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Evaluating Knowledge and Attitude about Premarital Screening among Princess Nourah Bint Abdulrahman University Students in Riyadh

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ABSTRACT

Objective: The awareness and attitudes of PNU students towards PMS program need to be evaluated.

Background: Consanguineous marriages are very common in the Middle East, especially Saudi Arabia, and it can cause hemoglobinopathies. Premarital test is very important to prevent and reduce infectious and hereditary diseases. By educating students we can decrease and limit genetically transmitted diseases.

Methods: The study was conducted at PNU from January to April 2019. The questionnaire was in both Arabic and English and was handed out by the researchers to 600 female participants, limiting them to unmarried and engaged students and then was analyzed using Excel.

Results: An overwhelming majority of participants (96.16%) were aware of PMS, and (90.16%) believe that the purpose of PMS is to control and reduce hereditary and infectious diseases. Almost half of the participants (48.16%) believe that PMS limits hereditary diseases; thus, (38.16%) of respondents favoured passing a law to prevent any marriage with incompatible results. However, some PNU participants (12.16%-16.16%) indicated they would still marry regardless if she or her partner is affected with hereditary diseases.

Conclusion: Most of the respondents were aware that the PMS is a preventive measure and believed that the PMS controls and reduces hereditary and infectious diseases.

Key words: Premarital screening program (PMS), Princess nourah university (PNU), Marriage, Inherited genetic diseases, Infectious diseases, Knowledge, Attitudes, Riyadh, Kingdom of saudi arabia (KSA)

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INTRODUCTION

The Saudi Arabian community is built by marriages which hopefully leads to the birth of healthy children. In Saudi Arabia the overall rate of consanguineous marriage is reported to be 57.7% with regional variation from a low of 34.0% to an astonishing high of 80.6% [1]. Reports showed high rates of consanguineous marriage across regions, which was associated with mental retardation, neural tube defects, and other hereditary neurological diseases. Studies have shown there is a strong link between epilepsy and consanguinity and with family history [2]. An estimated 70% of cases of kidney diseases in childhood are congenital with a likely genetic basis. In Kingdom of Saudi Arabia (KSA), due to the high rate of consanguineous marriages this percentage is presumably even higher particularly for diseases with an autosomal recessive transmission. KSA has an active Newborn Screening (NBS) Program addressing

inherited metabolic diseases (IMD). However, the program only reaches 10–20% of newborns and is selective, in that participation is by individual clinical centers or referral of symptomatic patients. Screening is based on dried blood spots (DBS) and tandem mass spectrometry (1) (MS–MS) [3]. NBS can treat diseases because of early detection and treatment. The KSA experience indicates that approximately 50% of diseases identified by MS–MS are manageable [4]. However, in many cases the phenotype cannot be prevented, or even with treatment results in significant morbidity.

To prevent these diseases, the Ministry of Health in the Kingdom of Saudi Arabia (KSA) sets the national Premarital Screening (PMS) Program [5]. The PMS was named "Healthy Marriage Program" by the Saudi Ministry of Health [5,6]. PMS mainly targets couples who plan to get married. The main purpose of PMS is to identify the genetic and infectious diseases in couples before they get married [7]. PMS is applied as a priority in many countries such as Australia, Hong Kong, Taiwan, France, Thailand, Cyprus, Greece, Italy, Singapore, Cuba, and Iran [8]. In 2002, the PMS was optional in KSA and it became a mandatory condition of marriage in 2004 [5]. Six years after launching the program, researchers have found a marked decrease in the number of at-risk marriages and have predicted a considerable reduction in the genetic disease burden in Saudi Arabia in upcoming years [9].

PMS can prevent inherited diseases and this type of marriage would be considered as a healthy marriage that protects the next generation from inherited genetic diseases as well as infectious diseases. Despite the prevalence of inherited diseases mainly due to consanguineous marriages, the current diagnosis of DGS in Saudi Arabia is mainly based on conventional high-resolution chromosome banding (karyotyping) and FISH techniques. This numerous disease causes inveterate defects, neurodevelopmental delays and medical ailment, and its increasing worldwide. Consequently, the deletion in chromosome 22 leads to various disorders such as Goldberg-Shprintzen syndrome, conotruncal anomaly face syndrome, palatal abnormalities, velocardiofacial [10,11] and particularly in Saudi Arabia, given the high consanguinity rates often arising from traditional Arabic marriages [12].

