A profile of the genetic counsellor and genetic nurse profession in European countries

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Abstract Quality genetic healthcare services should be available throughout Europe. However, due to enhanced diagnostic and genetic testing options, the pressure on genetic counselling services has increased. It has been shown in many countries that appropriately trained genetic counsellors and genetic nurses can offer clinical care for patients seeking information or testing for a wide range of genetic conditions. The European Society of Human Genetics is setting up a system of accreditation for genetic counsellors, to ensure safe practice, however there has been little information about the practice and education of non-medical genetic counsellors in Europe. To collect baseline data, we approached key informants (leaders in national genetics organisations or experienced practitioners) to complete an online survey, reporting on the situation in their own

country. Twenty-nine practitioners responded, providing data from 18 countries. The findings indicate huge variation in genetic counsellor numbers, roles, and education across Europe. For example, in UK and The Netherlands, there are more than four counsellors per million population, while in Germany, Hungary, Turkey, and Czech Republic, there are no non-medical counsellors. There are specific educational programmes for genetic counsellors in seven countries, but only France has a specific governing legal framework for genetic counsellors. In the post-genomic era, with added pressure on health systems due to increases in availability and use of genetic testing, these disparities are likely to result in inequalities in service provided to European citizens. This study underpins the need for a coherent European approach to accreditation of genetic counsellors.

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Background

Genetic counselling services should be available to families or individuals affected by genetic conditions in both developed and developing countries (World Health Organization 2011). The increasing emphasis on psychological care of patients, the need for genuinely informed consent to genetic testing and the increase in demand for services have placed a strain on provision of services. In addition to these issues, we are on the threshold of a further expansion of services due to the rapid development of genetic testing technologies. For example, the use of comparative genomic hybridisation arrays as a diagnostic tool in cases of dysmorphism with developmental delay (Lee et al. 2007), the introduction of non-invasive prenatal diagnosis for both single-gene

disorders (Lo et al. 2010) and aneuploidy (Ehrich et al. 2011) and the development of next-generation sequencing for clinical use (Schrader et al. 2011) will all increase the workload on genetic specialists. It is also likely that health professionals trained as genetic specialists will be required to be involved in guidance and education of other health professionals as well as delivery of direct patient care.

The inclusion of non-medical genetic counsellors or specialist genetic nurses as part of a multi-disciplinary team has been shown to be an effective way to deliver genetic counselling services in a number of countries including UK, USA, Canada and Australia and is considered to be an essential part of the specialist genetic services in Europe (Godard et al. 2003). The role of the genetic counsellor differs from that of a medical geneticist or a laboratory scientist because the genetic counsellor is not generally trained to make a diagnosis or perform laboratory tests but has specialist skills in providing information to patients in a format that can be easily understood, supporting patients in adjusting to the diagnosis and facilitating autonomous decision-making (especially with regard to genetic testing) (Skirton et al. 1997).

In addition to the contribution of genetic counsellors and nurses to the specialist genetics team, they are increasingly seen as integral to provision of patient care in non-genetics settings. These practitioners are providing genetic information and testing to patients in, for example, cardiology (Ingles & Semsarian 2007; Oliver et al. 2011), oncology (Calzone and Masny 2004; Snyder et al. 2009) and endocrinology (Matloff and Barnett 2011). In many cases, they are well-trained and experienced in the specialism but require additional education to acquire the knowledge, skills and attitudes (Skirton et al. 2010a) needed in a genetic context.

While appropriately trained genetic counsellors and genetic nurses can offer clinical care for patients seeking information or testing for a wide range of genetic conditions (Nuffield Trust Genetics Scenario project 2000), there is at present no legal or voluntary regulation of genetic counsellors in many European countries or in Europe as a whole. Following the acceptance of the specialisation of medical genetics at the European level (European Commission 2011a, b), The European Society of Human Genetics is making efforts to set up a system of accreditation for genetic counsellors, to ensure safe practice (Skirton et al. 2010b). However, in preparing for the development of such a system, it is necessary to have data on the number of genetic counsellors working in each country and the framework around their practice. In order to ascertain the level of genetic counsellor practice in various European countries, a Working Group of the ESHG Ad Hoc Genetic Nurse and Counsellor Accreditation Committee (all authors of this paper) undertook a study to obtain baseline data using key informants.

Aim

The aim of this study was to obtain a set of baseline data on the numbers, education and legal governance of genetic counsellors and genetic nurses in Europe.

Method

Design

We undertook a descriptive, cross-sectional survey to obtain baseline data on the role, education and practice of genetic counsellors and nurses in European countries.

