



## Knowledge and attitude towards premarital screening and genetic counseling program among female university students, Hail region, Saudi Arabia

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### Abstract

**Background:** In a step to minimize the risk of the propagation of genetic and some infectious diseases through the generation, Saudi Arabia had started the first national mandatory premarital screening program (NPMS) after the Saudi Royal Decree in 1424 to control inherited hemoglobin disorders. It presents a chance for the individuals to predict their genetic risks to disease and the possible genetic picture of their newborns.

**Objectives:** To detect the degree of knowledge and attitude of the female university students of Hail area towards that important program.

**Material and methods:** It is a cross sectional study carried out on the female students in Hail University, Saudi Arabia. The study was conducted during the year of 2014. Selection of the students was done randomly among students within 18-30 years old. A questionnaire with close-ended questions was designed to collect data from the participants.

**Results:** Although the majority of the participants were aware of the availability of the program (75.5%) and that it is obligatory to do before marriage, only, 64.4 % thought that it includes genetic blood disorders, while (51.1 %), ( 50.3 % ) and (65.2 % ) thought that hepatitis B, C and HIV were included. Knowledge was obtained from the participants from health colleges were better than others though some unsatisfactory knowledge about some modes of transmission of Hepatitis and HIV was encountered. Positive attitudes were obtained as most of the participants (74.4%) in the present study had as they thought that it is important to carry out NPMS. Concerning the participant attitude, most of the participants (74.4%) in the present study were Positive as they thought that it is important to carry out NPMS (48.1%) of the participant stated that medical counseling is important to be given after getting the results (Table 10). However, half of the students thought that Medical counseling is not important to be given after getting the results, and some of them thought it is against Islamic roles, interfere with God's well or cause psychological trouble to the couple. The students, at last, suggested adding Psychological diseases, chronic diseases and drug addiction to the NPMS program.

**Conclusion:** This study indicated that most of the students involved in the current study have a satisfactory knowledge towards the NPMS. However, when considering the diseases included in the program, it was found that their knowledge is not sufficient. There is a need to enhance perception, increase knowledge and improve the attitude of the university students regarding the benefits of NPMS program. This is actually running all through the academic year 2014-2015 by the faculty of Medicine, Hail University.

**Keywords:** national mandatory premarital screening program, Saudi, knowledge, attitude

### 1. Introduction

Pre-marital genetic screening (PMS) presents a good chance for individuals to predict the genetic predisposition to disease and the genetic picture of their newborns<sup>[1]</sup>.

Genetic diseases are the main causes of infant and child death, morbidity, and disability in Arab countries. Hereditary hematological diseases, especially sickle cell anemia (SCA), and thalassemia make up one of the most common groups of genetic disorders in the region. These are not considered fatal diseases, in as much as they have an impact on the health of affected individuals, since they require continuous support and health care, which is translated as economic and psychosocial burdens on both the family and society<sup>[2]</sup>.

Genetic diseases are highly common in the general population

of KSA. The carrier rate for SCA is more than 25% of the total population in some Saudi provinces. Many studies conducted over several years in the different Saudi cities, have detected a high rate of carrier for both sickle-cell anemia and thalassemia<sup>[3, 4]</sup>.

Hepatitis B, C and AIDS are kinds of infectious diseases that can be transferred through marital relationship. It was revealed that the average rate of HIV, HBV and HCV prevalence have to be considered.

In a step to minimize the risk of the propagation of disease through the generation, Saudi Arabia had started the first national obligatory premarital screening program (NPMS) after the Saudi Royal Decree in 1424 to control inherited hemoglobin disorders. It can give a chance to manage

according to the detected risk [5].

The aims of the PMS are mainly to minimizing the burden on the persons, families and the community, increase the knowledge of the community about the types of inheritance and genetic disorders and the appropriate way of selection [6].

The level of awareness of the population regarding various aspects of the relevant disorders included in the PMS is a necessary determinant for the success of such a program. It is therefore important to conduct studies among the community to assess this level of knowledge. University students are an important sub-group of the population since they have a relatively high level of education and they are in the marriageable age group [1]. Up to our knowledge, no studies were done in hail region. The current study is the first study to that deal with this subject among Hail population.

