

Compiling of curriculum for the Master of Science in genetic counseling

Mansoor Salehi, Fariba Haghani¹

Department of Biology and Genetics, School of Medicine, ¹Department of Medical Education, Medical Education Research Center, Medical Education Development Center, Isfahan University of Medical Sciences, Isfahan, Iran

ABSTRACT

Introduction: The demand for genetic counseling has been greatly increased in the recent years in Iran and the entire world. However, there are no systematic training courses for genetic counseling in the country. The purpose of this research was compiling the curriculum for the Master of Science (MSc) in genetic counseling. **Materials and Methods:** This descriptive study was conducted in 2010 and 2011 in Isfahan University of Medical Sciences. A questionnaire with 25 questions was prepared based on the literature review. The assessment was conducted by using the questionnaire as well as outcome of group discussions with three geneticist groups including, members of the board of medical genetics, genetics graduate students, and practitioners in genetic counseling. The curriculum was designed after determining the educational needs and priorities by the genetic board. **Results:** The results of this research led to set the educational goals for the MSc in genetic counseling. Finally, the course curriculum was compiled. **Discussion:** The designed MSc in genetic counseling in this study was generally similar with the courses in other universities. Although, the assessment results were different in some cases with the same academic courses such as to give more importance to basic medical needs in comparison with the needs of clinical sciences. Therefore, more attention should be paid on prerequisite courses rather than the rotational periods in the hospital. Among the reasons for this difference, it could be noted to the differences in undergraduate educations and differences in the status of provided genetics services in Iran. The final conclusion of this research was to design a fundamental course to overcome one of the severely tangible requirements in the country field of health, namely genetic counseling.

Key words: Genetic counseling, graduate courses, Master of Science, medical education

INTRODUCTION

Improving human health status, from the early 20th century has had an important role to reduce the risk of infectious diseases and cardiac and pulmonary diseases. This resulted in a growing increase in the role of genetic and inherited diseases in human morbidity and mortality. The required access to appropriate and accurate information by those who had a history of a genetic disease in their families, had led to the development of genetic counseling as a discrete field of expertise.^[1] This growing need was led to establish the first genetic counseling institution in the world about 40 years ago.^[1] Since then, genetic counseling centers are opening around the world extensively. In other words, it seems that

Address for correspondence: Dr. Fariba Haghani, Departments of Medical Education, Medical Education Research Center, Medical Education Development Center, Isfahan University of Medical Sciences, Isfahan, Iran.
E-mail: haghani@edc.mui.ac.ir

Access this article online	
Quick Response Code:	Website: www.jehp.net
	DOI: 10.4103/2277-9531.127546

Copyright: © 2014 Salehi M. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

This article may be cited as: Salehi M, Haghani F. Compiling of curriculum for the Master of Science in genetic counseling. J Edu Health Promot 2014;3:3.

the simplest way to deal with the growing problem of genetic diseases is the genetic counseling. Genetic counseling is a two-way relationship between counselor and the client with the aim of prevention of disabilities caused by genetic disorders. During genetic counseling process, proper information about diagnosis, prognosis, and disease control, will be given to the family. In addition, the counselor will try to provide useful information by finding the pattern of the disease inheritance and calculating the probability of its happening again in other family members. Informing the family about the existing methods to reduce risk-factors and explaining about the available supportive therapies for the disease for helping to select the most appropriate solution for the problem.^[2] The ambition of genetic counseling is to enable people to make informed decisions away from the unduly pressure and stress and not to decide instead of them.^[3] Consequently genetic counseling is a set of activities to take place in the fields such as diagnosis, calculating the percentage of risk and providing the necessary information about the existing facilities. Therefore, it emphasis points such as: Existing methods for prevention, prenatal diagnosis, methods of treatment, and costs.^[4,5] However, there is no independent university degree entitled genetic counseling in Iran. Nevertheless, many prominent universities in the world have this field of study. For example, in the United States American Board of Genetic Counseling is responsible for the accreditation of genetic counseling graduate courses. This organization divided the offering universities in three categories of: Universities with full accreditation including, 21 universities, universities with provisional accreditation including 9 universities and universities with probational accreditation. Currently, there is only one university in the third category. Universities in the following countries also offer MSc degree in genetic counseling: Japan (7 universities), Australia (5 universities), Canada (3 universities), South Africa (2 universities), Spain (2 universities), UK (2 universities), China, Cuba, France, the Netherlands, Norway, and Saudi Arabia (one university, each).^[6] The interesting point is that in all of the listed countries and even in the United States, which for several years many universities offer graduate programs in genetic counseling, this course is not very wide-spread. This is for two reasons; first, there is a definite role for these consultants as a liaison between patients or the public and clinical geneticists and therefore, the need for not too many number of the graduates of this course.^[7] The second reason is that the issue is a new field, which despite its importance; it still has not the worthy expansion. The Master of Science (MSc) in genetic counseling is between 2 and 4 semester courses. The difference in the length of the courses is associated, mostly with, the foreground of the applicant's undergraduate degree courses.^[7] Among the lessons, which are taught in all universities without exception, the following lessons can be pointed: "The principles of counseling or alternatively" similar courses such as "practical counseling," "basic counseling," "human genetics," "recombinant DNA technology," "genetic laboratory methods," and "legal and ethical issues in genetic counseling". This degree is offered in two forms, some universities are offering a series of courses

