

Oman: A Model for the Integration of Community Genetic Services into Primary Health

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The science of genetics and its potential applications in medicine have progressed very rapidly in the last two decades. To provide equitable access to quality genetic services for all those in need is a challenge to any country. This challenge can be met by integrating genetic services into the national primary health care system.

The state system in Oman provides free comprehensive health care, with almost negligible role for the private sector. The health care network includes primary health care clinics distributed throughout the country. These clinics are linked to seventeen secondary care regional hospitals and two tertiary care teaching hospitals in the capital, Muscat (1).

The estimated mid-year population in 1998 was 2,287,640, of which 1,684,850 were Omanis. Among the total population, 15% were under 5 years and 46% were under 15 years (2).

In the 1997 WHO, EMRO publication on the demographic and health indicators for countries of the Eastern Mediterranean (3), Oman was reported to have a rate of 12.5 physicians/10,000 population and 30.3 nursing and midwifery personnel/10,000 population. All the urban population and 90% of the rural population had access to local health services. Among the pregnant women, 98% were attended and 92% delivered by trained personnel, while trained personnel attended 98% of infants. The rate of use of contraception among the married women (15-49y) was 28%. The literacy rate among adult males and females was reported to be 84% and 76% respectively. The per capita GNP in 1996 was 6420 US dollars.

The demographic data suggest that the health system in Oman is capable of introducing some basic community genetic services into the reproductive primary health care program. The aim is to deliver genetic services in a more comprehensive and cost-effective manner to control common genetic and congenital disorders in the country.

To initiate a nationwide intervention program for the control of any health problem, there are two prerequisites. The first is to identify

priorities through evidence that the magnitude of certain health problems is significant, and, the second is an indication that control interventions are both feasible and cost-effective.

Priorities are defined by carrying out standardized epidemiological surveys and collecting demographic data, to identify the main national problems in the field of genetic and congenital disorders. Available data, though scarce, suggest the importance of genetic and congenital disorders as a health burden in Oman :

- 1- The consanguinity rate in Oman is high. First cousin marriages constitute between 24.1% and 34% among all marriages (4,5). Total consanguinity rate including beyond second cousins was reported to be around 57% (4,5), with an average inbreeding coefficient of 0.0198(4). Consanguineous marriages are known to increase the risks of expression of autosomal recessive conditions in the offspring, particularly the rare disorders.
- 2- There is a high prevalence of hemoglobinopathies and G6PD deficiency in Oman. Beta thalassemia carrier state and sickle cell carrier state has a prevalence of 2% and 6% respectively (5,6). Birth prevalence of beta thalassemia and sickle cell anemia were reported to be 0.4-0.7/1000 and 2-2.7/1000 respectively (5,1). G6PD deficiency was reported in 25% of males and 10% of females (5). The selective advantage of heterozygotes to malaria may have played a main role in sustaining the high prevalence of these disorders. In 1997, 1027 cases of malaria were reported in the Sultanate (3).
- 3- The high total fertility rate of 4.8 reported in 1997(3) may increase the number of affected in families with autosomal recessive conditions. It was estimated that if families limit the number of pregnancies after having one affected child with an autosomal recessive condition, the prevalence rate in the community of this disorder could be reduced by half (7).
- 4- The trend of continuing reproduction to menopause increases the number of over 35 years mothers. It is a known fact that elderly mothers are at an increased risk of having babies with Down syndrome and other trisomies. It was estimated that in countries where the percentage of births to mothers over 35 years is around 15%, more than 65% of Down syndrome cases would be born to such elderly mothers (7). Studies from Oman have reported an increased rate of fetal macrosomia (8) and neural tube defect (9) to older mothers compared to young mothers.
- 5- Genetic services at the community level are still minimal in Oman. In the last few years, efforts have been directed to the control of genetic blood disorders through the genetic blood disorders committee and the genetic blood disorder survey in the Ministry of Health (6,5). A national

congenital malformation registry has been recently initiated in the Sultanate. Molecular and cytogenetic laboratories, and genetic counseling clinics are presently functioning in the Sultan Qaboos University and the Ministry of Health. There is a need to extend community genetic services to the primary health care units to assure a more comprehensive coverage of the population.