Data collection

A survey comprising 26 questions was developed by the Working Group, which includes five non-medical genetic counsellors or nurses, one of whom is an experienced health researcher and another an epidemiologist. Areas of interest were agreed on and wording of questions was discussed until a consensus was reached. Both multi-choice questions and those requiring free-text responses were included. The questionnaire was piloted by five senior and experienced genetic counsellor colleagues, from four different countries to ensure that all questions were understandable and could be answered appropriately. We made several minor changes to the wording as a result of feedback.

Due to the wide geographical area in which potential respondents were located, we used an online survey tool, Survey MonkeyTM to maximise ease of data collection and therefore enhance numbers of responses. All genetic counsellors are expected to be able utilise Web-based information in their daily work, so there was reason to believe they would be able to use the tool with ease.

Participants

The aim of this study was to obtain a profile of the genetic counselling profession in European countries, rather than the practice of individual genetic counsellors. We therefore used key informants to collect the data, inviting at least two persons from each of 18 countries to participate. The 18 countries were identified as those where there was either a genetic counsellor professional organisation in place ($n=5$), where there was known to be at least one genetic nurse or counsellor in practice ($n=7$) or where there were other professionals interested in genetic counselling who had registered as members of the European Genetic Nurse and Counsellor Network ($n=6$). Ideally, we wanted to focus on leaders of genetic counsellor organizations in each country;

however, these existed in only five European countries (UK, The Netherlands, Norway, Sweden, and France) at the time of the study. We therefore also invited prominent genetic counsellors who were known to be active in the development of the profession in each country to participate. In some countries, where we were unable to identify genetic counsellors to invite, we sent the questionnaire to leaders of the national human genetics societies. Invitations were sent by E-mail, and we sent one reminder 4 weeks after the initial email. All participants gave consent for the data they contributed to be published.

Data analysis

The data were analyzed using descriptive statistics.

Results

Demographic characteristics of the participants

Twenty-nine individuals from 18 countries responded to the survey. Those who responded described their professional title as: genetic counsellor ($n=14$), genetic nurse ($n=3$), psychologist ($n=3$), medical geneticist ($n=6$), research geneticist ($n=1$), genetic assistant ($n=1$) and nurse ($n=1$). Eleven had a Master degree in Genetic Counselling; five had another type of Master degree; six had a medical degree,

and six had completed a nursing degree or diploma ($n=6$). One person had a PhD with no additional clinical qualifications, but two of those with clinical qualifications also had a PhD. Three of those with an MSc were also nurses.

Number of genetic counsellors or nurses in each country

The number of genetic counsellors or nurses per million population varied enormously (Table 1). The greatest number of genetic counsellors was in the UK, with over 300 genetic counsellors and 20 genetic nurses, equivalent to around six counsellors per million population. Five other countries had between three and five counsellors or nurses per million population, while in seven countries, there was less than one counsellor per million population. However, there were no genetic counsellors or nurses working in Germany, Hungary, Turkey or the Czech Republic. While no genetic counsellors were working in Italy, it was reported that there were currently 37 genetic nurses in post.

Overall, there were 494 genetic counsellors and 122 genetic nurses for a European population of over 319 million inhabitants, a ratio of one counsellor/nurse for every half a million population.

The first country in Europe in which genetic counsellors were working was the UK (1980) (Table 1). In Romania, genetic counsellors had started to work as recently as 2011.

Table 1 Number of genetic counselors and genetic nurses per country and per million population

Country (no. of respondents from that country)	Population	Year in which genetic counsellors/nurses first worked in that country	No. of genetic counsellors	No. of genetic nurses	Total number per million population
Czech Republic (2)	10,674,947	N/A	0	0	0
Denmark (1)	5,475,791	Unknown	15	10	4.5
Finland (1)	5,279,228	Unknown	0	20	3.8
France (2)	65,800,000	2005	75	0	1.1
Germany (1)	81,820,000	N/A	0	0	0
Hungary (1)	9,999,000	N/A	0	0	0
Iceland (1)	306,694	2006	1	0	3.2
Ireland (1)	4,446,000	1998	7	2	2
Italy (3)	60,157,214	Unknown	0	37	0.6
The Netherlands (2)	16,662,143	1990	65	0	3.9
Norway (1)	4,854, 000	1990	17	0	3.5
Portugal (2)	11,317,192	2004	1	0	0.9
Romania (1)	22,246,862	2011	0	20	0.9
Spain (1)	46, 661,950	2009	6	0	0.1
Sweden (4)	9,276,509	2002	10	10	0.5
Switzerland (2)	7,785,806	2004	3	3	1.3
Turkey (1)	77,804,122	N/A	0	0	0
UK (2)	61,524,872	1980	300	20	5.2

Legal framework for genetic counsellors

Only respondents from France and Norway reported that, in their country, there was a specific governing legal framework for genetic counsellors. However, in four other countries (Iceland, Sweden, Turkey and UK), the work of genetic counsellors was or would be subject to statutory regulation of a more general nature, for example, by laws governing a range of healthcare professions. In contrast, the work of genetic nurses is governed by the statutory regulation of nurses in each individual country.

