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Nurses' Professed Knowledge of Genetics and Genetic Counseling

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TOMATIR, A.G., SORKUN, H.C., DEMIRHAN, H. and AKDAĞ, B. *Nurses' Professed Knowledge of Genetics and Genetic Counseling*. Tohoku J. Exp. Med., 2006, **210** (4), 321-332 —— All over the world, the increased awareness of the importance of early diagnosis of genetic diseases has given them priority in primary health care. However, more recent surveys indicate that genetics content is still lacking in nursing curricula. This survey aimed to measure the current status of primary care nurses' knowledge about genetics and genetic counseling, and the educational needs of nurses related to human genetics in the Denizli region of Turkey. This area in western Turkey has an 11.7% rate of consanguineous marriages; about 3.5% of the population are hemoglobinopathies carrier and 3.2% are thalassemia carriers. Data were collected on forms that aimed to obtain information about nurses' approaches to genetics and genetic counseling. A total of 86 of 106 nurses working in Denizli province returned the questionnaire (response rate of 81.1%). Phenylketonuria, at 61.5%, and Cooley's anemia, at 60.0%, were identified as the subjects these nurses were most knowledgeable about in terms of genetic disorders. A high percentage of nurses admitted they had insufficient knowledge about the genetic basis of diseases (96.4%), inheritance patterns (98.9%), ethical and legal issues (100.0%), genetic counseling (100.0%), gene testing (95.9%), and genetic engineering (97.9%). About 67% of nurses stated they would like to attend a training course on these subjects. As a result of this study a genetics course is planned for nurses so they can actively participate in the prevention and early diagnosis of genetic diseases. ———— human genetics; genetic counseling; nurses; primary care

A turning point in the history of biology was reached a decade ago when significant research funding support was made available for the study of the human genome as part of the Human Genome Project (HGP) (Collins 1999). The explosion of genetic discoveries resulting from human genome research is creating new medical and nursing practice roles and expanding health opportunities for individuals, families, and communities around the world (Lea et al. 2002). The era of utilizing genomic information in all aspects of basic and applied research and health care has

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begun. The roles and activities of nurses in this new era include: (a) active participation in genomic research, including the study of the biologic, behavioral, family, ethical, legal, and social implications; (b) the development and integration of genomic technologies in health care and other settings; (c) the interpretation and use of genomic information and efforts to protect against the misuse of information; and (d) assuring that genomic research, technologies, and information be viewed in the context of other biopsychosocial factors and cultural norms so that reinforcement of the concept of genetic determinism is not an unintended by-product of this recent emphasis on genomics (Feetham et al. 2005).

It was recommended over 40 years ago (Brantl and Esslinger 1962) that genetics be included in nursing curricula. Moreover, Kenen (1984) stated that genetic counseling is an important new interdisciplinary occupational field for nurses. However, more recent surveys indicate that genetics content is still lacking (Hetteberg and Prows 2004). The National Coalition for Health Professional Education in Genetics (NCHPEG) in the United States has developed a set of recommendations for core competencies in genetics that they regard as essential for all health professionals (NCHPEG Working Group Committee Report 2001; Metcalfe and Burton 2003). To address the continuing need for genetics education amongst nursing faculty, a multifaceted Genetics Program for Nursing Faculty (GPNF) was proposed and subsequently funded in 1996 by the Ethical, Legal, and Social Implications Research Program (ELSI) of the National Human Genome Research Institute (NHGRI) at the National Institute of Health (NIH). The specific aims of the program are to increase faculty knowledge about genetics and to increase the amount of genetics content in entry-level nursing education program curricula. Other initiatives to address this issue include the vote by the American Nurses Association (ANA) in its House of Delegates convention held in June 1999 to support genetics in basic, graduate, and continuing education for all nurses. It is also worth mentioning the International Society of Nurses in Genetics (ISONG), which is dedicated to the scientific, professional, and personal development of nurses in the management of genetic information (http://www.isong.org/); an ISONG initiative designed to improve the quality of care succeeded in collaboration with the ANA in publishing a document outlining the scope of practice and identifying the characteristics of this specialty area. In summary, nurses require education in genetics and nursing practice to identify, refer, support, and care for persons affected by, or at risk from manifesting or transmitting, genetic conditions (Jenkins et al. 2001). There are several categories of inquiry that integrate genetic knowledge with nursing science (Williams et al. 2004). Nurses need to use genetic information in care; several areas of current need include cardiovascular nursing, geriatric nursing, oncology nursing, public health, nursing education, and primary care (Jenkins et al. 2001).

