Original Article

Knowledge and misconceptions about sickle cell anemia and glucose-6-phosphate dehydrogenase deficiency among adult sickle cell anemia patients in al Qatif Area (eastern KSA)

Abstract

Introduction and Background: Sickle cell disease (SCD) is an extremely challenging disease of global concern. The highest prevalence of SCD in Saudi Arabia is in the Eastern province. Compared to all other areas of Saudi Arabia, Al-Qatif area has the highest gene frequencies for HbS and glucose-6-phosphate dehydrogenase (G-6-PD) deficiency genes. **Objective:** The objective of this study was to assess the knowledge and misconceptions about SCD of adults (≥18 years) with sickle cell anemia in Al-Qatif area, Eastern Province, Saudi Arabia, and study factors that may affect them. **Materials and Methods:** A cross-sectional study using a self-administered questionnaire was distributed to 320 patients aged ≥18 years with sickle cell anemia, who attend the medical outpatient clinics in Qatif central hospital and primary care centers in the Qatif area, Eastern Province, Saudi Arabia. **Result:** A total of 300 participants completed their questionnaire. In general, 56.3% had poor knowledge of the disease. About 58.3% had good knowledge of the genetic transmission. The knowledge of 46.7% about the precipitating factors was poor. Moreover, 59.3% had poor knowledge of the diet of people with SCD and 81.3% had poor knowledge of the diet of people with G-6-PD deficiency. **Conclusion:** Our study revealed significant widespread misconceptions of patients with sickle cell anemia especially relating to their diet.

Key words: Knowledge, misconception, sickle cell anemia, G-6-PD deficiency

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INTRODUCTION

Sickle cell disease (SCD) is an extremely challenging disease of global concern.[1] Approximately, 5% of the world's population carries trait genes for hemoglobin disorders, mainly, sickle-cell disease and thalassemia.[12]

Sickle cell anemia is an autosomal recessive inherited disorder, characterized by the presence of HbS, a product of structural changes that occur in the β chain of hemoglobulin, in which the glutamic acid is replaced by valin at the 6th position. When deoxygenated, HbS polymerizes causing deformed red blood cells. This produces sickle cells, which are fragile, hemolyze, and block the small vessels. Patients usually present with pain "painful crisis" or chronic hemolytic anemia.[1,3,4]

The sickle cell gene was first recognized in Saudi Arabia in 1963 by Lehmann and co-workers in the eastern province of the country.[9,10]

Gelpi (1967) reported the presence of the HbS gene in the oasis population of Al-Qateef and Al-Hasa.[11]

The prevalence of SCD in Saudi Arabia varies significantly in different parts of the country, with the highest prevalence in the Eastern province followed by the South-western provinces.[3]

The reported prevalence for sickle-cell trait ranges from 2% to 27%, with up to 2.6% in some areas with SCD.[2] Compared to all other areas of Saudi Arabia, Al-Qatif area has the highest gene frequencies for HbS and glucose-6-phosphate dehydrogenase (G-6-PD) deficiency genes.[15]

According to a study by Nasserullah *et al.* of the neonatal screening program homozygous SCD was detected in 2.35% and 1.08% in Qatif and Al Hasa, respectively.[8] While G-6-PD deficiency revealed a high prevalence of 30.6% and 14.7% in Qatif and Al Hasa respectively.[8]

Because of the global seriousness of this disorder, a large number of studies have been undertaken. Unfortunately, very few have addressed the issue of misconceptions about the disease particularly in Saudi Arabia.

The aim of this study was to assess the knowledge and misconceptions about SCD of adults (≥18 years) with sickle cell anemia in the Qatif area, Eastern Province, Saudi Arabia, and study factors that may influence them.

Specific objectives

1. To assess knowledge and level of awareness of sickle cell adults (≥18 years) about SCD.
2. To assess misconceptions about SCD in the above group.
3. To study the effects of sociodemographic data on the knowledge and misconceptions about SCD.

MATERIALS AND METHODS

A cross-sectional study using a self-administered questionnaire was implemented. Informed consent was obtained from all participants after they were given an explanation of the objectives of the study.

All questionnaires were anonymous, and the collected data were kept confidential and used only for the purpose of the study.

All necessary approvals from the Ministry of Health were obtained before the conduct of the study. Also, the study was approved by Ethical Committee of Postgraduate Saudi Board Program, Eastern Province.

All sickle cell anemia patients attending medical outpatient clinics in Qatif Central Hospital and the selected primary care centers in Al Qatif area who agreed to participate during the planned period of the study (from first of December 2013 to the end of January 2014) were enrolled in the study.

