

## Taibah University

## Journal of Taibah University Medical Sciences





Original Article

# Comprehension of premarital screening and genetic disorders among the population of Riyadh



Shahad AlOtaiby, PhD <sup>a,\*</sup>, Abdulhadi Alqahtani, M.Sc. <sup>a</sup>, Ruba Saleh, MD <sup>b</sup>, Abeer Mazyad, MD <sup>c</sup>, Abdulrazaq Albohigan, M.Sc. <sup>d</sup> and Emad Kutbi, PhD <sup>a</sup>

Received 25 July 2022; revised 4 December 2022; accepted 6 January 2023; Available online 19 January 2023

#### المخلص

أهداف البحث: فحص ما قبل الزواج، للأسف، لم يشمل جميع الأمراض الوراثية المحتملة مثل أمراض القلب الخلقية والسكري وارتفاع ضغط الدم، بالاضافه الى الطفرات الجينية الغير معروفة التي يمكن أن تسبب عيوبا خطيرة في الجيل القادم. ومع ذلك، هناك معرفة محدودة بين السعوديين حول فحص ما قبل الزواج و نوعية الامراض التي يتم تحليلها. بناء على ذلك، فإننا نهدف في هذه المراسة إلى بحث معرفة وموقف سكان الرياض تجاه فحص ما قبل الزواج.

طرق البحث: تم إجراء دراسة مقطعية، قائمة على الملاحظة باستخدام استبانة مصممة للاجابة عليها ذاتيا. وقد شمل الاستطلاع أسئلة تتعلق بالبيانات الاجتماعية والديموغرافية، وعلم الوراثة، والاختبار الجيني، وفحص ما قبل الزواج. SPSS تم إدخال جميع البيانات وتحليلها من خلال الإصدار 22 من الحرمة الإحصائية.

النتائج: أجاب مجموعة 385 مشاركا على الاستبانة، ؤ كانكأن مستوى المعرفة بشكل علم جيد لغالبية المشاركين باختلاف مستوى التعليم، والجنس، علاوة على ذلك كان الموقف والسلوك العام للمشاركين إيجابيا تجاهفحص ما قبل الزواج بشكل ملحوظ الا انه كان هناك فئة معينه من المشاركين اختلفت في سلوكها تجاه فحص ماقبل الزواج عن بقية المشاركين بسبب تدني وعدم توفر المعلومات اللازمة عن فحص ماقبل الزواج والامراض الجينية.

الاستنتاجات: يجب تحسين معرفة وموقف سكان الرياض تجاه فحص ما قبل الزواج من خلال برامج التوعية الوطنية. في ضوء نتائجنا، هناك بالتأكيد حاجة

E-mail: shahody\_90@hotmail.com (S. AlOtaiby)
Peer review under responsibility of Taibah University.



Production and hosting by Elsevier

لمزيد من المعلومات والتعليم حول البرنامج. يجب إجراء مزيد من الدراسات في المناطق الحضرية والتحقيق في مستوى الرضا عن البرامج القائمة.

الكلمات المفتاحية: فحص ما قبل الزواج؛ استشارة وراثية؛ قرابة؛ السعودية

#### Abstract

**Objective:** Premarital, unfortunately, does not cover all possible genetic diseases, such as deafness and congenital heart diseases, diabetes mellitus, and hypertension, nor does it cover unknown genetic mutations that may cause severe defects in subsequent generations. However, the Saudi population has limited knowledge regarding premarital screening tests, which do not detect all genetic disorders or diseases. Hence, we aimed to explore the knowledge and attitudes among the population of Riyadh toward premarital screening.

**Methods:** A cross-sectional observational study was conducted with a self-administered designed questionnaire. The survey included questions regarding sociodemographic data, genetics, genetic testing, and premarital screening. All data were entered and analyzed in the statistical package SPSS version 22.

**Results:** A total of 385 participants responded to the questionnaire, and good knowledge among most participants was significantly associated with education level (p < 0.001), sex (p < 0.001), and prior screening (p = 0.001). The overall attitude was positive toward premarital screening, and significant associations of sex and social/marital status with a positive response to premarital screening were observed.

<sup>&</sup>lt;sup>a</sup> Research Center, King Fahad Medical City, Central Second Health Cluster, Ministry of Health, Riyadh, KSA

<sup>&</sup>lt;sup>b</sup> Obstetrics and Gynaecology Department, Maternity and Children Hospital, Almadinah Almunawwarah, KSA

<sup>&</sup>lt;sup>c</sup> College of Pharmacy, Riyadh Elm University, Riyadh, KSA

<sup>&</sup>lt;sup>d</sup> Pathology and Clinical Laboratory Medicine Administration, King Fahad Medical City, Central Second Health Cluster, Ministry of Health, Riyadh, KSA

<sup>\*</sup> Corresponding address: Research Center, King Fahad Medical City, Central Second Health Cluster, Ministry of Health, P.O. Box. 59046, Riyadh 11525, KSA.

Conclusion: Knowledge and attitudes among the population of Riyadh toward premarital screening must be improved through national awareness programs. In light of our results, a need exists to provide more information and education regarding screening. Further studies must be conducted in urban areas to investigate the level of satisfaction with existing programs.

**Keywords:** Consanguineous couples; Consanguinity; Genetic counseling; KSA; Premarital screening

© 2023 The Authors.

