Exploration of the aspects of genetic counseling from non-medical healthcare providers in Belgium

S. De Nobele[1], I. Slegers[2], D.F. Vears[3]
on behalf of the Workgroup of Genetic Counselors Belgium (established 2015)
[1]Center for Medical Genetics Ghent, Universital Hospital Ghent, [2]Center for Medical Genetics, University Hospital Brussels,
[3]Center for Biomedical Ethics and Law, KU Leuven, Leuven, Belgium

INTRODUCTION

Background:
In response to the growing demands being placed on genetics departments and in conjunction with recent advancements in genetic technologies, non-medical health care providers are being enlisted to assist in clinical genetics services. In Belgium, although the professional title of 'genetic counselor' has recently become accepted, no formal genetic counseling courses exist. In order to provide support for this growing profession in Belgium, a working group of ‘genetic counselors’ was established in 2015. However, little is known about the scope of the work these non-medical health care providers undertake within this role.

Purpose:
The goal of this study was to identify the scope of practice of non-medical healthcare providers operating in genetic centers in Belgium in order to 1) get a better understanding of the specific role they are fulfilling and 2) identify what additional training and support might be required.

METHODS

Recruitment:
A survey was administered by email to 24 non-medical healthcare providers working within the eight genetic centers in Belgium in March 2016.

Questionnaire:
This questionnaire was based on the tool used in the Delphi study by Skirton et al. 2013*, in order to determine the European core curriculum for Master programs in genetic counseling. Our questionnaire asked participants to rate how relevant a range of aspects related to genetic counseling were to their current practice at the genetic service. The questionnaires were divided into seven sections: 1) counseling 2) psychological issue 3) medical genetics 4) human genetics 5) ethics, law and sociology 6) professional practice and 7) education and research.

RESULTS

Participant characteristics:
Twelve participants returned the questionnaire (Response rate 50 %). Participants listed their current titles as genetic counselor (n=5), nurse (n=2), midwife (n=2), psychologist (n=1), social nurse (n=1) and lab technician (n=1). In terms of their experience as a genetic counselor or in a related profession, three participants had been working for one to three years, one participant had 5-10 years experience, two participants had 10-15 years experience, and one participant 20-25 years experience.

Counselling aspects
All participants indicated that they frequently use appropriate communication and counseling skills and communicate effectively with the patient and family. Although one participant never assesses the patient's psychological state, 50% of participants do so occasionally and 42% do so frequently.

Question	Never	Occasionally	Frequently
Use appropriate communication and counseling skills	0%	0%	100%
Communicate effectively with the patient and family	0%	0%	100%
Assessess patient’s psychological state	8%	50%	42%

Psychosocial aspects
92% of participants agreed that knowledge about psychosocial aspects such as the impact of family history on the individual and their family, the impact of positive and negative test results on the individual and their family, the impact of living with a disease and test results, and the potential reactions of the family to genetic risk or test results were very relevant to their practice. However, the use of psychosocial skills was more divided: 17% of participants never use tools to explore patients' past and current psychosocial situation while 50% frequently use these.

Question	Not at all relevant	Somewhat relevant	Very relevant
Impact of family history on the individual and their family	0%	8%	92%
Impact of positive and negative test results on the individual and their family	0%	8%	92%
Impact of living with a disease and test results	0%	8%	92%
Potential reactions of individuals such as siblings, parents, obligate carriers to genetic risk or test results	0%	8%	92%

Medical genetics aspects
All participants considered knowledge of traditional and non-traditional inheritance patterns and explaining inheritance and genetic concepts in patient appropriate language very relevant to their practice. However, views were mixed regarding therapeutic technologies and embryology with 33% and 42% considering these aspects to be not at all relevant to their practice respectively.

Question	Not at all relevant	Somewhat relevant	Very relevant
Traditional and non-traditional inheritance patters	0%	0%	100%
Explaining inheritance and genetic concepts in patient appropriate language	0%	0%	100%
Therapeutic technologies and embryology	33%	42%	0%

Human genetics aspects
Participants gave differing opinions concerning the relevance of some aspects of human genetic knowledge: 25% of participants rated knowledge about epigenetics, techniques for detecting genetic abnormalities and methods for disease gene detection as not at all relevant to their practice while 50% and 25% indicated these aspects where somewhat relevant or very relevant respectfully. Respectively 42% and 50% felt that knowledge about gametogenesis, recombination, non-disjunction and sister chromatid exchange are not at all relevant to their practice.

Question	Not at all relevant	Somewhat relevant	Very relevant
Transcription, translation, protein synthesis	25%	67%	8%
Gametogenesis	42%	58%	0%
Recombination, non-disjunction, sister chromatid exchange	50%	43%	8%
Epigenetics, Techniques for detecting abnormalities, Methods of finding a disease gene	25%	50%	25%

DISCUSSION

There appears to be a higher concordance between the participants in relation to the importance and relevance of psychosocial knowledge and skills than that of knowledge regarding human genetics and medical genetics. While this may be because a large proportion of the participants identify as genetic counselors or psychosocial workers, this requires further exploration. Given that genetic counseling is not a recognized profession in Belgium and there is no official training available, it would be beneficial to explore how comfortable non-medically trained health professionals are in understanding the boudaries of their roles.

CONCLUSION AND LIMITATIONS

As there are only eight genetic centers in Belgium, the field of genetic counseling is relatively small and it was not possible to recruit a large number of participants. However, we estimate that we have recruited at least 50% of the individuals practicing as non-medical healthcare providers in this sample.

By understanding the scope of the genetic counseling work performed by non-medical healthcare providers in Belgium, the working group can better assist these individuals in their practice, assess the need for additional training/education programs and provide recommendations for support within the healthcare system.

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REFERENCES

Skirton et al. (2013) A Delphi Study to determine the European core curriculum for Master programs in genetic counseling. European Journal of Human Genetics, 21, 1060-1066.