

University Students' knowledge, attitudes, and practices towards the National Premarital Screening Program of Saudi Arabia

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Original Article

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ABSTRACT

Background: There is an elevated rate of hereditary hemoglobinopathies in Arab populations. To address this, the Saudi government has implemented a mandatory premarital screening (PMS) program. Nevertheless, reports have shown that 48% of genetically incompatible partners have decided to marry. To address this, more information is needed on people's beliefs on these issues.

Aim: To investigate the knowledge, attitudes, and practices of Taif University students toward the national PMS program.

Materials and Methods: Using a questionnaire, a cross-sectional study was conducted during April-May 2016 on a random sample of university students in Taif City. It was administered electronically and primarily distributed through the social media.

Results: Most participants (97.4%) were aware that genes may transmit hereditary diseases and had heard about the PMS program. Most participants who partook in the PMS justified it based on preventing disease transmission to their offspring and ensuring their partner's health. A fair number (82.9%) were willing to change their decision to marry in the case of receiving incompatible results. Moreover, the majority of the participants (91.8%) demanded the implementation of a law that prohibits incompatible marriages.

Conclusion: Most Taif University students have a generally positive attitude and good intended practices toward PMS. However, targeted educational programs about the importance of PMS are strongly recommended to eliminate all factors that may affect the success of the PMS program.

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Key Words: Consanguinity, hereditary hemoglobinopathy, marriage, premarital screening, reproductive health, Saudi Arabia sickle cell anemia, thalassemia.

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INTRODUCTION

Marriage is considered one of the most significant milestones in one's life. It is a cornerstone on which families and consequently communities are built. Marriage stability and success depend dramatically on partners' compatibility. The presence of hereditary or chronic communicable diseases can disrupt a marriage whether it affects the partners or their offspring. Thus, assurance of the partners' fitness before marriage via detection of those diseases and the likelihood of their presentation in their offspring is of crucial importance.

Hereditary diseases are considered as one of the most common causes of mortality and morbidity in infants and children^[1]. Hereditary hemoglobinopathies – especially

sickle cell anemia and thalassemia – are the most prevalent hereditary diseases worldwide^[2]. Unfortunately, the Arab population has an elevated rate of those diseases in comparison with other populations^[3,4]. This is mostly due to the high rates of consanguinity, cultural restrictions, and due to lack of public health measures^[5].

There is a well-established relationship between hereditary diseases and consanguinity. Autosomal recessive inherited disorders have a high chance of developing in consanguineous marriages^[3-6]. In the Arab population, consanguinity rate ranges from 10% in Morocco to more than 50% in Saudi Arabia^[5]. Many cultural, traditional, social, and economic factors influence the preference of consanguinity in this population^[5,7,8].

The Kingdom of Saudi Arabia, a country with a

population of ~28 million, is known for its high prevalence of hereditary hemoglobinopathies^[6]. It is estimated that for every 10 000 people in Saudi Arabia, there are 424 with sickle cell trait, 27 with sickle cell disease, 180 with thalassemia trait, and five with thalassemia disease^[9]. These numbers along with the high rate of consanguinity have prompted the Saudi government to implement a mandatory premarital screening (PMS) program to protect future generations and ensure partner compatibility before marriage^[10,11].

In 2004, the Saudi National PMS Program started as a blood test for hereditary hemoglobinopathies, in particular; it aimed to detect sickle cell anemia and thalassemia^[10]. In 2008, it was updated to include chronic communicable diseases, hepatitis B and C viruses, as well as HIV^[12]. Even though the statistics show that Saudi Arabia has one of the lowest prevalence rates of hepatitis and HIV, this update was important to improving health education and clarifying unknown infection risks^[13].

Although the PMS is mandatory for every marriage in Saudi Arabia, partners have the right to marry regardless of the PMS results. Indeed, Alswaidi *et al.*^[14] found that 88% of incompatible partners that were screened in 2005–2006 decided to marry. Later data reported a significant decrease in this rate to 48% by 2009^[15]. This indicates that the screening program is likely highly effective in reducing at-risk marriages but there may be some cultural restrictions that need to be eliminated^[15].

Numerous studies have been conducted in Saudi Arabia to assess the knowledge and attitudes of university students toward the national PMS program^[16–20]. However, none of them was conducted in Taif City or on its university students. This is an important group of the population as they are living in a Saudi region with a consanguinity rate of 55.9%^[21]. In addition, it was supposed that they ought to have adequate education and knowledge alongside their high probability to soon experience these issues as they are at an age that is considered highly eligible for marriage^[22].

The primary objective of this study is to explore the knowledge, attitudes, and practice of Taif University students toward the national PMS program of Saudi Arabia. This could help assess the efficacy of the PMS program in this region. Furthermore, it could provide guidance in determining the major cultural and traditional barriers that adversely affect the achievement of the PMS program goals.