Respondents from France, The Netherlands, Norway, Switzerland and Turkey said it was illegal for genetic counsellors to work outside the supervision of a medical doctor in their country, while genetic counsellors from Iceland, Denmark, Ireland, Sweden and UK stated that genetic counsellors normally worked with medical doctors.

Preparation for the role

There are specific educational programmes for genetic counsellors in seven countries: France, The Netherlands, Norway, Portugal, Romania, Turkey and the UK. The number of graduates of these programmes varied from only two to three per year in The Netherlands to between 6–18 per year in France, and 5–18 per year in the UK. A new Master programme was being planned to serve the educational needs of genetic counsellors in the Nordic countries.

Additionally, there were genetic counsellors who had trained in the UK, Cuba, USA, Canada, South Africa and Australia working in European countries different from the country of training.

The educational background and professional preparation for the role differed enormously between countries. For example, in France, where there is a legal governance of genetic counselling, only genetic counsellors who have passed a professional Master degree may practice. This was only the case in France; in all other countries where genetic counsellors worked, they had a range of professional backgrounds. In Denmark, for example, it was reported that nurses, medical laboratory technologists, midwives and secretaries were all working in a role described as genetic counselling.

Factors affecting establishment of genetic counsellors or genetic nurses

Respondents to the survey were asked about factors that supported development of the genetic counsellor role in their country as well as those factors that were disadvantageous in establishing the profession. Pressure on genetic services from the growth of demand for genetic counselling, lack of sufficient medical geneticists to provide care and

increasing use of technology for genetic testing were seen as stimuli for involvement of genetic counsellors in the genetic specialist team. Several respondents replied that genetic counsellors were seen as a less costly way to provide clinical care than using a purely medical team. Having the support of medical colleagues was cited by four respondents as key to establishment of the profession. Conversely, lack of understanding of the role, lack of support from other health professionals and reluctance of medical doctors to involve genetic counsellors in clinical care were seen as barriers to the profession. Despite being seen as a cheaper way to provide a service, five respondents stated that budgetary restrictions had made it harder for genetic counsellors to be appointed in their country.

Areas of practice

Respondents stated that, in their country, genetic counsellors worked in hospitals, research centres, educational institutions, the community and private practice (Table 2). Only 13 responses were received concerning the departments in which genetic counsellors worked. Responses included in genetics departments (92.3%, $n=12$), oncology (61.5%, $n=8$), cardiology (38.5%, $n=5$), obstetrics/gynaecology (38.5%, $n=5$), paediatrics (15.4%, $n=2$) and neurology (15.4%, $n=2$). Although only two respondents stated that working with a medical colleague was a legal requirement for genetic counsellors, a further six (54.4%) replied that this was standard practice.

Professional organisations

Organisations created specifically for genetic counsellors exist in five countries. These are the Norwegian National Association of Genetic Counsellors, French Association of Genetic Counsellors, Association of Genetic Nurses and Counsellors (UK), Swedish Association of Genetic Counsellors (Svenska föreningen för genetiska vägledare) and the Dutch Society of Genetic Counsellors (Nederlandse Vereniging Genetisch Consulenten). In several other countries (such as Finland, Italy and Iceland), genetic counsellors were members of the national genetics society.

Table 2 Places of employment

Place of employment	Number of countries	%
Hospitals	11	64.7%
Research centres	5	29.4%
Educational institutions	3	17.6%
Community	1	5.8%
Private practice	1 (only in UK fertility clinics)	5.8%

Discussion

The findings of this study clearly indicate the huge variation in the role and preparation of genetic counsellors in Europe. Although Godard et al. were suggesting in 2003 that genetic counsellors should be part of the multi-disciplinary genetics team, the evidence from this survey shows that that is far from the case in many countries. This may be due to a number of factors, including interpretation of professional roles and the structure of healthcare services in each country. Lack of acceptance and support from medical colleagues was cited as a negative influence, and this has been shown to influence the role development of other non-medical health professionals such as nurse consultants (Stevenson et al. 2011), who reported the impact of the attitudes of medical colleagues on the way they were able to undertake their work. In addition, in countries where the status of non-medical health professionals (such as nurses) is low, this may lead to a lack of trust between professionals and reluctance to delegate responsibility to non-medical staff. Development of the genetic nurse role will also be influenced by legal restrictions on the ways in which non-medical staff can work, for example, in some countries such as Turkey, nurses are legally only able to provide treatment ordered by a doctor (Official Journal of Republic of Turkey 2007), and this limits not only their legal capacity to carry out genetic counselling work but also their status within the health services. In contrast, the role of the genetic counsellor is now legally protected in France (Voelckel 2007); however, even there, medical staff take ultimate responsibility for the work of their genetic counsellor colleagues.

