samples shared the same concept that bed rest and fluids in general are essential modalities in managing SCD crisis.

Regarding to the complications knowledge, about 90% of the study population aware that pain crisis is one complication of SCD. However, their knowledge was relatively low in knowing other complication as in life threating infections (28.1%), kidney failure (22.2%), and stroke (16.3%). A study conducted in Al-Ahsa reviled that 28.5% of SCD mortality cases are due to acute chest syndrome alone. In addition to 11.6% and 10.3% in salmonella septicemia and other sepsis respectively [15].

CONCLUSION

The results depicted that people's awareness of SCD was acceptable. However, knowledge and awareness should be increased by school campaigns and, adding more information about this disease in school curriculums which would have a great impact on students. Furthermore, public campaigns in mosques and malls would also be very effective. Nevertheless, government laws and premarital obligatory tests should be kept.

TABELS

Table1: Demographical data.

Variables	Categories	N	%
Gender	Male	90	40.7
	Female	131	59.3
Age	18Less than	39	17.6
	18-25	89	40.3
	26-33	35	15.8
	34-40	33	14.9
	40More than	25	11.3
Occupation	herTeac	35	15.8
	Doctor	1	.5
	Engineer	8	3.6
	Business	10	4.5
	Student	112	50.7
	Other	55	24.9
Marital status	Single	112	50.7
	Married	107	48.4
	Separated	2	.9
Income	3000Less than	135	61.1
	6000-3000	21	9.5
	1000-6001	31	14
	1000More than	34	15.4

Table 2: General knowledge about the disease.

Variables	*(%) Yes*	*(%) No*	*Don't (%) know*
Have you ever heard of SCD?	209(94.6)	6(2.7)	6(2.7)
Is SCD a disease of the blood?	204(92.3)	1(.5)	16(7.2)
Are there different types of SCD?	144(65.2)	8(3.6)	69(31.2)
Can SCD be identified by a blood test?	186(84.1)	5(2.3)	30(13.6)
Is SCD an inherited disorder?	193(87.3)	10(4.5)	18(8.2)
Do both parents need to have SCT for a baby to be born with SCD?	120(54.2)	64(29)	37(16.8)
If you have SCT could your brother and sister have it too?	133(60.2)	49(22.2)	39(17.6)
Are you aware if you are a carrier?	29(13.1)	174:Not a carrier(78.7)	18(8.2)
Is there a cure for SCD?	15(6.8)	118(53.4)	88(39.8)

Table 3: To what extent do you agree or disagree that sickle cell disease can impact a child's school performance?

Item	*Number (%)*
Strongly Agree	83(37.6)
Agree	99(44.8)
Neutral	18(8.1)
Disagree	16(7.2)
Strongly Disagree	5(2.3)
Total	221(100)

Table 4: Respondent answers to multiple choice questions about awareness of SCD.

Item	*Categories*	*N (%)*
What conditions may worsen SCD?	Cold weather	178 (80.5)
	Hot weather	8 (3.6)
	Fever	7 (3.1)
	Lack of air	27 (12.2)
	vomiting and diarrhea	1 (0.5)
What is the best way to increase awareness?	Television and internet	11 (4.9)
	Health education meetings	15 (6.7)
	Written information	4 (1.8)
	all of them	191 (86.4)
Which preventive measures are best?	Premarital checking	64 (28.9)
	Health education	9 (4.0)
	Enactment of laws	4 (1.8)
	All of them	144 (65)

Table 5: Treatment modalities for sickle cell disease

Item	*Yes (%)*	*No (%)*	*Don't know (%)*
Bed rest	186 (84.2)	15 (6.8)	20 (9)
Oral fluids	141 (63.8)	17 (7.7)	63 (28.5)
Intravenous saline	134 (60.6)	16 (7.2)	71 (32.1)
Specific type of food	132 (59.7)	40 (18.1)	49 (22.2)
Oral analgesia	135 (61.1)	24 (10.9)	62 (28.1)
Injected analgesia	136(61.5)	27 (12.2)	58 (26.2)
Blood transfusion	119 (53.8)	43 (19.5)	59 (26.7)

Table 6: How do you get sickle cell disease?

Item	*N (%)*
You are born with it (It's hereditary)	190 (86)
You get it from a blood transfusion	11 (5)
Food items trigger an attack	1 (.5)
You can get it some other way (e.g. food, airborne transmission)	2 (.9)
Don't know	17(7.7)
Total	221 (100.0)

.Complications of SCD :7Table

Item	*Yes (%)*	*No (%)*	*Don't know (%)*
Pain requiring hospitalization	198(89.6)	5(2.3)	18(8.1)
Life threatening infections	66(28.1)	57(25.8)	102(46.2)
Kidney failure	49(22.2)	53(24)	119(53.8)
Stroke	36(16.3)	53(24)	132(59.7)

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