Primary health care is defined as the first point of contact between patients and the health service. In high-resource countries this may be the family doctor, or a community-based specialist in internal medicine, pediatrics, or obstetrics and gynecology. In lower-resource countries the first point of contact is often a nurse or trained health worker in a local clinic (Christianson and Modell 2004). In our country the increased awareness of the importance of early diagnosis of genetic illnesses has given them priority in primary health care (Tunçbilek 1998). Primary care nurses who work in primary care in Turkey ensure that preventive and therapeutic services are provided.

Turkey has a high rate of consanguineous marriages (20-25%) (Tunçbilek 2001). The site of this study, Denizli province in Western Turkey, has an 11.7% rate of consanguineous marriages (Şimsek et al. 1999). In Turkey's Denizli province about 3.5% of the population are hemoglobinopathies carrier and 3.2% are thalassemia carriers (refer to Turkish Ministry of Health, Thalassemia Screening Program [www.denizli.saglik.gov.tr]). Overall, the high consanguinity rate is one of the underlying factors in the high infant and child mortality rate in Turkey (Tunçbilek

2001). For this reason, genetic screening of and counseling for consanguineous couples are important issues (Bennett et al. 2002). In the near future, nurses will use counseling and case management skills to assist patients, families, and communities in this new era of genomic-based health care. This article describes nurses' current approaches to and knowledge about human genetics and genetic education in Denizli, Turkey.

Materials and Methods

Permission was obtained from the Provincial Health Ministry to conduct this study and it was informed about the contents of the questionnaire. To provide consistent explanatory information about the subject and questions, the same investigator was available when all the nurses filled out the questionnaires. Only volunteers participated in the study and the data were collected anonymously. The items on the questionnaire were developed based on an article titled, "Illnesses that need genetic counseling" by Erdemir (1998) as well as studies by Mertens et al. (1984) and by Kirk (1999). Additionally, items asking about basic genetic information and disorders that are defined by the World Health Organization (WHO) as "point-of-entry" disorders that can be prevented were included. Questions relating to genetic counseling were developed based on WHO criteria defined in a public health study by Gökkoca (2000) (please see Appendix I). In this literature the skills and knowledge needed by primary health care personnel were defined as:

1. the ability to give accurate information about genetic risks that are common in the region in a way that will decrease the risks (questions 1-5),
2. a knowledge about widespread genetic diseases and approaches to these diseases (questions 6-7),
3. a knowledge of local specialist services and the ability to refer affected children and at risk couples appropriately (questions 8-10),
4. the ability to review a family's genetic history and recognize the necessity for specialist services (question 11),
5. the ability to organize screening and give counseling to carriers of single gene disorders (questions 12-13),
6. the ability to inform those who have a high risk of being carriers and their relatives and to recommend testing for them (question 14),
7. the ability to make recommendations to decrease risks that lead to common illnesses with genetic tendencies (questions 15-16),
8. an understanding of basic ethical principles and techniques of genetic counseling (questions 17, 18).

The questionnaire's validity and reliability were not researched because our main aim was not to create a research tool.

Procedures

This was a descriptive and cross-sectional study in which experiences relating to genetic diseases and genetic counseling and approaches within the scope of the duties and responsibilities of nurses were researched. To accomplish this, nurses who worked in all 26 of the health clinics in the centre of Denizli province were included in the study. A self-report method was used for data collection.