In this study, we aim to determine the degree of knowledge, attitude or beliefs towards NPMS program in a group of Female Saudi University students

## 2. Material and Methods

This is a cross sectional study carried out on 2014 among the female students in Hail University. Selection of the participants was done randomly among students aged between 18 and 30 years. Close-ended questions were chosen to fill the questionnaire that was designed after review of the literature on knowledge and attitude of the NPMS program. The questionnaire then translated to Arabic to be easy for the whole university students to fill. A pilot study was performed on a group of 50 students to test its clarity and easiness. Difficult questions were then modified or replaced. The questionnaire consisted of 4 main parts; the 1<sup>st</sup> part was on the socio-demographic data including age, nationality, college, academic year, marital status and parents' consanguinity. The 2<sup>nd</sup> part tested the students' knowledge regarding NPMS. The 3<sup>rd</sup> part was about the disease included in the NPMS. The 4<sup>th</sup> part included questions about the attitudes and beliefs about the PMS program. A brief explanation about the main objectives of the study was done before giving the questionnaires. Six hundred and forty students received questionnaires that cover all aspects of the study. The questionnaire was distributed to seven colleges inside Hail University, Saudi Arabia. Ethical considerations were followed throughout the study steps.

## 3. Results

The current study included a total of 640 students. Most were Saudi (97.8%), single (90.3%) and a from Hail region (97.3%). Their ages ranged from 18 to 30 years old. Less than one-third (29.8%) of the students were from health science colleges. Concerning consanguinity between parents, 63.9% experienced positive consanguinity and the others recorded distant or no relationship. More than half (53.3%) of the participants had a family income less than 10,000 Riyals per month.

Table 1 shows that majority of the participants were aware of the availability of the program (75.5%) and (76.2 %) knew that it is obligatory to do before marriage. Only 29.3% were aware of the validity period of the results. The main source of information on NPMS was obtained from relatives and family (45.2%), followed by the internet (40.3%) as illustrated in Figure 1. Concerning the knowledge about the diseases included in the NPMS, 64.4 % thought that NPMS targets genetic blood disorders, (51.1 %) for hepatitis C while (50.3 %) thought it was hepatitis B (65.2 %) believed that it involve HIV testing. Unexpectedly, 23.1, 18.9 % and 12.8 % thought that the NPMS included tests for drug, alcohols and psychological disease respectively (Table 1). When considering the awareness of hepatitis B & C, HIV and genetic blood diseases, it was revealed that more knowledge was obtained from the participants from health colleges than others (Tables 2-5). Unfortunately, the health college students revealed unsatisfactory knowledge about some aspects of the mode of transmission of Hepatitis and HIV. Concerning the participant attitude, most of the participants (74.4%) in the present study were Positive as they thought that it is important to carry out NPMS (48.1%) of the participant stated that medical counseling is important to be given after getting the results (Table 6). However, almost half of the students (51.9%) thought that Medical counseling is not important to be given after getting the results, and 14.4 % of them thought it is against Islamic roles or interfere with God's well. In addition, 20.9% imagined that NPMS cause psychological trouble to the couple and 45.1% felt doubt of the results Regarding tests suggested by the participants to be added to NPMS program, Psychological diseases represented the highest rate (75.8%) followed by chronic diseases (50.2%). (Figure 2)

**Table 1:** Awareness (knowledge) about NPMS among Female University Students, Hail Region, Saudi Arabia (2014) (n=640)

Knowledge about	Number of participants having knowledge		Number of participants don't have knowledge	
	No.	%	No.	%
The NPMS	483	(75.5)	154	(24.1)
Validity period of the result	188	(29.3)	452	(70.6)
Obligation of the PMC before marriage	488	(76.2)	152	(23.75)
Retesting before the following marriages	314	(49.1)	326	(50.9)
<b>Disease included in (NPMS)</b>				
Hepatitis B	322	(50.3)	318	(49.7)
Hepatitis C	327	(51.1)	313	(48.9)
HIV	417	(65.2)	223	(34.8)
Sickle cell anemia	244	(38.1)	396	(61.9)
Thalassemia	168	(26.3)	472	(73.7)
Drugs	148	(23.1)	492	(76.9)
Alcohols	121	(18.9)	519	(81.1)
Psychological diseases	82	(12.8)	558	(87.2)

<b>Knowledge about hepatitis B and C</b>				
General Knowledge	328	(82.0)	72	(18.0)
Methods of Prevention	94	(73.4)	34	(26.6)
Methods of Treatment	71	(79.8)	18	(20.2)

**Table 2:** Awareness (knowledge) about hepatitis B and C among Female University Students, Hail Region, Saudi Arabia (2014) (n=640)

Knowledge about	Number of participants having knowledge		Number of participants don't have knowledge	
	No.	%	No.	%
<b>Knowledge about Hepatitis B and C</b>				
General Knowledge	328	(82.0)	72	(18.0)
Methods of Prevention	94	(73.4)	34	(26.6)
Methods of Treatment	71	(79.8)	18	(20.2)
<b>Modes of Transmission</b>				
Sexual relations	318	(84.1%)	60	(15.8)
blood transfusion	310	(79.1%)	82	(20.9%)
Transplacental	287	(84.9%)	51	(15.1%)
Direct contact	49	(24.1%)	154	(75.9%)
Use of patients stuff	133	(51.4%)	126	(48.6%)
Insects	26	(12.6%)	180	(87.4%)

