A STUDY TO ASSESS KNOWLEDGE AND MISCONCEPTIONS ON SICKLE CELL DISEASE AMONG UNIVERSITY STUDENTS IN EASTERN PROVINCE OF SAUDI ARABIA.

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INTRODUCTION:

SCD is a group of conditions that are genetic in nature. It affects red blood cells in blood. Sickle cell anemia is the name of a specific form of Sickle Cell Disease in which red blood cells have a tendency to go out of shape and become sickle-shaped (like a crescent moon) - instead of its normal disc shape. This causesvarious problems. In between Episodes of illness, this will be felt well by the people with Sickle Cell Disease.Therefore a group of conditions that cause red cells tobecome sickle-shaped [1].

The sickle cell genes make the body to produce abnormal hemoglobin called ***HbS***. (Normal hemoglobin is calledHbA.) HbS behaves differently from HbA. Under certain circumstances',***HbS*** makes the red blood cells change its shape- Instead of the normal doughnut shape. It becomessickle-shaped, like a crescent moon. This is called sickling [1][2].Conditions that trigger sickling are cold, infection, lack of fluid in the body, low oxygen and acid produced during physical exercise [4].

The diagnosis is carried out by a blood test. A sample of blood is analyzed to check what type of hemoglobin is present in the blood by a test called hemoglobin electrophoresis or other methods [2][3].

In England, Scotland and Wales, there is a screening test for pregnant women and newborn babies for SCD and other hemoglobin disorders. Northern Ireland currently checks newborns but not pregnant women [3][1].

Americans and some millions of people around the world (Centers for Disease Controland Prevention [CDC], 2013 a). There have been more than 120 years of research to find a cure for Sickle Cell Disease, but so far, there is no universally accepted cure without side effects [6].
Current research supports the idea that SCD is preventable if individuals are aware oftheir sickle cell trait (SCT) status and undergo genetic counseling [7].However, most of the individuals do not know whether they have SCTor not.If people are aware, if they have SCT, then there is a higher likelihood that they willSeek genetic screening and genetic counseling prior, making reproductive decisions [7][8][9].

The highest prevalence of Sickle Cell Disease in Saudi Arabia is in Eastern province. Compared to all other areas of Saudi Arabia, Al-Qatif area hashighest gene frequencies for HbS and glucose-6-phosphate dehydrogenase (G-6-PD) deficiency genes [12].According to a study of neonatal screeningprogram homozygous SCD was detected in 3.36% and 2.04% in Qatifand Al Hasa, respectively.[13] While G-6-PD deficiency revealed a highPrevalence of 36.6% and 18.6% in Qatif and Al Hasa respectively.[12][13]

Consuming nutritious food is highly helpful in sickling crisis prevention. According to a study SCD opinion, regardingtriggering factors of sickle cell crisis, almost 65% of thesubject mentioned beans including broad beans as the more chances for the cause. An improvement in the patient's condition is noticed with increased in fluids, fruits, vegetables and milk intake in their nutrition diet [14][15].

Nutritional intervention utilizing single or multiple nutrient supplements led toimproved clinical outcome, growth and sexual maturation. A current study determines the best possible approach to applying nutritional intervention inthe management of Sickle Cell Disease [13].

The objective of this study is to assess knowledge and misconceptions of Sickle cell Disease among university students in Eastern Province of Saudi Arabia. The results of this study will help in identifying those areas of knowledge deficiency; will assist in developing health education programs among college students of Dammam University.

METHODOLOGY:

Study Design

A Cross sectional study design was conducted among the university students. Data were collected from different colleges of Imam Abdulrahman Bin Faisal University, Dammam, Kingdom of Saudi Arabia.

Data collection

The sample size used in the study is 330 college students and tool used for study is structured self-administered questionnaire, developed by researcher according to the review of literature. It has divided into three sections:

Section 1: Socio demographic data and medical history.
Section 2: Questions to determine the history and severity ofthe disease.
Section 3: Questions to assess knowledge and misconceptionsabout SCD through four-dimension. The first about genetic transmission; the second about precipitating factors of sickle cell crisis; the third about sickle cell diet, and the 4th about G-6-PD deficiency diet.

