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PUBLIC AWARENESS AND PRACTICE REGARDING PREMARITAL SCREENING FOR SICKLE CELL DISEASE, IN AL-BAHA REGION: A CROSS-SECTIONAL STUDY

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Abstract

Background

Sickle cell disease (SCD) is a hereditary blood disease that is prevalent in Saudi Arabia, especially in eastern and southwest regions, such as Al-Baha region. Premarital screening may be an effective practical way to decrease SCD prevalence and incidence in the future generations. The current study explores the frequency of premarital screening in Al-Baha region and investigated causes and barriers of not performing premarital screening.

Methods

This is a cross-sectional study conducted over a period of three months, from December 17, 2023, to March 17, 2024, among the general population of Saudi Arabia's Al-Baha region. An online questionnaire was used for data collection. Data included sociodemographic data, medical and family history of SCD, awareness, perception, and prevalence of undergoing premarital screening for SCD, and barriers for undergoing premarital screening for SCD.

Results

The study included 478 participants with age ranged between 18 and 60 years. Around 63.4% of the participants were females. Around 334 (69.9%) were married or engaged, and of whom 221 (66.2%) had consanguinity. The study showed that among the participants who were married or engaged, only 167 (50%) underwent premarital screening. The sickle cell trait was reported in 75 (15.7%), while SCD was reported by 54 (11.3%). Only 301 (63.0%) heard of premarital screening and 286 (59.8%) heard of SCD.

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Conclusion
Premarital screening in Al-Baha region is unsatisfactory compared to other parts of the country. This can be attributed to the low level of awareness and knowledge regarding premarital screening program and SCD among the general population of Al-Baha.
Keywords : Sickle cell disease; premarital screening; cross-sectional; Saudi; prevalence.

Introduction

Sickle cell disease (SCD) is a hereditary blood disease that is very prevalent in some parts of the world [1]. SCD is characterized by the production of abnormal hemoglobin (HbS) as a result of a gene mutation, which causes red blood cells to become sticky and deform into sickle shapes, resulting in abnormal flow through blood vessels and a variety of vaso-occlusion complications such as tissue ischemia, stroke, and acute severe pain, along with other complications such as anemia and infections [2]. In 2021, it was estimated that around 7.74 million people were living with SCD worldwide [3]. SCD mortality ranks as the 12th leading cause of mortality in children younger than 5 years old [3].
Early diagnosis of hereditary blood diseases, such as SCD, could prevent psychological, social, and economic consequences. Prenatal and premarital screening for hereditary disorders are thus viewed as cost-effective strategies that should be implemented [4]. However, prenatal screening and early termination of pregnancy are still not well-accepted in Saudi Arabia [5]. Premarital screening may thus be the most effective practical way to prevent SCD in Saudi Arabia.
Premarital screening for SCD is an important and necessary step toward ensuring the health and well-being of individuals and future generations. Premarital screening plays an important role in identifying people who carry inherited blood diseases in order to determine the risk of having children with severe forms of the disorder [6]. This screening entails testing individuals for the presence of the sickle cell trait prior to marriage or pregnancy, allowing couples who have been identified as carriers of the sickle cell gene to make informed reproductive decisions, including genetic counseling and prenatal testing [7,8]. Therefore, in 2003, the Saudi government made the decision to lower the incidence of SCD by implementing a mandatory premarital screening program [9].
The prevalence of SCD varies greatly across Saudi Arabia, with the eastern and southwest regions having the highest rates [9,10]. Therefore, it is vital to investigate the practices and attitudes regarding premarital screening in these regions. Al-Baha is a province in southwestern Saudi Arabia [11].
In this work, a cross-sectional study was conducted to determine the prevalence of SCD premarital screening in the Al-Baha region. Furthermore, it seeks to determine awareness and perceptions of premarital screening for SCD, as well as the hurdles to undergoing such screening in the Al-Baha region. The current study's findings will inform policymakers about whether the practice of premarital screening for sickle cell disease in the Al Baha region is adequate or if additional actions and strategies are required.

Methods

Study design

A descriptive cross-sectional study was conducted.

Study setting

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The study was conducted over three months, from December 17, 2023, to March 17, 2024, among the general population of Saudi Arabia's Al-Baha region. Al-Baha province is located in the southwestern part of Saudi Arabia between the Holy Makkah and Asir regions and has a population of 476,172 people [11].