Production and hosting by Elsevier Ltd on behalf of Taibah University. This is an open access article under the CC BY-NC-ND license (http://creativecommons.org/licenses/by-nc-nd/4.0/).

#### Introduction

Premarital counseling is a service offered to couples before marriage, with an aim to guide, educate, and prepare them for establishing a healthy family. The KSA, where the consanguineous marriage rate is rising, has the highest consanguinity rates among Middle Eastern countries.<sup>2</sup> The percentage range varies among regions in KSA but typically ranges from 25% to 60%. Consanguineous marriage can be life-threatening, and can cause several medical and psychosocial marital problems among couples intending to marry.<sup>3</sup> Under the Royal decree of March 2002, the Ministry of Health in KSA set organizational arrangements for the Saudi Premarital Screening Program (PMS), which started 2 years later under the second Royal decree and made premarital screening mandatory for all couples planning to marry. Marriage contracts are not issued until the results of screening tests are submitted. Thousands of couples have called off marriages after finding that they were genetically incompatible.4

In 2004, the PMS program started as a blood test for hereditary hemoglobinopathies. In particular, the PMS aimed to detect sickle cell anemia, and thalassemia. In 2008, it was updated to include chronic infectious diseases, hepatitis B and C viruses, and HIV. Although statistics have indicated that KSA has among the lowest prevalence rates of hepatitis and HIV, this update was essential to improving health education and clarifying unknown infection risks.6 consultations are aimed at indicating the odds of transmitting such diseases to possible partners or offspring, and providing solutions and alternatives to help soon-to-be-married couples plan for healthy families. One misconception among couples is that premarital testing is sufficient to determine whether they will have children with genetic diseases; many people do not realize that they could be at high risk for the many diseases that are not tested for. In Arab countries and the Gulf region, the leading cause of infant and child death, morbidity, and disability is genetic diseases. Therefore, several screening programs have been implemented in the Gulf region and the Middle East to address this issue. One solution is premarital genetic screening programs, which have been highly effective in preventing genetic disorders and multifactorial health problems in the Gulf region and the Middle East. Genetic

diseases greatly influence quality of life among affected individuals; moreover, they pose a major burden on national healthcare costs and substantially contribute to the USD\$30 billion annual healthcare expenditures in the Kingdom. Saudi premarital screening unfortunately does not cover all possible genetic diseases, such as deafness and congenital heart diseases, diabetes mellitus, and hypertension. A study by Al-Kahtani et al. on a population in Riyadh has reported that 75.2% of participants accepted the idea of premarital screening, thus indicating a positive attitude toward healthcare among the Saudi populace, as long as confidentiality is ensured, the study also showed that 82%, results correlated with adult age, marital status, educational level, and comprehension of Islamic health related issues. 10 A program to educate young people would be likely to shift the community's attitudes toward premarital screening. Ibrahim et al. have assessed the knowledge among voung unmarried college women and concluded that such programs are successful, and should be appropriately implemented at secondary and higher education levels. 11 Therefore the aim of this study was to explore the knowledge and attitudes of the Saudi population toward premarital screening programs. The novel data form this study should help establish awareness campaigns that could be customized and designed according to each person's level, to eliminate consanguineous marriages and potentially encourage the Ministry of Health to modify the existing PMS to include more genetic diseases.

#### **Materials and Methods**

Study design and data collection

This was a cross-sectional observational study conducted in Riyadh, the capital of the KSA. The study was performed during April 2019 to August 2020. The inclusion criteria were adults of both sexes 16 years of age or above in the general population, because this age range is considered acceptable for marriage. Participants were recruited from universities, public venues, and primary healthcare centers in Riyadh city. Those who did not meet the inclusion criteria were excluded. The data were collected by a trained data collector via a selfadministered, validated, and structured questionnaire designed in the Arabic language. The questionnaire consisted of multiple-choice questions to determine participants' knowledge, attitudes, and perceptions. The questionnaire was developed on the basis of perceived misconceptions regarding such screening programs reported in the literature. The questions included information on sociodemographic data, knowledge of premarital screening programs, countryprevalent hereditary diseases, and information on the Saudi Genome project. Research coordinators distributed the questionnaire to randomly selected individuals from the five regions of Riyadh (North, West, South, East, and Central).

#### Questionnaire validation

A pilot study was conducted during designing of the questionnaire, which was then validated. The content validity of the questionnaire was assessed and reviewed independently by four expert consultants in the field of medical genetics. The pilot testing was implemented after corrections

Table 1: Sociodemographic characteristics of the participants.					
Sociodemographic character	Frequency	Percentage			
Age (mean ± SD)	$(26.8 \pm 8.1)$	$(26.8 \pm 8.1)$			
Sex					
Male	102	15.6%			
Female	550	84.4%			
Marital status					
Single	413	63.3%			
Married	26	4.0%			
Engaged	213	32.7%			
Highest educational level					
Primary school	1	0.2%			
Intermediate school	2	0.3%			
High school	117	17.9%			
Diploma	9	1.4%			
University	504	77.3%			
Postgraduate	19	2.9%			
Have you ever heard about prema	arital screening?				
Yes	648	99.4%			
No	4	0.6%			
Did you perform premarital scree	ening?				
Yes	189	29.0%			
No	463	71.0%			

were made and the experts had approved. The reliability of the present questionnaires was also assessed with the internal consistency method with Cronbach's alpha coefficient. A total of 30 factors were deemed suitable for this study; for the null hypothesis,  $C_{A0}=0.702$  (adjusted Cronbach alpha derived for the pilot sample), and for the alternative hypothesis,  $C_{A1}=0.80$  (at least a 10% increase in the interim correlation was expected in the final outcome).