In KSA, PMS is focused on haemoglobinopathies diseases including SCA and thalassemia [13] as they are highly spread all over the country especially in Al-Ahsa and Jizan [14]. The expansion of SCA trait differ from 2% to 27% and has been found that SCA reached 1.2% in some KSA regions [14-16]. The most important reasons for the high rate of haemoglobinopathies diseases is consanguineous marriage, which highly occurs (42-67%) in KSA [14,17,18]. Consanguineous marriages are so common in the Middle East. It constitutes 42-67% of all marriages in KSA 54% in Qatar, 40-54% in the United Arab Emirate (UAE) 29-64% in Jordan, 21-33% in Egypt, 44-63% in Sudan, and 40-45% in Yemen [19]. In 2009, a study was conducted in Arar found that the percentage of genetic diseases caused by marriage are decreased 60% after one year incorporating the PMS [20].

The beginning of the PMS was mainly testing hemoglobinopathies, such as thalassemia and sickle cell anemia (SCA) in 2004 [21]. Thalassemia occurs because of the presence of mutated hemoglobin. There are two types of thalassemia: alpha (α-thalassemia) and beta (β- thalassemia) depending on the location of the mutation. The hemoglobin is made up of four-alpha genes, two inherit from the father and two from the mother, in addition of the two beta genes, each one is inherited from each parent [22]. On the other hand, SCA is a genetic disease that affects red blood cells, as it changes its properties and shape, so that it becomes semicircular or sickle shaped instead of its natural disk form [23]. Haemoglobinopathies and thalassemia's are very prevalent in KSA. The carrier frequency for hemoglobin S is >25%, for α-thalassemia it is 1–2% and for þ-thalassemia it is 50–60% in the Eastern province [24]. Similarly, other Mendelian traits such as hereditary deafness [25], spinal muscular atrophy [26] and cystic fibrosis are common [27]. The prevalence rates of b –thalassemia (b-thal) and SCD in Saudi Arabia are considered one of the highest compared to surrounding countries in the Middle East (0.05% and 4.50%, respectively) [9].

Also, PMS covers a lot of common infectious diseases that might be prevented and treated if detected early such as hepatitis B virus [13], hepatitis C virus as well as HIV [23,28,29]. In

KSA, hepatitis B was found to be prevalent (2.7–9.8%) in all regions; north, central, western and eastern [30-32].

The HIV infection in KSA was rare due to the social, cultural, and religious reasons. However, It has been found that the prevalence of HIV between 1984 -2001 was (21.3%) among Saudi citizens and (78.7%) were non-Saudi citizens [33]. Unfortunately, it has been found that 42.5% of applicants in KSA for PMS from the year 2004 to 2005 took the risk and completed the marriage with the knowledge that their spouse had a chance of developing sickle cell anemia [14,34].

The percentage of sensorineural hearing loss (SNHL) in KSA is 14 per 1000, much higher than the presence in developed countries. In Middle East about 76% may develop high risk for evolution of hearing loss in the generation of Consanguineous Marriage (CM). CM raise the hazard of evolution autosomal recessive condition in the offspring. As it is evident, the pre-marital screening program contributed to the reduction of many complex and serious genetic diseases [21,10].

METHODS

Research hypothesis and objectives

The knowledge and attitudes about the importance of PMS are high among PNU students. This study assessed the level of awareness and the attitudes of PNU students towards PMS.

Data collection and Study design

After obtaining the Institutional Review Board (IRB registration number with KACST, KSA: H-01-R-059) approval from PNU. The questionnaire used was adopted from (23) and it was partially changed in the marital status. The study focused on unmarried and engaged PNU students and no participants were excluded. The questionnaire was written in both Arabic and English languages. It was associated with a consent form that had the participant's name and signature. The objectives of the study were explained to the participants while distributing the questionnaire in three different colleges (Sciences, Health and Humanities). A total of 600 questionnaires (200 participants from each college) were distributed between January 2019 to April 2019.