**Table 3:** Awareness (knowledge) about HIV among Female University Students, Hail Region, Saudi Arabia (2014) (n=640)

Knowledge about	Number of participants having knowledge		Number of participants don't have knowledge	
	No.	%	No.	%
<b>Knowledge about HIV</b>				
General Knowledge	306	(73.4)	111	(26.6)
Methods of Prevention	185	(80.0)	46	(20.0)
Methods of Treatment	87	(80.6)	21	(19.4)
<b>Mode of Transmission</b>				
Sexual relations	326	(84.0)	62	(16.0)
blood transfusion	301	(79.8)	76	(20.2)
Transplacental	277	(82.0)	61	(18.0)
Direct contact	79	(30.1)	184	(69.9)
Use of patients stuff	108	(45.2)	131	(54.8)
Insects	37	(16.4)	188	(83.6)

**Table 4:** Awareness (knowledge) about sickle cell anaemia among Female University Students, Hail Region, Saudi Arabia (2014) (n=640)

Knowledge about Sickle cell Anemia	Health colleges' Student having the knowledge		Non Health colleges' Student having the knowledge		Total number of participants having knowledge's	p-value of chi-square test
	No.	%	No.	%		
General Knowledge	187	(76.6%)	57	(25.4%)	244 (38.1 % )	<0.001
Meaning of Carrier	185	(92.0%)	16	(8.0%)	201 (31.4 % )	<0.001
Mode of Transmission	179	(84.8%)	32	(15.2%)	211 (32.9%)	<0.001
Methods of Treatment	136	(84.5%)	25	(15.5%)	161(25.2%)	<0.001

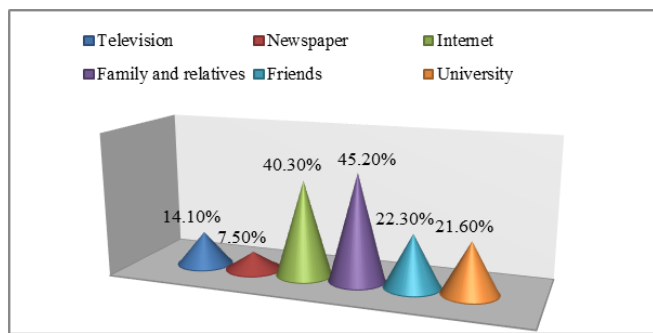
**Table 5:** Awareness (knowledge) about thalassemia among Female University Students, Hail Region, Saudi Arabia (2014) (n=640)

Knowledge about Thalassemia	Health colleges' Student having the knowledge		Non Health colleges' Student having the knowledge		Total number of participants having knowledge's	p-value of chi-square test
	No.	%	No.	%		
General knowledge	123	(73.2)	45	(26.8)	168 (26.3 )	<0.001
Meaning of carrier	119	(82.6)	25	(17.4)	144 (22.5 )	<0.001
Mode of transmission	126	(79.2)	33	(20.8)	159 (24.8 )	<0.001
Methods of treatment	131	(92.3)	11	(7.7)	142 (22.2)	<0.001

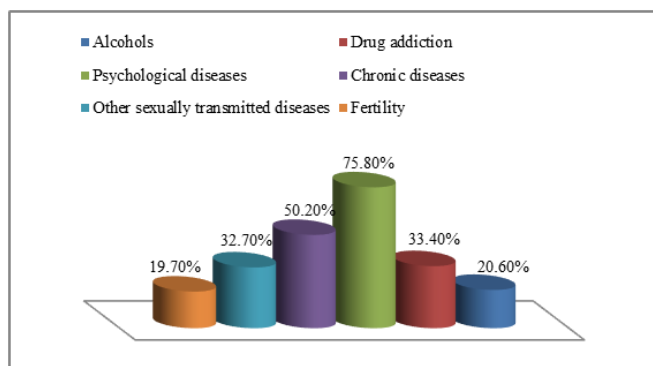
**Table 6:** Attitude towards (NPMS) among Female University Students, Hail Region, Saudi Arabia (2014) (n=640)

Attitude	Number of participants having +ve attitude		Number of participants having -ve attitude	
	No	%	No	%
NPMS is important	476	(74.4)	164	(25.6)
NPMS is against Islamic roles	92	(14.4)	548	(85.6)
Consanguinity can increase the risk of hereditary diseases	518	(80.9)	122	(19.1)
NPMS will reduction of prevalence of some genetic and STDs	189	(29.5)	451	(70.5)