Inclusion and exclusion criteria

Saudi men and women between the ages of 18 and 60 who were willing to participate in the study and who resided in the Al-Baha region during that time were included in the study. People who were younger than 18 years or older than 60 years, didn't reside in the Al-Baha region, or declined to take part in the study were all excluded.

Sample size and sampling technique

A total sample of 385 participants is required to estimate the average screening-based frequency of sickle cell disease in the Saudi population of 10% at 3% precision and a 95% confidence level with a design effect of 2 [9]. The sample size was calculated using the following known WHO formula [12]:

$$N=\frac{Z^2 \times P(1-P)}{E^2}$$

where N = sample size,

Z = Z statistic for a level of confidence (1.96 for a 95% confidence level),

P = expected prevalence or proportion, and

E = precision or margin of error.

Data collection

Data was collected consecutively from eligible participants until the required sample size was reached. A structured questionnaire was used and was administrated online. The questionnaire was created by the researchers following an extensive literature review, expert consultation, and relevant studies done in Saudi Arabia and the GULF countries [9,13,14]. The questionnaire included 36 questions and was divided into four sections:

1-Participant's socio-demographic data such as age, gender, residence, educational level, marital status, and monthly income.

2- Medical and family history of SCD

3- Knowledge and awareness about SCD

3- Awareness, perception, and prevalence of undergoing premarital screening for SCD

4- Barriers for undergoing premarital screening for SCD

Statistical methods

The data was retrieved from respondents and the analysis was performed on completed questionnaires through SPSS version 25. Descriptive statistical methods were used to summarize data on socio-demographic characteristics, awareness, and knowledge about sickle cell disease. Data were presented as frequencies (n) and percentages (%) for categorical variables and a mean with a standard deviation (SD) for continuous variables. The graphs were constructed using Microsoft Excel software.

Results

The study included 478 Saudi residents from the Al-Baha region. The sociodemographic data is summarized in **Table 1**. The study participants consisted of 303 (63.4%) females and 175 (36.6%) males. Around 188 (39.3%) of the respondents were in the age group of 26–35 years, while only 25 (5.2%) were in the age group of 46–60 years. Among the respondents, 121 (25.3%) were students, 104

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(21.8%) were unemployed, and 81 (16.9%) were government employees. There were 119 (24.9%) diploma or university graduates, 99 (20.7%) from intermediate school, and the same number from high school, while 49 (10.3%) had no official education. Of the study participants, 174 (36.4%) were married, whereas 144 (30.1%) were single. In the study sample, 221 (66.2%) of the 334 people in relationships were consanguineous.**Table 1.** Sociodemographic characteristics of the respondents (n= 478)

Variables		N (%)
Gender	Female	303 (63.4)
	Male	175 (36.6)
Age groups	18-25	171 (35.8)
	26-35	188 (39.3)
	36-45	94 (19.7)
	46-60	25 (5.2)
Marital status	Divorced	34 (7.1)
	Engaged	94 (19.7)
	Married	174 (36.4)
	Single	144 (30.1)
	Widowed	32 (6.7)
Relationship between couples*	Related	221(66.2)
	No relationship	113 (33.8)
Educational level	Diploma/university	119 (24.9)
	Elementary	72 (15.1)
	Intermediate	99 (20.7)
	No official education	49 (10.3)
	Postgraduate	40 (8.4)
	Secondary	99 (20.7)
Employment status	Governmental employees	81 (16.9)
	Housewife	70 (14.6)
	Military	49 (10.3)
	Private-sector employees	35 (7.3)
	Retired	18 (3.8)
	Student	121 (25.3)
	Unemployed	104 (21.8)
Do you have sickle cell disease	Carrier	75 (15.7)
	Diseased	54 (11.3)
	Don't know	182 (38.1)
	Healthy	167 (34.9)
Do you have family history of sickle cell disease	Don't know	173 (36.2)
	No	213 (44.6)
	Yes	92 (19. 2)

*Total sample size was 334, which composed of those with relationship in the study sample

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Medical and family history of SCD

Most of the study sample, 182 (38.1%), didn't know whether they had SCD or not. On the other hand, a significant percentage, 167 (34.9%), reported that they are healthy and don't have SCD, whether in a carrier state or diseased. Seventy-five (15.7%) were carriers, while 54 (11.3%) were diseased (**Figure 1**). Ninety-two (19.2%) had a family history of SCD, while 213 (44.6%) hadn't (**Table 1**).

