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Assessment of Knowledge and Attitude of Medical Student Toward Genetic Counselling and Therapeutic Abortion

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Genetic counselling concerns itself with the problems faced by patients and their families in the light of the occurrence, or the risk of occurrence, of an inherited genetic disorder. A primary goal of genetic testing is to enhance the capacity to diagnose, treat and potentially eliminate genetic disorders by selective abortion. In response to the increasing emphasis on genetics in medicine, it has been proposed that general practitioners should provide a frontline counseling service in clinical genetics. In view of this proposal and especially in the light of the importance and delicacy of the issues raised by genetic testing, this paper reports on the first ever stuffy, evaluating the knowledge and attitude of medical students in Iran towards genetic counselling and selective abortion. In Iran all medical students spend a period as a GP on qualification. Two hundred medical students, half of whom had taken a compulsory course on genetic medicine as part of their general practitioner training and half of whom had not, were invited to complete a questionnaire. The results show that both groups of students knowledge of genetic testing and its implications was very low before they sat the course and that it was not increased substantially by having done so. Perhaps most importantly, students in both groups continued to believe that abnormal foetuses should be terminated. The study revealed that, despite the rapid growth of medical genetics and awareness of genetic disorders, the education and training of medical staff and particularly family practitioners in Iran does not currently prepare medical students adequately for their future role.

Key words: General practitioner, training, genetic counselling, Iran

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INTRODUCTION

Within a variety of national health systems, developments in genetic medicine and an increased emphasis on genetics in clinical practice have given rise to debates about the future requirements for genetic services and in particular the likely demand for genetic counseling. Genetic counseling involves supporting an individual or family and helping them to understand a genetic condition: the diagnosis, the part played by heredity in the disorder, its possible course, how it can be managed and the risk of its recurrence in specified relatives. The genetic counselor guides the individual and/or family towards an understanding of the options that are available to them for dealing with the risk of recurrence and towards choosing a course of action which seems suitable to them in view of this risk. Their role is to facilitate the best possible adjustment to the disorder in the affected family members (Bernhardt *et al*., 2000; Evans *et al*., 2004). Until recently clinical genetics and genetic counseling have concerned themselves with the identification of and support for, patients affected by or at risk of rare genetic disorders and their families. In the relatively near future however, genetics is likely to expand rapidly beyond the scope of rare single gene disorders and extend to addressing the genetic components of some of the major common complex diseases such as cardiovascular disease and common cancers. With only one or two consultant geneticists per million population in Iran however, it seems unlikely there will be sufficient specialist counselors to meet patients' needs in the future with a rapid expansion in genetic services and health professional training. In response to these advances in genetic medicine and the inevitable growth in genetics departments, it has been proposed that at least some genetic services should be provided at the primary care level by family doctors; that is, that general practitioners should increasingly provide a frontline service in clinical genetics. This raises the question, though, as to whether-in addition to questions of time and other resources-GPs are going to be provided with sufficient training and support to take on this new role and to provide support to those at risk of genetic disorders (Watson *et al*., 1999). The main difficulties facing general practitioners with regards to genetic counseling are taught to relate to their lack of knowledge about genetics and molecular biology and their lack of expertise when it comes to the management of emotional conflicts and tensions (Clarke, 1990; Peters *et al*., 2004).

Cytogenetic analysis (karyotype and Fluorescent *in situ* hybridization) and some molecular genetic tests (for single gene disorders) are currently carried out in Iran. There are however currently very few genetic counselors working in Iran and most of these are based in the capital, Tehran where they usually work in university clinics and receive referrals not only from other consultants, such as pediatricians, obstetricians and gynecologists, but are also sometimes sought out by married couples directly. Following genetic counseling with such patients, decisions will be made about what laboratory tests they need and the couple will be informed about how they can be supported with their problem (if they have one). The increasing demands on medical geneticists in Iran means that there are not enough specialists in this area to meet demand and therefore, in line with recommendations elsewhere, it has been proposed that general practitioners should be trained to deal with people in need. In Iran, all medical students go through general practitioner training, regardless of whether they go on later to specialize in particular fields of medicine. As part of that training, they are required to pass a two-unit compulsory course in medical genetics. The course covers basic concepts in human genetics, cellular and molecular biology, in Mendelian inheritance, molecular genetics and cytogenetics, cancer genetics and immunogenetics. It requires that students be able to identify common genetic disorders and their clinical features, to know about prenatal diagnosis and treatment and to have some knowledge of what is involved in genetic counseling.