Patients aged <18 years, those in crisis, hospitalized or patients in the emergency room were excluded.

Primary health care centers were selected by systematic random sampling in which every third center from a list of 28 centers was chosen.

320 questionnaires were collected. All incomplete questionnaires were discarded, resulting in a total of 300 valid questionnaires.

162 completed questionnaires were collected from the hospital and 138 from 8 primary health care centers.

The questionnaire was divided into three sections:

- Section 1: Sociodemographic data and medical history
- Section 2: Questions to determine the history and severity of the disease.
- Section 3: Questions to assess knowledge and misconceptions about 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.

The questionnaire included a question that determined participants' sources of knowledge about sickle cell anemia.

The questionnaire was validated and modified in the light of the pilot study. The questionnaire was reviewed before and after the pilot study by 2 faculties and by 2 hematology consultants.

Reliability was calculated using Cronbach's Alpha and it was 0.875.

Sample size

The sample size was estimated according to the following equation:[16]

$$N = \frac{(Z_{(1-\alpha/2)} + Z_{(1-\beta)})^2 P\,(1-P)}{d^2}$$

N: Sample size

Z: Reliability coefficient (*Z* = 1.96 at 95% confidence interval);

Where *P* = Proportion.

As there were no large previous studies on knowledge and misconceptions about SCD in KSA as far as the investigator could ascertain from the literature search, *P* was considered to be 0.5 (50%), *d* = 0.08, that is, absolute precision of 8% (i.e., a range of prevalence of 42-58%) While type I error (α) was 0.05 and type II error (β) was 0.2 (i.e., a power of 80%).

The sample size was calculated as:

$$N = \frac{([1.96 + 0.84]^2 \times 0.5 \times 0.5) = 1.96}{(0.08)^2 = (0.0064)} = 306$$

Data processing and analysis

The data were coded, entered and analyzed in a personal computer using statistical package for social sciences (SPSS) software version 16 (SPSS Inc., Released 2007. SPSS for Windows, Chicago, USA). Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables and mean and standard deviation (SD) for quantitative variables. Chi-square test was used as appropriate to determine the association.

A score of one was given for each correct answer and zero for wrong or don't know answers. The maximum score was 34 points. The mean of each dimension and the total score were then calculated. Any score above the mean was considered as good knowledge while a score below the mean was considered poor knowledge.

RESULT

Out of 320 questionnaires, 300 were valid, and representing 300 sickle cell anemia patients' responses. The mean age for the study population in years was 31.7 ± 1.12 SD.

Table 1 shows that almost half of the study population (54%) were from the hospital setting while 46% were from the primary health care centers. Most of the patients (51%) were in the age range of 15-<30 years and most were married (62%). Educational level of 53.7% of the patients in this study was up to secondary school or diploma.

The income of 66.7% of the participants was <5000 Saudi Riyals (S.R), (≈1330$) and 49% of them were unemployed.

As shown in Table 2, (48.7%) had SCD while (51.3%) had the trait. The majority of the participants (65%) had no G-6-PD deficiency.

Table 3 shows the distribution of patients with sickle cell anemia according to their level of knowledge about SCD.

Of the study population, (56.3%) generally had poor knowledge. More than half of the participants (58.3%) had good knowledge about genetic transmission, and (53.3%) knew the precipitating factors of sickle cell crisis, yet they had poor knowledge of the diet of G-6-PD deficiency and SCD (81.3% and 59.3% respectively).

Figure 1 illustrates patients' level of knowledge about sickle cell anemia in general and for each section.

Table 4 shows the association between the levels of knowledge of sickle cell anemia patients with their sociodemographic characteristics. Most of the participants who had good knowledge (65.6%) were from the hospital setting, and most of those with poor knowledge (55%) were from the primary care setting ($P < 0.01$).

Those with good knowledge, (41.2%) belonged to the age group of 15-<30 years ($P < 0.05$), 60.3% of whom were female ($P < 0.01$), 71% were married ($P < 0.05$), 45.8% had secondary school education or a diploma ($P < 0.05$), 45.8% were not working ($P < 0.05$), 56.4% had an income of <5000 S.R ($P < 0.001$). The source of information for 63.4% was the hospital ($P < 0.01$) and 56.5% had SCD ($P < 0.05$).

Of those with poor knowledge, 56.2% were male ($P < 0.01$), 58.6% of them belonged to the age group of 15-<30 years ($P < 0.05$), 59.8% had an educational level of up to secondary school or a diploma ($P < 0.05$), 51.5% were not working ($P < 0.05$), 74.6% had an income of <5000 S.R ($P < 0.001$), and 57.4% had the sickle cell trait ($P < 0.05$).