Statistical analysis

The collected data were entered and analyzed using Excel (version (16.0.6769.2017)/2016).

RESULTS

This study was conducted in PNU in Riyadh region, KSA, 2019. The number of participants was 600 from three different colleges: Health, Science and Humanities. The distribution of the participants to their colleges were 226 (36.77%) Health, 180 (30%) Science, and 194 (32.33%) Humanities (Table 1). All participants were females and the academic years were, the first year (3.33%), second year (13.88%), third year (6.5%), fourth year (17.33%), fifth year (14%), sixth year (45%). There were 75 (9.5%) of participants that were engaged, whereas the majority were single 543 (90.5%) (Table 1).

According to the participants place of residence in Riyadh, the distribution was in Northern (36.66%), in Eastern (34%), in Western (15%), Southern (14.33 %). There were variations in the participants family income. According to their answers regarding the income levels, some of the participants were (4.16%) receiving less than 3000 SR, (6.66%) were receiving between 3000 to 5999 SR, (12.16%) receiving between 6000 to 8999 SR, (26%) receiving between 9000 to 12000 SR and half of them (51%) receiving more than 12000 SR (Table 1). Also, there were variations in the education level of the participants parents. The data showed that participants fathers education level rnaged from Illiterate (0.38%), Primary (3.66%), Intermediate (8%), Secondary (23.33%), University (58.16%) and 6% of participants answered Other without specification (Table 1). On the other hand, the education of participants mothers was (5.16%) Illiterate (8.5%) Primary (8%) Intermediate (25%) Secondary (50.83%) University and (2.5%) Other (Table 1).

The data showed that majority of the participants (96.16%) were aware of the PMS program. They knew about the importance of the PMS program (87.66%), except (12.33%). The percentage of participants that knew about the diseases, which are included in the PMS program, was (63.83%), whereas (36.16%) of participants did not know. Moreover, (60%) of participants said they knew about the complications of diseases that included in the PMS program; however, (40%) of participants did not know (Figure 1).

Table 1: Socio-demographic characteristics of study participants among PNU.

Characteristics	Number (NO)	Percentage (%)
	Colleges	
Health Colleges	226	37.66
Humanities Colleges	194	32.33
Science Colleges	180	30
	Academic year	
First Year	20	3.33
Second Year	83	13.88
Third Year	39	6.5
Fourth Year	104	17.33
Fifth Year	84	14
Sixth Year	270	45
	Marital status	
Single	543	90.5
Engaged	57	9.5
	Place of residency	
Northern Riyadh	220	36.66
Eastern Riyadh	204	34
Western Riyadh	90	15
Southern Riyadh	86	14.33
	Family income level	
Less than 3000	25	4.16
From 3000 to 5999	40	6.66
From 6000 to 8999	73	12.16
From 9000 to 12000	156	26
More than 12000	306	51
	Father's education level	
Illiterate	5	0.38
Primary	22	3.66
Intermediate	48	8
Secondary	140	23.33
University	349	58.16
Other	36	6
	Mother's education level	
Illiterate	31	5.16
Primary	51	8.5
Intermediate	48	8
Secondary	150	25
University	305	50.83
Other	15	2.5