without implementation of the research project in two or three semesters. Some others implement a project in addition to the courses for one or two semesters as well.^[8,9] In Iran, as mentioned, however, the need for genetic counseling is very well accepted, but there is no formal academic course for this degree. Considering the fact, that the majority of genetic counseling is somehow counselors is related to the prevention of disabilities, which is a part of the Social Welfare Organization duties, the organization in collaboration with its university attempted to hold a short-term course of genetic counseling training about 10 years ago for the interested physicians.^[2] This course, which perhaps passed from the idea of the course to appropriate design and implementation too quickly was repeatedly presented in different centers of the Social Welfare Organization. Although, the authorities made their sincere efforts to provide an effective course, but regarding two aspects of the legal positions (under the current law, only the Ministry of Health and Medical education has the right for the trainings related to medical fields) and presentation of the course (design and implementation of the course needed spending more time) the course was not as effective as it should be, so that it always has been a serious concern for the genetics related parts of the Ministry of Health and Medical education. The mentioned course had an entrance exam followed by 140 h of class attending lessons (theoretical–practical) in genetic counseling. After finishing the course and administration of the final exam, the attendees participate in the apprenticeship. After the study of 50 consulting cases in an accredited genetic counseling center and presenting the report, they received the permission to establish a center for genetic counseling.^[2] Nowadays, many genetic counseling centers have been established throughout the country by the people who have received this permission. Despite the uncertainty for the position of these centers in the health system of the country, the Deputies of treatment of the Universities of Medical Sciences are not willing to stop those activities for two reasons. The first reason is that these people are physicians and already received a license to establish medical clinic. Based on that, they have the permission to practice medicine and genetic counseling is part of their medical practice. The second reason is the lack of systematic genetic counseling courses in the Ministry of Health and Medical Education. Therefore, developing an academic course during the recent years has always been a priority of the genetic board of the Ministry of Health and Medical Education. About the current status of genetic counseling training in Iran, it is important to note that the Ministry of Health and Medical Education has taken steps in the arrangement of a limited short-term training course in order to solve its requirements especially in pre-marriage counseling centers. The course offered by the Ministry of Health and Medical Education has also emphasized the need for an official university degree in genetic counseling. On the other hand, by increasing the demand for the use of genetic counseling services, the need for this course is felt more day-by-day. In summary, the overall objective of this study was to develop the curriculum for graduate genetic counseling. In order to achieve this goal, other minor goals

were also considered including, the training needs analysis of genetic counseling graduate students, educational goals, educational content, materials and teaching methods and finally, to specify the evaluation method of the course.