Statistical Analysis:

All categorical data were represented by frequency with percentage, and it was analyzed for significance using Chi-square and Fisher-exact test. All the analysis were done by using SPSS 21.0 version. A p value less than 0.05 was considered as significant.

Ethical Consideration

Ethical approval obtained from the Ethics and Research Committee of the authors' institution. Participation was voluntary and anonymous. All participants Confidentiality is maintained, as no

names will be mentioning in the questionnaires and participants are assured contentment full confidentiality of the data collected.

Obtained permission from director of each research setting to conduct the study, after explaining the purpose, the consent from participants will be self-determined through their agreement to participate in the study and then the questionnaire distributed among students, asking them to fill the questionnaire and return it back.

Results:

Out of 330 samples, 110 were in the age group of less than 20 years (33.3%) and rest were more than 20 years of age (66.7%) (Table 1). Table 1 show that almost half of the study populations (54.5%) were male. Regarding education level, most of respondents (46.9%) father education was university degree and mothers also mostly were university degree (38.2%). The family income of 43.6% of the respondents was more than 15,000 Saudi Riyals.

Table 1: Respondents demographics

Variables	N (%)
Age in yrs.	
Less than 20 years	110 (33.3%)
More than 20 years	220(66.7%)
Gender	
Male	180 (54.5%)
Female	150 (45.4%)
Father education	
Illiterate	4 (1.2%)
Read and write	12(3.6%)
Primary or intermediate	38 (11.5%)
Secondary	121(36.7%)
University	155 (46.9%)
Mother Education	
Illiterate	11(3.3%)
Read and write	60(18.2%)
Primary or intermediate	89(26.9%)
Secondary	44(13.3%)
University	126(38.2%)
Family income in SAR	
Less than 5000	61(18.5%)
5000- 10000	89(26.9%)
10000- 15000	36(10.9%)
More than 15000	144(43.6%)

Table 2 shows the student's health information regarding SCD, Family history & Health history. Out of 330, 44 respondents suffer from SCD which shows the incidence rate (13.3%).Also table 2 shows that there is no significant family history and health history.

Table 2: Students health information

Variables	**Yes** **Number (%)**
Regarding sickle disease	
1. Do you suffer from sickle cell anemia	44(13.3%)
2. Do you have any symptoms	110(33.3%)
3. Have you ever had a severe seizure	12(3.6%)
4. Do you take any analgesic medication for pain	103(31.2%)
5. Do you consult a doctor at least once a year	120(36.4%)
6. Admitted in ER in the past 12 months	21(6.4%)
7. Admitted in hospital in the past 12 months	4(1.2%) 51(15.4%)
8. Illness had any negative effect	180(54.5%)
9. Regularity in the study	201(60.9%)
10. Ability in academic achievement	242(73.3%)
11. Follow exercise sports activities	160(48.4%)
12. Follow recreation activities	
Family history	
1. Any of your family members suffer from sickle cell disease?	58(17.8%)
2. Any of your family members have the trait of sickle cell anemia	36(10.9%)
Health history	
1. Do you suffer from chronic disease	40(12.1%)
2. Do you suffer from any disability	3(0.9%)

Table 3 conveys about the various items of SCD knowledge, as observed most of them are knowledgeable about SCD, 60.3% of them stated that SCD is due to genetic reasons, 71.0% due to recessive gene. 89.3% stated that sickle cell anemia is diagnosed by a blood sample, 56.4%respondents agreed that sickle cell anemia does not have a cure.

Table 3: Results on various items of SCD knowledge

Items	% sample correct
1 - sickle cell anemia is a genetic disease	60.3%
2 - the cause of sickle cell anemia (recessive gene)	71.0%
3 - sickle cell anemia due to defect in the hemoglobin part	84.9%
4- Age of red blood cells in sickle cell anemia is about 20 days	49.3%
5 - Red blood cells in sickle cell anemia can block blood vessels	48.9%
6 - The symptoms of sickle cell anemia due to lack of oxygen in the tissues	53.2%
7. Sickle cell anemia leads to bone pain	70.1%
8 - The pain of sickle cell anemia is acute and not chronic	60.0%