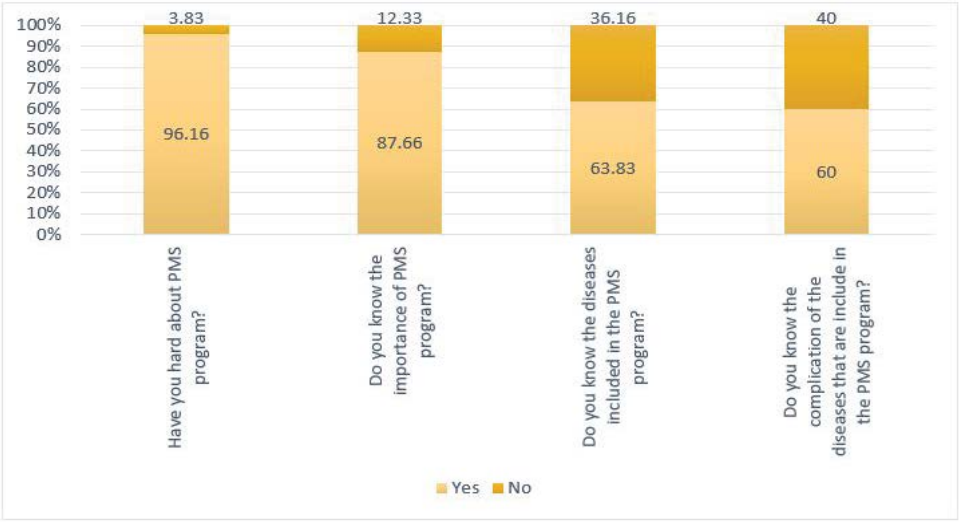

Figure 1: Knowledge of PNU students regarding the importance of PMS program.

The data showed the majority of participants (96.16%) knew that the aim of PMS program is to control and reduce hereditary and infectious diseases, while (9.83%) of participants thought that PMS is the routine requirements of marriage in KSA (Figure 2). The Ministry of health specified some centers all over KSA to run PMS, however, (79.16%) of participants said they will do the test in governmental hospitals, and (12.66%) in a non-governmental hospital, whereas (8.16%) didn't know where they can do the PMS (Figure 3). PNU students received their information about PMS from different sources. A high percentage of participants (58.5 %) knew about PMS from there family, and (21%) from the internet and (13.3%) from media, while (3.16%) of participants knew about PMS from their friends. Also, (3.5%) read books about PMS, (0. 1%) newspaper, while (0.3%) of participants knew about PMS without specifying the source (Figure 4). The participants answered differently regarding the diseases that were included in PMS program, (31.5%) said SCA, (25.5%) HIV and (20.33%) thalassemia. Moreover, participants thought about other infectious diseases that might be included in PMS such as hepatitis A (7.83%), hepatitis B (9.66%), and hepatitis C (7.5%) as well as syphilis (6.33%), gonorrhea (4.83%) and (1.33%) of students thought about other. diseases without specification (Figure 5).

Table 2 is about all the PNU students' attitudes about PMS program believes, decisions, and the degree of the participant's agreement to each one of them. As a preventative measure, (65.16%) strongly agreed, (32.33 %) agreed, (2.33%) didn't know, (0.16%) of students disagreed (Table 2). Moreover, the opinion of the participants to make a law for the PMS program to prevent any marriage with an incompatible result, (48.16%) strongly disagreed, (35%) agreed, (19.33%) didn't know, and (7%) disagreed (Table 2). We asked participants about their opinion if they decided to get married with incompatible result; is it a wrong decision or not, (30.66%) strongly agreed, (42.66%) agreed, (16.66%) didn't know, (8.66%) disagreed, (1.33%) strongly disagreed (Table 2).

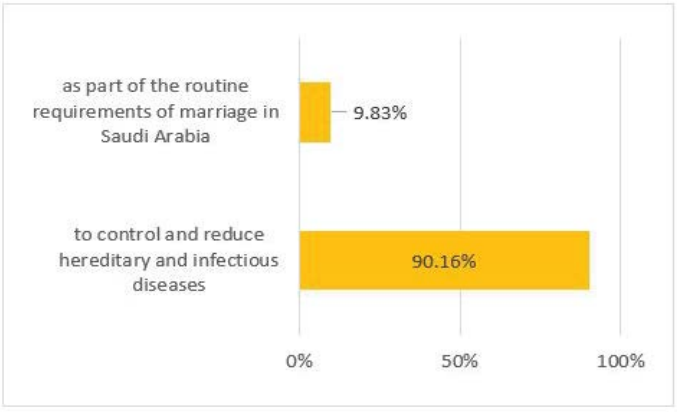

Figure 2: The Participants opinion about the reasons for establishing the PMS program.

