

Original Article

Knowledge, Attitude about Thalassemia and Sickle Cell Disease premarital screening among Saudi adults in Eastern Region, Saudi Arabia

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Received: 13 November 2021, Revised: 23 November 2021, Accepted: 24 November 2021, Published: 8 December 20

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Abstract

Background: Hereditary diseases are caused by an abnormality in an individual's DNA, which include thalassemia and sickle cell anemia (SCD). Premarital screening is defined as testing couples who are planning to get married for common hereditary blood disorders and some infectious diseases to prevent any risk of transmitting these diseases to their spouse and children. To assess knowledge and attitude about inherited diseases (Thalassemia and SCD) in premarital screening.

Methods: This is a cross-sectional study that was conducted in the Eastern Region of Saudi Arabia at different popular malls during the month of August 2019. A convenient sample of 675 was selected randomly recruited. The questionnaire included demographic data, diseases tested in premarital screening (PMS) knowledge and attitude towards PMS.

Results: The vast majority of participants, 645 (95.6%) thought that carrying out premarital screening is important, 651 (96.4%) agreed to carry premarital screening, 551(81.6%) participants had knowledge about the compulsory law to do PMS. Almost half of the participants agreed to take PMS for their partner's safety, furthermore, (22.2%) agreed to do PMS to prevent transmission of hereditary diseases. Approximately half of the participants would discontinue the engagement if there is a possibility of having affected children, while 21% would base their decision on the probability of getting affected children and 14.2 % would go ahead and get married. Regarding gender attitude towards possibility of having affected children; majority of females (55.7%) and males (44.3%) would not continue marriage.

Conclusion: There is very good knowledge about PMS, it is important to carry PMS, there is a need to increase awareness about SCD and Thalassemia to raise the number who will cancel marriage if any of these diseases are positive during PMS with the possibility of transmission to offspring.

Keywords: Premarital screening, sickle cell disease, ministry of health.

Introduction

Hereditary diseases are caused by an abnormality in an individual's DNA, abnormalities can be as small as single-base mutation in just one chromosome or involve the addition or subtraction of an entire chromosome. This kind of disorders include thalassemia and sickle cell anemia (SCA). Thalassemia is an inherited blood disorder characterized by low hemoglobin count and fewer red blood cells in the body, while in SCA there aren't enough healthy red blood cells to provide adequate oxygenation throughout the body. In Saudi Arabia, it has been estimated in 2017 that the total number of thalassemia and sickle cell anemia patients was 1,572,140, representing 0.06% of the entire population of Saudi Arabia, with the Eastern Region being the highest in the number of cases of SCD and Thalassemia. According to Ministry of Health (MOH) of Saudi Arabia, premarital screening is defined as a number of tests targeting those that are planning to get married for common genetic blood disorders and infectious diseases such as SCA and thalassemia, hepatitis B and hepatitis C. The premarital screening (PMS) aims to give medical consultation on the possibility of transmitting such diseases to the other partner or children and to provide the couple with an informed decision for a healthy family (1, 2).

A research done in Saudi Arabia between 2004 and 2009 studied the regional differences in sickle cell disease and β -thalassemia using national data. The carrier and case status of sickle cell disease and β -thalassemia were determined in couples approaching marriage between 2004 and 2009 using standard blood tests. Based on the national data from the PMS program, the prevalence of SCD was the highest in the Eastern region (134.1 per 1000), followed by Southern and Western regions (55.6 and 28.5 per 1000, respectively) and lowest in Central and Northern regions (13.7 and 13.5 per 1000, respectively). The prevalence of β -thalassemia was highest in the Eastern region (59.0) followed by the Southern, Western and Central regions (14.2, 10.2, and 10.1 per 1000, respectively) and was lowest in the Northern region (3.9 per 1000). There are vast differences in hemoglobinopathies among adult Saudi nationals approaching marriage, this may help policy makers better allocate resources for preventive and management programs (3). Therefore, we aim to study the knowledge, attitude and practice of the public in the Eastern region regarding SCA and β -thalassemia.

Methodology

This is a cross-sectional survey study which was conducted in the Eastern Region of Saudi Arabia at different popular

malls in Dammam and Khobar. The data was collected from July 2019 until September 2019. The data collection was through a simple randomization process with a total of 675 participants included in the study. The sample was taken from the general community attending these shopping malls. A total of six malls were chosen randomly in each geographical area. Two malls from Al-Khobar area, two malls from Dhahran area and two malls from Dammam area. Participants were selected using random sampling technique by taking every third person entering the mall. We included Saudi adults ≥ 18 years and those living in the eastern region only and excluded individuals younger than 18 years, those in healthcare sector and incomplete data.