MATERIALS AND METHODS

This descriptive study was conducted in several stages during the 2010-2011 at the Isfahan University of Medical Sciences. The first stage was to review the relevant literature by searching the library and internet resources. However, there were few resources in this field, but comprehensive information was collected from all of the genetic counseling sessions in various countries around the world. They were analyzed for similarities and differences in their courses. Moreover, at this stage, genetic counselors' duties of Social Welfare Organization and the Ministry of Health and Medical Education were studied. After reviewing the sources and by using the obtained information, it was necessary to identify the needs of graduates of this course for compilation of the course objectives. A questionnaire and opinions of focus group meetings were used to identify these needs. For this purpose, a questionnaire with 26 questions was prepared in two parts. The first part was included 25 questions in a 5 grade Likert scale (from 1 = completely disagree to totally agree = 5) to determine educational needs and to prioritize them. In the second part, there was an open-replied question to get the points that would likely have not been considered in the first part. For example, in the first part of the questionnaire, there was no question about dys-morphology, but in the second part of the questionnaire, many people were pointed to this issue. The outcome of the initial questionnaire, which was developed based on literature studies as well as internet search, were discussed at focus groups meetings and was edited. The content validity and face validity of questionnaire were assessed by group discussion sessions with experts. In order to assess the reliability, Cronbach's alpha method in Statistical Package for the Social Sciences (SPSS) software version 16, (IBM SPSS Data Collection), $\alpha = 0.9$) was used. Thus, the final questionnaire was developed with acceptable reliability and validity consisting of 25 questions on a 5 grade Likert scale and one open-reply question. The questions were in two areas. Five questions were about the perspectives of the participants about knowledge, skills and abilities of the genetic counselors. The purpose of the mentioned questions was to investigate the perspectives about the existing status of genetic counseling services. Other questions were to investigate task analysis as well as job analysis or in other words, those capabilities that a qualified genetic counselor should have them. The above mentioned focus group meetings were formed in the presence of 6-10 people from the associated groups with genetic counseling for several times, each time for 2 h. Since that, mainly three groups are associated with genetic counseling, the needed information was provided from these groups. These three groups were the members of genetics board of the Ministry of Health and Medical Education, currently employed physicians in genetic counseling and the students of

graduate studies of genetics at the time of this study. The first group was included 13 professionals who were the member of genetics board. This group due to their work experience and interactions with other geneticists could provide very useful comments. The second group was consisted of qualified genetic counselors, the physicians who had successfully completed the training course of genetic counseling. They were estimated about 500 people based on the number of the participants in the course of genetic counseling. Most likely, not all of the participants in these courses performed genetic counseling upon the completion of the course and the actual number should be less. The third group was included the students of graduate studies of genetics including MSc and PhD students of genetics that was estimated to be about 50 persons. All of the genetic board members ($n = 13$) participated in the study. However, among the members of other groups, 10 persons were selected from each group. The final questionnaire was completed by the members of each of the three groups (33 persons). The focus group meetings had several purposes including assessment of the initial questionnaire, compiling the final questionnaire for assessing the educational needs, identifying, and prioritizing the defined needs and finally, compiling the targets and curriculum of MSc in genetic counseling. The focus groups meetings were held with each of these groups separately. In the focus group sessions, the participants were asked to mention the educational needs of the MSc students in genetic counseling. The noted cases were collected and after the sessions were classified. Repetitive cases were removed and a list of preliminary educational needs was prepared. Then at the further meetings, the comments were collected again about the identified educational needs and their priorities. Ultimately, these needs were ranked according to the priorities. It is necessary to explain that in addition to the obtained scores from the assessment, several other factors contributed to decide about the educational priorities. Official lengths of the MSc course, as well as restrictions in providing necessary facilities are among of these limitations. Analysis of the collected data was performed by using descriptive methods (frequency, mean, and percent) using SPSS software version 16 (IBM SPSS Data Collection). In summary, after determining the general direction of the mentioned course, the educational needs were prioritized according to the obtained scores. These priorities had sometimes overlap and similarity. Based on these prioritized educational needs, educational objectives were compiled, classified, summarized, and organized in different lessons.

RESULTS

The required information for this research was collected from the mentioned three groups: The first group was consisted of the members of the genetics board with the number of 13 with the age distribution of 38-65 years (mean of 51 years old), included 12 males and 1 female. They all had PhD in genetics and had a rank of assistant professor (one case), associate professor (eight cases) and professor (four cases) who were all formally employed in the Universities of Medical Sciences.

