Premarital genetic counselling: A new law in the Kingdom of Bahrain

Shaikha Salim Al-Arrayed, *M.B.ch.B, DHCG-PhD, Head of Genetic Department, Salmaniya Medical Complex, Kingdom of Bahrain*

Amani Ali Al-Hajeri, *MD, RCSI in Family Medicine, Chief Resident, Assistant Editor-Bahrain Medical Bulletin, Genetic Department, Salmaniya Medical Complex, Kingdom of Bahrain*

Abstract

Genetic diseases, especially hereditary blood disorders such as sickle-cell disease and thalassaemia syndromes impose a significant burden on many countries. Their chronic nature with little or no prospect of cure makes them one of the leading causes of morbidity and mortality.

In Bahrain 1-2% of newborns have sickle-cell disease while 11% are carriers, and 2% are carriers of beta-thalassaemia. In an attempt to reduce the incidence of genetic diseases in the Kingdom of Bahrain a premarital screening programme was introduced in 1985, which included a national campaign to increase the awareness of genetic blood diseases among the population. In 1992 the premarital counselling service was expanded to include all health centres and more recently a law has been issued mandating premarital screening and counselling for all individuals wishing to get married.

The development of this law included wide consultation with all stakeholders to ensure that socio-cultural mores, theological issues and aspects of human rights had been exhaustively considered.

The benefits and effects of this premarital counselling programme will be seen in the improved genetic health of present and future generations.

Keywords

Genetic counselling, premarital counselling, genetic diseases

Introduction

Premarital counselling is a vitally important public health measure for many nations around the world. Its operational concepts were developed under the auspices of the World Health Organization (WHO). Data available from the WHO indicates that 240 million people world wide are heterozygous for genetic disorders and at least 200,000 lethally affected homozygotes are born annually, with a major proportion of these accounting for sickle-cell anaemia and thalassaemia syndromes (WHO 1982).

In an attempt to reduce the incidence of genetic diseases in Bahrain a premarital screening service was introduced at the Ministry of Health in 1985. This was expanded in 1992 and premarital counselling was subsequently included as a part of the primary health care services in all health centres throughout the Kingdom of Bahrain. More recently a law (Government Gazette: Issue 2640, 23rd June 2004) has been passed by the Bahrain Government which requires that all Bahraini couples, who are planning to marry, undergo mandatory premarital counselling.

Consanguineous marriage and genetic diseases

The word consanguineous is derived from the Latin *con sanguinis,* "of common blood" and consanguineous kinship is characterized by the sharing of common ancestors. Two or more individuals are said to be consanguineous if they have a common recent ancestor (Bodmer and Cavalli-Sforza, 1976) and a consanguineous marriage is typically defined as occurring between a couple related as second cousins or even closer. Worldwide figures have illustrated that there is a 4-5% increase in the risk of premature mortality among offspring of the union of first cousins (Modell and Darr, 2002). Consanguineous marriages are a significant factor in the propagation of genetic diseases, in Bahrain the rate of consanguineous marriage has decreased quite markedly from 39.4% (Al-Arrayed, 1999) to 20% (Al-Arrayed in press) but this is still substantially lower than in some neighbouring Arab countries. In Saudi Arabia where cultural reasons support a strong preference for consanguineous marriage the average rate is 58% with a range of 34-80% (El-Hazmi *et al.* 2005), and similarly in Jordan where the frequency of consanguineous marriage ranges from 50–66 % (El-Shanti, 2001).

Consanguineous marriage poses a significantly greater risk in that both parents will carry the same recessive allele for an inherited trait with the likelihood their offspring will be homozygous for that trait which will

result in expression of that specific genetic disease. Most recessive characteristics tend to be harmless and only minorities are associated with recessive genetic diseases (Bittles, 2003) which can also result in increased infant mortality (Harper, 2004). Unquestionably the early identification of carrier couples through premarital genetic counselling can help to reduce the number of affected births and it is for this reason that this service is being encouraged in a large number of countries.

Burden of genetic diseases and premarital genetic counselling

Genetic diseases are chronic in nature with no prospect of cure and require costly, complex, lifelong care and management strategies. In this way they can impose significant health care and psychosocial burdens on the patient, the family, the health care system and the community as a whole. However it is also recognised that their prevention can lead to significant benefits across the healthcare spectrum (WHO, 2002).

In Bahrain, the burden of genetic blood disorders constitutes 1-2% of neonates with sickle-cell disease, whilst those with the carrier state account for 11% (Al-Arrayed and Haites, 1995) and b-thalassaemia carriers a rate of 2% (Nadkarni, Al Arrayed and Bapat, 1991). Although there has been no comprehensive economic assessment of direct and indirect costs to the Bahrain economy, nevertheless the incidence of these diseases appears to support considerable economic cost implications. The economic costs and the societal and life-long healthcare treatment costs of these diseases are inestimable and "…they are imposing an increasing drain on health resources, particularly as countries go through the demographic transition" (WHO 1999 pg 6).

Genetic counselling has been defined as "the process by which patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, the probability of developing or transmitting it and the ways this may be prevented, avoided or ameliorated" (Harper, 2004, pg3). Central to the process of premarital genetic counselling is its educational, voluntary and non-prescriptive nature with a principal goal of empowering individuals and at risk couples to make their own informed decisions according to their own values.