A structured questionnaire was used to collect the data in Arabic and English. The survey consisted of questions regarding demographic data, knowledge about premarital screening, law regarding PMS, diseases screened in PMS, attitude towards PMS and decisions about it and knowledge about inheritance of Sickle Cell Disease and Thalassemia. The questions were checked in the study setting for completeness and consistency by experts in community medicine and it was statistically validated. Data management included cleaning, coding, entry, analysis and presentation in tables and graphs and a correlation testing using chi square were done by Statistical Package for Social Sciences (SPSS) version 25. The ethical approval was obtained from the Research and Ethics Committee at the College of Medicine and Medical Sciences at the Arabian Gulf University (AGU). Official permissions to conduct the study were obtained from all the selected malls. An informed oral consent was taken from the participants prior to filling the questionnaire by the researchers, explaining to them the purpose of the research. Participants were assured of the confidentiality of the information they provided.

Results:

A total of 675 participants were included in the study. Out of those, the majority were females 393 (58.2%) and 274 (40.6%) of the participants were between 18-27 years old. About half of the participants (54.1%) were married while 40.7% were single and 50.8% of the population had children. Educational level of the participants varied but most of them (76.3%) had university degree and 19.9% had only high school degree. In regard to job distribution, 47.3% were employed, 24.1% were students, 20% were unemployed and 8.6% were retired (**Table1**).

Table 1: Demographic data of the included participants

		N	%
Age group	18-27	274	40.6
	28-37	163	24.1
	38-47	110	16.3
	> 48	128	19
	Total	675	100
Gender	Male	282	41.8
	Female	393	58.2
	Total	675	100
Marital status	single	275	40.7
	Marriage	365	54.1
	Divorce	24	3.6
	Widowed	11	1.6
	Total	675	100
Children	Yes	332	49.2
	No	343	50.8
	Total	675	100
Education	Intermediate and below	26	3.9
	High school	134	19.9
	University	515	76.3
	Total	675	100
Occupation	Student	163	24.1
	Employee	319	47.3
	Retired	58	8.6
	unemployed	135	20
	Total	675	100

N: numbers

Table 2: Participants' Awareness about compulsory Premarital Screening

	N	%
Yes	551	81.6
No	124	18.4
Total	675	100.0

N: numbers

The vast majority of participants, 645 (95.6%) thought that carrying out premarital screening is important. Similarly, 651 (96.4 %) agreed to carry out the premarital screening compared to only nine participants (1.3%) did not agree to carry out the premarital screening. Lastly, 81.6% knew about the law of compulsory PMS in Saudi Arabia (**Table 2**).

Analysis regarding the reasons to carry PMS showed that almost half (54.5%) of the participants agreed to take PMS to prevent transmission of disease to their offspring, 22.2% agree to prevent transmission of infectious diseases to themselves, 14.4% agree to ensure healthy state of the partner and 5.3% agree to ensure a healthy fitness for marriage (**Figure 1**). When asked about the knowledge of the diseases for which tests are done in the premarital screening, 77.2% and 65.2% of the participants knew about the inclusion of SCA and β -thalassemia in PMS, respectively. In addition, 59.4% and 66.8% knew that hepatitis and autoimmune deficiency disease (AIDS) are included in the PMS (**Table 3**).

Results regarding relationship between the agreement of the participants to carry out PMS and the educational level showed that the educational level had a significant impact