The questionnaire began with open-ended questions regarding socio-demographic information. On the questions relating to basic genetic information the nurses were asked to mark one of these options: "*knowledgeable", "need more information"*, or "*no information"*; for those about knowledge of genetic diseases or disorders the options were: "*classroom"*, "*clinical"*, "*classroom and clinical"* and "*no information"*; and on questions related to genetic counseling they could choose between: "*yes", "no"* and "*no information"*.

Categories of data

On the questionnaires the following categories of information were asked:

- *Socio-demographic information*: Age, gender, profession, educational level and number of years' work experience in this job.
- *Basic knowledge of genetics*: Chromosome abnormalities, sex linked defects, mitosis and meiosis, human genetic diseases, genetic counseling, genetic screening, prenatal diagnosis of genetic diseases, nucleic acids in protein synthesis, et cetera.
- *Theoretical/practical knowledge of genetic diseases/disorders*: PKU, Rh factor, Cooley's anemia, sickle cell anemia, Down syndrome, and so on.
- *Genetic counseling experience*: Awareness of the ethical regulations and techniques of genetic counseling, organizing a screening program for genetic diseases, recognizing genetic diseases common in the region, and so on.

- *Sources of information*: school and college education, books, training courses, seminars, the media, conferences, computer-based learning, word-of-mouth.

Data analysis

In this cross-sectional and descriptive study, data were analyzed using the SPSS (version 13.0) package program. Descriptive statistics, including mean ± S.D., frequencies, and percentages were calculated. The Chi-square test was used to determine the relationship between two categorical variables. Statistical significance was set at 5% ($p \leqq 0.05$).

Results

Response rate and demographic characteristics

A total of 86 of the 106 nurses who work full time in the 26 health clinics in the center of the province answered the questionnaire (response rate of 81.1%) and thus were included in the study. The age of the 86 nurses who answered the questionnaire ranged from 23 to 49 years with a mean of 34.55 ± 6.53 years. Their length of time in the profession ranged from 3 to 28 years with a mean of 15.27 ± 6.29 (Table 1).

Genetic knowledge

The examination of the responses to the section on basic knowledge of genetics showed that knowledge of mitosis and meiosis was identified by the largest number of nurses, 4.2% (n = 2), and the areas with the lowest levels of awareness were genetic counseling, genes and the environment, the ethics of human genetics, principles of probability, mitochondrial inheritance, and polygenic inheritance (Table 2).

The examination of the knowledge of genetic abnormalities and illnesses showed that those that the nurses were most aware of were PKU at 61.5% (n = 32) of the informants, and Cooley's anemia at 60.0% (n = 33), and the disorders that were least known about were achondroplasia, alcaptonuria, Patau syndrome, and Edwards syndrome (Table 3).

Knowledge associated with genetic counseling

For the answers related to genetic counsel-

Table 1. Sociodemographic variables of nurses surveyed (n = 86).

Variable	Category	n	%
Age	20-30	31	36.0
	31-40	36	41.9
	41 ≧	19	22.1
	Years (mean ± S.D.)		34.55 ± 6.53
Gender	Female	86	100.0
Profession	Nurse	86	100.0
Attained level of education	High school	25	29.1
	University (2 years)	59	68.6
	University (4 years)	2	2.3
Years working as a care provider	0-5	6	7.0
	6-10	18	20.9
	11-15	21	24.4
	16-20	19	22.1
	21 ≧	22	25.6
	Years (mean ± S.D.)		11.25 ± 6.96
Length of time in current profession	Years (mean ± S.D.)		15.27 ± 6.29

TABLE 2. Nurses answers related to basic genetics information.

