# Knowledge regarding the national premarital screening program among university students in western Saudi Arabia

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## ABSTRACT

**الأهداف:** استطلاع إدراك طلبة وطالبات جامعة الملك عبد العزيز بمفاهيم الفحص المبكر قبل الزواج (PMS) في المملكة العربية السعودية.

**الطريقة:** تم توزيع استبيانات مغلقة الخيارات على 800 طالب وطالبة من مختلف الكليات في جامعة الملك عبد العزيز بجدة – المملكة العربية السعودية، خلال العام الأكاديمي 2005م – 2006م. شمل الاستبيان 21 سؤالاً موزعة على ثلاثة أجزاء، يفيد الجزء الأول بتاريخ المشاركين، والجزء الثاني باختبار معلوماتهم العامة عن الأمراض الوراثية، وأما الجزء الثالث يفيد باختبار معلوماتهم عن الفحص المبكر قبل الزواج.

**النتائج:** أجاب 85% أن طفرات المورثات قد تؤدي إلى أمراض وراثية، و 84% أجابوا بأن زواج الأقارب عامل هام يؤدي إلى الإصابة بالأمراض الجينية، وعرف 65% أن الأمراض الوراثية قد تصيب أي جهاز في الجسم، ولكن أقل من ثلث المشاركين كانوا على علم بماهية الأمراض التي يتم الكشف عنها في الفحص المبكر قبل الزواج (PMS)، وقد اعتقد 54% أن الفحص يكشف عن جميع الأمراض الوراثية، فقط 35% منهم ادرك ما معنى أن النتيجة غير متوافقة، بينما اعتقد 59% أن النتيجة المتوافقة تعني الخلو التام من الأمراض الوراثية.

**خاتمة:** بالرغم من أن معظم الطلبة في جامعة الملك عبد العزيز لديهم معلومات عامة جيدة عن الأمراض الوراثية، إلا أن إدراكهم لمفاهيم الفحص المبكر قبل الزواج (PMS) غير كافية. لذلك، يلزم تكثيف الاسترشاد الوراثي عن هذا الموضوع، وتثقيف المجتمع حتى يتم الحصول على الاستفادة القصوى من هذا المشروع الوقائي.

**Objective:** To explore the knowledge of university students in Jeddah, western Saudi Arabia, regarding the national premarital screening (PMS) program.

**Methods:** A self-administered questionnaire was distributed to a sample of 800 students at King Abdulaziz University (KAU), Jeddah, Kingdom of Saudi Arabia during the first semester of the academic year 2005-2006. This included questions regarding socio-demographic data, personal history of hereditary disease, or premarital screening, knowledge on hereditary diseases, and on the national PMS program. Data were analyzed using the Statistical Package for Social Sciences version 13. A *p*-value less than 0.05 was considered significant.

**Results:** Eighty-five percent of the students believed that gene mutations may lead to hereditary disorders, and 84% of the respondents believed that consanguinity can increase the risk for genetic diseases. Fifty-six percent were aware that hereditary disease could affect any body system. Less than one-third of the students knew which disorders are tested for by the PMS, and 54% of the students thought that PMS detects all hereditary diseases. Only 35% knew what a non-compatible test result meant, while 59% believed that a compatible result meant freedom from all hereditary diseases.

**Conclusion:** Most of the students at KAU have good general knowledge concerning hereditary diseases, but had inadequate knowledge in relation to the national PMS program. The majority did not know which diseases were tested for, and what the test result meant. Public education regarding the disorders tested for, and the implication of screening is essential for the success of the premarital program.

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Congenital and genetic disorders are responsible for a major proportion of infant and child mortality, morbidity, and handicap in Arab countries.[1,2] Hereditary hematological diseases, especially sickle cell anemia (SCA), and thalassemia make up one of the most common groups of genetic disorders in the region.[2] 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. The carrier rate for SCA exceeds 25% of the population in some Saudi cities.[3] In the region of the Arabian Gulf, consanguineous marriages represent up to 60% of all unions, and are believed to be a major factor in increasing the magnitude of hereditary disorders in the area. The population of the region is characterized by large family size, advanced maternal and paternal ages, and a high level of inbreeding with consanguinity rates in the range of 25-60%.[1,2,4-6] A screening program for genetic carriers is a systematic attempt to identify and counsel as many people, at a genetic risk in a given population as possible, whether or not they have a family history of a genetic disorder. Several countries in both the Arab region and the Mediterranean have introduced premarital screening for hemoglobinopathies. Countries like Bahrain, Iran, and Cyprus proved the effectiveness of such programs in decreasing the incidence of the diseases tested for.[7-9] In Saudi Arabia, the national premarital screening (PMS) program is mandatory. The level of education of the population regarding various aspects of the relevant disorders and their prevention, is an important determinant for the success of such a program. It is therefore important to conduct studies among the community to assess this level of knowledge. In this study, we aim to determine the degree of knowledge regarding genetic disorders, and the national PMS program in a group of Saudi university students. This is an important sub-group of the population since they are at a relatively high level of education, and in the marriageable age group.

