Premarital counselling: an experience from Bahrain

Shaikha Salim Al-Arrayed,[1] Nada Hafadh [2] and Samera Al-Serafi [3]

التوعية قبل الزواج: تجربة من البحرين

شيخة سالم العريض وندى حفاظ وسميرة الصيرفي

خلاصة: أجريت هذه الدراسة لتحليل بيانات أول خمسمئة شخص تقدموا باختيارهم طالبين التوعية قبل الزواج خلال العامين 1993 - 1994. ولقد وجد أن 74.1% من المتقدمين لم يكونوا أقرباء لمن يزمعون الزواج منهم، بينما كان 23.2% من أقارب الدرجة الأولى، وكان 1.5% من أقارب الدرجة الثانية. وكان الباقون من الأقارب البعيدين. ووجد مرض الخلايا المنجلية في 1.6% من المتقدمين، وخلة الخلايا المنجلية في 13.0%، وخلة التلاسيمية بيتا في 2.0% وعَوَز G6PD في 26.0%. ومن بين ثنائيات الأزواج المتقدمين للتوعية، تبيَّن أن 8.1% كانوا معرَّضين لإنجاب أطفال غير أسوياء. وكان معدل القرابة بين ثنائيات الأزواج المعرَّضين لهذا الخطر 15.4%.

ABSTRACT The present study was conducted to analyse data of the first 500 clients who voluntarily attended premarital counselling during 1993–1994. It was found that 74.1% of clients were not related to their partner, 23.2% were first cousins and 1.5% were second cousins; the rest were distant relatives. Sickle-cell disease was found in 1.6% of clients, sickle-cell trait in 13.0%, β-thalassaemia trait in 2.0% and glucose-6-phosphate dehydrogenase deficiency in 26.0%. Of the couples attending counselling, 8.1% were found to be at risk of having affected offspring. The consanguinity rate among the couples at risk was 15.4%.

Consultations prénuptiales: expérience à Bahreïn

RESUME La présente étude a été réalisée pour analyser les données relatives aux 500 premières personnes qui ont effectué une consultation prénuptiale volontairement au cours des années 1993 et 1994. On a constaté que 74,1% de ces personnes n'avaient pas de lien de parenté avec leur partenaire, que 23,2% d'entre eux étaient cousins germains et 1,5% petits cousins. Les autres étaient des parents éloignés. La drépanocytose a été dépistée chez 1,6% de ces personnes, un trait drépanocytaire chez 13,0% d'entre elles, un trait b-thalassémique chez 2,0% et l'anémie hémolytique enzymoprive chez 26,0%. On a trouvé que 8,1% des couples qui ont consulté risquaient d'avoir des enfants atteints. Le taux de consanguinité parmi les couples à risque s'élevait à 15,4%.

[1]*Head, Genetics Deparment, Salmaniya Medical Centre, Bahrain.*
[2]*Head, Maternal and Child Health, Ministry of Health, Bahrain.*
[3]*Family Physician, Ministry of Health, Bahrain.*
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Introduction

The inherited haemoglobinopathies are a group of disorders that include thalassaemias and sickle-cell disease. These diseases are a major public health problem in the Mediterranean area, the Middle East, the Indian subcontinent, Asia, tropical Africa and the Caribbean. However, because of population flow, they are now widespread and occur in Europe and North and South America. According to the World Health Organization, the approximate estimates of affected individuals indicate that 240 million people are heterozygous for these disorders and at least 200 000 lethally affected homozygotes are born annually, approximately equally divided between sickle-cell anaemia and thalassaemia syndromes [*1,2*].

The Cyprus Thalassaemia Control Programme has succeeded in reducing the incidence of β-thalassaemia major in the country through measures such as health education, carrier screening, premarital counselling and prenatal diagnosis. This success has encouraged other countries to adopt the practice of premarital counselling. Countries or communities practising such counselling, either voluntarily or by law, are Italy and Greece for thalassaemia, the Ashkanazi Jews for Tay-Sachs disease and some European communities for cystic fibrosis [*3,4*].