As suggested earlier, the trend in the literature points towards the increased involvement of general practitioners in genetic counseling and this is certainly a specific and practical need in Iran. Despite training initiatives such as the above, it remains unclear how much GPs in Iran know about genetics and genetic counseling and what their attitudes to it are. In order to begin to address these questions, the descriptive study reported below examined medical students' knowledge and outlook towards genetic counseling and pregnancy termination. More specifically, it attempted to identify the effects of the compulsory genetics course on the students' attitude towards care for patients who require genetic counseling, focusing in particular on whether the students were likely to encourage patients to refuse or accept selective abortion. This is one of the first examining ethical issues in the field of genetic counseling and selective abortion in Iran.

MATERIALS AND METHODS

A multiple choice questionnaire was completed by 200 medical students. Half of these students had not taken the compulsory course in medical genetics, half of them had passed the course. The survey was designed to

identify, firstly, how much knowledge about genetic counseling and selective abortion these two groups of students had (the first seven questions address this issue) and secondly, what kinds of attitudes towards genetic counseling and selective abortion they held (this was the focus of the last four questions). The purpose of the study was explained to the students in advance and they were given instructions on how to complete the questionnaire.

The study questions were as follows:

- What does a genetic counselor do?
- What is a common indication for genetic counseling?
- What is the earliest gestational age for prenatal diagnosis?
- What assessment and investigation is available in genetic counseling?
- Which tests are used in prenatal diagnosis?
- When is selective abortion legal in Iran?
- In which situations is selective abortion recommended?
- What are your views about selective abortion?
- What course of action would you suggest to a pregnant woman with an abnormal fetus?
- What is the difference between an abnormal fetus and abnormal people?
- What is the difference between selective abortion and euthanasia?

Students were given a range of statements from which to choose an answer or answers to these questions. All answers were tested statistically by Chi-square test.

RESULTS

Most of the students' answers to the question as to what exactly a genetic counselor does were incomplete. None of the medical students who had taken the genetics course knew exactly what genetic counselors do; 22% of those who had passed the course did. A significant difference was seen between them (Chi-square test, $p = 0.00$).

Of the students who had not sat the genetics course, 70% were unable to identify the common indication for genetic counseling. Of those who had sat the course, more than 80% of were able to identify most of the correct indicators (Table 1). No significant differences were found between the two groups (Chi-square test).

A significant difference was found between the two groups of students (chi-square test, $p = 0.017$) on the question of what stage a pregnancy prenatal diagnosis is carried out in Iran. While 24% of the medical students who had not sat the course on medical genetics were able to answer this question, unfortunately only 46% of students who had taken the course were able to answer it.

Only 10% of medical students who had not taken the course on genetics and 16% of those who had taken it knew what the necessary assessment and investigation in genetic counseling was. Less than 10% of both groups knew which tests are used for prenatal diagnosis (Fig. 1 and 2). There are no significant differences between two groups (Chi-square test).