Topic	Knowledgeable		Need more information		No information		Respondents
	n	%	*n*	%	*n*	%	*n*
Mitosis and meiosis	2	4.2	15	31.3	31	64.6	48
Prenatal diagnosis of genetic disease	2	4.1	14	28.6	33	67.3	49
Sex related defects	2	3.8	29	55.8	21	40.4	52
Autozomal recessive disorders	2	3.8	27	50.9	24	45.3	53
Human genetic diseases	2	3.6	37	67.3	16	29.1	55
Mendelian inheritance	1	2.1	8	17.0	38	80.9	47
Nucleic acids in protein synthesis	1	2.1	8	16.7	39	81.3	48
Genetic screening	1	2.1	10	20.8	37	77.1	48
Genetic engineering	1	2.1	6	12.5	41	85.4	48
Genes and mental retardation	1	2.0	19	38.8	29	59.2	49
Autozomal dominant disorders	1	2.0	15	30.6	33	67.3	49
Chromosome abnormalities	1	1.9	24	45.3	28	52.8	53
Genetic counseling	-	-	13	27.7	34	72.3	47
Genes and the environment	-	-	13	26.5	36	73.5	49
Ethics of human genetics	-	-	11	22.9	37	77.1	48
Principles of probability	-	-	9	18.8	39	81.3	48
Mitochondrial inheritance	-	-	5	10.6	42	89.4	47
Polygenic inheritance	-	-	4	8.3	44	91.7	48

ing, the item which received the highest number of positive answers was that concerning recommending maternal serum screening test for mothers 35 years and over at 90.8% ($n = 59$); the items with the lowest number of such responses indicated those who knew the ethical regulations and techniques related to genetic counseling ($n = 8$) at 12.5%, and those who knew some of the genetic counseling centers in Turkey ($n = 7$) 38.9%. In addition, 28.3% ($n = 17$) of the informants were able to develop a family tree by learning the genetic history of individuals suspected of having a genetic disorder, 31.0% ($n = 18$) were able to organize a screening program for genetic diseases and 15.6% ($n = 10$) knew about the genetic counseling center in Denizli, while 28.6% ($n = 18$) stated that they knew about genetic diseases common in the region. Primary care nurses stated that they would like to participate in an educational program ($n = 42$) (66.7%) (Table 4).

Sources of information

The distribution of answers to the multiple-choice question about nurses' sources of information was, in descending order: books ($n = 43$); school and college education ($n = 40$), the media ($n = 24$), word-of-mouth ($n = 6$), training courses ($n = 6$), seminars ($n = 2$), conferences ($n = 2$) and computer-based learning ($n = 2$) (Table 5).

Curriculum contents of genetics education

Some of the important genetic topics that were answered as, "need more information," or "no information" (Table 2) were classified according to Kirk (1999): Genetic basis of diseases ($n = 53$) 96.4%, inheritance patterns ($n = 47$) 98.9%, ethical and legal issues ($n = 48$) 100.0%, genetic counseling ($n = 47$) 100.0%, gene testing ($n = 47$) 95.9%, and genetic engineering ($n = 47$) 97.9% (Table 6).

TABLE 3. Nurses answers related to genetic diseases and disorders.

Disease/Defect	Classroom		Clinical		Classroom and Clinical		No information		Respondents
	n	%	*n*	%	*n*	%	*n*	%	*n*
Cooley's anemia	33	60.0	7	12.7	10	18.2	5	9.1	55
PKU	32	61.5	8	15.4	5	9.6	7	13.5	52
Rh factor	32	60.4	7	13.2	9	17.0	5	9.4	53
Down syndrome	32	62.7	6	11.8	4	7.8	9	17.6	51
Spina bifida/anencephaly	26	53.1	10	20.4	6	12.2	7	14.3	49
Diabetes mellitus	30	52.6	6	10.5	18	31.6	3	5.3	57
Sickle cell anemia	23	52.3	2	4.5	4	9.1	15	34.1	44
Cleft lip /palate	26	50.0	12	23.1	10	19.2	4	7.7	52
Colorblindness	20	45.5	5	11.4	-	-	19	43.2	44
Hemophilia A and B	21	42.9	3	6.1	1	2.0	24	49.0	49
Albinism	10	24.4	3	7.3	3	7.3	25	61.0	41
Cystic fibrosis	9	22.0	4	9.8	-	-	28	68.3	41
Polydactyly	7	16.7	2	4.8	2	4.8	31	93.8	42
Muscular dystrophy	4	9.5	1	2.4	-	-	37	88.1	42
Brachydactyly	2	5.0	1	2.5	-	-	37	92.5	40
Galactosemia	2	4.9	-	-	-	-	39	95.1	41
Porphyria	1	2.5	39	97.5	-	-	-	-	40
Cri du chat syndrome	1	2.5	2	5.0	-	-	37	92.5	40
Turner syndrome	1	2.4	1	2.4	-	-	39	95.1	41
Osteogenesis imperfecta	1	2.4	-	-	1	2.4	40	95.2	42
Klinefelter syndrome	1	2.4	-	-	-	-	40	97.6	41
Xeroderma pigmentosum	-	-	2	5.0	-	-	38	95.0	40
Patau syndrome	-	-	-	-	-	-	39	100.0	39
Edwards syndrome	-	-	-	-	-	-	40	100.0	40
Alcaptonuria	-	-	-	-	-	-	40	100.0	40
Achondroplasia	-	-	-	-	-	-	40	100.0	40