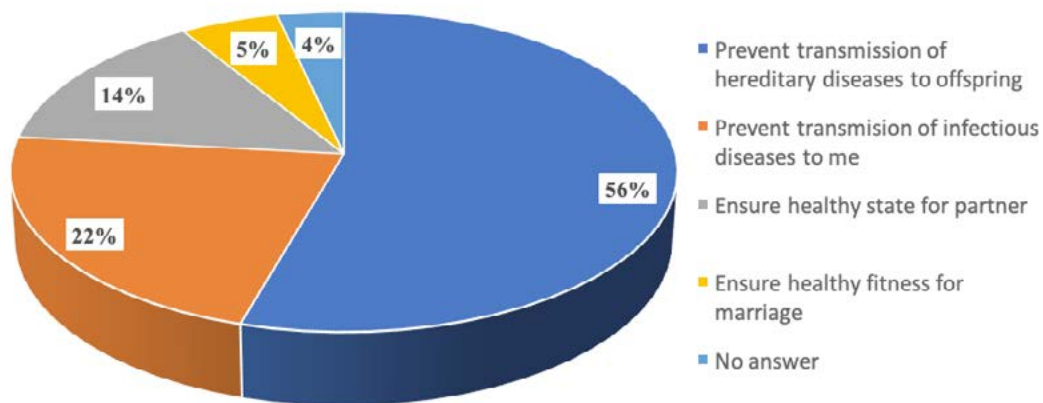


Figure 1: Reasons for agreement to carry out premarital screening

on the agreement to carry out PMS as the majority of the participants agreed to do PMS were highest among university graduates (98.1%) and lowest among intermediate school graduates (80.8%) (p-value 0.00) (Table 4).

In relation to the attitude towards the possibility of having affected children, approximately half of the participants would not continue the marriage, while 21% would base their decision on the probability of getting affected children with the diseases, 14.2% would get married anyway and (13.8%) did not know what to do. Females were more likely to cancel the marriage (55.7%) compared to males (44.3%) if there was a possibility of having affected children. Furthermore, 20.6% of male participants and 9.7% of female participants would continue the marriage if PMS were positive for SCD or thalassemia (Figure 2).

Table 3: Knowledge about diseases included in the premarital screening (n=675)

		N	%
SCD	Yes	521	77.2
	No	154	22.8
Thalassemia	Yes	440	65.2
	No	235	34.8
Hepatitis	Yes	401	59.4
	No	274	40.6
AIDS	Yes	451	66.8
	No	224	33.2

N: numbers

Table 4: Association between education level and agreement to carry out premarital screening

	Intermediate and below		High school		University		P-value
	n	%	n	%	n	%	
Agree	21	80.8	125	93.3	505	98.1	0.000*
Neutral	1	3.8	9	6.7	5	1	
Disagree	4	15.4	0	0	5	1	
Total	26	100	134	100	515	100	

* Chi-square test of statistical significance

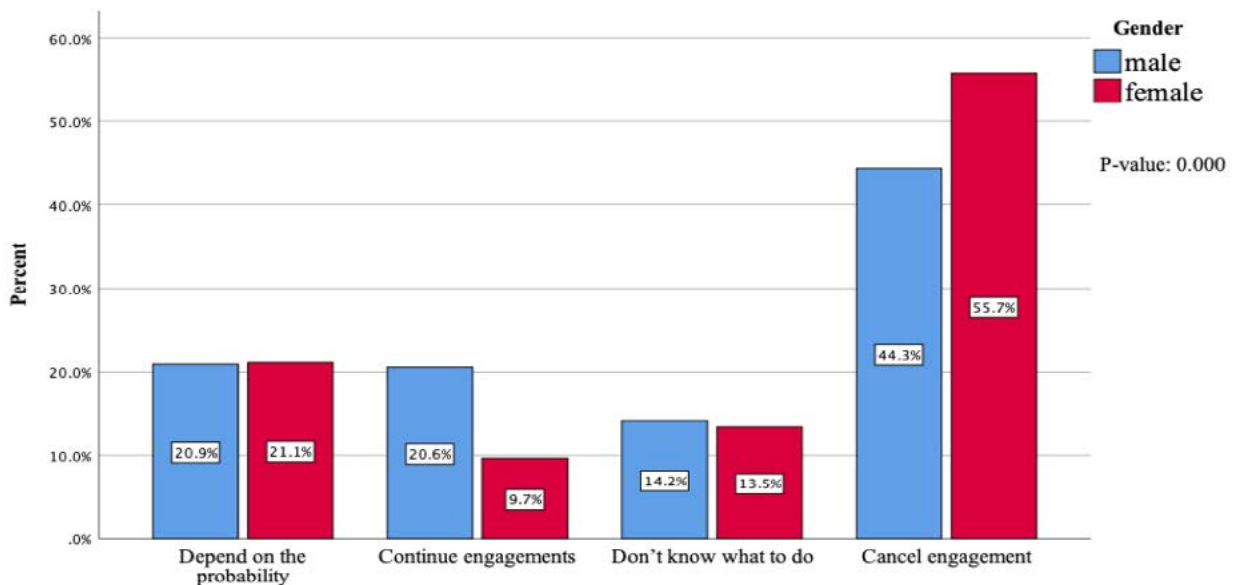


Figure 2: Reasons for agreement to carry out premarital screening

Discussion:

This study was conducted to assess knowledge and attitude about pre-marital counselling that is aimed to reduce hereditary diseases in the community. The majority of participants, 645 (95.6%) thought that carrying out premarital screening (PMS) was important and that among 551 participants, (81.6%) knew that PMS is compulsory by law. In comparison, our results was slightly higher in comparison with a study done in Jeddah in 2013 where they found that 93.7% of the participants had heard about PMS. Having high knowledge of those who knew about PMS could be due to the fact that PMS is compulsory by law in Saudi Arabia and it has been there for many years (4).

Regarding reasons that encourages couples to carry PMS prior to marriage, almost half of the participants (54.5%) responded that it is necessary to prevent transmission of diseases to their offspring's and 22.2% responded that it is aimed to prevent transmission of hereditary diseases. Screening timing, socio-religious issues, access to prenatal detection, awareness and counselling affected decisions in similar study. Meanwhile, a study in China among newly married respondents found that factors such as individual perceived benefits, barriers and attitudes were determinants of premarital medical examination decision (5). Another study among public high schools in Oman concluded that the majority of students (87.4%) believed that PMS is important, and most students (87.2%) indicated that they would undergo this service. These results confirm that perceived risk and benefits are important factors for people to conduct PMS (6, 7).

In a study conducted in Al Madinah in Saudi Arabia, participants were asked about the possibility to diagnose sickle cell disease (SCD) and thalassemia by PMS. Among 2,554 participants, around two-thirds (61.3%) of the included population responded with "true" and one-third responded with "I don't know". This is similar to our current study as 440 (65.2%) knew that thalassemia is included in PMS. However, in regard to SCD, the percentage was slightly higher 521 (77.2%), this indicates that the general population know more about SCD than thalassemia. This can be due to the higher prevalence of SCD in the eastern region in Saudi Arabia (1, 5).

In our study we observed that the highest percentage of agreement with PMS was with those with higher education level. Among 515 participants with university education, 505 (98.1%) agreed on carrying PMS. These results are similar with that of a study conducted in 2010 among

unmarried female students in King Abdulaziz university in Jeddah, Saudi Arabia which showed that (99%) of female students either strongly agreed or agreed on the importance of PMS (8).

A study conducted in 10 public high schools in Muscat, Oman between May and July of 2016 on a total of 1,541 participants asking whether PMS can affect their children, 36.6% responded to continue the marriage, 10 % to discontinue the engagement, 6.6% to proceed with marriage due to emotional reasons, 1.2 % would proceed with marriage due to family pressure and 17.4% wouldn't know what to do (7). In comparison with our study, 51% choose to cancel marriage if PMS would affect their offspring, 14.2% would continue engagement, 13.8% don't know what to do and 21% responded that the decision will depend on the probability of getting the disease. In addition, regarding gender attitude towards the possibility to get an affected child, we found that majority of females (55.7%) and males (44.3%) would not continue the marriage (9).

Regarding our study limitation, the study was carried only among 3 areas of close proximity cities, which is not reflective of the whole Eastern Region population. Furthermore, two of the largest malls in the region refused to give us permission to conduct the study and we had to get it from other malls nearby. Other variables were not explored such as the effect of educational campaigns from the ministry of health and school education about the importance of PMS.

Conclusion:

This study revealed that there is very good knowledge about premarital screening. There is a need to increase awareness about sickle cell anemia and thalassemia to raise the number who would cancel the marriage if any of these diseases are found to be positive during premarital screening with the possibility of transmission such diseases to offspring.

Acknowledgments:

We would like to thank all the malls who allowed us to conduct our study and the participants who took their time to fill in the survey during the study duration.

Disclosure:

Conflict of interest:

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding:

None

Ethical Consideration:

The ethical approval was obtained from the Research and Ethics Committee at the College of Medicine and Medical Sciences at the Arabian Gulf University (AGU). Official permissions to conduct the study were obtained from all the selected malls.

Data Availability:

The survey used in this paper is attached as a supplementary material.

Author Contribution:

All authors contributed in data collection, data analysis, writing, drafting, proofreading and finalizing the manuscript.

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