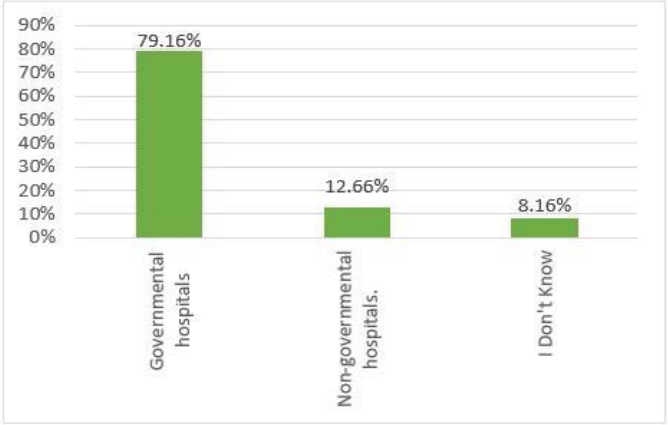

Figure 3: Centers can participants run PMS program test in.

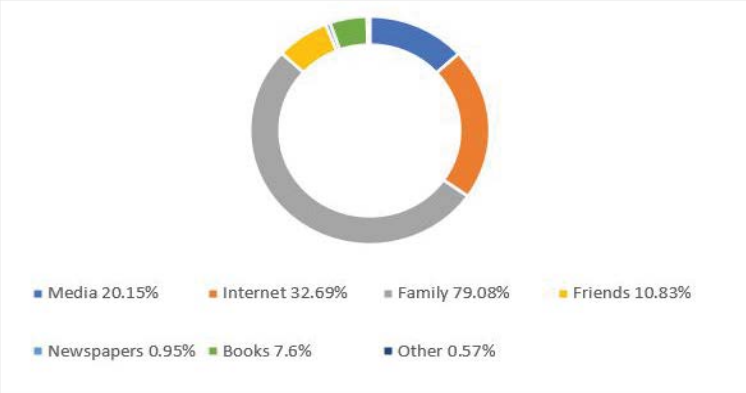

Figure 4: The sources (s) of information about the PMS program.

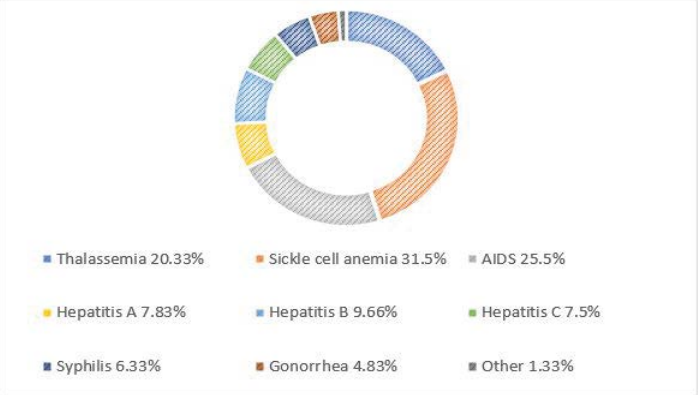

Figure 5: Diseases included in PMS program.

Table 2: Attitude of the PNU students towards PMS program.

Attitude	SA	A	IDK	D	SD
Do you think that the PMS program is considered a preventive measure?	(391; 65.16%)	(194; 32.33%)	(14; 2.33%)	(1; 0.16%)	(0; 0%)
Do you think that we should have a law to prevent any marriage with incompatible result?	(289; 48.16%)	(270; 45%)	(33; 5.5%)	(8; 1.33%)	(0; 0%)
Do you think that the decision to get married with incompatible result is a wrong decision?	(184; 30.66%)	(256; 42.66%)	(100; 16.66%)	(52; 8.66%)	(8; 1.33%)
If the test result indicate that you are affected with hereditary diseases while the other partner is not, will you get married?	(27; 4.5%)	(70; 11.66%)	(200; 33.33%)	(222; 37%)	(81; 13.5%)
If the test result indicate that your partner is affected with heredity diseases while you are not, will you get married?	(26; 4.33%)	(47; 7.83%)	(196; 32.66%)	(239; 39.83%)	(92; 1533%)

SA: Strongly Agree., A: Agree., IDK: I Don't Know., D: Disagree., SD: Strongly Disagree

Also, we asked participants if were they affected with hereditary diseases while their partner isn't, (4.5%) strongly agreed to get married, (11.66%) agreed, (33.33%) didn't know, (37%) disagreed and (13.5%) strongly disagreed (Table 2). Moreover, most of the participants said if their partner is affected with hereditary diseases while they weren't, (4.33%) of participants strongly agreed, while (7.83%) agreed, (32.66%) didn't know (39.83%), disagreed and (15.33%) strongly disagreed (Table 2).