#### Sample size calculation

The cross-sectional survey regarding the Saudi PMS and genetic disorders was collected from April 2020 to August 2021. The sample size was calculated in Rao soft® sample size software for prevalence studies by considering the total population of approximately 50,000 non-medical

professionals, including IT professionals, researchers, academicians, educators, etc. These non-medical professionals might have different knowledge, attitudes, opinions, and constraints regarding premarital screening and its application compared with medical professionals with medical knowledge and background about PMS, followed by 95% C.I. and 5% margin of error. To overcome intra-cluster variance among groups, the respective sample size was multiplied by a minimum design effect of 1.5. Hence, the total sample size was 652 for assessing premarital screening.

#### Statistical analysis

All categorical variables (sex, marital status, educational level, etc.) are presented as numbers and percentages. The continuous variable of age is expressed as mean  $\pm$  S.D. The chi-square test was applied according to whether the expected frequency was smaller than 5, and was used to evaluate significant associations among categorical variables. A P-value less than 0.05 was considered statistically significant. All data were entered and analyzed in the statistical package SPSS version 22.

#### Results

#### Sample characteristics

A total of 652 Saudi men and women from Riyadh responded to this survey; the age range of the participants was 16–60 years, and 84.4% were women. Analysis according to socio-demographic characteristics of the participants was performed (Table 1). A total of 98.8% of the participants were aware of premarital screening; however, because most of our sample comprised singles, only 25.8% had actually performed the screening, and 1.2% had not known or heard about premarital screening. The majority of responders did not have a personal history of hereditary disease, whereas 6.1% had a history of hereditary disease, and 18.4% did not know whether they were carriers of genetic mutations associated with a disease (Figure 1).

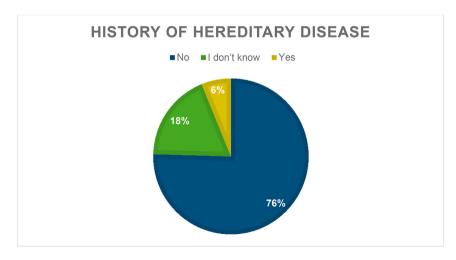


Figure 1: History of hereditary disease in the Riyadh population.

Table 2: Indicators of participants' knowledge of pre-marital genetic screening.

Factor	Knowledge score				
	Poor	Good	<i>p</i> -value		
	n	n			
Age (mean $\pm$ SD)	$(26.7 \pm 8)$	3.09)			
Sex					
Male	63	11	0.038		
Female	487	91			
Marital status					
Single	375	38	0.075		
Married	22	4			
Engaged	181	32			
Education					
Primary school	0	1	0.001		
Intermediate school	2	0			
High school	108	9			
Diploma	8	1			
University	448	56			
Postgraduate	12	7			
Have you ever heard abo	out premarital	l screening?			
Yes	574	74	0.473		
No	4	0			

Table 3: Multivariate logistic regression analysis of factors significantly associated with knowledge of premarital screening.

	В	95% co interval	<i>p</i> -value	
Sex	0.07	0.543	2.109	0.83
Primary school	-19.296	4.167	4.167	
Intermediate school	14.709	0.000	0.000	0.992
High school	1.946	2.208	22.192	0.001
Diploma	1.540	0.478	45.546	0.185
University	1.540	1.764	12.343	0.002
Postgraduate	0.00		•	

Knowledge of premarital screening and deciphering the genetic code

In this study, 99.4% of participants had known about premarital screening, and 95.1% knew that screening is important and is mandatory by the government. The top three main sources of information on premarital screening for most (68.6%) participants included (books/educational publications, family and friends, and internet/social media). Statistically significant differences in participants' knowledge were observed according to sex and education level. Female participants had significantly better and knowledge than male participants in the population of Riyadh. Moreover, approximately 12.5% of those with good knowledge had higher education levels (university/postgraduate). Table 2 shows indicators of participants' knowledge of pre-marital screening and deciphering the genetic code. Moreover, multinomial logistic regression was performed to predict a nominal dependent variable given one or more independent variables, as an extension of binomial logistic regression to allow for a dependent variable with more than two categories (Table 3). Overall, the score for the knowledge section was moderate in the population of Riyadh. To assess their knowledge, we asked the participants whether detection of genetic diseases is included in the premarital screening testing. Almost half (54.4%) the participants reported no. Figure 2 shows the participants' responses regarding what diseases are not included in premarital screening. Only 17.6% of the population of Riyadh were aware of the Saudi Genome project, and 41.7% saw the importance of deciphering the genetic codes of Saudi people Nearly half (32.2%) understood that decoding of the Saudi society genetic code will help in the detection of genetic disorders and diseases (Table 4).