DISCUSSION

One of the most common questions asked by nurses when thinking about referring a client or family for further genetic evaluation is whether it is necessary or appropriate to refer the client or family to genetic services. This is one of the hardest questions to answer as it depends on the nurse having the knowledge and skills to determine if "something is genetic or not" (Benjamin and Gamet 2005). In this study, most of the participants reported having insufficient knowledge about basic genetics, the ethics of human genetics, and genetic counseling.

In this study, nurses recognized their lack of knowledge and a significant percentage of them requested participation in a training program. This echoes Terzioğlu and Dinç's (2004) findings of the need for educational preparation for nurses in both genetics and ethics as well as another study by Tomatır et al. (2006) in which the need for this education in primary care was emphasized. Bankhead et al. (2001) found that there is a need for further education for practice nurses regarding family history information and new genetics so that this information is managed

TABLE 4. Nurses answers related to genetic counseling.

Topic	Yes		No		No information		Respondents
	n	%	*n*	%	*n*	%	*n*
Recommending maternal serum screening test for mothers 35 years and over	59	90.8	-	-	6	9.2	65
Directing the parents of and couples at risk of having a child affected by a genetic disease to an expert or a genetic counselling center	59	90.8	1	1.5	5	7.7	65
Recommending ultrasound during pregnancy	53	82.6	3	4.7	8	12.5	64
Being confronted with babies with congenital anomalies	47	73.4	10	15.6	7	10.9	64
Determining carriers of or individuals with inherited diseases such as β-thalassemia	43	67.2	9	14.1	12	18.8	64
Request participation in an educational course about genetic diseases and genetic counseling	42	66.7	21	33.3	-	-	63
Recommending use of folic acid during pregnancy	37	62.7	7	11.9	15	25.4	59
Informing and recommending testing of carriers and next of kin	37	60.7	12	19.7	12	19.7	61
Recording and informing individuals who have married a relative	34	55.7	15	24.6	12	19.7	61
Routinely informing individuals about subjects such as risky pregnancies and marriage with relatives	33	50.0	26	39.4	7	10.6	66
Making recommendations to decrease the risk of diseases with genetic tendencies such as Type 2 diabetes	26	44.8	20	34.5	12	20.7	58
Giving genetic counseling about the maternal serum screening test	24	40.0	18	30.0	18	30.0	60
Organizing a screening program for genetic diseases	18	31.0	27	46.6	13	22.4	58
Recognizing genetic diseases common in the region	18	28.6	26	41.3	19	30.2	63
Developing a family tree by learning the genetic history of individual's suspected of having a genetic disorder	17	28.3	27	45.0	16	26.7	60
Knowing about the genetic counseling center in Denizli	10	15.6	10	15.6	44	68.8	64
Knowing the ethical regulations and techniques of genetic counseling	8	12.5	32	50.0	24	37.5	64
Knowing about some of the genetic counseling centers in Turkey	7	38.9	5	27.8	6	33.3	18

appropriately. Kirk (2000) has focused on the genetics education of nurses and midwives in the UK. Metcalfe and Burton (2003) suggest that education and training of clinical nurses in genetics is critical in integrating genetics with nursing science.

In this study, only seven nurses knew about some of the genetic counseling centers in Turkey,

TABLE 5. Sources of information about nursing methods related to genetics.

