

Pre-marital examination as a method of prevention from blood genetic disorders

Community views

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ABSTRACT

The Saudi Royal Cabinet issued the Saudi Royal Decree No. 3 dated 11-7-1424, establishing the pre-marital examination as a health preventive measure for all Saudis, and requesting the 2 prospective partners (male and female) to carry out a pre-marital examination and present a certificate of pre-marital examination before the wedding. However, the prospective husband and wife are not obliged to abide by the laboratory results if they so wish. This program started officially on the 1st of Muharram, 1425. As a consequence, the community perception and views on the pre-marital examination program as a preventive measure become crucial. Therefore, this study was organized and conducted to reveal the perception of the community regarding the program, through a purpose-made questionnaire that was distributed during symposia and awareness lectures held throughout the Kingdom (Riyadh, Jeddah, Dammam, Al-Khobar, Al-Ahsa, Al-Qassim, and Madinah). The questionnaire covers the opinions of the participants in various aspects related to genetic diseases including nature of diseases, mode of transmission, affecting factors, complications, management, and prevention. In addition, the questionnaire also covers opinions regarding the pre-marital examination as a preventive measure of blood genetic diseases, and its contribution to the control of these diseases. The questionnaire also covers methods in obtaining information, whether from studies, lectures, information media, and awareness lectures. The results revealed that the majority of the participants (94.3%) were convinced that the pre-marital examination is an effective mean of prevention of blood genetic diseases. The majority (86.9%) of the participants were also convinced that the pre-marital examination should be mandatory. These are indications that the community is aware of the pre-marital examination, and the effectiveness of the awareness program is enriching the knowledge of the citizens.

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The genetic disorders, particularly blood genetic disorders, pose a remarkable health, economical, and psychosocial burdens on the individual, the family, and the community. This is due to the high frequency in the Arab and Islamic community, and due to the fact that to date there is no definitive cure. Hence, the health care programs are ineffective in controlling disease manifestation and complications.¹

In addition, the pattern of marriage, which encourages consanguineous and other forms of relative marriages, leads to an increase in the occurrence of recessive genetic disorders, wherein the gene share in the first degree of consanguineous marriage is 1 of 8. If these patterns are repeated in the following generations they will lead to an increase, where its occurrence in non-consanguineous marriage is 2-4%, while in

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consanguineous marriages this could rise to 4-8%.²⁻⁶ The genetic disorders in general, represent a group of a heterogeneous diseases some of which are inherited from parents through mutated genetic material. The most common of this class are the blood genetic disorders, sickle cell disease, and the thalassemias. These are recessive genetic disorders, which are inherited by children from their apparently healthy carrier parents. The blood genetic disorders cause a variety of negative effects on health and psychosocial aspects due to the following: 1) Its wide spread in the community. 2) Chronicity and non-availability of definitive treatment, and 3) Negative effect on the life style of the concerned individual, family, and the community at large.

Due to these factors, namely, consanguineous marriages and high frequency of blood genetic disorders, the Saudi Royal Cabinet issued an order stating that all Saudis be subjected to the pre-marital, examination and present a certificate to that effect before the wedding, however, they are not obliged to abide to the results of the examination, if they so wish.⁷ The pre-marital examination is aimed at revealing the following: 1) Affliction with a blood genetic disorder. 2) The carriers of blood genetic disorders, which could give rise to the birth of affected children. 3) Explanation of the inheritance pattern in the light of laboratory findings of abnormal results. The program of pre-marital examination concentrates on the prevention of the blood genetic disorders through educational symposia, conferences, and educational lectures using purpose-made simplified publications.⁸⁻¹⁷

The pre-marital examination is considered the most effective means of prevention that could limit the birth of affected children, through minimizing the marriage of the carriers of the blood genetic disorder. It is also the most appropriate procedure, as it is generally acceptable from the religious and ethical point of view as well as its minimal health, and economical requirements. However, it requires a high degree of confidentiality related, particularly, to data management. The relevant order of the Saudi Royal Cabinet is in accordance with health principles and in line with traditions and religious and ethical guidelines. It particularly respects the autonomy of the person leaving the decision of marriage to those concerns after making them fully aware of the interpretation and consequences of the laboratory findings. The informative decision made by those who are directly concerned should follow appropriate genetic counseling covering all aspects of relevance, leaving the door open for them to arrive at an informative and non-directive decision.¹⁸

The invitation for pre-marital examination.