Correlation of level of knowledge with the number of children, source of information as relatives, friends, magazines, brochures, internet and primary health care centers, family history of sickle cell anemia, and G-6-PD deficiency was statistically not significant.

Table 5: Represents the results of the logistic regression analysis of the significant factors predictive of the level of knowledge about SCDs among studied sample. The following factors were found to be independently and significantly associated with a good level of knowledge; Patients attending the hospital, Female gender, higher income, and the hospital as a source of information.

Table 1: Sociodemographic characteristics of the study population

Sociodemographic characteristics	Total (*n* = 300) Number (%)
Study setting	
Hospital	162 (54.0)
Primary health care centers	138 (46.0)
Age in years	
15-<30	153 (51.0)
30-<45	104 (34.7)
45-<60	34 (11.3)
60-75	9 (3.0)
Mean age in years±SD	31.7±1.12
Marital status	
Single	112 (37.3)
Married	186 (62.0)
Divorced	2 (0.7)
Educational level	
Illiterate	4 (1.3)
Read and write	4 (1.3)
Primary school	16 (5.3)
Intermediate school	36 (12.1)
Secondary school or diploma	161 (53.7)
University	79 (26.3)
Occupation	
Unemployed	147 (49.0)
Manual worker	28 (9.3)
Professional	39 (13.0)
Others: student-retired-clerk	86 (28.7)
Personal income in S.R	
<5000 S.R	200 (66.7)
5000-<10,000 S.R	61 (20.3)
10,000-<15,000 S.R	27 (9.0)
≥15,000 S.R	12 (4.0)

S.R = Saudi Riyals, SD = Standard deviation

Table 2: Medical history of blood disorders in the study population

Personal history of blood disorder	Total (*n* = 300) Number (%)
Sickle cell anemia	
Sickle cell disease	146 (48.7)
Sickle cell trait	154 (51.3)
G-6-PD deficiency	
Deficient	105 (35.0)
Nondeficient	195 (65.0)

G-6-PD = Glucose-6-phosphate dehydrogenase

Table 6 shows sources of information about SCD among participants. The most frequent sources were the hospital (52.3%), and the relatives (49.3%).

DISCUSSION

In general, we found in our study that more than half of the respondents (56.3%) had poor knowledge about sickle cell anemia. Most of these participants who had poor knowledge (55%) were from the primary care setting ($P < 0.01$).

Table 3: Distribution of patients with SCD according to their level of knowledge about sickle cell anemia

Knowledge item	Total (*n* = 300)		
	Yes	No	Don't know
	Number (%)	Number (%)	Number (%)
A baby will be born with SCD when			
Healthy person is married to someone with the trait*	58 (19.3)	195 (65.0)	47 (15.7)
Healthy person married to someone with the disease	100 (33.3)	149 (49.7)	51 (17.0)
Person with the trait married another with the trait	228 (76.0)	36 (12.0)	36 (12.0)
Person with disease married to someone with the trait	244 (81.3)	30 (10.0)	26 (8.7)
Healthy person married to another healthy person*	33 (11.0)	234 (78.0)	33 (11.0)
Precipitating factors of sickle cell crisis			
Fever	186 (62.0)	44 (14.7)	70 (23.3)
Cold weather	261 (87.0)	17 (5.7)	22 (7.3)
Hot weather	158 (52.6)	65 (21.7)	77 (25.7)
Infection	127 (42.4)	64 (21.3)	109 (36.3)
Psychological stressors	195 (65.0)	38 (12.7)	67 (22.3)
Traveling at high altitudes	163 (54.4)	31 (10.3)	106 (35.3)
Good hydration*	42 (14.0)	200 (66.7)	58 (19.3)
Light exercises*	42 (14.0)	200 (66.7)	58 (19.3)
Strenuous exercises	213 (71.0)	40 (13.3)	47 (15.7)
Patients with SCD should abstain from the following foods to avoid a crisis			
Fava beans*	171 (57.0)	108 (36.0)	21 (7.0)
Lentils*	145 (48.3)	127 (42.3)	28 (9.4)
Hummus or chickpeas*	153 (51.0)	120 (40.0)	27 (9.0)
Kidney beans (*Phaseolus*)*	144 (48.0)	125 (41.7)	31 (10.3)
Vigna (*Lobia*)*	140 (46.6)	122 (40.7)	38 (12.7)
Nuts*	140 (46.7)	123 (41.0)	37 (12.3)
Peanuts*	163 (54.3)	117 (39.0)	20 (6.7)
Qulabah (fava beans)*	152 (50.6)	119 (39.7)	29 (9.7)
Falafel made with Hummus or chickpeas*	163 (54.4)	118 (39.3)	19 (6.3)
Falafel made with fava beans*	169 (56.4)	106 (35.3)	25 (8.3)
Patients with G-6-PD deficiency should abstain from the following foods to avoid a crisis			
Fava beans	261 (87.0)	10 (3.3)	29 (9.7)
Lentils*	225 (75.0)	39 (13.0)	36 (12.0)
Hummus or chickpeas*	229 (76.4	37 (12.3	34 (11.3
Kidney beans (*Phaseolus*)*	218 (72.7)	39 (13.0)	43 (14.3)
Vigna (*Lobia*)*	223 (74.4)	34 (11.3)	43 (14.3)
Nuts*	215 (71.7)	46 (15.3)	39 (13.0)
Peanuts*	238 (79.4)	25 (8.3)	37 (12.3)
Qulabah (fava beans)	239 (79.7)	18 (6.0)	43 (14.3)
Falafel made with Hummus or chickpeas*	230 (76.7)	31 (10.3)	39 (13.0)
Falafel made with fava beans	253 (84.3)	14 (4.7)	33 (11.0)