NPMS breaks personal privacy	221	(34.5)	419	(65.5)
PMS cause psychological trouble to the couples	134	(20.9)	506	(79.1)
Test positive results of genetic diseases should change marriage decision	198	(30.9)	442	(69.1)
Medical counseling is important to be given after getting the results	308	(48.1)	332	(51.9)
Doubt of the results	289	(45.1)	351	(54.9)



**Fig 1:** Source of information about national pre-marital screening program among Hail female University students



**Fig 2:** Diseases suggested by female University students to be included in NPMS

**4. Discussion**

In a program like PMS, there is need to focus on the target population, mostly the young adults like high schools and university students because their attitudes will affect their choice on a partner. The importance of PMS cannot be denied as many countries have confirmed its importance in minimizing the incidence of genetic diseases<sup>[7]</sup>.

The results of the present study clearly demonstrated that most of the participants had knowledge about the availability of NPMS in KSA but unfortunately, their knowledge was not adequate about the items included or the diseases it tests. This result is similar to what was reported in some studies in Egypt<sup>[8]</sup>, Saudi Arabia<sup>[9]</sup> and Syria<sup>[10]</sup>. This could be explained due to the participants' young age where they don't have the ability to detect the seriousness of the genetic blood diseases on the emotional and economic status of the families. It should be noted that health education should be given regularly to improve the young adults' awareness as regards this point.

Concerning consanguinity between parents, 63.9% in the current study ensured positive family history and others gave history of remote or no relationship. Likewise, high percentages of consanguineous marriages and tribal marriages with high incidence of genetic diseases in the whole kingdom is existing<sup>[11]</sup>. The consanguinity rate in some region is in the

kingdom ranges from 25 to 60%<sup>[12, 13]</sup>. Majority of the participants in the present work were aware of the availability of the program and that it is obligatory to do before marriages well. Although (68.4 %) of the participants clarified the role of NPMS in minimizing the hereditary diseases, only half of them (55.1%) thought it is important to carry it out. (48.6%) of the participants knew the diseases involved in NPMS while only (29.3%) were aware of the validity period of the result. This can be explained on the basis of the deficient health education programs for the university students and this put a great responsibility on the health colleges to educate this kind of population.

As regards the knowledge about the diseases included in the NPMS, (85.9.%) thought that NPMS targets genetic blood disorders, (63.3 %) thought that that the NPMS includes hepatitis C while (62.5 %) thought it was hepatitis. In addition, (B. 72.5 %) said that it involve HIV testing. Unfortunately, (36.6 %), (39.2%) and (20%) of the students were confused and thought that the NPMS includes testing for alcohol, drugs and psychological disease. This is also could be explained on the bases of their young ages as well and the lack of health education.

The main sources of information of the students about the NPMS in the current study was obtained from relatives and family (45.2%), followed by the Internet 40.3%), and then friends (22.3%), university (21.6%) TV (14.1%), and newspaper (7.5%). Unexpectedly, only 21.6% of the participants got their information on NPMS from their colleges. This can be improved by establishing policies like giving the NPMS program in the university programs and enhancing the students' knowledge through regular educational sessions on the NPMS. Workshops about the included diseases in the NPMS program can also be a facilitation tool for the students to get more information on the program. It was found that the main source of information on NPMS was the families and relatives. This could clarify the importance of simultaneous provision of the NPMS to both the students and their families to spread the information on the program and increased its success. An important additional source of information on NPMS that was reported by nearly (40.3%) of the students was the internet. This is less than expected from this kind of population who are extensively using this type of information technology on daily basis. Unfortunately, only 14.1% of the students got their knowledge from the TV. This reflects that the role of this important kind of media is no longer fully effective to disseminate the importance of NPMS as a preventive program. So, governmental attention has to be concentrated on this aspect as well.

Newspaper on the other hand, came at the end as source of information about NPMS. This indicates that this tool is not as efficient as expected in spreading information on NPMS and more effort is required on this regard. The role of the newspapers can be further amplified by involving health

workers and giving them a daily area to write in.

The current study showed that students' knowledge about the NPMS program was good (75.5%). This is because in recent years, premarital counseling has gained more acceptances. Unexpectedly, these results is higher than that a study conducted in Jeddah and found that university students had inadequate knowledge about the NPMS program were less than one-third of the students knew<sup>[10]</sup>.