Attitudes toward premarital screening and expected outcomes

The measurement of the studied sample's attitudes toward premarital screening revealed that almost half (39%)

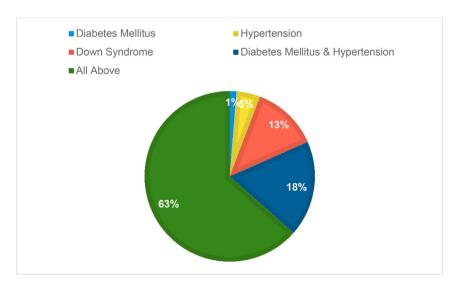


Figure 2: Knowledge of the Riyadh population regarding diseases in premarital screening.

the participants believed that premarital screening limits the spread of genetic diseases, whereas 53% did not know whether premarital screening could help limit genetic diseases (Figure 3).

Table 5 indicates that most participants (96.32%) strongly believed that premarital screening was considered a preventive measure, and 61.81% believed that premarital screening should be legally enforced by the authorities. Unexpectedly, most participants indicated that they would not proceed with marriage if one or both members of the couple were found to carry or to be affected by a hereditary disease. In addition, 88.6% of the sample strongly agreed that preventing couples from marriage in the event of positive screening is important; however, 47.3% were uncertain regarding the possibility of having unaffected children from parents with hereditary disease.

We observed statistically significant differences according to sex and social/marital status in participants' attitudes regarding proceeding with marriage if the partner were a carrier, and whether a positive screening result should prevent couples from marriage (Table 6). Although no significant differences were observed for the other questions, the differences in participants' attitudes were near the significance level.

#### Discussion

Detection of hereditary or genetic disease carriers to control disease prevalence is among the most effective prevention strategies, particularly in countries with a high prevalence of consanguineous marriages. KSA's consanguinity rate exceeds 50%, and the prevalence of first-degree relative marriages is high. Premarital screening usually targets unmarried adults, because their attitudes and perception will affect their lives, particularly in their choice of a partner, thereby affecting the quality of their marriage and the health of future generations. All The purpose of this quantitative study was to evaluate levels of knowledge and attitudes regarding the existing premarital screening program and the importance of genetic testing in the PMS program among the population of Riyadh.

The PMS program was initiated in 2004 in KSA, aiming to screen individuals intending to marry for common genetic diseases such as sickle cell disease, thalassemia, HIV, and hepatitis B and C. 15 In our study only 25.8% of respondents had undergone screening, because most of our sample comprised singles. Our participants had some knowledge regarding the basics of genetic testing, and 54.4% of the participants knew that the PMS program does not screen for all genetic diseases; however, almost half the participants believed that PMS covers all genetic diseases, a finding whose importance cannot be underestimated. Furthermore, the respondents' knowledge of what diseases are included in the PMS was poor, thus suggesting that the participants had limited information on genetic diseases. The data were similar to those from studies in Oatar and Oman, where knowledge deficiencies have been observed regardless of understanding of the importance of PMC. 16,17 Our results are consistent with those from many previous studies conducted in specific populations in KSA. For instance, one study has reported that unmarried female

Table 4: Responses to knowledge questions.				
Questions	Frequency	Percentage		
Why is premarital screening performed	1?			
Routine procedure in KSA	20	3.1		
To reduce hereditary and infectious	629	96.5		
diseases				
All of the above	3	0.5		
Did you know the importance of prema	arital screenin	g?		
Yes	620	95.1		
No	32	4.9		
What is the source of information you	have about pr	emarital		
screening?				
Internet	37	5.7		
Family	110	16.9		
Friends	58	8.9		
Books	447	68.6		
Select where premarital screening is do				
Government hospitals	530	81.3		
Private hospitals	42	6.4		
I do not know	80	12.3		
Do you think premarital screening invo	olves the detec	tion of		
all genetic diseases?	207	45.6		
Yes	297	45.6		
No	355	54.4		
If your answer was no, what diseases ar				
premarital screening? (More than one Diabetes mellitus	49	10.5		
Hypertension	63	13.5		
Down syndrome	59	9.0		
All of the above	297	45.6		
Do you know the complications of the				
premarital screening?	uiscases invol	reu iii		
Yes	448	68.7		
No	204	31.3		
If you answered yes, choose the compli		51.5		
Transmission of infectious diseases	317	31.2		
Transmission of genetic diseases	376	37.01		
Social effects	153	15.1		
Psychological effects	170	16.7		
Have you heard of the Saudi Genome	project?			
Yes	115	17.6		
No	506	77.6		
Maybe	31	4.8		
Do you realize the importance of deciph	ering the gene	tic code		
among Saudi people?				
Yes	272	41.7		
No	285	43.7		
Maybe	95	14.6		
If your answer was yes, how important Saudi society?	is the decodi	ng of		
Detection of infectious diseases	21	3.2		
Detection of genetic disorders and	119	18.3		
diseases All of the above	229	35.1		

university students had inadequate knowledge: less than one-third of participants knew which disorders are tested for. <sup>18,19</sup> Similar findings have been reported in Jeddah: participants from governmental outpatient clinics have been found to have low knowledge of premarital screening. <sup>20</sup> Similarly, in a study by Al-Shroby et al. among participants randomly selected from all 20 health regions in KSA, only 9.2% had satisfactory knowledge of premarital screening, and related screened genetic and

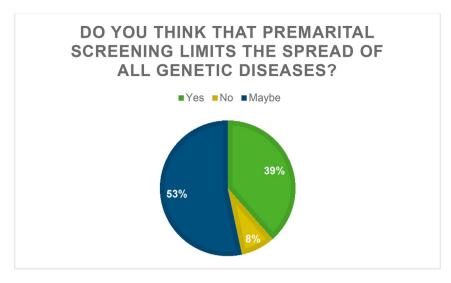


Figure 3: Respondents' understanding of premarital screening and genetic diseases.