In Bahrain, the burden of genetic blood disorders has long been recognized, as studies have shown that 1%–2% of neonates have sickle-cell disease and the carrier state is found in nearly 11% of neonates; the β-thalassaemia rate is much lower at 2% [*5,6*].

In an attempt to reduce the incidence of babies born with sickle-cell disease and β-thalassaemia, the genetic clinic at the Salmaniya Medical Centre initiated a premarital screening service in 1985. Recognizing the importance of this clinic, the Ministry of Health decided in 1992 to expand the service and make it available as part of the general primary health care in all health centres. Couples at high risk are identified, counselled and treated, and those with an abnormal genetic history are referred to the Department of Genetics at Salmaniya Medical Centre.

In the present study, data from the premarital counselling clinics covering the period between 1993 and 1994 are presented.

Subjects and methods

The service was started on an expanded basis in December 1992. It was preceded by an information and training course for all physicians, nurses and health educators. The course included information about: common genetic disorders in the community, how to take a family genetic history, the basics and ethics of the techniques of genetic counselling, how to evaluate the risk of recurrence and the needs of the clients, how to discuss the risk and benefit burden, how to form a plan of action, giving advice and follow-up. The training course was followed by a mass media campaign on the availability of the service.

A special risk assessment sheet was designed for each sex separately. It includes information about sociodemographic data—sex, age, education, occupation, sequence of marriage, consanguinity, medical history, surgical history, infection history, history of sexually transmitted diseases, family genetic history, information on habits such as smoking, alcohol and drugs, pregnancy readiness, past obstetric history and contraception, if applicable. This is completed for all clients and is followed by a physical examination which includes measurement of height, weight, blood pres-

sure, pulse and examination of other systems, such as the cardiovascular and respiratory systems. Investigations include a full blood count, blood group analysis, and screening for haemoglobin disorders, glucose-6-phosphate dehydrogenase deficiency (G6PD), rubella antibodies and syphilis [venereal disease research laboratory test (VDRL)]. Some cases are screened for human immuno deficiency virus (HIV) and hepatitis B.

On the second visit, the results are discussed with the client and counselling and management are provided, such as immunization against rubella. An information booklet is given, which includes information about haemoglobinopathies, prevention of rhesus haemolytic diseases of neonates, the genetic risks associated with advanced maternal age, the effect of smoking, alcohol and drugs on conception, the effect of infection, including sexually transmitted diseases, on conception, sex education from the Islamic point of view, methods of contraception, and nutrition and its effect on conception. This educational material has been found to be essential during the screening programme as the counsellor can save a great deal of time by giving people at risk written material to read and keep for future reference. The couples at risk are referred to the genetic clinic for further advice and management

Results

Of the first 500 clients who voluntarily attended counselling during the period 1993 1994, the male/female ratio was 52.5/47.5 (262/238) The mean age for males was 26.5 years and for females 21.9 years; the minimum age was 15 years and the maximum 45 years.

With regard to education, data on 495 clients showed that 340 (68.7%) were secondary-school graduates, 140 (28.3%) were college graduates and 15 (3.0%) primary-school educated or illiterate. Males were more likely to be primary- and secondary school educated while females were more likely to be college educated.

Data on consanguinity revealed that 74.1% of clients were not related to their partner, 23.2% were first cousins, 1.5% were second cousins and 0.3% were distant relatives. It would be the first marriage for 97.6% of clients, the second marriage for 2.2% and the third marriage for the rest.

With regard to smoking and drinking habits, 88.5% (of 488) were nonsmokers and only 2.3% said that they drank alcohol. Normal appearance was found in 98.4% of the clients and abnormal features, such as extreme short stature, and skeletal deformity, in 1.6%. The cardiovascular system was normal in 99.8% of clients (one had a minor congenital abnormality); 11.9% (58/486) had high blood pressure. It was found that 7.8% were not immune to rubella and were in need of vaccination; all of them were females. VDRL was positive in 1.3% of clients (4/318).