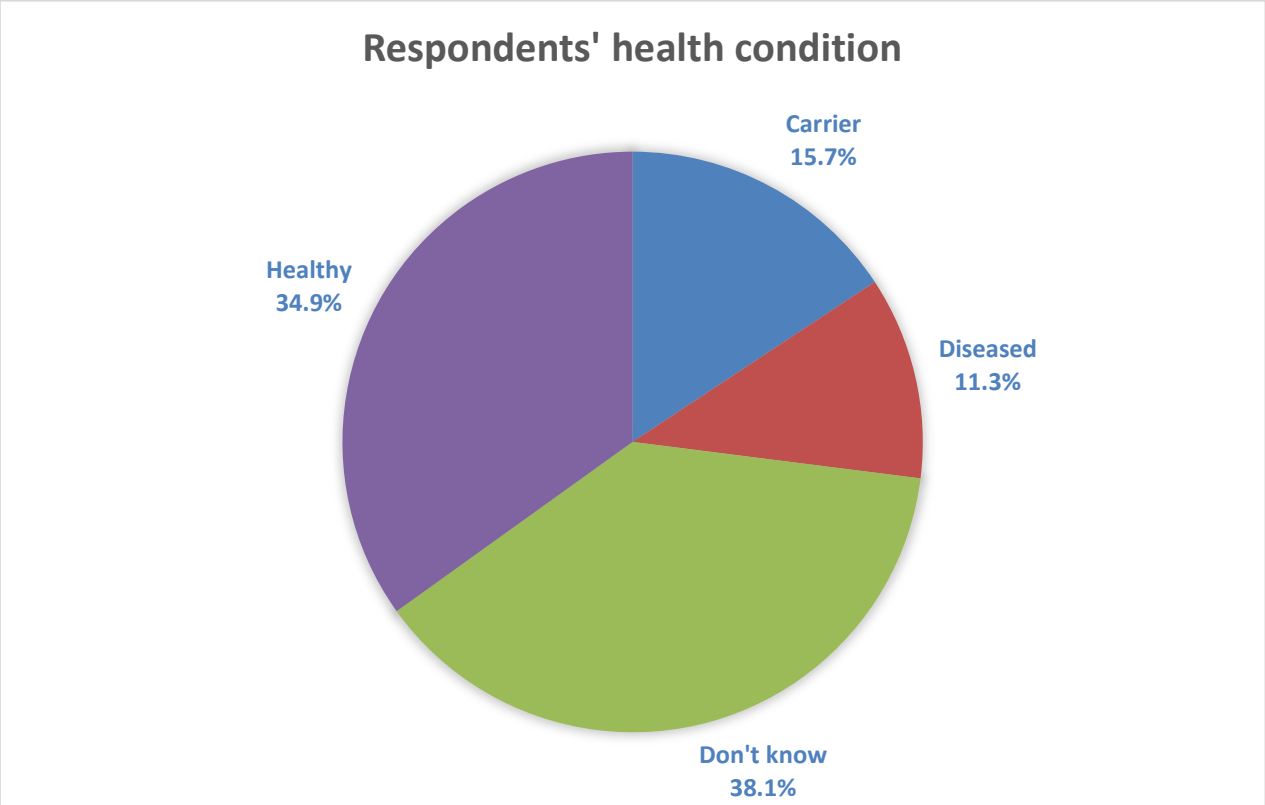

Figure 1. Respondents' health condition.**Knowledge and awareness about SCD**

Findings from this study revealed that the majority of the participants, 286 (59.8%), heard of SCD, while 192 (40.2%) indicated that they had never heard of the disease and most of the study participants, 235 (49.2%), didn't know if this disease was prevalent in the Al-Baha Region. Only 64 (13.4%) indicated correctly that sickle cell disease is a hereditary disease. The majority of the study participants were unaware of the complications of SCD, with the exception that SCD can result in hospitalization owing to severe anemia requiring blood transfusions, as stated by 224 (46.9%). Around 50.6% were aware of the implications of marrying a carrier of SCD for the born child. Other relevant details on knowledge about sickle cell disease are presented **Table 2**.