The pre-marital medical examination takes into consideration the Islamic Code of "Shareeah" and ethical principles, that consider marriage a religious and social bond in the family, with specific rights in one hand, and specific obligations in the other. In line with the Prophet Mohammed direction, peace be upon Him (PBUH) to a man who propose to a woman "looked at her eye",¹⁹ which indicates the need to know the mishaps and the malformation, if any, before the wedding. That is to say that the pre-marital examination is a means to uncover the ill health and malformations. Therefore, the pre-marital examination is a health requirement as the prophet PBUH, said: "not to join healthy and the sick".²⁰ For these reasons, and others, the Saudi Authority considered that the pre-marital examination is an effective means of limiting the birth of genetically sick children and, therefore, the Saudi Royal Cabinet appropriately issued an order to make it mandatory in the Kingdom. (Tables 1 & 2).

The main objectives of the pre-marital examination program. The main objectives of the pre-marital examination can be summarized as follows: 1) To uncover blood genetic disorders, in those who are preparing for marriage. 2) To limit the occurrence of blood genetic disorders. 3) To limit those marriages among those who are carriers or suffering from blood genetic disorders. 4) Explaining the pattern of inheritance of genetic disorders and the means that are appropriate to adopt in the case of carriers of these disorders, where it is feasible for the carrier or the affected to marry a normal person and have normal children or carrier children, but not diseased. 5) Save the families from having affected children suffering from a chronic disease and psychosocial problems. 6) Minimizing the economic burden on the family and on the government that results from seeking treatment for chronic and disabling genetic disorders. For example, the management for blood genetic diseases such as sickle-cell cell presentation may reach SR50,000 per year, and the bone marrow transplant may cost up to SR500,000. Taking all the above into consideration, and to find out the degree of success of the pre-marital examination program this study was carried out.

Procedure of the studies.

1. **Study community.** Various community members who were attending the educational and awareness program.

2. **Sample of the study.** Participants in conferences, symposia and awareness lectures, held in various

Table 1 - The Saudi Royal Decree No. 3 dated 11-7-1424 on the pre-marital examination.

The Cabinet agreed on the request of Ministry of Justice to accept pre-marital examination under the Cabinet decision No. 5 dated 41-1423, as a the health control related to the marriages of all Saudis and making it mandatory for the 2 prospective partners to present certification of pre-marital examination before wedding starting 1/1/1425 but not obligatory for them to abide by the results if they so wished.

Table 2 - The Saudi Royal Decree No. 5 dated 41-1423 on pre-marital examination.**The Ministry of Health has to:**

1. Organize awareness program through the media outlining the advantages of pre-marital examination and the effect of infectious and inherited diseases over 3 years.
2. Prepare laboratories and make available equipment and training in all regions to facilitate laboratory testing of diseases that Ministry of Health decide upon including infectious and inherited diseases.
3. Carry out pre-marital screening for those Saudis who wish to do so and observe the confidentiality in dealing with information and its retrieval and use.
4. Coordinate with the Ministry of Justice and for the wedding licensee to explain the usefulness of pre-marital examination.

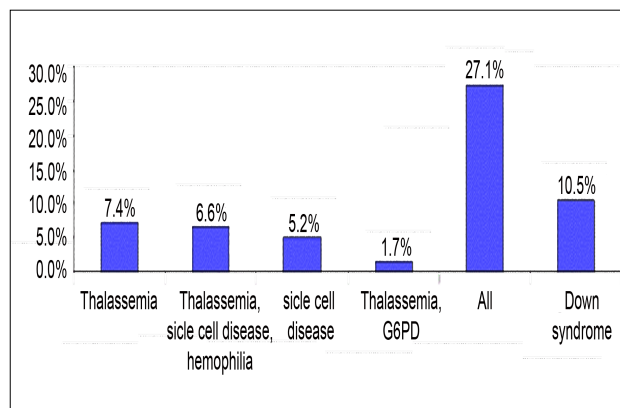
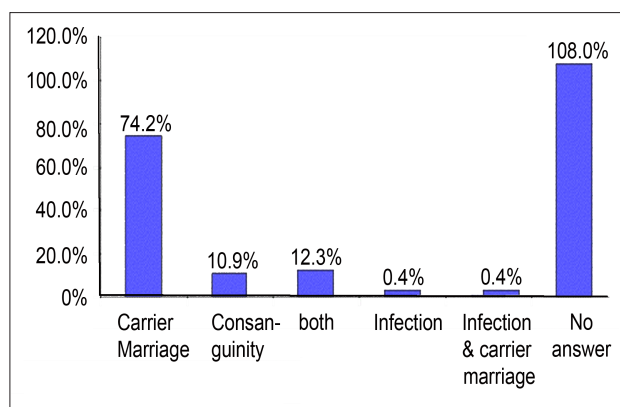
regions of the Kingdom. This includes the cities of Riyadh, Jeddah, Dammam, Madinah, Al-Ahsa, Al-Khobar and Al-Qassim where a total of 329 persons responded to the questionnaire.