infectious diseases.<sup>21</sup> These results indicate the need for structured educational programs and awareness campaigns for the community, because the gap in knowledge among participants did not decrease and remained at unsatisfactory level. This lack of knowledge can be resolved through proper genetic counseling campaigns in schools, universities, and public places, particularly if participation is free of charge, according to Ibrahim et al.<sup>18</sup>

The present study indicated that respondents had positive attitudes regarding premarital screening tests, and the findings were largely favorable: most respondents indicated that they would not proceed with marriage if they were found to carry or to be affected by a hereditary disease. Moreover, the majority agreed that deciding to marry if the PMS results were incompatible would be wrong. These results are simtle to those previously reported in the Saudi population. <sup>22–26</sup> The findings from this study also indicated that a high number of participants agreed with the idea of a compulsory premarital screening test before marriage and were in favor

of laws prohibiting marriages in the event of positive results. However, a small percentage of participants had insufficient attitude toward PMS, yet this small percentage is negligible with respect to that reported in a study by Alhamdan et al. in 2007, in which approximately 90% of high-risk couples still opted to marry despite being aware of the risk of having offspring with a genetic disease.<sup>27</sup> Establishing a law preventing marriage among people who have received incompatible results and conducting good educational awareness campaigns could significantly decrease this number. Additionally, we observed a significant association between positive attitudes regarding premarital screening tests and both female sex and social status, given that the percentage of women outnumbered that of men. Most respondents were willing to change their marriage decisions in the event of incompatibility, a finding in line with those from other studies in the literature. 19,22 Notably, another program called the National Newborn Screening Program aims to screen newborns across the Kingdom to achieve

Data	Participants (n = 652) [n ( $\%$ )]				
	Agree	Neutral	Disagree		
Do you think premarital screening is a preventive measure?	628 (96.32%)	13 (1.99%)	11 (1.69%)		
Should a positive screening result prevent couples from marriage, as enforced by legal measures?	403 (61.81%)	170 (26.07%)	78 (11.96%)		
If a positive screening indicated that both you and your partner were carriers of a known hereditary disease, would you proceed with the marriage?	38 (5.83%)	164 (25.15%)	448 (68.712%)		
If a positive screening indicated that you had carrier status and your partner was affected by the same hereditary disease, would you proceed with marriage?	28 (4.29%)	153 (23.47%)	471 (72.24%)		
If premarital screening indicated that you had a hereditary disease and your partner was affected, would you get married?	32 (4.91%)	116 (17.79%)	504 (77.30%)		
Do you think that the decision to marry in cases of incompatibility between spouses is wrong?	349 (53.53%)	123 (18.87%)	180 (27.61%)		
If premarital screening indicated that you had a hereditary disease and your partner was affected, do you expect alternative solutions for unaffected children?	168 (25.77%)	309 (47.39%)	175 (26.84%)		
In your view, should a positive screening prevent couples from marriage?	578 (88.65%)	43 (6.60%)	31 (4.75%)		