Seven of them were working at the different universities in Tehran and six in other cities. Their work experience was between 10 and 30 years with a mean of 22 years.

The second group was consisted of genetic counselors including 10 physicians. They have participated in the course of genetic counseling provided by Social Welfare Organization or the Ministry of Health and Medical Education. They had received the counseling authorization and all of them were female.

The third group consisted of students of graduate studies of genetics (MSc and PhD in genetics) and there were 10 persons with the age distribution of 23-42 years old (mean of 27 years) with four MSc students and six doctoral students and 50% of them were female and 50% were male, all living in Tehran. Except for three doctorate students, the other students had no work experience in the field of genetics.

The mean scores of the five questions about current knowledge and skills of genetic counselors, was calculated to be 1.75 out of 5 points. In fact, 65% of the participants believed that the knowledge and skills of the genetic counselors in counseling principles, is insufficient. About the other 20 questions of the questionnaire, which assessed the perspectives about the learning needs for genetic counseling, all of the questions received a score of 4 or 5. The highest score was related to communication skills. In fact, 100% of the participants believed that the communication skills are the most basic need of genetic counselors. The lowest score was related to the 13th options. Only 18% of people were agreed to this case, "genetic counselors should be aware of the details of the happened events in various stages of cell division, cell cycle and its association with genetic diseases." The obtained educational requirements from the focus groups were used as a basis for writing the course objectives. The total of collected requirements was over 1800 cases. The needs were then used to prepare course objectives in the board of genetics meetings, and then were classified and organized in different modules. The main obtained result from this study was the curriculum for the MSc in genetic counseling course. Based on the designed course, the student should pass between 5 and 10 units of deficiency or compensatory courses based on decision of the educational group and confirmation of the faculty. The designed MSc course in genetic counseling was designed in four sections: An overview of the course, features of educational programs, course specifications and course evaluation. The numbers of proposed units were 32 units, including 20 units of specialized compulsory courses, 6 units of specialized voluntary courses, and 6 units of thesis. The lessons of the course were divided into three categories including deficiency – compensatory courses, specialized compulsory courses (core), and voluntary specialized courses (non-core). In section three, the specifications of MSc course of genetic counseling for each of the 26 mentioned units of this course were defined separately in the following formats: Course title, course code, prerequisites, number of units, and type of units, the overall

objective of the course, course syllabus, course materials, and student evaluation method. The fourth section devoted to evaluation of the course and determined the method of the course evaluation and the evaluation criteria. The course evaluation would be both formative and summative during the course and in the form of task-oriented evaluation. For this evaluation, a variety of ways would be used as follows, investigation of the graduates satisfaction, sense of being effective to meet community needs, investigation of the satisfaction of teachers from the knowledge and learning performance of the students in the field of professional duties, assessment of the graduates activities and their impact on the improvement of genetic health of the community and finally conformity assessment of the graduates from practical and theoretical learning regarding the community needs in the field of genetic counseling. Evaluation criteria were identified in the evaluation section and the indexes for achieving the defined objectives were determined.

DISCUSSION

Given the increasing importance of genetic diseases as one of the most important health issues and the lack of a formal university course for efficient training of genetic counselors, compilation of MSc curriculum for genetic counseling has been one of the concerns of the Genetics Board Committee. This study was conducted in order to design the course during 2010-2011 at the Isfahan University of Medical Sciences. In the design of this study, the focus group sessions with three groups included the members of the genetics board; genetic counselors who were the managers of counseling centers and the students of graduate studies in genetics were used. These groups also completed the researcher-made questionnaire to assess the training needs of MSc of genetic counseling. They also expressed their perspectives at focused group meetings and indicated their specific educational needs for the field and the priorities. In the next stage, the board of genetics based on these needs and the related objectives that they have set, provided the related educational plane for the discontinuous degree in MSc of genetic counseling. Although, the literature review indicated the need to design such a course, the results of the questionnaires completed by the participants about the knowledge and capabilities of genetic counselors emphasized the need to design the course too. The comparison of the compiled objectives for this course in this study with other similar academic courses has shown many similarities between them. For example, the following cases were common in all curricula: Comprehensive knowledge from issues such as human genetics, molecular cell biology, human embryology, genetic laboratory skills, principles of counseling, advanced genetic counseling, and bioethics. These common cases comprise about 60% of the course. This similarity is due to the nature of the course, which unlike some other courses cannot be influenced by different perceptions and leads to the development of widely different curricula.¹⁷⁻⁹¹ In the other 40% of the designed course, there are relevant lessons that only some universities have been considered for this course. Examples of these