Funding of services may play a part in the acceptance and appointment of genetic counsellors and nurses within a country. For example, in Germany, the insurance-based health system is organised so that it would not be possible for genetic counsellors to be reimbursed for their services, while in the UK, under the National Health Service, the costs of the services of most health professionals including genetic counsellors are funded centrally by the Government. However, it was stated by some participants that genetic counsellors could provide genetic counseling services at a lower cost than medical doctors, and this sometimes acted as a catalyst for the establishment of the profession. The lower cost of services was also suggested in a study of nurse and allied health professional consultants as a pragmatic reason for employing non-medical staff who could perform a similar role (Stevenson et al. 2011) to their more expensive medical counterparts.

Proposed European legislation changes (European Commission 2011a, b) to base awarding of professional recognition on a set of agreed core curricula may make establishment of the profession achievable. A set of core competences for genetic counsellors (Skirton et al. 2010a, b) has already been

agreed by expert groups of genetic health professionals and has been endorsed by the European Society of Human Genetics, and this could form the basis of the core curriculum in Europe to establish common standards of expertise.

It can be seen from the results that, at present, there is no coherent system of educational preparation for the role of genetic counsellor. While in eight countries a Master programme has been established specifically for this purpose, in others, there are individuals with a wide range of backgrounds and qualifications undertaking genetic counselling. While a group of interested genetic counsellor educators has formed under the title ‘Transnational Alliance of Genetic Counselors’ to address educational issues (<http://tagc.med.sc.edu/>), this currently has no official standing and is focused on established Master programmes, the majority of which are in the USA. The situation in Europe is complex due to the different health and educational systems and legal standing of non-medical practitioners. Studies of genetic counselling education and practice in Australia, Canada, UK and the USA (Sahhar et al. 2005; Alliman et al. 2009) demonstrate that, while there may be strong similarities, there are also important differences related to culture and context. Any European recommendations therefore need to be flexible enough to enable adaptation for national requirements. It will be useful to learn from the experiences of colleagues in other regions of the world as we try to determine an approach for Europe that will enable an inclusive and rigorous approach to accreditation of practitioners.

As stated, support from other health professionals, particularly medical colleagues, was seen as key to the success of the establishment of the genetic counselling profession in each country. Where colleagues were supportive, the profession flourished; where they were obstructive, it floundered. We would suggest that the aim of health professionals should be the delivery of excellent and equitable genetic health services and that working in collaboration to ensure there are sufficient, affordable, trained health professionals to deliver that care would benefit patients and their families. However, the newness of the profession and the low numbers of genetic counsellors in practice may contribute to current limitations in the understanding of the role of genetic counsellors by other health professionals and healthcare managers. Another important aspect of this discussion is the use of the term genetic counsellor. In some contexts, it is clear that the term is used to describe any health professional who provides information and testing associated with a genetic condition (Rantanen et al. 2008). However, we would argue that genetic counselling is itself a profession, and genetic counsellor should be used only to describe a (usually non-medical) health professional specifically trained and educated for this role (Skirton et al. 2010b).

It is a concern that, with the current lack of any accreditation system in many countries, there is nothing to prevent

any individual using the title genetic counsellor. With such a discrepancy in professional backgrounds and an overall lack of educational standards for entry to the profession, there must be concerns about safety of practice. A committee of the European Society of Human Genetics has now produced a set of standards for practice, educational requirements and a code of ethics for European genetic counsellors (Skirton et al. 2010b). We would suggest that this is used alongside European regulatory frameworks to place the profession on a more rigorous foundation and ultimately contribute to greater understanding and development of the role of the genetic counsellor.

Strengths and limitations of the study

The survey was sent to known professional leaders in each country who will have had knowledge of the national situation regarding the profession; however, in some cases, the informants may not have had access to all the data required. The data provide a general overview of the situation in each country, but there may be differences in both education and practice of genetic counsellors and nurses within each country that are not reflected in the results of this study.

Conclusions

These data provide a general overview of the situation regarding genetic counsellors and genetic nurses in 18 European countries. While further research is needed to clarify the range of genetic counsellor and genetic nurse practice within and between countries, it is clear that a coherent and rigorous system of accreditation for genetic counsellors is urgently required to ensure that individuals and families receive safe and effective care.

Conflict of interest The authors declare that they have no conflict of interest.

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