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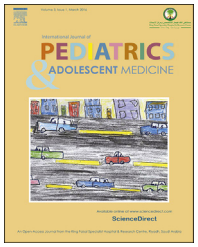

REVIEW ARTICLE

Genetic counselors' scope of practice and challenges in genetic counseling services in Saudi Arabia

Ameera Balobaid [a,b,*], **Alya Qari** [a,b], **Hamad Al-Zaidan** [a,b]

[a] *Department of Medical Genetics, King Faisal Specialist Hospital & Research Centre, Riyadh, Saudi Arabia*
[b] *College of Medicine, Alfaisal University, Riyadh, Saudi Arabia*

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Abstract Genetic counseling is an evolving field in Saudi Arabia. In 2015, genetic counseling was recognized as a Master's program by the Saudi Commission for Health Specialties. Our genetic counselors combine their knowledge of genetics, counseling theory and interpersonal communication to serve Saudi and non-Saudi patients affected with a range of genetic conditions and/or birth defects. Most patients are referred to the clinic from different clinics at King Faisal Specialist Hospital and Research Centre (KFSHRC) and outside of KFSHRC for various indications. Carrier testing and preventative reproduction options rank highly on the reasons for referral to our clinics.

The Saudi population has unique customs and beliefs, such as consanguinity and the evil eye. Challenges that are routinely encountered in our genetic counseling clinics include, but are not limited to, preventative reproductive options and termination of pregnancy, manifesting carriers, stigmatization of women and approaches to complex molecular findings. Working with families from different backgrounds and beliefs undoubtedly requires professionals with a distinctive set of skills and a structured clinical setting. This review article presents the scope of genetic counseling practice and tackles some of the challenges faced in providing genetic counseling in Saudi Arabia.

* Corresponding author. Department of Medical Genetics, MBC-75, King Faisal Specialist Hospital & Research Centre, P.O Box 3354, Riyadh 11211, Saudi Arabia. Tel.: +966 11 4424988; fax: +966 11 4424126.
E-mail address: ablobaid@kfshrc.edu.sa (A. Balobaid).
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1. Introduction

The term "genetic counseling" was first introduced in 1947 by Sheldon Reed [1]. The American Society of Human Genetics proposed a definition of genetic counseling in 1975, which was redefined after the professional society of genetic counselors known as "The National Society of Genetic Counselors" was incorporated in 1979. Genetic counseling is a "process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease" [2]. The first genetic counseling program was established by Professor Melissa Richter in 1969 at Sarah Lawrence College, which is located in New York, in the United States [3]. At present, there are several genetic counseling Master's programs in the United States, Canada, Europe and South Africa.

Training in genetic counseling was not available in the Middle Eastern countries until 2003, when the late Professor Ahmed Teebi was hired by King Faisal Specialist Hospital and Research Center (KFSHRC) as Head of the Department of Genetics. He championed the development of a training program in the kingdom and hired a Canadian genetic counselor, Shelley Kennedy, as supervisor of the program to develop its curriculum. One year later, with Professor Moeenaldeen Al-Sayed, as Medical Director, a diploma in genetic counseling was established at KFSHRC in Riyadh, Saudi Arabia [4]. Nine years later, Saudi Arabia witnessed the birth of a Master's program in genetic counseling. As an expansion of the successful development of this field in Saudi Arabia, the Master's program in genetic counseling was recognized and accredited by the Saudi Commission for Health Specialties in 2015. The inclusion of this Master's program in the Ministry of Higher Education in Saudi Arabia will provide genetic counselors throughout the Kingdom, which will alleviate the burden placed on non-geneticist health care providers who have little training in medical genetics. The availability of genetic counselors in many of the governmental hospitals in the Kingdom of Saudi Arabia will provide tremendous advantages to patients and to other health care providers. This article reviews the genetic counselor's scope of practice at KFSHRC, placing particular emphasis on the challenges encountered in our genetic counseling service.

1.1. Genetic counselors' scope of practice

Genetic counselors are Master's trained health care professionals who combine their knowledge of basic science, medical genetics, epidemiological principles, counseling theory with their skills in genetic risk assessment, education, interpersonal communication and counseling to provide services to patients and their families for a diverse set of genetic or genomic indications. Some genetic counselors offer general genetic counseling, while others subspecialize in a particular area of interest, such as cancer or prenatal care, assisted reproduction, cardiovascular health, research, public health and education.

Genetic counselors see patients and their families for several reasons, including but not limited to, a family history of an inherited condition, a previous child with intellectual disability, multiple congenital anomalies or birth defects, repeated pregnancy loss or infertility, a positive newborn screening test, a newly diagnosed abnormality or genetic condition and to enroll patients in research studies. Moreover, they provide carrier testing, premarital genetic testing and counseling regarding preventative reproductive options, which include prenatal diagnosis (PND) and pre-implantation genetic diagnosis (PGD) for various underlying genetic defects and chromosomal abnormalities.

1.2. Genetic counseling clinics: the KFSHRC experience

Our genetic counseling clinics serve patients from different provinces of Saudi Arabia, the gulf and Arab countries. We have six genetic counseling clinics per week. These clinics are separate from the genetic and metabolic clinics, which are operated by geneticists. The time allocated for each patient ranges from 25 min for a follow-up to 75 min for a new case. Some cases require multiple counseling sessions, whereas other cases require only one or two visits to the genetic counseling clinic.

Cases are referred to our clinics from different specialties both within and outside of KFSHRC, such as medical genetics, high risk obstetric gynecology, cancer, dermatology, neurology, hematology, pediatrics and in vitro fertilization clinics. Referrals are primarily for extensive genetic counseling, molecular and cytogenetic testing, premarital screening, carrier testing and preventative reproductive options.

Many families seek genetic counseling to understand the nature and consequences of genetic conditions, the risk of recurrence and preventative reproductive options and to address their uncertainty regarding genetics and inheritance. Our teams provide support for these families by identifying their concerns, addressing their needs, providing psychosocial counseling and promoting their decision-making process regarding testing or methods of prevention.

2. Challenges in genetic counseling services: the KFSHRC experience

Genetic counseling often raises ethical and professional challenges. The most frequently encountered challenges among physicians in Western countries such as in Austria have been informed consent, organizational constraints, withholding information, and attaining/maintaining proficiency. [5].

The major ethical principles that govern the attitudes of genetic counselors include respect for the patients' autonomy and right to make their own decisions, beneficence, i.e., taking actions to help others, non-maleficence, i.e., to do no harm, and justice, or administering services fairly between others [6].

There are several unique and difficult issues that are faced routinely in genetic counseling clinics in Saudi Arabia. Below is an overview of these issues based on several experiences at KFSHRC.