*Indicate the wrong statement. SCD = Sickle cell disease, G-6-PD = Glucose-6-phosphate dehydrogenase

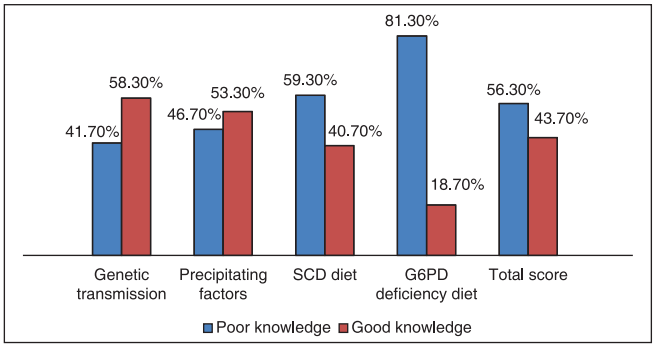

Figure 1: Distribution of patients according to their level of knowledge about sickle cell disease

Therefore, health education programs are needed, especially at the level of primary health care, to increase the level of awareness and to correct widespread misconceptions about sickle cell anemia in this vulnerable group of patients, particularly in view of the high prevalence of sickle cell anemia and G-6-PD deficiency in Qatif area.

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]

Table 4: Association between levels of knowledge among sickle cell disease patients with their sociodemographic characteristics

Variables	Level of knowledge		Test of significance (*P*)
	Poor (*n* = 169) Number (%)	Good (*n* = 131) Number (%)	
Study setting			
Hospital	76 (45.0)	86 (65.6)	χ^2=24.3 (*P*<0.01)=0.002
Primary health care centers	93 (55.0)	45 (34.4)	
Gender			
Male	95 (56.2)	52 (39.7)	χ^2=8.1 (*P*<0.01)=0.005
Female	74 (43.8)	79 (60.3)	
Age in years			
15-<30	99 (58.6)	54 (41.2)	χ^2=9.8 (*P*<0.05)=0.021
30-<45	52 (30.7)	52 (39.7)	
45-<60	14 (8.3)	20 (15.3)	
60-75	4 (2.4)	5 (3.8)	
Marital status			
Single	75 (44.4)	37 (28.2)	χ^2=8.3 (*P*<0.05)=0.016
Married	93 (55.0)	93 (71.0)	
Divorced	1 (0.6)	1 (0.8)	
Educational level			
Illiterate	3 (1.8)	1 (0.8)	χ^2=11.7 (*P*<0.05)=0.039
Read and write	2 (1.2)	2 (1.5)	
Primary school	9 (5.3)	7 (5.3)	
Intermediate school	22 (13.0)	14 (10.7)	
Secondary/diploma	101 (59.8)	60 (45.8)	
University	32 (18.9)	47 (35.9)	
Occupation			
Unemployed	87 (51.5)	60 (45.8)	χ^2=13.2 (*P*<0.05)=0.011
Manual worker	18 (10.6)	10 (7.6)	
Professional	12 (7.1)	27 (20.6)	
Others	52 (30.8)	34 (26.0)	
Personal income in S.R			
<5000 S.R	126 (74.6)	74 (56.4)	χ^2=20.8 (*P*<0.001)=0.000
5000-<10,000 S.R	33 (19.5)	28 (21.4)	
10,000-<15,000 S.R	9 (5.3)	18 (13.7)	
≥15,000 S.R	1 (0.6)	11 (8.4)	
Hospital as a source of information			
Yes	74 (43.8)	83 (63.4)	χ^2=11.4 (*P*<0.01)=0.001
No	95 (56.2)	48 (36.6)	
Classification of sickle cell anemia			
Sickle cell disease	72 (42.6)	74 (56.5)	χ^2=5.7 (*P*<0.05)=0.017
Sickle cell trait	97 (57.4)	57 (43.5)	