A: Sex				
Do you think premarital screening is a preventive measure?	Male	Female	p	-value
Negative	2	9	0	.31
Positive	96	532		
Neutral	4	9		
Should a positive screening result prevent couples from marriage, a	s enforced by lega	l measures?		
Negative	18	60	0	.15
Positive Neutral	58 26	345 145		
f a positive screening indicated that both you and your partner wer			ase, would you p	proceed with
the marriage? Negative	5	33	0	.07
Positive	62	388	Ū	,
Neutral	35	129		
f a positive screening indicated that you had carrier status and you proceed with marriage?	ur partner was affe	ected by the same he	ereditary disease	e, would you
Negative	6	22	0	.004
Positive	60	411		
Neutral	36	117		
f premarital screening indicated that you had a hereditary disease				
Negative Positive	6	26 435	0	.033
rosnive Neutral	69 27	433 89		
	<del></del> _			
Do you think that the decision to marry in cases of incompatibility Negative	between spouses i. 29	s wrong?	0	.644
Positive	29	142	V	.044
Neutral	44	265		
vent at				
f premarital screening indicated that you had a hereditary disease unaffected children?	and your partner	was affected, do you	_	
f premarital screening indicated that you had a hereditary disease unaffected children? Negative	and your partner	was affected, do you	_	tive solutions j
f premarital screening indicated that you had a hereditary disease unaffected children?	and your partner	was affected, do you	_	
f premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral	and your partner of 3 95 4	was affected, do you 20 521	_	
if premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marr	and your partner of 3 95 4	was affected, do you 20 521	0	
f premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral	and your partner of 3 95 4 riage?	was affected, do you 20 521 9	0	.302
if premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marn Negative	and your partner of 3 95 4 riage?	was affected, do you 20 521 9	0	.302
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative  Positive  Neutral  In your view, should a positive screening prevent couples from marr  Negative  Positive  Neutral  Seculated:  New Transaction of the screening	and your partner of 3 95 4 riage? 9 84 9	20 521 9 22 494 34	0	.059
If premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marr Negative Positive Neutral 3: Social status Do you think premarital screening is a preventive measure?	and your partner of 3 95 4 4 riage? 9 84 9	20 521 9 22 494 34 Married	0 Engaged	.302 .059
If premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from mark Negative Positive Neutral 3: Social status Do you think premarital screening is a preventive measure? Negative	and your partner (	20 521 9 22 494 34 Married	0 Engaged 4	.059
If premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marn Negative Positive Neutral B: Social status Do you think premarital screening is a preventive measure? Negative Positive	and your partner (	20 521 9 22 494 34 Married 0 26	0 Engaged	.302 .059
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative  Positive  Neutral  In your view, should a positive screening prevent couples from marr  Negative  Positive  Neutral  B: Social status  Do you think premarital screening is a preventive measure?  Negative  Positive  Negative  Positive  Neutral	and your partner s 3 95 4 riage? 9 84 9 Single 7 398 8	20 521 9 22 494 34 Married 0 26 0	0 Engaged 4 204	.302 .059
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative  Neutral  In your view, should a positive screening prevent couples from marr Negative  Positive  Neutral  3: Social status  Do you think premarital screening is a preventive measure?  Negative  Positive  Neutral  Should a positive screening result prevent couples from marriage, a.	and your partner of 3 95 4 95 4 9 9 Single 7 398 8 8 8 senforced by legal	20 521 9 22 494 34 Married 0 26 0	0 Engaged 4 204 5	.302 .059 
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative  Positive  Neutral  In your view, should a positive screening prevent couples from marr  Negative  Positive  Neutral  B: Social status  Do you think premarital screening is a preventive measure?  Negative  Positive  Negative  Positive  Neutral	and your partner s 3 95 4 riage? 9 84 9 Single 7 398 8	20 521 9 22 494 34 Married 0 26 0	0 Engaged 4 204	.302 .059
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative  Positive  Neutral  In your view, should a positive screening prevent couples from marr Negative  Positive  Neutral  B: Social status  Do you think premarital screening is a preventive measure?  Negative  Positive  Negative  Positive  Neutral  Should a positive screening result prevent couples from marriage, and Negative	and your partner of 3 95 4 4 95 4 9 Single 7 398 8 8 8 senforced by legal 58	20 521 9 22 494 34 Married 0 26 0	0 Engaged 4 204 5	.302 .059 
If premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marn Negative Positive Neutral 3: Social status Do you think premarital screening is a preventive measure? Negative Positive Neutral Should a positive screening result prevent couples from marriage, a Negative Positive Neutral Should a positive screening result prevent couples from marriage, a Negative Positive Neutral If a positive screening indicated that both you and your partner were	3 95 4 7 108	20 521 9 22 494 34 Married 0 26 0 1 measures? 4 14 8	Engaged 4 204 5 16 142 55	.302 .059 
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative Positive Neutral  In your view, should a positive screening prevent couples from marr Negative Positive Neutral  3: Social status  Do you think premarital screening is a preventive measure?  Negative Positive Neutral  Should a positive screening result prevent couples from marriage, and Negative Positive Positive Positive	3 95 4 7 108	20 521 9 22 494 34 Married 0 26 0 1 measures? 4 14 8	Engaged 4 204 5 16 142 55	.302 .059 
If premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marn Negative Positive Neutral B: Social status Do you think premarital screening is a preventive measure? Negative Positive Neutral Should a positive screening result prevent couples from marriage, as Negative Positive Neutral Should a positive screening result prevent couples from marriage, as Negative Positive Neutral If a positive screening indicated that both you and your partner were the marriage?	3 95 4 95 4 riage? 9 84 9 Single 7 398 8 8 247 108 re carriers of a know 30 271	20 521 9 22 494 34 Married 0 26 0 1 measures? 4 14 8	Engaged  4 204 5 16 142 55 ase, would you p	.302 .059 .059 .0880 0.144 .0roceed with
If premarital screening indicated that you had a hereditary disease unaffected children? Negative Positive Neutral In your view, should a positive screening prevent couples from marn Negative Positive Neutral B: Social status Do you think premarital screening is a preventive measure? Negative Positive Neutral Should a positive screening result prevent couples from marriage, as Negative Positive Neutral Should a positive screening result prevent couples from marriage, as Negative Positive Neutral If a positive screening indicated that both you and your partner were the marriage? Negative	and your partner of 3 95 4 95 4 95 9 84 9 9 84 9 9 8 8 8 8 8 8 8 247 108 re carriers of a know 30	20 521 9 22 494 34 Married 0 26 0 1 measures? 4 14 8	Engaged  4 204 5  16 142 55  ase, would you p	.302 .059 .059 .0880 0.144 .0000000000000000000000000000000
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative Positive Neutral  In your view, should a positive screening prevent couples from marn Negative Positive Neutral  B: Social status  Do you think premarital screening is a preventive measure?  Negative Positive Neutral  Should a positive screening result prevent couples from marriage, and Negative Positive Neutral  If a positive screening indicated that both you and your partner were the marriage?  Negative Positive	3 95 4 4 riage? 9 84 9 Single 7 398 8 8 247 108 re carriers of a known 30 271 112	20 521 9 22 494 34 Married 0 26 0 1 measures? 4 14 8	Engaged 4 204 5 16 142 55 ase, would you p 3 161 49	.302 .059 .059 .0880 0.144 .0005
If premarital screening indicated that you had a hereditary disease unaffected children?  Negative Positive Neutral In your view, should a positive screening prevent couples from mark Negative Positive Neutral B: Social status Do you think premarital screening is a preventive measure?  Negative Positive Neutral Should a positive screening result prevent couples from marriage, at Negative Positive Neutral If a positive screening indicated that both you and your partner were the marriage?  Negative Positive Negative Positive Neutral If a positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had carrier status and your far positive screening indicated that you had your far positive screening indicated that you had your far positive screening your far positive screening your far positive screeni	3 95 4 4 riage? 9 84 9 Single 7 398 8 8 247 108 re carriers of a known 30 271 112	20 521 9 22 494 34 Married 0 26 0 1 measures? 4 14 8	Engaged 4 204 5 16 142 55 ase, would you p 3 161 49	.302 .059 .059 .0880 0.144 .0005