MATERIALS AND METHODS

A questionnaire was developed based on the literature review of studies using the relevant questionnaires^[12,16, 20,23,24]. It was piloted on 10 participants to examine its reliability and clarity. Accordingly, ambiguous and conflicting items were modified.

The final form of the questionnaire comprised four main sections and 36 close-ended items. The first section

included sociodemographic data and history of hereditary diseases. The second section aimed to test the participant's knowledge concerning hereditary diseases and the PMS program of Saudi Arabia. The third section assessed the participant's attitude toward and perspective of the PMS program. The last section assessed the participant's degree of commitment to the PMS result in various scenarios.

The survey was conducted during April–May 2016. The target sample of 380 participants was estimated using the online EZSurvey software (Raosoft Inc., Seattle, Washington, USA, <http://www.raosoft.com/sampleize.html>) with a 5% margin of error and 95% confidence level. All male and female students of Taif University from various colleges, except those in the pilot group, were included in the study. The sample was selected using the convenience sampling method. The questionnaire was administered electronically and distributed through the social media. The official twitter account for deanship of students' affairs in Taif University posted a tweet with our questionnaire link and encouraged students to participate. In addition, the link was broadcasted to 'WhatsApp' as almost every class of the university has a student group in this application. Responses were reviewed periodically during data collection to ensure that all participants are Taif University students. Responses from the faculty members or other Taif University employees were excluded. Once the target sample was reached, the questionnaire link was disabled.

Statistical analysis

All collected data were coded, entered, and analyzed using the statistical package for the social sciences software (version 23.0; IBM Corp., Armonk, New York, USA). Descriptive statistics (frequencies) were used to describe the sample characteristics.

Ethical approval

The Research Ethics Committee of Taif University granted approval to conduct this study in April 2016. The questionnaire was administered electronically and predominantly distributed via social media. It was emphasized that participation was optional and the confidentiality of the participant's information was assured.

RESULTS

The sample consisted of 380 eligible participants. Almost all of them were Saudis (98.4%) with an age range of 19–25 years. Approximately half of the participants (48.4%) were men and half of them (51.6%) were women. Only 6.6% of all participants reported a personal history of hereditary diseases, whereas 16.6% reported a family history of hereditary diseases. Half of them (50.5%) had consanguineous parents and 77.1% of them were first-degree relatives. The sociodemographic characteristics and history of hereditary diseases are, respectively, summarized in Table 1.

Table 1A: Sociodemographic characteristics of Taif University Students, Taif City, KSA, 2016

Characteristic	No. (%)
Gender	
Male	184 (48.4)
Female	196 (51.6)
Age	
<18	20 (5.3)
19-25	301(79.2)
>25	59 (15.5)
Nationality	
Saudi	374 (98.4)
Non-Saudi	6 (1.6)
Family's monthly income	
< 5000 SR	80 (21.1)
5000- 10000 SR	137 (36.1)
10000-20000 SR	113 (29.7)
>20000 SR	50 (13.1)
Home/town	
Taif	315 (82.9)
Makkah	15 (2.6)
Jeddah	21 (5.5)
Taif Suburbs	20 (5.3)
Others	14 (3.7)
Marital status	
Married	76 (20.0)
Single	302 (79.4)
Divorced	1 (0.3)
Widower	1 (0.3)
Academic year	
1 st year	62 (16.3)
2 nd year	38 (10.0)
3 rd year	66 (17.4)
4 th year	66 (17.4)
5 th year	50 (13.2)
6 th year	98 (25.8)
College	
Education	33 (8.7)
Science	52 (13.7)
Medicine	106 (27.9)
Computer and IT	13 (3.4)
Admins and financial	44 (11.6)
Pharmacy	23 (6.1)
Art	12 (3.2)
Engineering	13 (3.4)
Community and CE	17 (4.5)
Health science	9 (2.4)

Al-sharia and regulations	15 (3.9)
Designs and home economics	21 (5.5)
Dentistry	9 (2.4)
Others	13 (3.4)

SR: Saudi Riyals, IT: Information Technology, CE: Continuous Education

Table 1B: History of consanguinity and hereditary diseases of Taif university students, Taif city, KSA, 2016

Characteristic	No. (%)
Parental consanguinity (n=380)	
Yes	193 (50.8)
No	187 (49.2)
Type of consanguinity (n=193)	
1st Relative	148 (76.7)
2nd Relative	45 (23.3)
Personal history of hereditary diseases	
Sickle cell anemia	1 (0.3)
Thalassemia	1 (0.3)
G6PD deficiency	4 (1.1)
Other	19 (5.0)
None	355 (93.4)
Family history of hereditary diseases	
Sickle cell anemia	7 (1.8)
Thalassemia	3 (0.8)
G6PD deficiency	7 (1.8)
Other	46 (12.1)
None	317 (83.4)