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Variables		N (%)
Have you ever heard of sickle cell anemia?	No	192 (40.2)
	Yes	286 (59.8)
Is sickle cell disease prevalent in Al-Baha Region?	Don't know	235 (49.2)
	No	107 (22.4)
	Yes	136 (28.5)
From where you get sickle cell disease?	Airborne	11 (2.3)
	Blood transfusion	58 (12.1)
	Don't know	182 (38.1)
	Food	38 (7.9)
	Hereditary	64 (13.4)
	NR	89 (18.6)
	Others	36 (7.5)
If you and your partner are carrier, would you go ahead with your marriage?	Don't know	176 (36.8)
	No	167 (34.9)
	Yes	135 (28.2)
If you are Carrier and your partner is carrier?	Don't know	169 (35.4)
	You might have diseased child	132 (27.6)
	You must have diseased child	110 (23.0)
	You will have healthy child	23 (4.8)
	You will have only carrier child	44 (9.2)
Are the patients with sickle disease frequently prone to hospitalization for?		
1- Pain which leads to admission	Don't know	193 (40.

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		4)
	No	89 (18.6)
	Yes	196 (41.0)
2- Infection which required IV antibiotics	Don't know	195 (40.8)
	No	93 (19.5)
	Yes	190 (39.7)
3- Chest infection and pain which might be lethal	Don't know	233 (48.7)
	No	82 (17.2)
	Yes	163 (34.1)
4- Severe anemia which needs blood transfusion	Don't know	164 (34.3)
	No	90 (18.8)
	Yes	224 (46.9)
5- Stroke	Don't know	235 (49.2)
	No	107 (22.4)
	Yes	136 (28.5)
What is your source of information regarding sickle cell disease?	Affected individuals	51 (10.7)
	At school/university	93 (19.5)
	Doctors/healthcare workers	60 (12.6)
	Internet websites	105 (22.0)
	NR	1 (0.2)
	Social media	85 (17.8)

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	TV	83 (17.4)
What is the best way to prevent sickle cell disease?	Health education	130 (27.2)
	Premarital test	169 (35.4)
	Specific diet	88 (18.4)
	Vaccination	91 (19.0)
What do you think the best way to increase awareness of the disease?	At school	121 (25.3)
	Social media	239 (50.0)
	TV	118 (24.7)

Around 77 (16.1%) had an affected child and the majority of them, 31 (41.9%), advised risky couples about to get married to go ahead, while only 23 (31.1%) of them were not with this idea. Furthermore, half of these parents reported that they believe that there is an association between consanguinity and developing SCD (**Table 3**).**Table 3.** Parents with affected child attitude towards SCD (n = 478)

Variables		N (%)
Are you parents with affected child?	No	230 (48.1)
	NR	171 (35.8)
	Yes	77 (16.1)
Yes answers (n= 77)		
For risky couples about to get married what is your advice?	Don't get married	23 (31.1)
	Go ahead	31 (41.9)
	No advice up to them	20 (27.0)
Is there an association between consanguinity and the risk of the sickle cell disease?	Don't know	13 (16.9)
	No	14 (18.2)
	Yes	50 (64.9)

Sources of information about sickle cell disease

The major sources of information about sickle cell disease were internet website 105 (22%), At school/university 93 (19.5%), social media 85 (17.8%), followed by TV 83 (17.4%). **Figure 2** below gives an overview of sources of information about sickle cell disease. Many responses indicated that social media is the best way to increase awareness of the disease SCD 239 (50%), followed by school

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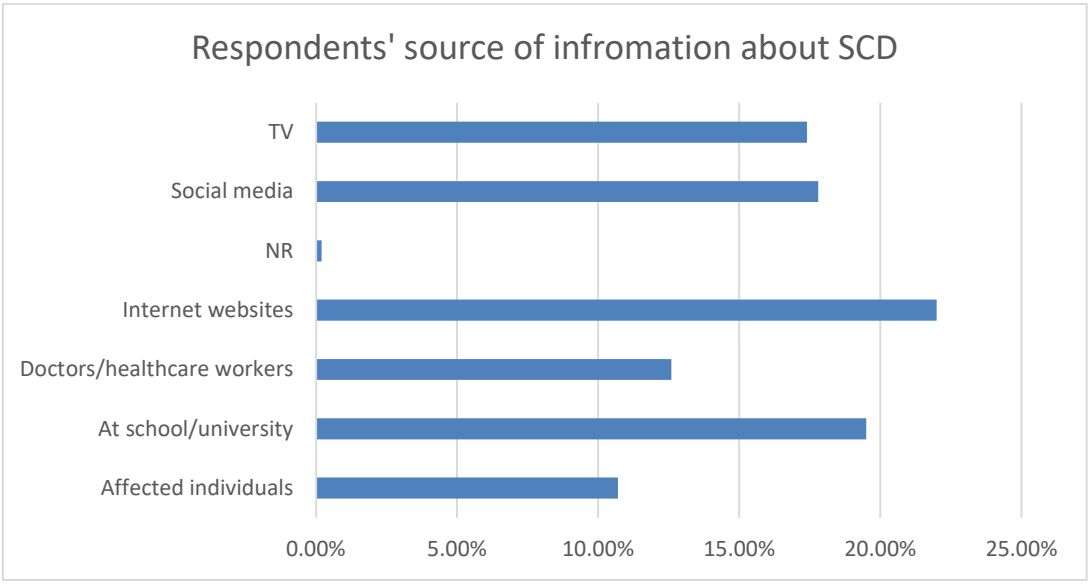