**Methods.** A stratified random sampling was conducted among the students of King Abdulaziz University (KAU) in Jeddah, western Saudi Arabia, during the first semester of the academic year of 2005-2006. A representative sample from each college in the university was interviewed. The acceptable sample size was selected according to the actual number of students in each college, and was calculated using the EPI Info statistical package version 6. A larger sample was then used. The questionnaires were distributed among the various colleges according to the percentage of students in each college (**Table 1**). With regard to the area of origin, 64.6% of those who received the questionnaire and responded were raised in Jeddah, 7.4% in the southern region of the Kingdom, 7% in Makkah, 5.8% in Taif, and 4.3% in Madinah, the latter 3 being neighboring cities. A pretest pilot study was conducted on a sample of 54 students after which, the questionnaire was modified. The students who answered the questionnaire in the pilot study were excluded from the final study. All regular undergraduate male and female students in the various colleges of KAU selected by random sampling and willing to participate - apart from those in the pilot group - were included in the study. A self-administered questionnaire was distributed to a sample of 800 students (of which 400 were men), who answered it under the direct supervision of the investigators. The questionnaire consisted of 21 questions and was divided into 3 main parts. Part one recorded the sociodemographic data and personal history of hereditary diseases, and premarital screening among the students. The second part aimed to test the knowledge on hereditary disorders in general. The third part assessed the participants' knowledge regarding premarital screening and counseling, particularly with regard to the PMS in the Kingdom. Finally, a space was left for further comments. Regarding the PMS test results, a positive result meant both partners were found to be carriers of the same hematologic disorder. A normal PMS meant that at least one partner was neither affected nor a carrier for the disease tested. Ethical approval was obtained from the local Research Ethics Committee. Participating students were guaranteed full confidentiality and privacy. The team members did not check the questionnaire in front of the students. After completing the questionnaire and returning it, the students were given educational pamphlets containing appropriate information regarding the national PMS program, and correct answers to various questions in the questionnaire.

After collection, the data were entered into the computer, and analyzed using the SPSS PC software package. Chi-squared test, and t-test were used when appropriate. A $p$-value was considered significant if it was less than 0.05.

**Results.** All of the participating students were Saudis. The age range was 18-29, and the mean was 21.4 years. The demographics of the study group are summarized in **Table 1**. Of the married students, 60.7% had personally carried out the PMS. While 6.2% of all the students reported personally having hereditary disease, 34.9% reported having hereditary disease in one or more of their family members. Among these, the reported disorders were SCA (1.1%), thalassemia (0.4%),

glucose-6-phosphate dehydrogenase deficiency (0.4%), and hemophilia (0.2%). The remainder considered diabetes mellitus (18.8%), or allergy (4.6%) as hereditary disorders. The results regarding general knowledge on hereditary disorders are summarized in **Table 2**. Fifty-six percent of the students knew that hereditary disorders could affect any part of the body, while 24.2% thought that they affect only the hematologic system, and 14.4% preferred to answer as "don't know". More medical (80.4%) than non-medical students (52%) answered this part correctly ($p$-value=0.000). **Table 3** depicts the students' sources of knowledge regarding the PMS. Regarding which disorders are detected by the PMS, 53.9% of the students thought that PMS detects all hereditary diseases, 29.1% some hereditary diseases, and 16.3% answered as "do not know". Among those who actually had the PMS themselves, 49% thought the test detects all hereditary diseases, while 47% thought it detected some diseases, and 4% did not know. On stratification according to the region of upbringing, 27.2% of the students raised in Jeddah answered the PMS detection question correctly compared with 31.1% raised elsewhere ($p$=0.238) (**Table 4**). Among the men this was 22% versus 21%, whereas 31.2% of the women who were raised in Jeddah answered it correctly compared with 44.6% of the women who were raised in the other areas ($p$=0.010). The results for testing whether the students understood what a positive (or non-compatible) PMS result meant are in **Table 5**. On testing the students' understanding of what a normal PMS result meant, fewer than 11% of the sample correctly believed that their offspring would be free of some hereditary blood disorders. Of the remainder, 59.2% of the students thought that if the PMS is negative, they would not be carriers of any hereditary disorders, and 19% thought that none of their children would have any form of hereditary disease, and 10.4% thought that all of their children would be free of all hereditary blood diseases. Overall, 35.4% of the male students answered this question correctly in comparison with 64.6% of the women ($p$=0.005). Among the students from medical colleges, 28% of the men answered correctly compared to 17.7% of the women ($p$=0.195). Among the other colleges, 4.3% of the men answered correctly compared to 12.4% of the women ($p$=0.000). Overall, 8.3% of the non-medical students answered correctly compared to 22.3% of the medical students ($p$=0.000). Among the men, 4.3% of the non-medical students answered it correctly compared with 28% of the medical students ($p$=0.000). Among the women, 12.4% of the non-medical students answered correctly compared to 17.7% of the women medical students ($p$=0.256). Based on the presence or absence of a positive family history of hereditary disease, 12.2% of those who had a positive family history of hereditary disease answered correctly in comparison with 9.1% of those without the same history ($p$=0.172). Based on the place of origin, 9.9% of those who were raised in Jeddah answered correctly compared with 10.8% of those raised elsewhere ($p$=0.675).