DISCUSSION AND CONCLUSION

The consequences of this examination demonstrated that participants knew and had learning with respect to the accessibility of PMS in KSA. However, there was a small percentage of participants with insufficient attitude towards PMS. This could possibly be due to not having a firm law that prevents the marriage from happening after receiving incompatible results.

The results of this study showed that PNU participants had affirmative knowledge. Similar studies have been reported in different universities all over KSA [21,23,29,35]. The students of King Saud University Jizan Region (KSUJ) had a high rate of knowledge about PMS at 99.9% [23] when (96.16%) of PNU students said that they heard about PMS. This study demonstrated that the greater part of Taif University (TU) understudies realized that genes could transmit inherited illnesses and a reasonable number of them have heard sickle cell anemia and thalassemia. Interestingly, just 58% of members realized that PMS identifies both genetic and perpetual transferable illnesses. In addition, 42.1% knew that it tested the fertility of participants. These outcomes are predictable with different reports from various areas in Saudi Arabia [29]. The present study in [35] showed that 20% of female Students had poor knowledge, 55% had reasonable comprehension when 25% were well educated about it.

A high percentage of respondents had a great knowledge towards the importance of PMS (87.66%) in PNU, whereas (72.4%) in KSUJ [23]. As of late, the PMS program is supported from the general population. However, they had a low understanding of the test results [36,37]. Numerous investigations from various areas of Saudi Arabia consent to this [25]. Yahia et al. revealed 70% acknowledgment rate of the PMS program among wellbeing science understudies in Abha. Additionally, an investigation in King Abdulaziz University, Jeddah, revealed that 99% of female understudies commonly conceded to the significance of PMS [21]. In a network-based investigation directed in Riyadh, 94% considered PMS as a critical preventive measure for a hereditary blood disorder [13].

The present examination additionally announced general uplifting frame of mind toward PMS among Taif University understudies. In KSA, awareness towards PMS has considerably increased throughout the years. A study that was conducted in 2000 stated that most of participants 364 (75.2%) acknowledged the idea of PMS, and the individuals who acknowledged it were more established than the individuals who rejected it. The gathering that had the least level of awareness towards PMS were under 20 years old. This finding can be clarified by one's level of education, life experiences and health issues that are caused by marriage. Ibrahim, Al-Bar [21] portrays the awareness of participants towards PMS. 83.2% strongly agreed with the importance of PMS and how that the program will contribute to a reduction in the prevalence of some genetic diseases Ibrahim, Al-Bar [21] explained the awareness with members towards the PMS. 83.2 % strongly agreed with the significance of PMS and how that the program will add to a decrease in the commonness of some hereditary diseases. When the recent study [23] demonstrated that most of members had an outstanding information about the significance of pre-marriage screening programs (95.8%). That might be due to the massive efforts from Ministry of health that introduced the PMS to citizens through the educational systems, internet and media as well as campaigns in different regions to make sure it reaches out to all KSA regions.