In KSA, high percentages of consanguineous marriages have resulted in high incidence of genetically based disorders<sup>[14]</sup>. The consanguinity rate in the region is in the region ranges from 25 to 60%<sup>[8, 9]</sup>. Similarly, the current study revealed that (63.9%) of students' parents had consanguineous marriage.

It was recorded in the present study that (64.4 %) thought that NPMS targets genetic blood disorders. On the other hand, Al Sulaiman *et al.* found a lack of awareness about genetic diseases and a misunderstanding of the impact of genes on health<sup>[15]</sup>. Opposite to the current work, It was also reported in Syria, 2009, showed that although university students had a considerable knowledge of premarital testing, they had a limited knowledge about certain aspects<sup>[9]</sup>. Moreover, In Nigeria, the knowledge of University students about genetic diseases was very satisfactory<sup>[16]</sup>.

When considering the awareness of hepatitis B & C, HIV and genetic blood diseases, it was revealed that more knowledge was obtained from the participants from health colleges than others. This result is logic and it is due to the medical information the health college students used to learn during their annual curriculum However and unexpectedly, the health college students revealed unsatisfactory knowledge about some aspects of the mode of transmission of Hepatitis and HIV as (12.6%) and (16.4 %) respectively thought wrongly the insects can transmit these diseases. This further confirms the need to apply educational programs about the NPMS. Similar results were obtained by a study conducted among students of Health Sciences College in Abha<sup>[17]</sup> and Pakistan<sup>[18]</sup>.

Although most of the participants (74.4 %) thought it is important to carry out NPMS and they were ready to do it in the future, 29.5% gave their reason as to prevent propagation of diseases to their kids, 48.1% stated that medical counseling is Important to be given after getting the results and, 51.1% indicated that presence of genetic blood diseases should change marriage decision.

Among those who didn't find the NPMC important, (14.4 %) thought it is against Islamic roles or interfere with God's well. In addition, 20.9% imagined that NPMS cause psychological trouble to the couple and 45.1% felt doubt of the results. This is similar to what has been recorded in other Arab countries<sup>[8, 10, 19]</sup>. Where the majority of their participants stated that they believe that the NPMS will help to prevent the transmission of diseases to their generations. This indicates that some students had negative attitudes as they were unaware of the importance of NPMS and that they see this kind of obligatory law as an insult against an individual's well and freedom. This misconception of the Islamic rules can be contributed to the loss of the effectiveness of the program. Similarly, this result was also noticed in some studies conducted in Saudi Arabia<sup>[17, 19]</sup>. Therefore, religious leaders are strongly recommended to help in correcting this wrong belief.

Unfortunately, only 29.5 % of the participants preferred changing in marriage decision when the test results of genetic diseases are positive. This is far less than what has been reported in Riyadh city, where 85% agreed on applying the NPMS as an obligatory step before marriage and 63% agreed on putting laws to prevent marriage in case of positive results<sup>[19]</sup>. This result could be explained due to the high rate of consanguineous marriages among Hail community; in which a procedure like NPMS might cause some social problems among the families. However this negative attitude could be improved by regular health education sessions especially for high-risk groups liable for genetic disorders. Another point to encourage people to consider the decision after results of the NPMS is to spread religious information through the media. Counselor working in the NPMS centers should be considerate, compassionate and should keep the secrets of the person or family involved. He/she should not impose his/her views on the clients.

Regarding tests suggested by the participants to be added to NPMS program, Psychological diseases represented the highest rate (75.8%) followed by chronic diseases (50.2%). These suggestions were expected as those disease prevalence have progressive increase nowadays<sup>[3]</sup>. Likewise, positive attitude of Saudi population towards the program importance to be applied to all couples in all regions of the kingdom.

The important limitation of this study was its application only on the university students this sample is not considered enough to represent the whole Hail community, so in the future, it should extend to cover more areas of hail region specially the remote villages.

In conclusion, this study showed that most of the students involved in the current study have a satisfactory knowledge towards the NPMS. However, when considering the diseases included in the program, it was found that the their knowledge is not sufficient. Although the majority of the students had positive attitude and thought emphasis the important to carry it, others had doubts and found it against Islamic roles, interfere with God's well or cause psychological trouble to the couple. In the light of that, there is a need to enhance perception, increase knowledge, and improve the attitude of the university students regarding the benefits of NPMS program. This is actually running all through the academic year 2014-2015 by the faculty of Medicine, Hail University. It is a comprehensive campaign for health education of the whole faculties of the university about the NPMS. Post education research will be carried out to assess the effectiveness of the health education campaign God willing, education for the public is particularly important through application of the same campaign on a public level through different mass media or through the main governmental and private institutions and including the NPMS in the curricula of both secondary schools and university students as well.

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