There has been considerable debate over the value of screening for haemoglobinopathies in persons of reproductive age. Critics cite evidence that previous sickle cell screening programmes have failed to adequately educate patients and the public about the significant differences between sickle cell trait and sickle cell disease often causing unnecessary anxiety for carriers (USPSTF 1996). Moral and ethical dilemmas, social, cultural, political and religious factors vary quite considerably between nations but it is the responsibility of governments to ensure the health of its citizens by minimising genetic diseases through appropriate policies that respect human rights and recognise the individual's freedom of choice. These policies should also ensure that no social or political pressure is applied to people to make childbearing decisions on the basis of genetic information.

Although the process of development, ratification and promulgation of the recent law in Bahrain has been quite lengthy, it is considered that this has provided an opportunity to educate the population and to permit open discussion which has resulted in a significantly easier transition than in countries where there has been a more abrupt implementation.

The new law

The aim of the premarital counselling programme is to provide baseline assessment of couples and to identify and reduce the reproductive genetic risks and incidence of the common haemoglobinopathies in Bahrain. In this regard the Kingdom of Bahrain enacted Law number 11 for the year 2004 requiring mandatory premarital counselling for couples wishing to marry.

The genetic counselling programme was initiated in 1986 by the Ministry of Health through the Genetics Department in collaboration with the Bahrain National Hereditary Anemia Society (BNHAS). The development of this programme started with national campaigns to increase the awareness of genetic blood diseases among the population, which consisted of educational campaigns in schools, clubs and at other public venues. The premarital screening service was initially only available in the genetic department of the Salmaniyah Medical Complex (SMC). In 1991 it was decided that the service should be extended and the former Minister of Health, Jawad Salem Al-Arrayed established a National Committee for the Prevention of Genetic Blood Diseases which was tasked with examining the feasibility of introducing premarital counselling into all the health centres.

The possibility of issuing a law making premarital counselling obligatory was raised by the Ministry of Health with the Shura Council (a consultative body) where it was discussed, subsequently approved and forwarded through the ministerial cabinet to Parliament and was finally passed into law in 2004.

In view of its high degree of sensitivity the draft law was subjected to extensive consultation involving a wide range of stakeholders and quite importantly included a number of religious scholars. In Islamic countries ethical issues in genetics include a significant religious overlay with an emphasis on primary prevention of genetic diseases. To forestall any potentially sensitive social issues the development of the law included consultation with focus and advocacy groups and subsequently received positive support and backing from the Islamic clergy.

Although the WHO was not directly involved its guidelines and recommendations (WHO1983), were followed at all stages of the project. In addition the recommendations of the Genomics and World Health Report (WHO 2002), which provides guidance on ELSI (ethical, legal and social implications) in genetic screening, and stresses the key points of informed consent, confidentiality, stigmatization and discrimination, were carefully considered prior to implementation of the new law.

The process of premarital counselling

Any Bahraini citizen wishing to get married is now required to undergo obligatory premarital counselling for hereditary diseases according to regulations issued by the Minister of Health (2004) and without which it is not possible to obtain a legal marriage document. Premarital counselling is provided by physicians supported by trained health nurses at all health centres and is based on clearly defined protocols and guidelines laid down by the Ministry of Health.

The initial screening consists of history taking, physical examination and laboratory tests for hereditary as well as infectious diseases, any further investigations will be dictated by the individual's health status. Couples shown to be at risk of haemoglobinopathies are then referred to the genetic department of the SMC where they receive counselling and are provided with further information in the form of booklets and educational materials. It should be stressed that according to the new genetic counselling decree it is "compulsory to be tested but not compulsory to take the advice" and therefore individuals are not obliged to accept the advice given by the geneticist.

After counselling a certificate is issued to the individual stating that they have received pre-marital counselling. This certificate does not contain any personal genetic health status information, but merely states that the individual has received premarital counselling and is the formal document required by the Ministry of Religious Affairs to permit the issuing of a legal marriage document.

Impact of the new law

Premarital counselling is now available free of charge to Bahraini citizens at all health centres which guarantees equity in access. The implementation of the recent law has meant that the 'uptake' for premarital counselling and screening which was previously <50% is now expected to approach 100%. As premarital counselling is now obligatory this means that all potential carriers can be identified which will not only enable individuals to make informed choices but also assist in future planning of appropriate healthcare services for patients with genetic diseases.

There have been two noticeable effects of obligatory premarital counselling; an increase of 'separation before engagement' in 'arranged' marriages and a decline of 50% in incidence of sickle cell disease in neonates (Al-Arrayed, 2005). Furthermore, it is expected that the introduction of a plan to computerize all premarital counselling records will permit a more accurate and up to date picture of the genetic health status of the population.

Conclusion

In the development of this law the government of Bahrain has taken steps to ensure wide consultation with all stakeholders, to respect human rights and to ensure that socio-cultural mores and theological issues have been considered. In the implementation of this law it has adequately affirmed its lead role in the primary prevention of genetic diseases whilst expecting individuals to shoulder some responsibility for their individual risk by assisting them in making wise choices in marital partners.

The benefits and effects of this premarital counselling programme will be seen in the improved genetic health of present and future generations.

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Corresponding author:

Dr. Shaikha. S. Al-Arrayed
Department of Genetics
Salmaniyah Medical Complex
Ministry of Health
PO Box 12
Kingdom of Bahrain.

Email: sarrayed@health.gov.bh