S.R = Saudi riyals

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]

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]

The major misconceptions found in our study related to the dietary factors that precipitate sickle cell crisis and G-6-PD hemolytic crisis. On the diet of G-6-PD deficiency patients, 81.3% of the respondent generally exhibited poor knowledge.

Though most of the participants (87%) were aware that beans could precipitate the hemolysis in patients with G-6-PD deficiency, they wrongly thought that other legumes (Lentils [87%], Hummus [87.7%], Kidney beans [87%], Lobia [88.7%], Nuts [84.7%], Peanuts [91.7%] and Falafel made with Hummus [89.7%]) could also precipitate hemolysis.

We are encouraged by our results to focus in the health education program on foods that patients with G-6-PD deficiency may

Table 5: Logistic regression analysis of significant factors predicting the level of knowledge about sickle cell diseases among studied sample

Variables	*B* coefficient	*B*	*P*	OR	95% CI of OR Lower-upper
Study facility	−0.119	0.047	<0.05	0.88	0.809-0.974
Gender	1.231	0.316	<0.001	3.42	1.843-6.362
Income	0.439	0.152	<0.01	1.551	1.152-2.089
Hospital as the source of information	−0.626	0.295	<0.05	0.535	0.300-0.952
Constant	−1.715	1.6116			

Model $\chi^2_{(18)}$ =71.23, *P*<0.001. OR = Odds ratio, CI = Confidence interval

Table 6: Sources of information about sickle cell disease in the study sample

Sources of information*	Total (*n* = 300)
	Number (%)
Relatives	148 (49.3)
Friends	42 (14.0)
Magazines	31 (10.3)
Brochures	68 (22.7)
Internet	79 (26.3)
Primary health care	64 (21.3)
Hospital	157 (52.3)

*Response categories were not mutually exclusive

or may not eat and those which are likely to precipitate the hemolysis.

In this study, 59.3% of the participants had poor knowledge of the diet restrictions of patients with sickle cell anemia.

The misconception that a sickle cell crisis could be precipitated by Fava beans was high among respondents (64%).

This misconception extended to other legumes as well: (Lentils [57.7%], Hummus [60%], Kidney beans [58.3%], Lobia [59.3%], Nuts [59%], Peanuts [61%], Qulabah or minced beans [60.3%] and Falafel made either with Hummus [60.7%] or with Beans [64.7%]).

Hence, there is a need to explain to patients with sickle cell anemia that there is no evidence to support the view that the consumption of Fava beans and other legumes would trigger a crisis.

Our result was consistent with the Al Arrayed and Al Hajeri study, (2011) that showed that almost two-third (58%) of their study participants stated that certain types of food could trigger an attack. However, in fact, food items do not trigger SCD crises unless there is accompanying G-6-PD deficiency. In which case, only the consumption of fava beans would trigger an attack.[13]

Our result showed that the knowledge of respondents with SCD was better than those with sickle cell trait, which seemed logical. This was similar to the result of the study by Acharya *et al.*, in which parents who had a child with SCD had better knowledge than those did not have a child with SCD (78% vs. 58%, *P* = 002).[5]

The source of information in our study population was mainly the hospital (52.3%) and relatives (49.3%).

This suggested comprehensive educational program will focus and concentrate on the families of the patients, and in hospitals where these patients go for follow-up since they seem to be the main source of information as indicated by the study.

In a study by Acharya *et al.*, the most common sources of information for parents with a child with SCD were pediatricians (89%) and SCD clinic staff (89%).[5]

The study by Olakunle *et al.*, showed that the major source of information included health professionals (36.5%), the Internet (11.1%), friends (13.8%) and family (18.2%).[14]

CONCLUSION

Our study revealed significant widespread misconceptions among patients with sickle cell anemia especially those related to diet.

Male participants had more misconceptions, and attendees of primary health care centers had more in comparison with those attending hospital. Participants with SCD were more knowledgeable than those with the sickle cell trait.

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