G6PD: Glucose-6-Phosphate Dehydrogenase Deficiency

Most of the participants (97.4%) were aware that genes could transmit hereditary disease. Furthermore, the majority of them (98.9%) had heard about the PMS program. In terms of knowledge of hemoglobinopathies, a high percentage of medical students (96.6 and 89.1%) compared with nonmedical students (61.8 and 31.6%) have heard about sickle cell anemia and thalassemia, respectively. Less than

60% (58%) of the participants knew that PMS detects both hereditary and chronic communicable diseases. In contrast, 42.1% thought that PMS tested the participant's fertility and thus their capacity to have children. Among those, 55.6% were men and 44.4% were women. The results concerning the participants' knowledge is shown in Table 2.

Table 2: Knowledge of Taif university students about PMS, Taif city, KSA, 2016

Knowledge	%
Hereditary diseases can be transmitted by genes	97.4
Heard of sickle cell anemia	75.3
Heard of thalassemia	53.9
Heard of PMS	98.9
PMS detects hereditary diseases only	34.5
PMS detects communicable diseases	85.3
PMS tests the ability to get children	42.1

Table 3 lists all attitudes, beliefs, and the degree of the participants' agreement to each one of them. The vast majority (85.3%) of the participants generally agreed that consanguinity could increase the chance of hereditary diseases. However, 41.1% were unsure if they prefer consanguineous marriage or not. For most of the

participants, the reasons for partaking in a PMS were to prevent disease transmission to the offspring (94.5%) and to ensure the health of their partner (94.2%). Remarkably, 36.1% strongly disagreed that the PMS could prevent disease transmission to them, whereas 29.2% reported being unsure.

Table 3: Attitudes, beliefs and motives of Taif university students towards PMS, Taif city, KSA, 2016

Attitude and motives	5	4	3	2	1
Attitude					
I prefer consanguineous marriage	8.2	26.1	41.1	41.1	11.3
Consanguinity can increase the chance of hereditary diseases	50.3	35.0	12.1	12.1	0.0
Hereditary diseases have a psychological burden on families	55.0	33.7	8.2	8.2	0.5
Hereditary diseases have an economic burden on families	47.4	32.4	13.7	13.7	1.1
PMS does not interfere with a belief in destiny	63.2	31.1	4.7	4.7	0.5
Motives for carrying out PMS:					
I will/was carry out PMS for the following motives:					
- to prevent disease transmission to offspring	79.2		15.3	4.7	0.3
- to ensure health of the partner	68.9		25.3	4.2	0.5
- to prevent disease transmission to me	5.5		9.7	29.2	36.1
- because I was obliged by law	14.2		20.8	29.7	17.6
I will/was not carry out PMS for the following motives:					
- because I will marry my cousin any way	5.8		8.7	29.2	33.4
- because it may not be in favor of my choice	72.4		20.8	4.5	1.1

1= Strongly Disagree, 2= Disagree, 3= Unsure, 4= Agree, 5= Strongly Agree (in %)

Regarding compliance to the PMS, only 23.4% reported they would decide to marry with the risk of hereditary diseases and 9.5% with a risk of communicable diseases. In contrast, 82.9% were willing to change their decision to marry in the case of

a result demonstrating incompatibility. Most of the participants (91.8%) reported that they would demand the implementation of a law that prohibits incompatible marriages. Participants' practices concerning PMS are shown in Table 4.

Table 4: Intended practices of Taif university students, Taif city, KSA, 2016

Practice	%
Will/would carry out PMS	95.3
Decisions post-PMS	
- Will/would decide to marry even if there is a hereditary disease risk	23.4
- Will/would decide to marry even if there is a communicable disease risk	9.5
- Willing to change decision to marry in the case of incompatibility	82.9
- Will demand implementation of a law that prohibits incompatible marriages	91.8
- Will contribute to raising awareness about the importance of PMS	92.9

DISCUSSION

Detection of hereditary or communicable disease carriers to control prevalence is an acceptable international practice^[10]. It is also considered one of the most effective prevention strategies in highly consanguineous populations^[11]. Thus, the implementation of screening programs like the national PMS program of Saudi Arabia is very important. It is also important to know the degree of this program's approval among university students to enhance its effectiveness and reach to this population.