cases are principles of epidemiology, assisted reproductive technologies, dys-morphology, cancer genetics, and population genetics. There are several reasons, which have been led to these differences. For example, one of the factors that can affect everywhere on the course content is the duration of the course.^[7] Increased duration of the course, although increases the participants' abilities but on the other hand, a prolonged course is less attractive to recruit the volunteers. Thus, a balance must be established between these two cases. Another reason for these differences are the different background of the entering students from different fields.^[8,9] Due to the different BSc degrees of the entering students, the designed course is more or less different to meet their needs. For example, if the students were more from basic science fields, there would be more focus on the clinical courses and if they were from the fields such as nursing and midwifery, the emphasis would be on basic sciences. Another reason for the difference between the designed course and other similar courses is the available resources. For example, "clinical rotation" in the hospital wards has received little attention in this study. Meanwhile, in many universities, it is considered as one of the main courses.^[10] The source of this difference is that our country is still in the beginning steps in terms of clinical genetics and lack of consideration of clinical genetics has been one of the main constraints in the design of the course. By the attention to this point that the position of genetic counseling would be correctly defined as the link between clinical genetic and the patient, in the absence of appropriate clinical genetics in the country, it provides the concern about the performance of the genetic counselors in MSc course. This issue should seriously be considered in MSc genetic counseling course, because, if they are going to visit the patients independently, inadequate background of medical science can cause undesirable effects.

CONCLUSION

The conclusion of the present study was compiling the curriculum for the MSc course in genetic counseling in order to resolve one of deeply perceptible needs in the country

health arena. It was shown in this study that although most of the course design was consistent with similar programs in other countries, there are also some differences in the courses that should be considered in the design of other courses.

ACKNOWLEDGMENT

This work was funded by the Medical Education Research Center, Research Affair of the Isfahan University of Medical Sciences. We also would like to thank members of Genetics Board, Genetic Counselors, and graduate students of genetics for their unending help and support.

REFERENCES

1. Turnpenny P, Ellard S. *Elements of Medical Genetics*. 14th ed. Philadelphia: Elsevier; 2011. p. 263-272
2. Genetic counseling in rehabilitation organization of Iran. Available from: <http://www.behzisti.ir/Documents/Show.aspx?id=252>. [Last cited 2011 May 20].
3. Nussbaum R, McInnes R, Willard F. *Thompson and Thompson Genetics in Medicine*. Baltimore: Saunders Elsevier; 2007. p. 507-522.
4. Evans C. *Genetic Counseling: A Psychological Approach*. Cambridge: Cambridge University Press; 2006. p. 175-187.
5. Uhlmann W., Schuette J., Yashar B. *A Guide to Genetic Counseling* (second edition). New Jersey: Wiley Publishing Inc.; 2009. p. 283-312.
6. Translational alliance for genetic counseling Available from: <http://www.tagc.med.sc.edu/>. [Last cited 2011 May 20].
7. Genetic Counseling MSc, School of Medicine, The University of Manchester. Available from: http://www.medicine.manchester.ac.uk/postgraduate/taught/genetic_counselling/. [Last cited 2011 May 20].
8. Genetic counseling programs Available from: <http://www.kumc.edu/gec/prof/gcprogs.html>. [Last cited 2011 May 20].
9. Counseling graduate programs Available from: <http://www.gradschools.com/search-programs/genetic-counseling>. [Last cited 2011 May 20].
10. Clinical rotation in genetic counseling, 2011 Available from: <http://www.mcgill.ca/humangenetics/current-students/genetic-counselling-students/clinical-rotations>. [Last cited 2011 May 20].

Source of Support: Nil, Conflict of Interest: None declared