121 (25.3%).

Figure 2. Respondents'' source of information about SCD

Awareness, perception, and prevalence of undergoing premarital screening for SCD in Al-Baha region and the characteristics of the program

Around 301 (63.0%) heard about premarital screening. Furthermore, 214 (44.8%) knew that premarital screening involves more than screening for SCD, and only 117 (24.5%) thought it was only for SCD, while 147 (30.8%) didn't know. Nevertheless, most of them agreed that screening is important in preventing SCD 252 (52.7%) (**Table 4**).

Of the 334 people who were engaged or married in the study sample, the half, 167 (50%), performed the premarital screening in Al-Baha region. The results were incompatible for ninety-nine (20.7%) and of whom, 42 (42.4%) refused the counseling advice and proceed with marriage (**Table 4**).

Among those performed the premarital screening, 43 (25.7%) reported it only took less than five minutes, and it took between 5-10 minutes in 28 (16.7%) and more than 15 minutes in 28 (16.7%) (**Table 4**). Important information about the risk of transmitting diseases and complications of disease was quietly given to 61 (36.5%) and 53 (31.7%) of the respondents, respectively, and 44 (26.3%) reported that the physician was able to answer their queries about sickle cell disease. The most common educational material provided during premarital counseling session was posters, which were provided for 56 (33.5%) (**Table 4)**.**Table 4.** Perception, awareness, prevalence of undergoing premarital screening for SCD, and the characteristics of the program in Al-Baha region (n= 478)

Variables		N (%)
Have you ever heard of premarital screening?	No	177 (37.0)
	Yes	301 (63.0)
Do you think premarital screening is only for SCD?	Don't know	147 (30.8)
	No	214 (44.8)

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	Yes	117 (24.5)
Do you think premarital screening helps in the prevention of SCD?	Don't know	135 (28.2)
	No	91 (19.0)
	Yes	252 (52.7)
Did you perform premarital screening in Al-Baha region? (n = 334) *	No	167 (50)
	Yes	167 (50)
Yes answers (n= 167)		
What is the average duration of counseling session in minutes?	Between 10 and 15 minutes	28 (16.7)
	Between 5 and 10 minutes	27 (16.1)
	Less than 5 minutes	43 (25.7)
	More than 15 minutes	28 (16.7)
	Not reported	69 (41.3)
Was the risk of transmitting diseases explained?	Don't remember	31 (18.6)
	No	31 (18.6)
	NR	44 (26.3)
	Yes	61 (36.5)
Were complications of disease explained?	Don't remember	31 (18.6)
	No	33 (19.8)
	NR	52 (29.9)
	Yes	53 (31.7)
Was the physician able to answer your queries about sickle cell disease?	Don't remember	33 (19.8)

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	No	35 (31.1)
	NR	53 (31.7)
	Yes	44 (26.3)
Educational material was provided during counseling session?	Booklets	20 (12)
	No supplementary materials were provided	29 (17.3)
	NR	33 (19.7)
	Pamphlets	11 (6.6)
	Posters	56 (33.5)
	Video	18 (10.8)

*Total sample size was 334, which composed of those with relationship in the study sample

Barriers for undergoing premarital screening for SCD in Al- Baha region

As shown in **Table 4**, ninety-nine (20.7%) were risky parents and most of them, 42 (42.4%), refused the counseling advice and proceed with marriage. The most common reason for the refusal of the counseling advice, 7 (7.1%), was that their marriage was unavoidable destiny. The second most common reason was because financial marriage arrangements were completed before premarital test, as reported by 6 (6.1%). Other reasons included those who felt the counseling was not convincing 5 (5.1%), that sickle cell disease does not affect children's lives 5 (5.1%), and that they did not realize the seriousness of the disease 5 (5.1%). Other barriers are shown in **Table 4** and **Figure 3Table 5.** Barriers for undergoing premarital screening for sickle cell disease in Al- Baha region (n = 478)