9. Sickle cell anemia increases the risk of infection	40.0%
10.Swelling of hands and feet has nothing to do with sickle cell anemia	52.0%
11. Sickle cell anemia may inhibit the child's development	79.0%
12. Sickle cell anemia has no effect on puberty	41.0%
13. Sickle cell anemia may affect the retina	80.0%
14 - sickle cell anemia may lead to yellowing of the skin or eyes	71.0%
15. Sickle cell anemia may cause a stroke	51.2%
16. Ulcers of the feet have nothing to do with sickle cell anemia	42.0%
17. Sickle cell anemia leads to spleen enlargement	31.0%
18 - sickle cell anemia does not have a cure	56.5%
19 - sickle cell anemia is diagnosed by testing a sample of blood	89.3%
20. Sickle cell anemia can be diagnosed in the child during pregnancy	61.2%

Table 4 shows about the other knowledge about the SCD as factors that increase the risk of SCA as drinking of cold water and (25.2%) have said that it is due to heavy exercise, regarding diet (62.6%) have said that eating chickpeas may cause SCA and least of (32.8%) have said that eating fish also can cause SCA.

Regarding the source of information, Major source of information include fiends having 54.6%, magazine and brouchers (61.9%), and internet 31.2%. Also table 4 shows that the correct responses towards the risk factors of acute SCD, most respondents was aware and knowledgeable. Regarding SCD diet, almost only half of the respondents was aware the specified diet items.

Table 4: Other items of SCD knowledge

	Percentage
Any of the following factors increases the risk of acute sickle cell anemia (Precipitating factors)	
1. Fever	86.3%
2. Cold water	91.8%
3. Weather	43.6%
4. Infection	49.2%
5. Psychological stress	72.3%
6. Light exercises*	39.2%
7. Heavy exercises*	25.2%
8. Drink water heavily*	31.0%
9. Travel at high altitudes	61.8%
Any of the following foods should be avoided to avoid acute sickle cell anemia	
(SCD diet)	41.3%
Fava Beans	52.2%
Lentils	62.6%
Chickpeas	39.8%
Bean	51.0%

Libya	62.0%
Nuts	43.1%
Peanuts	52.4%
Koulaba	62.2%
Falafel	49.2%
Red meat	51.2%
Vegetables	32.8%
fish	
Sources of information	
Internet	31.2%
Relatives	21.6%
Friends having the disease	54.6%
Family	10.3%
Magazines and brochures	61.9%

Figure 1 shows the academic relationship between the normal students and the SCD Students in which the performance of normal students was better as compared to SCD students (40% vs. 22%), also this study found more number of failures among SCD students (39% vs 18%).

Figure 1: Academic Achievements

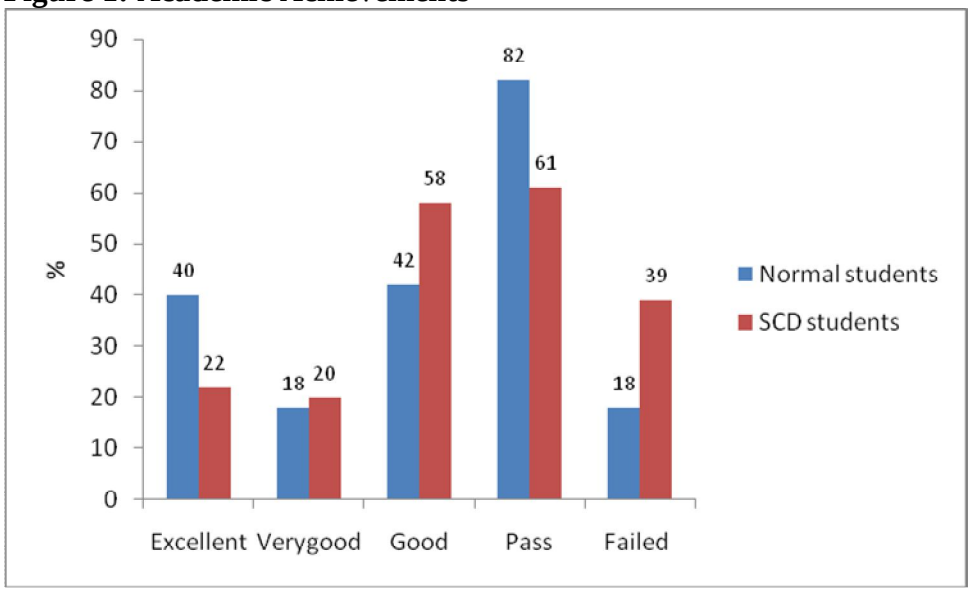

Figure 2: Shows the distribution of students according to their level of knowledge about sickle cell disease. Of the study sample, 40% generally had poor knowledge. Overall 39 percent of students had good knowledge and 21% had excellent knowledge.

