The Gulf Cooperation Countries genetic services

Understanding individuals, families, and community needs

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In the past 30 years, the Gulf Cooperation Countries (GCC) have witnessed a remarkable social and economic growth, which is best reflected in the health care system. With these achievements, came the focus on genetic diseases, where the incidence of stillbirths is 0.9%, and, 6.9% for congenital anomalies. The incidence of congenital malformations and genetic disorders in GCC amounts to 7.3% of births,[1-3] compared to the average of 4.4% in Europe.[1,4] The major increase in genetic diseases, particularly recessive genetic diseases, is attributed to the high rate of consanguineous marriages.[5-8] In Saudi Arabia, the sickle cell gene and β-thalassaemia occur at a rate of 1-20%, with 2000 affected new borns added to the pool annually.[2,3] These findings are of national concern, and pose remarkable economical, social, and health challenges to health care authorities, and necessitates the adoption of an acceptable and effective prevention program. In the USA, Australia, New Zealand, UK, and other countries of western Europe, the control measures of genetic diseases incorporated genetic screening and counseling, and sometimes, prenatal diagnosis.[9,10] The latter is restricted in the Islamic communities in the light of the relevant Islamic teachings.[11,12]

The family with a genetic disease - a multifaceted problem in the GCC. Children occupy a central position in traditional Muslim communities, being considered an important part of prosperity, pride of the family, and the beauty and continuation of life. For women in the GCC, as in other Muslim countries, childbearing is of prime importance. Considerable number of women are totally devoted to bringing up children and caring for the family. In recent years, genetic services have been developed and consequently, families with children affected with a genetic disease became more aware of the causative factors and management of the affected patients. However, with better knowledge came appreciable psychological and social problems linked to the chronic nature of the genetic disease. Families of children with genetically affected disease, often feel stigmatized and discriminated against. They also see the genetic illness as unfair affliction. The whole family suffers from the daily strain of observing and caring for the affected individuals. It is notable that mothers with one affected child would be stressed; a mother with 2 or 3 affected children may become psychologically disturbed or depressed.[13] Fathers are weary, visiting many hospitals, searching for someone who can offer treatment, or explain to them how to deal with the affected children better. In addition, financial difficulties often arise, especially in families with multiple affected children. A father with multiple affected children may be forced to be absent from work to keep numerous appointments, and may consequently lose his employment. Disadvantages in relation to insurance and employment are an additional worry to the family with an affected member. These aspects need further consideration and regulations that ensure a supportive community.

The current concept of genetic diseases in the GCC. The concept of "genetic disease care" is a relatively new addition to the health care scheme in the GCC. In the

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absence of accurate genetic diagnosis, vague terms such as dysmorphic, handicapped, or "cerebral palsy" are often used to explain relevant illness. Diagnostic and prognostic uncertainty is one of the major psychological stressors for the parents, and patients with chronic illness and disabilities.[13] The modern term "genetic" or "wirathi" seems to carry negative notions. The responses from the concerned family to a genetic disease are associated with feelings of fear, misfortune, shame, guilt, anger, isolation, and blame, and are accentuated by negative notions in the mass media, and unavailability of a definitive cure in most conditions. However, most of the individuals in the community are receptive to genetic counseling, are able to understand the concept of recessive inheritance, and are eager to learn ways to avoid the disease. In recent years, more couples, with genetic disadvantages, have sought genetic information prior to cousin-marriage, and have expressed concern regarding the risks of having affected children. An increasing number of couples now seek pre-marital information on the risk of having genetically affected children. In some GCC countries, pre-marital screening for blood genetic disorders is currently offered to those who seek this service. Encouraged with increased public awareness, the Saudi Arabian authority made the optional program obligatory in the year 1425 Ah, (2004 AD).[14,15]

Proposed appropriate approaches. In light of the currently available information, a comprehensive scheme, and acceptable approaches for prevention care and rehabilitation, incorporating the following elements are proposed:

A) Health awareness and education. The use of genetic knowledge for prevention. Community Health Awareness and Education Programs are required to educate people in the community on the nature of genetic diseases, modes of inheritance, their prevention, and available management. Education packages should encompass relevant information on various common genetic disorders, and the fact that genetic disorders can affect anyone, and that no one is at fault in the way they are inherited, management, and possible approaches for prevention.[16-23] In its appropriate concept, awareness of the features of genetic diseases plays a major role in preventing the occurrence of genetic diseases.[24,25]

B) Genetic testing and counseling. Genetic testing and linked-counseling are central in efforts for prevention of genetic diseases. There are 3 main reasons why an appropriate counseling approach is essential: 1) Psychological, social, and ethical problems can arise as the result of genetic testing; 2) Genetic tests have high predictive values, thus can exclude or identify particular risks; and 3) Currently, a large gap exists between the ability to diagnose, and the ability to treat genetic diseases. Genetic testing for more than one individual requires special care in the timing and the process of giving such information. The framework of counseling should fall within the societal values and beliefs. The principles of ethical genetic counseling encompass a set of internationally accepted codes that can be locally adapted to community beliefs and culture, and exclude directive or coercive advice.[24,25]

C) Maintaining ethical principles. With the advent of new genetic technologies, additional medical, social, ethical, and economic issues are emerging. The applications of genetic information and technologies to genetic services require the adoption of a set of guidelines and standardized approaches in medical practice. The national guidelines being developed in the GCC are compatible with their set-up and culture.[12]

D) Sensitive approaches. Health providers and practitioners have to adopt a sensitive approach in providing health information, and pay attention to the vocabulary used in genetic counseling in order to ensure that inappropriate messages are not communicated to the counselee. Families with affected children should not be blamed, criticized, judged or ridiculed, but should be supported in all ways possible. It is essential to discuss, with the counselee, the components of the prevention program as well as what support services they need to care for the affected children. In the setting of pre-marital clinics, special attention and encouragement should be given to women, especially those who are carriers. Clear explanations of possible genetic tests should be linked to how diseases can be avoided. The option of pre-implantation and pre-natal genetic diagnoses should be presented, with the understanding that abortion of the affected fetus can be carried out only within the framework of the religious guidelines.[11]

E) Integrated management. Prevention endeavors, care, and rehabilitation should always be complementary and take into account a holistic approach, including psychological rehabilitation for the affected individual, and his family. If accompanied by commitment to the care of an affected individual, the prevention program will be credible, and be able to gain the confidence and cooperation of the concerned families. An integrated approach to the management of the disadvantaged requires support from a health care team, social agencies, and community support groups. The community support groups and associations are particularly suited to play a major role in helping parents to manage affected children, in terms of sharing practical experience with other parents on therapies and increasing relevant skills, and with respect to emotional aspects, such as getting a sense of belonging to a community.[9]

We conclude, that in order to structure an efficient intervention program for common genetic diseases, a complete package of integrated prevention and care in health care delivery is needed, where the genetic health

services have to incorporate care and rehabilitation schemes, in addition to the prevention endeavour. The service programme should be based on the understanding and respect of societal beliefs, appropriate for the set up and traditions of the local community, and take into consideration the education level, ethical concerns, and adopt appropriate approaches to the whole family that is affected by genetic illness.

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