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Variables		N (%)
Are you risky parents?	No	266 (55.6)
	NR	113 (23.6)
	Yes	99 (20.7)
Yes answers (n= 99)		
Why did you refused the counseling advice and proceed with marriage?		
Refused because our marriage was unavoidable destiny		7 (7.1)
Refused because the chance of transmission of sickle cell disease was small		4 (4.0)
Refused because financial marriage arrangements were completed before premarital test		6 (6.1)
Refused because the counseling was not convincing		5 (5.1)
Refused because sickle cell disease does not affect children s lives		5 (5.1)
Refused counseling advice since I was in love with my fiancé		4 (4.0)
Refused counseling advice due to pressure of my family		2 (2.0)
Refused counseling advice to avoid being lonely		4 (4.0)
Refused counseling advice due to not realizing the seriousness of the sickle cell disease		5 (5.1)

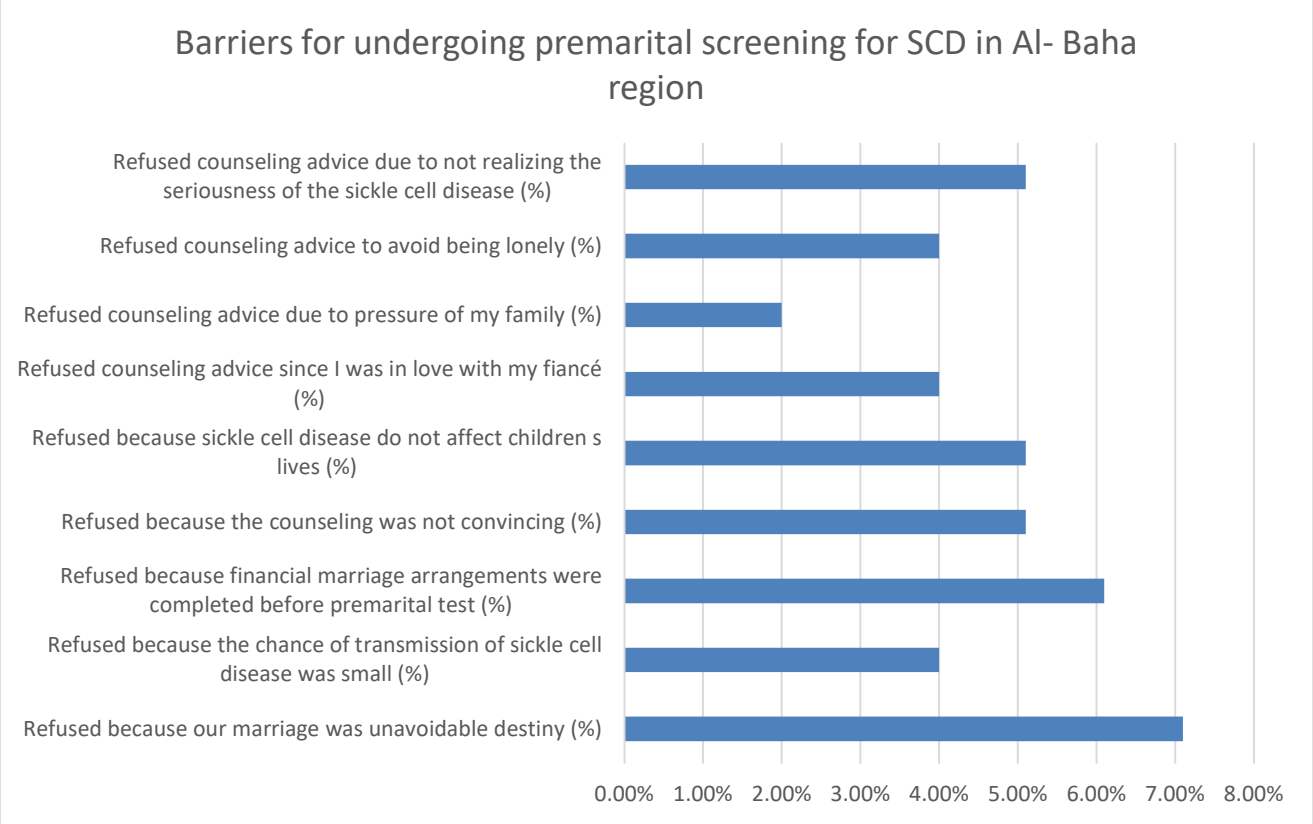

Figure 3. Barrier for undergoing premarital screening

Discussion

The study revealed that premarital screening in the Al-Baha region is lower compared to what was