3. **The method of the study.** A purpose-designed questionnaire was prepared including names, level of education, occupation and the specialty; various aspects related to blood genetic disorders including transmission, prevention, and opinions regarding blood genetic disease were incorporated.

4. **The statistical analysis.** The HPSS statistical package was used to analyze the information gathered by the questionnaire.

5. **The results.** The results showed the following: a. Educational levels vary from a primary school certificate up to the doctorate. and b. Knowledge level concerning blood genetic disorders are adequate (**Figure 1**). The majority believed that the transmission of blood genetic disorders were from marriage of 2 carriers (74.2%) (**Figure 2**). c. The availability of the affected member in the family was 24% and the sickle cell was 10.21%.

6. **Knowledge of the person affected with a blood genetic disorder.** The results indicated that 63.5% know a person suffering from blood genetic

**Figure 1** - What is blood genetic diseases?**Figure 2** - Methods of transmission of blood genetic diseases.

disorders. Sickle cell was the most common type of blood genetic disorder (10%).

7. **Availability of treatment.** The results showed that 18.9% said that there is a definitive treatment. A percentage of 4.1% reported medical treatment as successful and 3.7% reported bone marrow transplant as definitive treatment. The majority (73.8%), has indicated non-availability of effective treatment (**Figure 3**).

8. **Means of control and prevention.** The results indicated that 37.5% believe that the pre-marital examination is an effective means of prevention and control, compared with 24.2% who did not agree to this means, while 1.4-4.4% indicated other means of control and prevention.

9. **Source of information.** A percentage of 28.2% obtained their information from awareness and publications, and 27.4% from the media, whereas a minority of 4.8-14% obtained their information from mixed sources (**Figure 4**).

10. **The role of the pre-marital examination in reduction of blood genetic disorders.** A majority

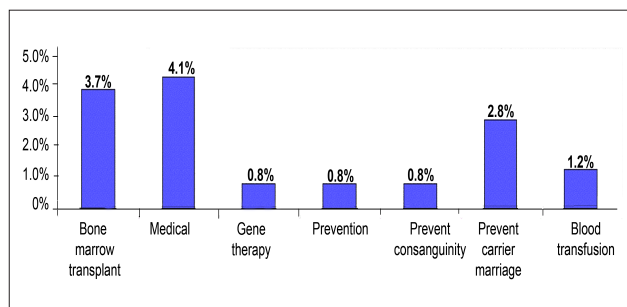


Figure 3 - Methods of treatment of genetic diseases.

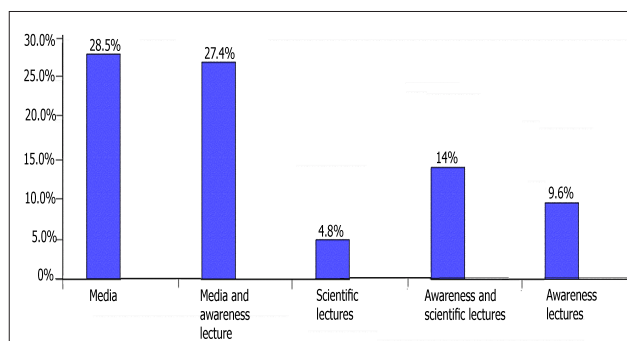


Figure 4 - Sources of information.

of 36.9% believed that the pre-marital examination has a principal role in the reduction of blood genetic disorders, 12% did not agree, and 1.9% did not provide an answer.

11. The adoption of the pre-marital examination as a mandatory program. The results showed that 86.9% believed that the pre-marital examination should be mandatory in high risk groups, and 60.3% believed that it should be mandatory for all individuals in the community. A remarkable percentage (45%) sees the social aspect as the main obstacle in the application of pre-marital screening. A minority of 0.4-2.4% expressed a differential opinion for these varieties of reasons, including personal attitude (**Figure 5**).

