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An Assessment of Knowledge towards Complications of Sickle Cell Disease among General Population in Jeddah City

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ABSTRACT

Background: Sickle cell disease (SCD) is an autosomal recessive disorder characterized by production of abnormal hemoglobin S, and it is associated with high morbidity and mortality. The highest prevalence of SCD in Saudi Arabia is in the Eastern province.

Objectives: To assess perceptions and the level of knowledge about SCD and to study factors that may affect them among general population in Jeddah city, Saudi Arabia.

Methods: A self-administered questionnaire was distributed among general population residing in Jeddah city, Saudi Arabia. The questionnaire consisted of two sections: (1) socio-demographic information and previous experience with SCD and (2) knowledge about SCD and its complications, which was measured by 20 closed-ended questions. **Results:** A total of 424 subjectscompleted the questionnaires and participated in the study. More than half (51.4%) of the participants showed good level of knowledge about SCD and its complications. Sex, education level, and previous experience with SCD child had significant association with the level of knowledge ($p<0.05$). The majority of participants with good level of knowledge were females (86.2%) and at the level of university education (84.4%). Furthermore, all subjects (100%) who had previous experience with SCD child showed good level of knowledge.

Conclusion: A moderate level of awareness regarding SCD and its complications was found in our study sample. Educational programs should target the male population, and emphasize the nature of inheritance of the common blood diseases and their complications.

Keywords: knowledge; survey; perceptions; sickle cell disease; Saudi Arabia.

INTRODUCTION

Sickle cell disease (SCD) is a hemolytic anemia characterized by abnormally shaped (sickle) red blood cells (RBCs), which are removed from the circulation and destroyed at increased rates leading to anemia[(1)]. Abnormality in RBCs shape is mainly attributed to the presence of hemoglobin S, which, when deoxygenated, becomes relatively insoluble and forms aggregates with other hemoglobin molecules within the RBCs[(2)]. A point mutation in the gene coding the β chain of the hemoglobin molecule results in a single amino acid substitution (valine for glutamic acid), which leads to hemoglobin S. Sickle cell disease is one of the most commongenetically inherited diseases affecting mainly African Americans[(3)]. In addition, it is a prevalent disorder among those from Mediterranean area like Turkey, and the Arabian Peninsula[(4)].

Regarding SCD treatment, routine general prophylactic and corrective measures have been associated with marked improvement in life expectancy and quality of life among sickle cell disease patients in developed nations[(5)],which points to the importance of providing the public with proper information on SCD. Early community-based surveys conducted on African Americans in large urban areas demonstrated limited awareness of SCD in these communities[(6)].

In addition, **Adewoyin *et al.*[(7)]** demonstrated moderate level of public health knowledge regarding SCD in Nigeria. In the Middle East, **Al Arrayed and Al Hajeri[(8)]** reported a good level of knowledge about SCD, and a wide acceptance and appreciation of SCD prevention campaigns among the public in Bahrain.

Recently, Saudi Arabia has been reported to have an increasing prevalence of SCD. The carrier status for SCD ranged from 2% to 27%, and up to 1.4% had SCD in Saudi Arabia[(9)]. In addition, the prevalence of consanguinity ranges from about60% in Saudi Arabia up to 90% in some Bedouin communities[(10)]. Therefore, the current study was carried out to assess perceptions and level of knowledge about SCD and its complications and to study factors that may affect them among general population in Jeddah city, Saudi Arabia.

METHODS

Study design:

Questionnaire-based cross-sectional study.

Inclusion and exclusion criteria

We includedadult, male and female,Saudi and non-Saudi,residents of Jeddah, Saudi Arabia.

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Setting and duration

The study was conducted on different sectors located within Jeddah city. Data collection took place during November and December, 2017.

Data collection instrument

We used a self-administrated questionnaire that was published elsewhere[11]. The questionnaire consisted of two sections: (1) socio-demographic information and previous experience with SCD and (2) knowledge about SCD and its complications, which was measured by 20 closed-ended questions.