T-	LI	-	-	(cont	2	1
1 a	IJ	е	v	CORL	mue	a

B: Social status				
Do you think premarital screening is a preventive measure?	Single	Married	Engaged	<i>p</i> -value
If premarital screening indicated that you had a hereditary disease your partner was affected, would you get married?	and			0.087
Negative	20	3	5	
Positive	290	20	161	
Neutral	103	3	47	
Do you think that the decision to marry in cases of incompatibility	between spouses i	s wrong?		_
Negative	212	17	120	0.448
Positive	119	4	57	
Neutral	82	5	36	
If premarital screening indicated that you had a hereditary disease unaffected children?	and your partner	was affected, do y	ou expect alterna	tive solutions for
Negative	104	6	62	0.498
Positive	110	10	51	
Neutral	199	10	100	
Do you think premarital screening limits the spread of certain gene	tic diseases?			
Negative	16	1	6	0.775
Positive	387	25	204	
Neutral	10	0	3	
In your view, should a positive screening prevent couples from marr	iage?			
Negative	27	0	4	0.008
Positive	352	25	201	
Neutral	34	1	8	

early detection of hereditary diseases that would cause serious health complications. <sup>28,29</sup> However, having a compulsory preventive program that screens for genetic and hereditary diseases in individuals who intend to marry is essential to decrease the transmission of these diseases, particularly in cultures with a high rate of consanguineous marriages, which increase the frequency of congenital diseases affecting the population.

#### Conclusion

Overall knowledge regarding premarital screening tests must be improved. On the basis of the study results, participants had positive attitudes toward premarital screening and understood its importance. The study data may aid in developing educational programs designed to enhance awareness of, and positive inclinations toward, premarital screening tests. These results could be changed by raising awareness through educational programs in the media, which should be a powerful tool to achieve this goal. The limitation of this study is its sex bias, because most of our sample comprised women. Further studies that cover the whole kingdom will be crucial to understanding the knowledge and attitudes of people who are far from urban cities and to potentially target couples with consanguineous marriages.

### Source of funding

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

#### Conflict of interest

The authors have no conflict of interest to declare.

#### Ethical approval

Ethical approval was obtained from the Institutional Review Board at King Fahad Medical City, Riyadh, KSA, before collection of the data (IRB # 19-182, 2019). The questionnaire was distributed and completed electronically; replying was optional, and confidentiality was assured.

#### Consent

Informed consent was obtained from all participants before participation in this study, and no names or IDs were collected from the participants.

#### **Authors contributions**

E.K., R.S., A.A., and A.M. worked on the conceptualization of the study and data curation. Formal analysis was performed by A. AlQhtani and S.A. The original draft was written by R.S. and S.A. Final review and editing were performed by S.A. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

### Acknowledgment

The authors thank the research center at KFMC for their valuable support.

