



In the name of God, the Compassionate, the Merciful

Address by

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to the

FIRST SYMPOSIUM ON ETHICAL AND GENETIC COUNSELLING ISSUES

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Distinguished Colleagues, Ladies and Gentlemen,

I am delighted to be with you at the first symposium on ethical and genetic counselling issues. I would like to thank the organisers of this symposium for inviting me to address you during the inauguration session.

Recent evidence from scientific research has proved that genetic factors play a role in most human disorders. Besides the primarily genetic diseases and congenital malformations, most common disorders, such as diabetes, hypertension, coronary heart disease, schizophrenia and many forms of cancer, are now known to be partly caused by abnormal genes.

In the Eastern Mediterranean Region, available data indicates that congenital and genetically determined disorders occur in rates similar to, and sometimes even exceeding those in industrialized countries. There is an extremely high rate of consanguineous marriage in the Region, a high frequency of haemoglobinopathies and glucose-6-phosphate dehydrogenase deficiency, a relatively high percentage of increased maternal and paternal age, a tendency for large family size, and a generally low awareness of genetic issues among the public and health professionals.

Genetic and congenital disorders cause a considerable proportion of perinatal and neonatal mortality in many countries in the Region. In some of these countries, congenital malformations are now recognized as one of the leading causes of infant mortality, and are reported to contribute to a considerable proportion of perinatal deaths and neonatal admissions. Additionally, the data available in the Region on the causes of disability suggest genetic factors play a major role in mental handicap and deaf-mutism.

Initiation of community programmes for the prevention and control of genetically determined diseases is therefore becoming a priority for countries where the magnitude of primarily environmental diseases is declining due to improved social and economic conditions. Ethical considerations dictate that genetic services for the prevention, diagnosis and treatment of disease should be available to all and as part of these services, genetic counselling and education of the public are of paramount importance.

Genetic counselling aims to provide correct information regarding the causes of genetic diseases, and on how to promote people's control of their family's health by informing them of the resources available for diagnosis, treatment and prevention. Although counselling has a role in many medical consultations, it is particularly important in medical genetics because of the often predictive nature of genetic information, the implications for other family members, the difficult choices that sometimes have to be made and the important ethical problems that can be involved.

It is important, however, to recognize that genetic counselling cannot be transferred in entirety from one social context to another. In the Eastern Mediterranean Region, social and religious beliefs could lead to a rather different evolution of opinion on the priorities of the

genetic services that should be available. The wide range of family and social structures, religious and legal conventions and economic resources may also lead to different conclusions in different countries. Your symposium will therefore provide a unique opportunity to discuss the priorities for genetic counselling in this Region. I also hope that you will be able to review the current status of genetic counselling services in Member States and develop practical recommendations to strengthen such services.

Because the choices facing people at genetic risk can be so difficult and can have life-long consequences, experienced genetic counsellors generally consider that informed individuals or couples are themselves the best judges of what to do. Thus, it is important to remember that, in all populations, ethical practice in genetic counselling should always be based on autonomy of the individual or couple, their right to complete information, and the highest standards of confidentiality.

Dear Colleagues,

While it is essential for the countries of our Region to develop effective community genetics services and take account of the exciting developments taking place in this field, it is imperative to study the ethical, religious, legal and social issues related to genetic diagnosis and prevention and to the applications of new genetic techniques. No doubt these techniques may contribute to the achievement of better health for people in all countries, but they can only be acceptable if carried out ethically and with due regard to personal autonomy and the laws and beliefs of each country. If such developments are integrated into primary health care with adequate attention to cultural and religious values, the increased benefits for prevention, diagnosis and treatment of human conditions will be better appreciated.

The rapid progress in the science of genetics and the potential applications in medicine have necessitated the prompt definition of ethical issues in the provision of medical genetic services. Medical ethics, in general, includes offering the best service to improve or sustain health in a confidential, sympathetic and truthful atmosphere. Ethics in medical genetics should also include helping individuals to deal with information on possible diseases

in future offspring, and guiding them to make their own decisions in accordance with their beliefs and national legislation.

Recognizing the importance of ethical issues in the practice of medical genetics, many international committees, commissions and advisory groups have convened and several reports and sets of guidelines have been produced on specific biomedical issues. But none of these has resulted in the development of comprehensive global guidelines. Since WHO aims to enhance the integration of ethics in overall public health policies and practices, a meeting on ethical issues in medical genetics and genetic services was convened in Geneva in December 1997. Although experts from different regions participated in the meeting, the guidelines clearly recognize that some ethical problems in human genetics are highly contentious and may even be beyond the reach of practical consensus among countries. For this reason, the proposed guidelines will require careful review and should be subject to consideration by regional experts if these guidelines are to be adopted regionally and nationally. In this respect, I am pleased that these guidelines will be reviewed later this week in the workshop that follows this symposium and I look forward to the outcome of your review and discussions.

I am confident that your symposium will clarify many debatable issues and produce practical recommendations consistent with the spirit and teachings of Islam and that these recommendations will be valuable in reviewing and enriching the globally produced guidelines.

I wish you a productive and enjoyable meeting.

God bless you.