Table 1 shows the frequency of blood diseases among the clients. Sickle-cell disease was found in 1.6% (8/500) of clients, sickle-cell trait in 13.0% and β-thalassaemia trait in 2.0%; the haemoglobin ($Hb A_2$) average in β-thalassaemia was 5.6%. G6PD deficiency was found in 26.0% (130/500) of clients; the male to female ratio among them was about 2:1 (86/44). Out of 161 couples who attended counselling, 13 (8.1%) were at risk as both partners were carriers of the haemoglobinopathy gene. They either both had the sickle-cell trait or β-thalassaemia trait, or one partner had the sickle-cell trait and the other had the β-thalassaemia trait. Among cou-

Table 1 **Premarital screening statistics (1993–1994)**

	No.	%
Clients with sickle-cell disease	8/500	1.6
Clients with sickle-cell trait	65/500	13.0
β-thalassaemia carriers	10/500	2.0
Clients with G6PD deficiency	130/500	26.0
Couples at risk of having affected children	13/161	8.1
Consanguineous couples at risk	2/13	15.4
Nonconsanguineous couples at risk	11/13	84.6

ples at risk, only 2 of the 13 were related (15.4%).

Discussion

Because of the demographic factors and population structure in Middle Eastern countries, e.g. old paternal and maternal age and the high frequency of consanguineous marriages, there is a considerable need for genetic services in order to avoid misinformation and mismanagement of consanguinity on genetic grounds. Premarital counselling is one of the important measures which can help reduce the incidence of genetic diseases in such circumstances [*7–10*].

Premarital counselling provides an opportunity to intervene according to the identified risks. This intervention includes: treatment of diseases such as infections, modification of chronic disease medication to decrease teratogenic risks, vaccination, counselling regarding behaviour, including those related to HIV and other infections, nutrition counselling, advice regarding contraception or genetic counselling. The service in Bahrain is provided on a voluntary basis and clients come for counselling of their own accord. The counselling is nondirective and clients are free to act upon the advice as they see fit.

In the first two years (1993–1994), 8.1% of couples were at risk of producing affected offspring. In the following year (1995), the rate increased, which suggests that the service was being utilized more by people at risk because they knew of the presence of an affected person(s) in their family and they went voluntarily for testing. Among the couples at risk, only 15.4% were related whereas 84.6% were not. Thus, even if we advise against consanguineous marriage, this will not solve the problem of genetic blood disorders because of the high gene frequency in the population. The rates of sickle-cell trait (13%) and G6PD deficiency (26%) are similar to results in previous studies [*3–6*].

The World Health Organization has recommended several measures for the prevention of genetic diseases, such as health education, screening to identify individuals or couples at risk, genetic counselling and prenatal diagnosis. For these aspects of prevention to be applied to a population, various ethical, legal, and cultural issues have to be taken into consideration. These arise because genetic prevention affects marriage habits, choice of partner and reproductive behaviour. Any campaign must be tailored to the needs of each culture, and health education must be sensitive to these considerations, even though they may affect the final efficiency of the programme [*1,2*].

Many of the religious leaders in Bahrain are now convinced of the benefits of premarital counselling and are advocating that it should be made a legal requirement, as long as the client is free to take the medical

advice and act according to his/her decision.

Recommendations

Premarital counselling should be compulsory by law but the freedom of couples to act upon the advice should be ensured. Appropriate and simple information on human genetics should be incorporated into the school curriculum so that all students are informed of the issues. The public should be made aware of the fact that everyone may carry an inherited disease so as to prevent prejudice and misinformation. Professionals in genetics, health education and the media can work together to increase the awareness of the adult population, for example through television documentaries on specific diseases or videos to watch prior to counselling.

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