#### References

- Al-Aama JY. Attitudes towards mandatory national premarital screening for hereditary hemolytic disorders. Health Policy 2010 Sep 1; 97(1): 32-37.
- Meyer BF. Strategies for the prevention of hereditary diseases in a highly consanguineous population. Ann Hum Biol 2005; 32(2): 174–179.
- El-Hazmi MA, Al-Swailem AR, Warsy AS, Al-Swailem AM, Sulaimani R, Al-Meshari AA. Consanguinity among the Saudi Arabian population. J Med Genet 1995 Aug 1; 32(8): 623–626.
- Al-Aama Jumana Y, Al-Nabulsi Baraa K, Alyousef Mohammad A, Asiri Nawal A, Al-Blewi Sawsan M. Knowledge regarding the national premarital screening program among university students in western Saudi Arabia. Saudi Med J 2008; 29(11): 1649–1653.
- Alswaidi FM, O'Brien SJ. Is there a need to include HIV, HBV and HCV viruses in the Saudi premarital screening program on the basis of their prevalence and transmission risk factors?
   J Epidemiol Community Health 2010; 64(11): 989–997.
- 6. MOH. *Premarital Screening*; 2017. 31 July 2017; Available from: <a href="https://www.moh.gov.sa/en/HealthAwareness/Beforemarriage/Pages/default.aspx">https://www.moh.gov.sa/en/HealthAwareness/Beforemarriage/Pages/default.aspx</a>.
- Alhamdan NA, AlMazrou YY, AlSwaidi FM, Choudhry AJ. Premarital screening for thalassemia and sickle cell disease in Saudi Arabia. Genet Med 2007; 9(6): 372–377.
- 8. WHO. Hereditary anemia: genetic basis, clinical International Journal of Medical and Health Research features, diagnosis and treatment. **Bull World Health Organ 1982**; 60(5): 643–660.
- Alkuraya FS. Genetics and genomic medicine in Saudi Arabia.
   Mol Genet Genomic Med 2014 Sep 1; 2(5): 369-378.
- Al-Kahtani NH. Acceptance of premarital health counseling in riyadh city, 1417h. J Family Community Med 2000; 7(2): 27–34.
- Ibrahim NK, Al-Bar H, Al-Fakeeh A, Al Ahmadi J, Qadi M, Al-Bar A, Milaat W. An educational program about premarital screening for unmarried female students in King Abdul-Aziz University, Jeddah. J Infect Public Health 2011; 4(1): 30–40.
- Hamamy H, Antonarakis SE, Cavalli-Sforza LL, Temtamy S, Romeo G, Ten Kate LP, et al. Consanguineous marriages, pearls and perils: Geneva international consanguinity workshop report. Genet Med 2011 Sep; 13(9): 841–847.
- Cohen J, Rothschild C, Golub G, Omondi GN, Kruk ME, McConnell M. Measuring the impact of cash transfers and behavioral 'nudges' on maternity care in Nairobi, Kenya. Health Aff 2017 Nov 1; 36(11): 1956–1964.
- Al-Kahtani NH. Acceptance of premarital health counseling in Riyadh city, 1417H. J Family Community Med 2000 May; 7(2): 27.
- Gosadi IM. National screening programs in Saudi Arabia: overview, outcomes, and effectiveness. J Infect Public Health 2019 Sep 1; 12(5): 608-614.
- Bener A, Al-Mulla M, Clarke A. Premarital screening and genetic counseling program: studies from an endogamous population. Int J Appl Basic Med Res 2019 Jan; 9(1): 20.
- Alkalbani A, Alharrasi M, Achura S, Al Badi A, Al Rumhi A, Alqassabi K, et al. Factors affecting the willingness to undertake premarital screening test among prospective marital individuals. SAGE Open Nurs 2022 Feb; 8: 23779608221078156.

- 18. Ibrahim NK, Bashawri J, Al Bar H, Al Ahmadi J, Al Bar A, Qadi M, et al. Premarital Screening and Genetic Counseling program: knowledge, attitude, and satisfaction of attendees of governmental outpatient clinics in Jeddah. J Infect Public Health 2013 Feb 1; 6(1): 41–54.
- Melaibari M, Shilbayeh S, Kabli A. University students' knowledge, attitudes, and practices towards the national premarital screening program of Saudi Arabia. J Egypt Public Health Assoc 2017 Mar 1; 92(1): 36–43.
- Ibrahim NKR, Al-Bar H, Al-Fakeeh A, Al Ahmadi J, Qadi M, Al-Bar A, Milaat W. An educational program about premarital screening for unmarried female students in King Abdul-Aziz University, Jeddah. J Infect Public Health 2011; 4(1): 30–40. https://doi.org/10.1016/j.jiph.2010.11.001.
- Al-Shroby WA, Sulimani SM, Alhurishi SA, Dayel ME, Alsanie NA, Alhraiwil NJ. Awareness of premarital screening and genetic counseling among Saudis and its association with sociodemographic factors: a national study. J Multidiscip Healthc 2021; 14: 389.
- 22. Al Sulaiman A, Suliman A, Al Mishari M, Al Sawadi A, Owaidah TM. Knowledge and attitude toward the hemoglobinopathies premarital screening program in Saudi Arabia: population-based survey. Hemoglobin 2008 Jan 1; 32(6): 531-538.
- 23. Albadrani GM, Alshanbari HM, Baraja DA, Alahaideb LK, Alabdullah SM, Alzahrani SM, et al. Evaluating knowledge and attitude about premarital screening among Princess Nourah Bint Abdulrahman University students in Riyadh. J Res Med Dent Sci 2020; 8(6): 205–214.
- Al-Aama JY, Al-Nabulsi BK, Alyousef MA, Asiri NA, Al-Blewi SM. Knowledge regarding the national premarital screening program among university students in western Saudi Arabia. Saudi Med J 2008; 29: 1649–1653.
- Sindi A, Altayyari S, Omer A, Aljifri H, Magadmi B, Nemri A, et al. Knowledge and awareness on personalised medicine amongst medical students: a cross-sectional survey. J Health Spec 2017; 5: 17.
- 26. Khalil EMF, Abdelkader SM, Alsaeed MD, Alshahrany NM. Knowledge, beliefs and behavior intention about premarital screening among King Saud University female students in Riyadh. Sch J Appl Med Sci 2014; 2(5E): 1797–1805.
- AlHamdan NA, AlMazrou YY, AlSwaidi FM, Choudhry AJ. Premarital screening for thalassemia and sickle cell disease in Saudi Arabia. Genet Med 2007 Jun; 9(6): 372-377.
- Ministry of Health (MoH). National Newborn Screening Program Continues. Available from, <u>shorturl.at/fJLWZ</u> 2017; 2017.
- Mujamammi AH. Insights into national laboratory newborn screening and future prospects. Medicina 2022 Feb 11; 58(2): 272.

How to cite this article: AlOtaiby S, Alqahtani A, Saleh R, Mazyad A, Albohigan A, Kutbi E. Comprehension of premarital screening and genetic disorders among the population of Riyadh. J Taibah Univ Med Sc 2023;18(4):822–830.