**Table 1 -** Social characteristics of the university students.

| Demographics | Percentage |
|---|---|
| *Gender* | |
| Men | 50.0 |
| Women | 50.0 |
| Age (years): 18-29 | 100 |
| *Social status* | |
| Single-never married | 88.4 |
| Married | 11.1 |
| Divorced | 0.4 |
| Personal history of hereditary disease | 6.2 |
| *Upbringing* | |
| Jeddah | 64.6 |
| Southern Region | 7.4 |
| Makkah | 7.0 |
| Taif | 5.8 |
| Madinah | 4.3 |
| *College* | |
| Arts and Humanities | 24.5 |
| Administration/Economics | 21.6 |
| Science | 18.5 |
| Medicine/Health Sciences | 6.4 |
| Dentistry | 2.2 |

**Table 2 -** General knowledge regarding hereditary disorders.

| Variable tested | Percent correct answer |
|---|---|
| Respondents know that hereditary disorders can be transmitted by genes | 84.8 |
| Respondents know that hereditary disorders can affect any body system | 56.0 |
| Respondents know that consanguinity increases the chance of hereditary disorders in offspring | 84.5 |

**Table 3 -** Sources of knowledge on premarital screening.

| Sources | Percentage |
|---|---|
| Television | 43 |
| Newspaper/ Magazine | 42 |
| Friends | 40 |
| College | 24 |
| School | 15 |
| Medical recourses/Health professionals | 7 |

**Discussion.** Genetic disorders cause a significant burden in Saudi Arabia, and hereditary hematologic disorders make up a significant proportion of these genetic disorders.[1-4] Screening for carrier status of hereditary hematologic disorders may help in decreasing

**Table 4 -** Testing knowledge regarding which disorders are tested by the national premarital screening

| Variables | Percent correct answers | *P*-value |
|---|---|---|
| Total correct | 29.1 | |
| Respondents have personally carried out the test | 47.0 | |
| ***Family History*** | | |
| Positive | 30.3 | 0.420 |
| Negative | 27.6 | |
| ***Medical Background*** | | |
| Medical students | 62.5 | 0.001 |
| Non-medical students | 23.1 | |
| ***Region of upbringing*** | | |
| Jeddah | 27.2 | 0.238 |
| Other than Jeddah | 31.1 | |
| ***Gender*** | | |
| Women | 35.2 | |
| Men | 21.9 | 0.001 |
| ***Gender and medical background*** | | |
| Women medical students | 61.3 | 0.768 |
| Men medical students | 64.0 | |

**Table 5 -** Testing of student's understanding of a non-compatible test result.

| Variables | Percent correct answer (%) | *P*-value |
|---|---|---|
| Total | 35.0 | 0.531 |
| ***Family history*** | | |
| Positive | 39.7 | |
| Negative | 31.1 | |
| ***Medical background*** | | |
| Medical students | 51.8 | 0.001 |
| Non-medical students | 31.3 | |
| ***Gender*** | | |
| Women | 39.0 | 0.004 |
| Men | 29.4 | |
| ***Gender and medical background*** | | |
| Women medical students | 61.3 | 0.001 |
| Women non-medical students | 34.9 | |
| Men medical students | 40.0 | 0.079 |
| Men non-medical students | 27.9 | |
| ***Place of origin*** | | |
| Jeddah | 32.2 | 0.114 |
| Other | 37.8 | |
| Women raised in Jeddah | 38.0 | 0.53 |
| Women raised elsewhere | 41.3 | |
| Men raised in Jeddah | 25.4 | 0.035 |
| Men raised elsewhere | 35.2 | |
| ***Gender and place of origin*** | | |
| Women raised in Jeddah | 38.0 | 0.002 |
| Men raised in Jeddah | 25.4 | |
| Women raised elsewhere | 41.3 | 0.288 |
| Men raised elsewhere | 35.2 | |