This study was carried out to unveil the opinion of the community regarding the pre-marital examination that aimed at serving the community and find out the degree of perception of the program, and its background. The programs encompass samples of various community members. The educational levels of the participants vary with 77% from that of the participants holding bachelor or higher degrees. The study revealed the followings: 1) The majority of the participants in the study believed that the pre-marital examination is an effective preventive measure for limiting and controlling blood genetic disorders. 2) The majority of the participants believed that the

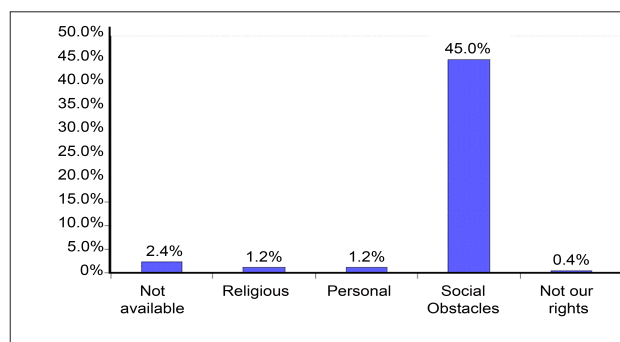


Figure 5 - Why pre-marital screening is not applied and what are the reasons.

program should be mandatory for all members of the community. 3) There is a relative deficiency in awareness and the educational means as a supportive measure for limiting the occurrence of blood genetic disorders. 4) There is a need for genetic counseling and preparing the staff and requirements for this important function, where it is appropriate.

This study made it permissible to conclude that the pre-marital examination program is an effective means of prevention. However, other programs of prevention, including screening of school children remain to be studied and evaluated as additional approaches to control and as prevention of the commonly encountered blood genetic disorders in Saudi Arabia and other Islamic Countries.

References

1. El-Hazmi MAF. Genetic in health and disease (in Arabic). Riyadh, KSA: Dar Al-Oloum Bookstore; 2003.
2. Hafiz MH. Consanguinity in Egyptian communities. *Med Genet* 1983; 20: 11-18.
3. Al-Awdi SAM. Consanguinity in Kuwaiti communities. *Clin Genet* 1985; 27: 35-42.
4. El-Hazmi MAF, Al-Swailem AR, Warsy AS, Al-Swailem AM, Sulaimani R, Al-Meshari AA. Consanguinity among the Saudi Arabian population. *J Med Genet* 1995; 32: 623-626.
5. Bazaran NA. Consanguinity between parents have Down's Syndrome. *Clin Genet* 1992; 42: 122-127.
6. Azaran NBS. Consanguinity in Turkey communities. *Med Genet* 1983; 20: 77-82.
7. Saudi Royal Decree No. 3 issues at 7/ 11/ 1424 Ah.
8. El-Hazmi MAF. Pre-marital screening for prevention from genetic diseases-Scientific background and objectives (in Arabic). Riyadh, KSA: Dar Al-Oloum Bookstore; 2004.
9. El-Hazmi MAF. Ethics of genetic counseling in Islamic communities (in Arabic). Riyadh, KSA: Al-Obeikan Bookstore; 2002.
10. El-Hazmi MAF. Thalassemic disorders (in Arabic). Riyadh, KSA: Al-Humaid Press; 1997.
11. El-Hazmi MAF. Sickle cell anemia-What is it and what the family can do toward it? (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1997.

12. El-Hazmi MAF. Blood genetic disorders-inheritance of genetic disorders (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1997.
13. El-Hazmi MAF. Blood genetic disorders- How to deal with it (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1997.
14. El-Hazmi MAF. Pregnancy and blood genetic disorders-relevant information (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1997.
15. El-Hazmi MAF. Enzymopathies-G6PD deficiency (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1997.
16. El-Hazmi MAF. Hemophilia (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1997.
17. El-Hazmi MAF. Down's syndrome (in Arabic). Riyadh, KSA: Al-Humaidi Press; 1977.
18. Beard BAT. Genetic disorders in children and adults a community study. *Am J Hum Genet* 1988; 42: 322-327.
19. Sonan Al Nisaie. Al Mojetaba Marriage Book; permission of premarital viewing of the other couple. Hadeeth no. 3234, Modern Press, Cairo.
20. Musnad Al-Imam Ahmad. Completion of Musnad ABU Horairah Hadeeth no. 9010, Arabic Education Office for Gulf Arabic Countries, 1988.

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