There were significant differences between two groups on the question of the legal time for selective abortion in Iran (Chi-square test, $p = 0.07$). 27.5% of medical students knew this time before taking the course

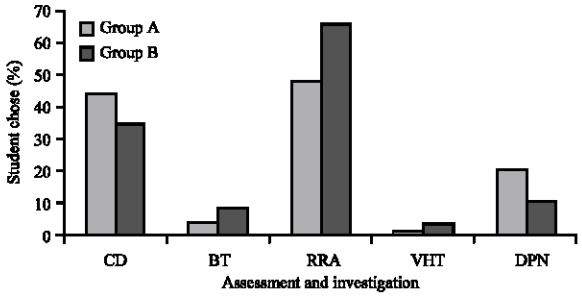

Fig. 1: Necessary Assessment and Investigation in Genetic Counselling. Group A = Did not pass genetic course, Group B = passed genetic course. CD = Carrier detection, BT = blood test (CBC, FBS, TG, CHOL), RPA = Recurrence risk assessment, VHT = Visual and hearing test, DPN = Determining PND needed or not. * Everyone can choose more than one test

Table 1: Common indication for genetic counseling

	A				B			
Patients condition	C (%)	PC (%)	IC (%)	NI (%)	C (%)	PC (%)	IC (%)	NI(%)
Previous baby with congenital anomaly	87.9	5.1	-	6.8	92	6	2	-
Advanced maternal age (over 30)	44.8	36.2	6.8	12.0	48	34	18	-
History of infectious disease	5.1	18.9	37.9	37.9	-	20	74	6
History of gastrointestinal disease	10.3	17.2	37.9	34.4	4	28	66	2
Infertility and repeated pregnancy loss	53.4	29.3	6.8	10.3	84	14	2	-
Teratogen exposure	31.0	25.8	8.6	34.4	70	18	10	2
TORCH syndrome	36.2	12.0	5.1	46.5	48	10	34	8

C = Correct; PC = Partially Correct; IC = Incorrect; NI = No Idea; A = Did not pass genetic course; B = Passed genetic course

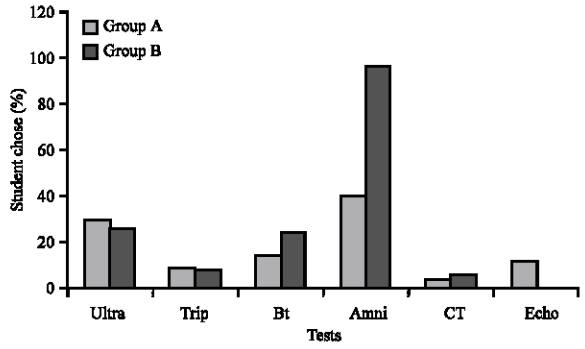

Fig. 2: Prenatal Diagnostic Test. Group A = Did not pass genetic course, Group B = passed genetic course. Ultra = ultrasound, Triple = triple test, Bt = blood test and HLA typing, Amni = amniocentesis. CT = CT scan, Echo = echocardiography. * Everyone can choose more than one test

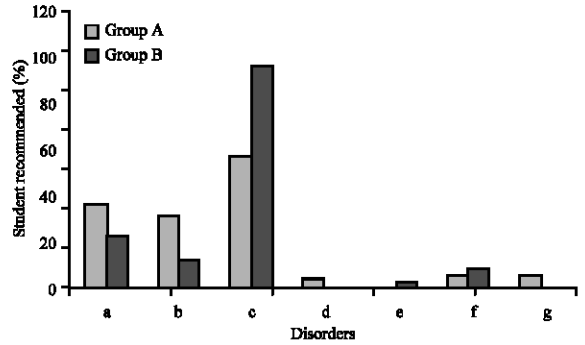

Fig. 3: Selective Abortion Recommended. a = feotus with Down syndrome, b = feotus with Turner syndrome, c = feotus with major Thalassemia, d = feotus with minor Thalassemia, e = male feotus if mother have 5 other boys, f = male feotus if mother has autosomal recessive disease and g = feotus carrier for autosomal recessive disease. A = Did not pass genetic course and B = passed genetic course. * Everyone can choose more than one test

on medical genetic, while 46% were able to identify it after taking the course. However no significant differences were seen between these groups when it came to the question of their attitudes towards selective abortion (chi-square test, $p = 0.31$). Here, 94% of medical students who had sat the course and 79.2% who had not, agreed with selective abortion. Nevertheless, less than 10% of both groups recommended abortion for right pregnant women (Fig. 3).