the occurrence. In Saudi Arabia, a royal decree was passed in 2003 for a mandatory premarital screening test followed by nondirective genetic counseling for hemoglobinopathies, the decision to marry is then left to the couple. Prenatal diagnosis and termination of pregnancy are not offered to carrier couples, even though a 1990 ruling allows termination of pregnancy in the first 120 days after conception, if the fetus had shown beyond doubt to be affected with a severe disorder that is not amenable to treatment.[4,10,11] The effectiveness of carrier screening programs depends largely on the knowledge and attitudes of the target population.

Jeddah, a cosmopolitan city, and the commercial capital of Saudi Arabia with a population of over 3.4 million people, is situated on the Western Coast by the Red Sea. The median age is 21.4 years and the population growth rate is 2.1%.[12] King Abdulaziz University is the major university in the city with approximately 40,000 students, many who come from neighboring cities and villages. The knowledge of the students' sample was explored using a structured questionnaire designed by the authors. The first set of questions crudely tested the student's knowledge of genetic disorders in general. Most students answered these questions correctly. The second set of questions, however, tested the students' knowledge on the specifics of the national PMS program in KSA. Here, much fewer students answered the questions correctly. It was particularly striking that less than one third of the total group knew the correct answer to the question, "Which disorders are detected by the PMS?". What was even more significant was the fact that when this same question was posed among the subgroup of students who actually had the test themselves, less than half of them answered correctly, making one question whether these individuals received genetic counseling prior to, or after testing, and if so, what was the quality of counseling, and how much did the clients comprehend. This contrasts sharply with the original principles of the national PMS, where the informed decision should follow appropriate genetic counseling covering all aspects of relevance, and where the clients are expected to receive an adequate explanation of the inheritance pattern in the light of laboratory findings of abnormal results.[10,11]

It is particularly alarming that the majority of students, whether or not they had undergone testing themselves thought that the PMS detected all genetic disorders. This may have serious consequences, including neglecting any personal, or familial risk factors for offspring with genetic disorders or congenital malformation, especially in cases of consanguineous marriages. This further underscores the need for both population education regarding the PMS, and individual pre-testing and post-testing counseling. Of note is that the sample in this study represents a highly educated group in one of the most industrialized cities of the Kingdom. One would expect even less adequate knowledge among other groups of the society. Interestingly, it appears that the major sources of knowledge regarding PMS are the media, followed by friends. Only 7% reported learning anything, regarding the PMS from medical professionals.

Similar results were obtained when testing the participants on the specifics of the PMS including the interpretation of the tests results. When breaking the group down, medical students consistently had more knowledge than non-medical students, and women had more knowledge than men. We speculate that this latter finding may reflect the notion that women in many parts of this society may bear more of the burden of a handicapped or chronically ill child. In addition, they have less opportunity to a "second chance" than men. Of note, however, was that this gender difference in knowledge was not apparent among medical students, further underscoring the important role of education. Contrary to expectation, having a family history of genetic disease did not influence knowledge significantly. This may partially be explained by the fact that many students included multifactorial disorders such as diabetes mellitus, and allergy as hereditary disorders. There was no significant difference in knowledge among those raised in Jeddah compared to those raised in the surrounding less industrialized cities, towns, and villages. The role of education at the university level may therefore, override any cultural, or familial differences. Public education regarding these genetic disorders, and the implication of testing is essential for the success of the premarital program. This has been shown both by this study, and by previous ones.[13] In addition to formal counseling at the time of testing, mass education especially at high school and university levels can play a major role in increasing the level of knowledge regarding PMS. It has also been suggested that education on PMS be included in the university curriculum.[14] We also propose that opportunistic counseling be carried out by health professionals during general check-ups, or other physician office visits may help in addition to educational pamphlets, targeted TV programs, and advertisement. Perhaps education must start with those in the medical profession especially those in certain specialties such as Family Medicine, or Obstetrics and Gynecology, so that they can be equipped to play their role in the education process, and be qualified to answer related questions.

Although the sample size is considered representative of the KAU student population, the study did not assess the knowledge in other geographical regions of this multicultural society, nor did it study other essential members of the population, such as those who have not continued their education, and the elders whose decisions may have an impact on other family members. The success of the PMS for hereditary hematologic disorders may lead to the inclusion of further prevalent disorders such as spinal muscular atrophy. Finally, the role of repeated audit with quality assurance guidelines can not be overestimated. Studies similar to this one can help understand the deficiencies, and take opportunity of the available strengths.

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