Data entry and statistical analysis

Data were analyzed using statistical package for social sciences (SPSS) software version 20. Qualitative variables were presented as numbers and percentages in brackets, while quantitative variables were represented as median and interquartile range (IQR). Chi-square test was used to determine the association between two variables. A score of one was given for each correct answer and zero for wrong or don't know answers,and then thetotal knowledge score for each participantwas calculated. Any score above the median value was considered as good knowledge, while a score below that was considered poor knowledge. P value <0.05 was considered significant.

Ethical considerations

This study got ethical approval from the Institutional Human Ethics Committee, Ibn Sina National College for Medical Studies, Jeddah, KSA. The study didn'tshow any physical, psychological, social, legal, economic, or any other risks to the study's participants.The study conserved participants' privacy. Investigators were responsible for keeping the security of the data.All participants' datawere not used for any other purpose outside this study. Personal data (e.g. Name, Contact info) were notentered in our data entry software to conserve the participants' privacy, however, each subject was given a unique identifier code. Participants were informed about the study objectives andmethodology. Subjects, who agreedto fill the questionnaire, implied that they agreed to participate in the study.

RESULTS

This study was carried out on 424Saudi subjects residing inJeddah Citywho completed the self-administered questionnaires during the study period.

The majority (78.8%)of the study participants were females. Their ages ranged from 15 to 60 years with a median age of 24.00 (IQR = 22.00-30.50)**.** More than half (58.0%) of them were single, while 40.6% were married. Students and professionals including physicians, nurses, teachers, policemen, and others constituted the majority of them (51.4% and 31.1% respectively). High percent (82.1%)of them were at the level of university education as shown in **table 1**.

Table 2 shows participant's perceptions about SCD, most (86.3%) of the study population heard about SCD, and only 16 (3.8%) had previous experience with SCD child. Most (55.7%) of the respondents knew that SCD is a blood disease, and 74 (17.5%) stated that it could be identified by a blood test. Two-thirds (66.0%) of them did not know if there are racial differences in the incidence of this disorder, whereas 144 (34.0%) subjects had recognized that it mostly affects Africans. Moreover, most (79.7%) of the study participants did not have accurate information about incidence of SCD among Saudi population.

Information about the cause of SCD is illustrated in **table3**. Most (77.8%) of the surveyed subjects knew that SCD is a hereditary disorder, and 254 (59.9%) subjects recognized that SCD sometimes skip generations in families. Nonetheless, most of the study participants did not have in depth information of SCD genetics, and most (60.8%) of them did not know different types of traits that can lead to SCD or have ever heard of C or beta thalassemia traits (75.9% and 60.4% respectively).

More than half of the respondents did not know if they personally have C or beta thalassemia traits (58.6% and 52.9% respectively).

Knowledge of the study participants about complications of SCD is demonstrated in **table 4**. Most (71.7%) of the study population identified that SCD causes severe pain that requires hospitalization, but lower percentages (41.5%, 42.0%, and 39.6%) recognized that SCD could lead to life threatening infections, renal failure or stroke respectively.

There was agreement that SCD could decrease the child school performance (78.3%). Moreover, 136 (32.1%) stated that there is no currently a cure for SCD though the majority did not have correct information about treatment of this disorder.

Finally, most of the surveyed subjects suggested that health education of the public through TV, community meetings, distribution of written information, videos or CDs as methods to increase awareness about SCD.

Overall knowledge score was calculated, it ranged from 1.00 to 15.00 with a median of 8.00 (IQR = 5.00-10.00). According to this score, 51.4% of participants showed good level of knowledge.

Table 5 shows that sex, education level, and the previous experience with SCD child had significant association with the level of knowledge ($p<0.05$). The majority of participants with good level of knowledge were females (86.2%) and at the level of university education (84.4%).

Furthermore, all subjects (100%) who had previous experience with SCD child showed good level of knowledge.