As previously mentioned, Saudi Arabia has a reported consanguinity rate of more than 50% with a high prevalence of first-degree relative marriages^[5]. This is consistent with the findings of the present study, 50.5% of the participants had consanguineous parents and 77.1% of them were first-degree relatives. Ibrahim *et al.*^[12] reported a slightly lower consanguinity rate of 44.5% in a similar study targeted at attendees of governmental outpatient clinics in Jeddah. Ibrahim *et al.*^[19] also reported much lower rate (34.6%) from students in King Abdulaziz University in Jeddah. This could be explained by the significant cultural and traditional variations between these two cities in Saudi Arabia.

This study showed that most of Taif University students knew that genes could transmit hereditary diseases and a fair number of them have heard about sickle cell anemia and thalassemia. In contrast, only 58% of participants knew that PMS detects both hereditary and chronic communicable diseases⁷. Furthermore, 42.1% thought it tested the fertility of participants. These results are consistent with other reports from different regions in Saudi Arabia. A similar study conducted in King Abdulaziz University, Jeddah, found that most of their students had sufficient knowledge about hereditary diseases in general, but they had inadequate knowledge of PMS^[17]. Another study conducted in King Saud University, Riyadh, reported that 20% of university students had inadequate knowledge about PMS^[20]. This is an indication of the need for PMS educational programs as well as genetic counseling programs targeting university students. Notably, Ibrahim *et al.*^[19] conducted a study to assess the knowledge and attitudes of unmarried female students in King Abdulaziz University, Jeddah, toward PMS before and after an educational campaign. They

found that 80.9% of the sample had inadequate knowledge about PMS. Interestingly, this percentage significantly declined to 21.9% after attending an educational campaign about PMS^[19].

Recently, the PMS program has gained acceptance from the general population^[25]. Many studies from different regions of Saudi Arabia agree to this. Al-Kaldi *et al.*^[16] reported 70% acceptance rate of the PMS program among health science students in Abha. Similarly, a study in King Abdulaziz University, Jeddah, reported that 99% of female students generally agreed on the importance of PMS^[19]. In a community-based study conducted in Riyadh, 94% considered PMS as an important preventive measure for a genetic blood disorder^[24]. The current study also reported general positive attitude toward PMS among Taif University students.

PMS is carried out for several reasons. Most of this study's participants partook in the PMS to prevent disease transmission to their offspring and to ensure the health of their partner. One remarkable finding is that only a small portion agreed that they partook in PMS to prevent disease transmission to themselves. In contrast, the most common reason for PMS rejection for nearly all participants in this study was the fear of receiving incompatible PMS results and consequently the termination of an otherwise favorable marriage. Health Science students in Abha agreed to these same reasons with contradictory results. The prevention of disease transmission to them and their offspring was the primary reason for partaking in a PMS rather than to certify the health of their partners. In addition, their main reason for rejecting PMS was to not interfere with God's will^[16]. Older studies reported the presence of misconceptions about Islamic principles that lead to PMS rejection^[24]. Only 1% of participants in the present study had a religious misconception regarding PMS as they thought it interfered with their belief in destiny. Moreover, studies from Riyadh and Jeddah reported few students with similar misconception^[12,20].

In this study, the majority (82.9%) were willing to change their marriage decision in case of incompatibility. In Jeddah, 67.1% of unmarried female students in King Abdulaziz University were in favor of marriage cancellation when PMS results revealed a genetic disease^[19]. In Riyadh, Al Sulaiman *et al.*^[23] also report that more than 60% of

all participants from Riyadh believe that marriage plans should be canceled with a high risk of hereditary disease. These numbers reflect a significant improvement in the PMS program acceptance. However, the remaining percentages of those planned to continue incompatible marriages indicate the presence of cultural barriers that need to be addressed.

As mentioned previously, even if the PMS program is mandatory to get married, each partner is free to marry regardless of their test results. In the present study, most of Taif University students (91.8%) are demanding the implementation of a law that prohibits incompatible marriages. In consistence, a study in Jeddah (2011) showed that 64.6% of female university students agreed that the decision to marry should be free regardless of the risk of hereditary disease^[19]. Conversely, earlier reports from Riyadh showed a 63% approval rating in favor of legal interference in case of incompatibility^[24], whereas more recent reports have shown a far lower percentage, with only 36% participants, agreeing to implement laws and regulations to prevent at-risk marriages^[20].

STUDY LIMITATIONS

Convenience sampling was a clear limitation of this study. Some faculties were overrepresented as they accessed the link first, whereas others have much lower responses. Stratified random sampling would eliminate this problem, but it could not be done due to limited information about students' numbers in each faculty.

CONCLUSION

Most Taif University students have a generally positive attitude and reported good intended practices toward PMS. However, targeted educational programs that are concerned with the diseases are tested by PMS and how its results could affect their partners and offspring are strongly recommended to clarify any conflicts and eliminate any barriers that could affect the PMS program success.

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CONFLICT OF INTEREST

There are no conflicts of interest.

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