Remarkably, [21] led an examination to evaluate the knowledge and attitudes of unmarried female understudies in King Abdulaziz University, Jeddah towards PMS before and after an educational campaign. They found that 80.9% of the example had insufficient knowledge about PMS. Strikingly, this rate altogether declined to 21.9% after going to an educational campaign about PMS. However, participants with the rate of (5.1%) strongly disagreed as PMS being a preventive measure. In [21] few of the participants attitudes (11.7%) had religious misunderstandings regarding PMS. The most well-known explanation behind PMS dismissal for almost all participants in this examination was the dread of accepting incongruent PMS results and thusly, the end of a generally ideal marriage. Health Science understudies in Abha consented to these equivalent reasons with conflicting outcomes. The counteractive action of malady transmission to them and their offspring was the essential explanation behind sharing in a PMS as opposed to ensure the wellbeing of their partner. What is more, their fundamental purpose behind dismissing PMS was to not meddle with God's will [25]. More established examinations announced the nearness of misinterpretations about Islamic rules that lead to PMS rejection [13]. Just 1% of participants in the present investigation had a religious misguided judgment seeing PMS as they suspected it meddled with their confidence in predetermination. In addition, participants from Riyadh and Jeddah revealed couple of

understudies with comparable misconception [21,35].

The negative attitude towards PMS could possibly be due to not having a firm law that prevents the marriage from happening after receiving incompatible results [23]. As referenced beforehand, regardless of whether the PMS program is required to get married, each partner can get married regardless to their test outcomes. In [23] strongly agreed to make a law for PMS were (32.8%). In PNU almost half of the participants (48.16%) strongly agreed it is important to have a law that prevents marriages from happening if results were indeed incompatible. In [29] most participants (91.8%) requested the execution of a law that forbids incompatible marriages [23].

An investigation in [21] demonstrated that 64.6% of female college understudies concurred that the choice to get married ought to be free paying little mind to the danger of genetic disease. Alternately, prior reports from Riyadh demonstrated a 63% endorsement rating for legitimate obstruction if there should be an occurrence of incompatibility [13], though later reports have appeared far lower rate, with just 36% members, consenting to execute laws and guidelines to anticipate in danger marriages [35].

The current PMS in KSA included two inherited genetic diseases and two infectious diseases. The inherited genetic diseases are SCA and thalassemia. However, it has been found that 2100 Saudi males were screened for G6PD deficiency, of whom 100 (4.76 %) were found to be G6PD deficient. On molecular characterization, 6% of those with G6PD deficiency had the mutation A376 G and 2% had the mutation G202A, giving a 2% overall frequency of the mutation G6PD A- [38]. Glocose-6-phosphate dehydrogenase (G6PD) is an enzyme in the pentose phosphate pathway (PPP) that plays an important role in protecting cells from oxidative damage through NADPH production and reduced glutathione production [38].

Furthermore, the two infectious diseases that included in PMS are (Hepatitis and HIV) remain the same regardless of the reported suggestion of adding Syphilis; a sexually transmitted disease with varied and often subtle clinical manifestations [39] and Gonorrhea; Gonorrhea is a sexually transmitted disease (STD) that can contaminate the two partners. It can cause diseases in the private parts, rectum, and throat [40].

PMS is an especially important step towards a future with a generation that has minimum genetically inherited and sexually transmitted infectious diseases as possible. It is important to apply firm laws to those who break or manipulate it, such as having a penalty list that varies from minimum to maximum fines as a health payment for the affected child.

LIMITATION AND FUTURE DIRECTION

Hard copy questionnaire was a clear limitation of this study. Entering the data took a lot of time as the data was an enormous number of participants. However, an online questionnaire would eliminate this problem.

More data analysis is necessary using statistical software such as R software. Also, it is important to explore the possible relationships between knowledge and attitudes of PNU students regarding PMS program using Linear correlation. Despite the high awareness of PNU students towards PMS program, it has been found that there was a slight lack of attitude among PNU students. In order to resolve this issue, the intensification of courses could be suggested to improve the awareness that leads to improving the attitude of university students in KSA.

Moreover, linking the health record with the electronic marriage application form is highly suggested. The marriage request should be an electronic request, doing and receiving PMS results are required to complete the electronic marriage application form. The result of the PMS should be uploaded as a PDF file in the system by PMS center if there are no issues. In case of incompatibility, it is strongly suggested to book an immediate appointment for transferring the applicants to visit premarital counselling clinic. The applicant who did not attend has to pay a fine.

Regarding updating the list of tests that is included in the current PMS, G6PD enzyme deficiency is strongly recommended to be included on the PMS program as well as Syphilis and Gonorrhea.

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