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observed in other parts of Saudi Arabia. In the current study, half (50%) of people in the Al-Baha region still don't perform premarital screening. However, a very recent cross-sectional study reported that the prevalence of premarital screening in a representative national sample drawn from across the country was 73.0% [15]. This can be attributed to the fact that awareness and knowledge in the Al-Baha region regarding premarital screening and SCD are lower than in other parts of the country. In the previous study [15], all of the study participants (100%) heard about the premarital screening program. However, in the current study, only 63.0% heard about the program. Furthermore, a recent cross-sectional study conducted in Tabuk revealed that around 87.6% heard of SCD and that 77.6% knew that it is an inherited disease [16]. However, in the current study, around 40.2% didn't hear about SCD and only 13.4% knew that SCD is a hereditary disease. Future actions and policies need to address the low awareness and knowledge in the Al-Baha region about premarital screening and SCD, which is the first step to increasing premarital screening and decreasing the incidence of inherited diseases such as SCD. Performing premarital screening alone is not sufficient. Compliance with counseling advice is a critical aspect of determining the efficacy of premarital screening. Among those performed the premarital screening in the current study, around 20% were found to be carrier. However, 42.4% of them proceeded with the marriage against the counselling advice. Previous studies in Saudi Arabia reported that 90% of the participants in Riyadh area accept and support the premarital screening program [17]. However, the findings in the current study revealed that several barriers affected this acceptance in Al-Baha region and that future actions and polices must address these barriers.

The Middle East, sub-Saharan and North-East Africa, and India are thought to have the highest rates of SCD [18]. However, the prevalence of SCD between Arab countries showed great variability and ranged from 0.3% to 30% [1]. The prevalence of sickle cell trait, the carrier state, in the study sample was 15%, which is similar to what was reported in the literature for in the southwestern region of Saudi Arabia, which was around 12% [10].

However, the prevalence of those with SCD was 11%, which was higher than that reported in the literature for Saudi Arabia [9,10]. SCD is a hereditary disease and is associated with consanguinity [19]. According to studies, the prevalence of SCD varies significantly across Saudi Arabia, with the eastern region having the highest prevalence, followed by the southwestern region [9,10]. The Eastern region was found also to have the highest consanguinity [10], indicating a strong relationship between consanguinity and SCD. Furthermore, a recent cross-sectional study conducted in the Al-Baha region found that those with consanguinity had a significantly higher incidence of blood diseases in their children [20]. The prevalence of consanguinity in Saudi Arabia is highly variable and it ranges between 42% and 67% [5,20]. In this study sample, the percentage of those with consanguinity was at the highest level (66.2%). Furthermore, among those with SCD, around 92.6% had consanguinity. According to reports from Saudi Arabia, having a consanguineous marriage in offspring is strongly correlated with the presence of consanguinity among parents [21]. This could explain the high incidence of SCD in the sample of the current study and in Al-Baha region. Another factor is the fact revealed by this study that prevalence of premarital screening is low. Future polices should also take into consideration the importance of addressing the high consanguinity in the region.

Limitations

Although we tried to find causes and barriers of low prevalence of premarital screening, causal

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relationship can't be established as this is a cross-sectional study. Furthermore, sample size in those reporting barriers is small and further larger studies are needed to explore the causes and barriers behind the low prevalence of premarital screening in Al-Baha region.

Conclusion

The low frequency of premarital screening in the Al-Baha region may account for the current study's high prevalence of SCD. The Al-Baha region has a lower level of knowledge and awareness regarding premarital screening and SCD than other parts of Saudi Arabia, which contributes to the low prevalence of premarital screening. Future policies should focus on increasing knowledge and awareness in the Al-Baha region, particularly where SCD prevalence is high.

Conflict of interest

None.

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Ethical consideration

Ethical approval was obtained from the Al-Baha Institutional Review Board. The consent from participants was obtained by first question in the online questionnaire.

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