Source	Respondents (n)
Books	43
School or college education	40
The media	24
Word-of-mouth	6
Course	6
Seminar	2
Conference	2
Computer-based learning	2

TABLE 6. Curriculum contents of genetics teaching.

Genetics topic	Respondents	
	n	%
Genetic basis of diseases	53	96.4
Ethical and legal issues	48	100.0
Inheritance patterns	47	98.9
Genetic counselling	47	100.0
Genetic engineering	47	97.9
Gene testing	47	95.9

Responses given as "Need more information" and "No information".

and only ten nurses knew about the genetic counseling center in Denizli. Therefore, based on these findings, it is necessary to advertise the genetic services that are provided in these centers in Turkey. Not only that, but the awareness of genetic services in the region and the country in consideration of the medical genetics services offered and the application of supporting genomic technologies should also be made an integral part of education in genetics at all levels (Jenkins et al. 2001).

In this study it was determined that nurses learned about genetics primarily from their school and university nursing education and textbooks. Only two individuals used computer-based learning. This reflects that many nurses still feel unsure about how to conduct a literature search (Veeramah 2004) despite the ease of accessing information in the modern world. Knowledge can be acquired from a range of sources: academic programs, study days and conferences, informal contact with specialist practitioners, using the internet (www.ovid.com, www.ncbi.nlm.nih.gov, www.google.com), textbooks (Bennett 1999; Skirton and Patch 2002; Pritchard and Korf 2003; Harper 2004; Lashley 2005) and journals (Skirton and Barnes 2005).

Genetic education needs to be provided not only to primary care nurses, but also to the students who will soon join their ranks. Nursing faculty must become more knowledgeable in genetics before they can be expected to increase genetics content in entry-level nursing curricula (Jenkins et al. 2001). Translating genetics into health care will affect clinical outcomes. Only with ongoing efforts by nurses can human benefits result from the application of genetic scientific discoveries (Jenkins 2002). The successful integration of genetics into the nursing role will provide opportunities for nurses through science and practice to participate fully as major players and collaborators in changing the nature of health care (Frazier et al. 2004). An example of this is in the United Kingdom, where patients already attend genetic nursing clinics in primary care (Westwood et al. 2006).

We suggest that in the future educational programs be made available to help bring about the prevention of genetic diseases. This education could be provided by the Ministry of Health in cooperation with university instructors and clinical geneticists. International cooperation on this subject could also be arranged. The recent WHO publication *Genomics and World Health* (WHO 2003) recognizes this concern and offers recommendations on appropriate action that can be taken to address this issue. These recommendations include developing the ability of the WHO to assess the relevance of genetic advances, providing member countries with technical assistance through forging partnerships between and within international organizations and countries, supporting regional meetings, training programs and professional and public education, developing programs for bioinformatics and bioethics, and

promoting allocation of research resources according to the priorities of developing countries (Alwan and Modell 2003).

Centers that provide education in genetics can be established in Turkey and other countries. In recognition of the need to prepare nurses who are qualified to practice in the genetics era, the Department of Health in the United Kingdom has established the National Health Service's National Genetics Education and Development Center (www.geneticseducation.nhs.uk) to take a central role in co-coordinating education initiatives to promote the integration of genetics into everyday practice (Skirton and Barnes 2005). Another possibility for Turkey and other countries is developing a model like the one in Japan by having primary care personnel educated and certified in genetics counseling. Fukushima (2001) proposed a multidisciplinary approach to genetic counseling, which might become more widely applied in the Japanese medical system. Shinshu University Hospital established a division of clinical and molecular genetics as one of its central service departments in 1996. This division is composed of several physicians from the departments of neurology, endocrinology, pediatrics, oncology, laboratory medicine and medical genetics, a clinical psychologist, and a genetics nurse. They have a staff meeting once a week to discuss each case for providing the suitable counseling, and they discuss the ethical, legal and social issues.