Table 1: Socio-demographic characteristics of the studied subjects

Age (years)	Range	15.00-60.00	
	Median	24.00	
	IQR	22.00-30.50	
		N=424	%
Sex	Female	334	78.8
	Male	90	21.2
Marital status	Single	246	58.0
	Married	172	40.6
	Widow	4	0.9
	Divorced	2	0.5
Educational level	Pre-university	76	17.9
	University	348	82.1
Occupation	Professional	132	31.1
	Employee	20	4.7
	Student	218	51.4
	House wife	38	9.0
	No	16	3.8

Table 2: Participant's perceptions about sickle cell disease

		N=424	%
Have you ever heard of SCD?	Yes	366	86.3
	No	58	13.7
Previous experience with SCD child?	Yes	16	3.8
	No	408	96.2
Which of the following are true of SCD?	A blood disease	236	55.7
	Has many different types	64	15.1
	Can be identified by a blood test	74	17.5
	Blood transfusion is an important way of treatment	50	11.8
Who gets SCD?	Mostly Africans	144	34.0
	All races are equally as likely	132	31.1
	I don't Know	148	34.9
How common SCD is among Saudi population?	Less than 0.1	16	3.8
	1-2%	86	20.3
	10%	148	34.9
	Don't know	174	41.0

Table 3: Information of the studied subjects about heredity of sickle cell disease

		N=424	%
How do you get SCD?	Hereditary	330	77.8
	From a blood transfusion	12	2.8
	Don't know	82	19.3
Does SCD sometimes skip generations in families?	Yes	254	59.9
	No	40	9.4
	Don't know	130	30.7
Do you know if there are different types of traits that can lead to SCD?	Yes	124	29.2
	No	42	9.9
	Don't know	258	60.8
Do you know, if you, personally, have sickle cell trait?	Yes	40	9.4
	No	112	26.4
	Don't know	272	64.2
Have you ever heard of C-trait?	Yes	102	24.1
	No	322	75.9
Do you know, if you, personally, have C-trait?	Yes	12	3.3
	No	138	38.1
	Don't know	212	58.6
Have you ever heard of b-thalassemia trait?	Yes	168	39.6
	No	256	60.4
Do you know, if you, personally, have Beta-thalassemia trait?	Yes	26	6.8
	No	154	40.3
	Don't know	202	52.9

Table 4: Knowledge of the study participants towards complications of sickle cell disease.

		N=424	%
Complication of SCD in children	Pain requiring hospitalization	274	64.6
	Life threatening infections	80	18.9
	Stroke	42	9.9
	Kidney failure	28	6.6
Can SCD impact a child's school performance?	Strongly agree	184	43.4
	Agree	148	34.9
	Disagree	20	4.7
	Strongly disagree	4	0.9
	Don’t know	68	16.0
Is there currently a cure for SCD?	Yes	108	25.5
	No	136	32.1
	Don’t know	180	42.5
Does pain in SCD require hospitalization?	Yes	304	71.7
	No	14	3.3
	Don’t know	106	25.0
Does SCD lead to Life threatening infections?	Yes	176	41.5
	No	100	23.6
	Don’t know	148	34.9
Does SCD lead to Kidney failure?	Yes	178	42.0
	No	38	9.0
	Don’t know	208	49.1
Does SCD lead to Stroke?	Yes	168	39.6
	No	28	6.6
	Don’t know	228	53.8
Does SCD lead to Poor school performance?	Yes	288	67.9
	No	32	7.5
	Don’t know	104	24.5
The best way to increase awareness about SCD in the community?	Community meetings	104	24.5
	Mail out written information	52	12.3
	Distribute a video or CD	46	10.8
	Social media	36	8.5
	Publicize on TV	176	41.5
	Publicize on radio	6	1.4
	Schools	2	0.5
	Don’t know	2	0.5

Table 5: Association between levels of knowledge about sickle cell disease and Socio-demographic characteristics of the studied subjects