Figure 2: Distribution of students according to their level of knowledge about sickle cell disease

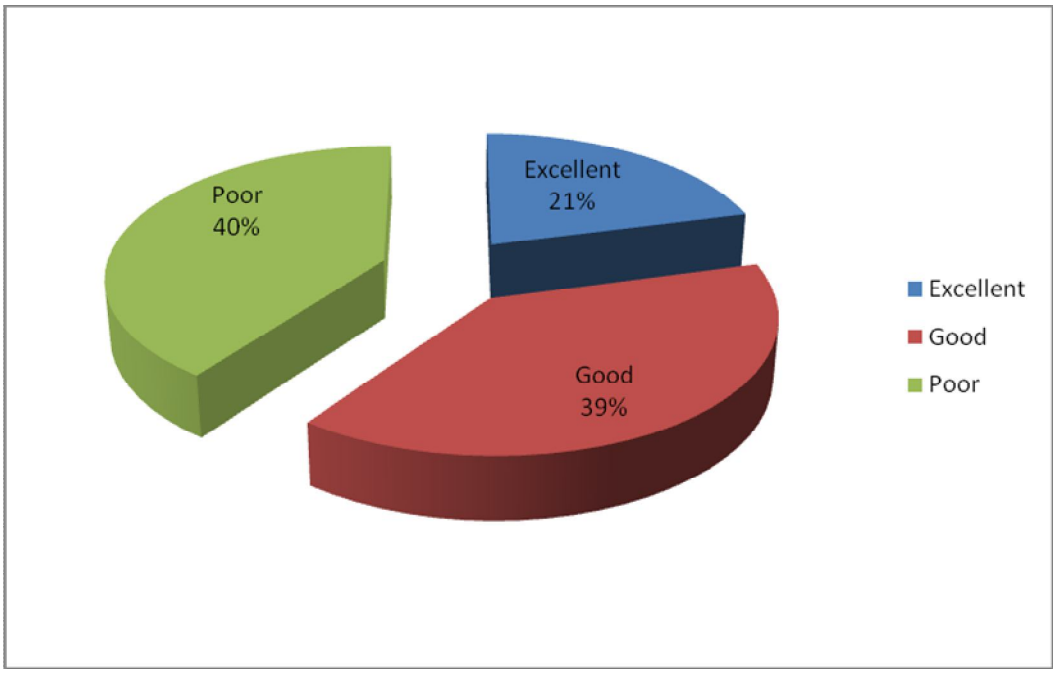

Table 5: Shows about the association between levels of knowledge among sickle cell disease students with their sociodemographic characteristics as the age difference has highly statistically significant with P value of 0.021, if they are more than 20 years they had good knowledge about SCD. Other variable like, Gender, father, mother's education, monthly income were not significantly associated with the level of knowledge. The students those who affected with the SCD have better knowledge as compared with others, which is Statistically significant (P <0.001).

Table 5: Association between levels of knowledge among sickle cell disease students with their sociodemographic characteristics

Variables	Level of knowledge		P value
	Poor	Good	
Age in yrs. Less than 20 years More than 20 years	 80(72.7) 90(40.9)	 30(27.3) 130(59.1)	 0.021*
Gender Male Female	 40(22.2) 31(20.7)	 140(77.8) 119(79.3)	 0.569