6- Infant mortality rate in Oman in 1997 was reported to be 18/1000 livebirths (3). The fraction of infant mortality attributed to congenital malformations reached 21.6%, the second leading cause for infant mortality in the country (7).

The above mentioned factors suggest that genetic and congenital disorders contribute to an identifiable portion of infant mortality and morbidity in the Sultanate of Oman . A factor that adds to the problem is the minimal awareness among the public as a whole and among some health care personnel of simple and feasible control measures.

A multitude of control approaches can be feasibly integrated within the interventions in primary health care clinics(10). Although some additional training of health personnel will be required, the cost-benefit should be considerably high, compared with the suffering as well as the health and economic burden imposed on the families and the state in the absence of a control program.

The basic objectives of a control program include primary prevention, as well as early and effective management of genetic and congenital disorders. The strategies adopted to achieve these objectives should be carefully selected to match the unique demographic, cultural and religious characteristics of the population. For example, primary prevention is an essential pillar in the control program in Oman. The cultural, religious and social trends minimize the role of other control measures such as the selective abortion of an affected fetus.

Primary prevention measures, which could be integrated into primary care, include information that can be given in the preconception period to the married couple comprising:

- 1- reducing disorders related to advanced parental age ,such as Down syndrome, and autosomal dominant disorders due to new dominant mutation, as part of the family planning services;
- 2- reducing the occurrence of congenital abnormalities such as neural tube defect related to folate deficiency, and mental deficiency due to iodine deficiency , by promoting healthy nutrition for women of reproductive age;
- 3- reducing the occurrence of hereditary disorders in high risk families through genetic counseling;

- 4- providing information on the implications and availability of carrier testing for common disorders such as the hemoglobinopathies and G6PD deficiency;
- 5- preventing congenital rubella syndrome by immunization;
- 6- reducing mortality and chronic handicap due to rhesus hemolytic disease through routine prenatal screening;
- 7- Reducing congenital abnormalities and stillbirths by better control of maternal diabetes prior to and during pregnancy;
- 8- Reducing the risk of miscarriage, congenital abnormality and fetal growth retardation through avoidance of smoking during pregnancy;
- 9- Avoiding congenital abnormalities caused by certain infections such as syphilis and toxoplasmosis , through prevention, early detection and prompt treatment;
- 10-Minimizing exposure to industrial and domestic teratogens before and during pregnancy.

Early diagnosis and proper management can be implemented through newborn screening for disorders such as phenylketonuria, congenital hypothyroidism, hemoglobinopathies and G6PD deficiency.

The above mentioned interventions can be incorporated into the existing primary health care system in the country. Providing training courses that supply the basic requirements could strengthen the capabilities of primary health care workers. These requirements include the ability to provide preconception information on how to maximize the chances of a couple to have a healthy baby, the ability to recognize high risk families and refer them to genetic centers, and the ability to provide premarital and prescreening counseling. Training programs for midwives could include the ability to detect congenital disorders and the prompt referral of the affected neonates to appropriate centers.

Genetic registers play an important role in providing and evaluating community genetic services. Besides supplying important epidemiological data, the main aims of genetic registries include: providing prospective counseling, monitoring the changes in prevalence rates, evaluating genetic services and picking up risk factors for congenital disorders.

Education is an integral part of any community health program. Organized information, education and communication need to be addressed to the population in general, to mothers to be and their families and to all health personnel. Channels to address people in general could include school curricula, premarital centers, primary health care clinics . Messages through the media should be properly formulated according to

evidence-based criteria; inaccurate and non-scientific messages could do more harm than good.

Another integral part of community genetic services is the presence of at least one national specialized center. The center serves the triple function of receiving referred cases; cooperating in education ,and implementing research projects. The center can be progressively upgraded to introduce new technologies for diagnosis and management of genetic and congenital disorders.

The considerable challenge posed by genetic and congenital disorders calls for the development of control programs through the establishment of community genetic services. The strategies proposed here are primarily based on strengthening training of health professionals and on public education. The rapidly progressing technology in diagnosis and management of genetic and congenital disorders could be gradually introduced into the national control programs.

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