		Level of knowledge						
		Good N=218(51.4%)		Poor N=206(48.6%)		Total		
		N	%	N	%	N	%	P value
Sex	Female	188	86.2	146	70.9	334	78.8	<0.001*
	Male	30	13.8	60	29.1	90	21.2	
Level of education	Pre-university	34	15.6	42	20.4	76	17.9	0.001*
	University	184	84.4	164	79.6	348	82.1	
Occupation	Professional	72	33.0	60	29.1	132	31.1	0.199
	Student	124	56.9	94	45.6	218	51.4	
	Employee	8	3.7	12	5.8	20	4.7	
	House wife	10	4.6	28	13.6	38	9.0	
	No	4	1.8	12	5.8	16	3.8	
Previous experience with SCD child	Yes	16	7.3	0	0.0	16	3.8	<0.001*
	No	202	92.7	206	100.0	408	96.2	

*significant

DISCUSSION

Sickle cell disease is an autosomal recessive disorder characterized by production of abnormal hemoglobin S and is associated with high morbidity and mortality[12]. The prevalence of SCD in Saudi Arabia varies significantly in different parts of the country, with the highest prevalence found in the Eastern followed by the Southwestern provinces. The reported prevalence for sickle-cell trait ranges from 2% to 27%, and up to 2.6% will have SCD in some areas[13]. So, this study focused on assessment of the level of knowledge about SCD and its complications, thereby targeted health education and preventive measure can be conducted.

This study demonstrated that more than half (51.4% %)of the general population in Jeddah cityhad good knowledge about sickle cell disease and its complications.Most (77.8%) of the surveyed subjects identified that SCD is a hereditary disorder that sometimes skip generations in families. Additionally, favorable percentages ofthe study population were aware about different complications of SCD such as severe pain that requires hospitalization, life threatening infections, renal failure or stroke, with high (78.3%) agreement of the participants that SCD could decrease the child school performance. Nonetheless, there was considerable lacking of in depth information about SCD genetic transmission and itsepidemiology among different races and locally among Saudi population. In consistence with this finding, a study in Bahrain by **Al Arrayed and Al Hajeri[8]** showed good level of knowledge about SCD among the public. In addition, **Treadwell *et al*.[14]** reported that 68% of their study population responded correctly to knowledge questions about SCD. In contrast, a low level of knowledgewas reported among SCD patients in Al-Qatif area, Eastern Province, Saudi Arabia and secondary school students in Nigeria[15,16]. Furthermore, **Siddiqui *et al*.[17]** revealed substantial knowledge gaps about sickle cells in surveyed people of reproductive age from the Dominican and African American communities in Northern Manhattan, despite the high prevalence of SCD in both groups.

In the current study, there was a significant associationbetweensex and the level of knowledge where females constituted 86.2% of participants with good level of knowledge. This finding is in agreement with **Al Arrayed and Al Hajeri[8]** and could be explained by frequent health education among females as part of their antenatal care. Additionally, females tend to be more interestedin learning about genetic diseases.

This survey revealed that the respondents' level of education had an impact on their level of awareness. College graduates were more aware about SCD than those at lower level of education. Furthermore, upon relating the level of awareness and previous knowledge about SCD, it wasfound that all subjects who had previous experience of SCD child answered more questions correctly.

Most of the surveyed subjects in this study suggested health education of the public through TV, community meetings, or distribution

of written information, videos or CDs as methods to increase awareness about SCD. Based on this, we recommend educational programs that inform the public through TV broadcasts, life lectures, and community meetings. They should emphasize on the nature of inheritance, prevalence of the disease, and preventive measures. Male population and those who did not complete university education are important targets for these health education programs. Integrating important information about blood diseases including SCD into the school curriculums is also essential.

CONCLUSION

a moderate level of awareness regarding SCD and its complications was found in our study sample. There were significant associations between each of the gender, level of education, and previous experience with SCD child and the level of knowledge. Most of the respondents support and appreciate community health education meetings and/or TV programs to increase the public awareness. Educational programs should target the male population, and emphasize the nature of inheritance of the common blood diseases and their complications.

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