How do the percentages in this paragraph fit with the one above, 44.8% of the students who had not sat the medical genetics course believed that selective abortion was the best choice for a woman whose fetus had been identified as abnormal. After sitting the course, 54% thought that it was the best choice. Only 13.7% of the former group and 18% of latter thought the woman herself should be able to make the decision for herself and her pregnancy. No significant difference was found between them (Chi-square test).

Finally, 62.3% of the students who had not sat the course in medical genetics and 68% of the students who had taken it, believed that an abnormal baby is partially or completely identical with an abnormal person. With regards to the relation between selective abortion and euthanasia, 27.4% of the students who had not sat the course considered these to be partially or completely different. Having sat the course, 64% of students were able to identify the difference.

DISCUSSION

Genetic counselors work with patients and their families to help them understand the genetic information that they are given and to explain the possible risks. Their aim is also to support and guide the patient and their family and to help with the expression and management of their feelings. This requires that at least basic knowledge and careful training be given to those involved in such counseling and yet, as the responses to question one of the survey indicates, even when medical students in Iran have sat a course on genetics, they do not have enough information to enable them to identify what exactly genetic counselors do. This unfamiliarity with genetics (Emery, 1999) is clearly problematic in a context where genetics has become relevant to every general practitioner's daily practice (Qureshi *et al.*, 2004).

One of the key ethical issues raised in relation to genetics concerns the question of directive or non-directive counseling. A good counselor should be able to explain the outlook for a child with an abnormality and to describe what treatment might be necessary. Patients should be supported in making their own decisions about whether to have a child with disabilities or to end the pregnancy (Headings, 1997). In other words, even though genetic counselors should provide high levels of support and guidance for patients and their families, they should not ultimately make their decisions for them, nor should they suggest that they follow one course of action over another. The results of the present study (and especially question nine) indicates however that GPs in Iran are likely to give a patient a direct order which usually involves dictating that the woman have an abortion.

This finding is in keeping with other research which suggests that non-geneticists are more likely to be directive in counseling than geneticists (Holtzman, 1993; Plunkett and Simpson, 2002).

All existing prenatal diagnostic tests are available in Iran. Depending on the test, the best time for these to be carried out is between ten and eighteen weeks. The legal time for selective abortion in Iran is eighteen weeks. The decision to terminate a pregnancy requires the support of a genetic counselor and a legal medicine consultant. Unfortunately, as the responses to questions two to seven show, the majority of these students did not know when carrier testing is appropriate, what the indicators for prenatal testing are, nor what prenatal diagnosis tests are available in Iran. Most of the students who completed the questionnaire were not able to identify the right time to carry out a prenatal diagnosis, nor did they know the legal limits on selective abortion in Iran. In this respect the questionnaire confirmed studies from other countries which show that general physicians have limited knowledge about genetics, find it difficult to assess risks and have a tendency to overestimate genetic risk (Boulton and Williamson, 1995; Boulton *et al*., 1996; Firth and Lindenbaum, 1992; Julian *et al*., 1986; Shickle and May, 1989; Fry *et al*., 1999). Indeed, the results of this survey (in particular questions eight, ten and eleven) show that most of the students adopted what one might call a 'merciless' attitude towards abnormal fetuses and that they were likely to encourage patients to terminate pregnancies. This was especially the case after they had sat the course on genetics and in spite of the fact that they could not for the most part distinguish between untreatable and/or fatal cases and those that were treatable (question seven).

CONCLUSIONS

Genetic counselors, medical geneticists and increasingly, general practitioners are required to give patients important advice and guidance about genetic medicine. For this, they need some understanding of the key ethical issues involved and of the approaches available when dealing with difficult choices. They need to be able: to know which disorders are able to be diagnosed by prenatal testing; to be able to disclose the risks and benefits of such tests; to provide the tests; to provide non-directive counseling and to support parental independence in abortion choices. They need to be able to do all this in a way that is informed by basic ethical principles and which is sensitive to the needs of the individual as well as to their society (Skirton and Eiser, 2003).

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