In this study a high percentage of nurses admitted they had insufficient knowledge about the genetic basis of diseases, ethical and legal issues, inheritance patterns, genetic counseling, gene testing, and genetic engineering and requested genetics education. United Kingdom guidelines for education and training of genetics nurses and counselors are helpful (Skirton et al. 1998); their principles should be extended to all nurses (Kirk 1999). Although areas of good performance were revealed, many studies identified gaps in professional competence and/or education. In its 2003 White Paper on genetics, the UK Department of Health emphasized that education for health professionals is vital if advances in genetics are to be translated effectively into everyday practice (Waters 2004). Therefore, the development of educational programs for nursing knowledge and counseling as well as basic curricula in genetic nursing at universities are essential for the near future (Kim 2003; Bottorff et al. 2005).

Basic genetic counseling is both feasible and increasingly necessary in primary health care (WHO 1999). Nonphysician genetic counselors have been in practice only since 1971 (Dailey et al. 1995). Professional genetic counselor accreditation is possible in the United Kingdom, United States of America, Australia and Canada (Westwood et al. 2006). In addition to specialized genetic counseling services, training programs, as an integral part of patient education, should ensure that all medical staff, from nurses to physicians, are able to discuss genetic information relevant to a wide range of pathologies (WHO 2005). Continued advances in genetics will progressively reach all aspects of the health care sector and it is increasingly important that nurses receive education to prepare them for the clinical and ethicolegal consequences of such developments. The findings from this study and other studies will help guide the development of an educational strategy in genetics for primary care nurses.

Limitations of the study

The first limitation is that not all of the questions on the survey were answered; some were only answered by 18 of the 86 nurses and even the largest number of responses to any one question was 65 of the 86 nurses. In interviews that were conducted after the questionnaires had been completed, the nurses explained that they were afraid of possible repercussions from the institutions where they worked. A further limitation was that some of the questions on the survey were in two parts. For example in the third question the nurses were asked whether or not they informed individuals of the possibility of genetic disorders after they have recorded that they had married a relative. In this situation the nurse may have recorded the information about the individuals but not actually informed the individual, since this task may have been carried out by a doctor.

Moreover, because the survey did not have open-ended questions, the reasons for some practices were not asked for. In addition, the fact that the nurses reported their knowledge of different conditions themselves means that there is no evidence to confirm that they possessed this knowledge. It is possible that a desire to appear more informed than they were may have played a part in the way they responded.

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Appendix: Questions

1. Do you recommend ultrasound during pregnancy?

Yes/No/No Information

2. Do you recommend maternal serum screening test for mothers 35 years and over?

Yes/No/No Information

3. Do you record and inform individuals who have married a relative?

Yes/No/No Information

4. Do you determine carriers of or individuals with inherited diseases such as β-thalassemia?

Yes/No/No Information

5. Do you routinely inform individuals about subjects such as risky pregnancies and marriage with relatives?

Yes/No/No Information

6. Do you recognize genetic diseases common in the region?

Yes/No/No Information

7. Do you coincidentally see infants with congenital anomalies?

Yes/No/No Information

8. Do you direct the parents of children and couples at risk of having a child affected by a genetic disease to an expert or a genetic counseling center?

Yes/No/No Information

9. Do you know about the genetic counseling center in Denizli?

Yes/No/No Information

10. Do you know about some of the genetic counseling centers in Turkey?

Yes/No/No Information

11. Do you develop a family tree by learning the genetic history of individuals suspected of having a genetic disorder?

Yes/No/No Information

12. Do you give genetic counseling about the maternal serum screening test?

Yes/No/No Information

13. Do you organize a screening program for genetic diseases?

Yes/No/No Information

14. Do you inform and recommend testing of carriers and next of kin?

Yes/No/No Information

15. Do you recommend use of folic acid during pregnancy?

Yes/No/No Information

16. Do you make recommendations to decrease the risk of diseases with genetic tendencies such as Type 2 diabetes?

Yes/No/No Information

17. Do you know the ethical regulations and techniques of genetic counseling?

Yes/No/No Information

18. Do you request participation in an educational course about genetic diseases and genetic counseling?

Yes/No/No Information