Father education			
Illiterate	3(75.0)	1(25.0)	
Read and write	7(58.3)	5(41.7)	0.312
Primary or intermediate	8(21.1)	30(78.9)	
Secondary	31(25.6)	90 (74.3)	
University	49(31.6)	106 (68.4)	
Mother Education			
Illiterate	7(63.6)	4(36.4)	
Read and write	6(10.0)	54(90.0)	0.119
Primary or intermediate	19(21.3)	70(78.6)	
Secondary	16(36.4)	28(63.6)	
University	37((29.3)	89(70.7)	
Family income in SAR			
Less than 5000	11(18.1)	50(81.9)	
5000- 10000	39(43.8)	50(56.2)	
10000- 15000	18(50.0)	18(50.0)	0.059
More than 15000	56(38.9)	88(61.1)	
Do you suffer from sickle cell anemia			
Yes	11(25.0)	33(75.0)	<0.001*
No	180(62.9)	106(37.1)	

*Statistically significant

Discussion:

In general, we found in our study that around 40 percentages of students had poor knowledge about sickle cell disease. This finding was comparable with other study [16]. Also we found most of these students who had poor knowledge were from the non-SCD students. Therefore, education curriculum needs to include health education program, especially those students who had poor academic performance due to health problem. This result was consistent with that in the study by Siddiqui *et al*., (2012) which 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.[6]

In this study, 33.3% students are in the age group of less than 20 and 66.7% are in the age group of more than 20 where as 180 participants are male and remaining 150 participants are female. Regarding sickle disease totally 44 participants (i.e 13.3%) are suffer from SCD among 330. 33.3% participants have symptoms for SCD and 6.4% participants are admitted in hospital in the past 12 months. According to the family history, 17.8% of participants' family members suffer from SCD where 10.9% of family members having the SCD disease. It is also consistent with the study by Olakunle *et al*., which reported low comprehensive knowledge about SCD despite good awareness recorded among respondents.[14]

Most of participants are knowledgeable about SCD, 60.3% of them stated that SCD is due to genetic reasons, 71.0% due to recessive gene. 89.3% stated that sickle cell anemia is diagnosed by a

blood sample, 56.4% respondents agreed that sickle cell anemia does not have a cure. 80 % of them agreed that Sickle cell anemia may affect the retina. On the other hand, our results are different from those of a study in Bahrain by Al Arrayed and Al Hajeri, (2010) which showed that the level of knowledge about SCD among the public was good.[13] They also differ from the study by Treadwell *et al.*, in which over 68% responded correctly to knowledge questions about SCD.[7]

Majority of the participants exhibited positive attitude to people living with SCD. In addition, majority of those who had positive attitude towards people living with SCD were also found to have adequate knowledge about SCD. A higher proportion of those who had negative attitude exhibited inadequate knowledge about SCD. This is similar to findings of other studies.18,19 Negative attitude will result to denial and concealment of the disease by the affected individuals as well as carriers, with adverse consequences. Elimination of negative attitude, discrimination and stigmatization depends largely on the extent of enlightenment of the society on issues concerning SCD.

There are many factors may increase the risk of SCD, 91.8% cold water may increase the risk in SCD patients. The second high risk factor is fever (86.3%) and third one is psychological stress (72.3%). Even light and heavy exercise also will increase the risk of SCD patients as 39.2% and 25.2% respectively. Food diet also need to be follow to avoid acute sickle cell anemia. Regarding SCD diet, almost only half of the respondents was aware the specified diet items. Major source of information include fiends having 54.6%, magazine and brouchers (61.9%), and internet 31.2%.

The responses of participants in this study also suggest that a lot of people are likely to seek help from prayer houses and other unorthodox places rather than from Western trained Practitioners. We think therefore that to win the battle against SCD widespread community intervention strategy is imperative. Television and other media programmes may be useful for promoting accurate knowledge of SCD. It may also be beneficial to include SCD as a topic in the integrated science and social studies books of our primary and secondary schools.

According to our study students above 20 years and those who have affected with the SCD had a very good knowledge about SCD, even they were aware about diets. Education achievement was very poor among SCD students when compared to normal students. Actually there is no similar study in Saudi Arabia, especially in Eastern Province. Therefore, this study outcome is more useful for the academic management peoples and also for the students to know the impact of SCD severity and its significance. Hence this study recommends that to include more about SCD in health education program.

Conclusion:

This study revealed significant low level of knowledge among the university students also students had some moderate level of misconceptions. Academic achievement was significantly low among SCD students. Students with SCD were more knowledgeable than those with the sickle cell disease.

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