



Developing a national certification pathway for genetic counselors in Sweden—a short report

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Received: 5 November 2018 / Accepted: 9 May 2019
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Abstract

There is no Master's level education for genetic counseling in Sweden, meaning that genetic counselor professionals have very different backgrounds. Hence, there is a need to harmonize the quality of genetic counseling and introduce standards for practice. The Swedish Society for Genetic Counselors and the Swedish Society of Medical Genetics and Genomics collaborated to determine professional requirements and a career pathway, defining three vocational levels within the genetic counselor profession. We report here an individual educational pathway leading up to eligibility for certification as a genetic counselor in Sweden.

Keywords Genetic counseling · Education · Training · Quality care · Patient safety

Introduction

The demand and necessity for non-medical staff to provide and support the genetic counseling process are constantly increasing (Paneque et al. 2017; Skirton et al. 2015). This also increases demands on professionals and services providing genetic counseling along with genetic testing. Genetic counseling involves knowing and understanding the genetic, medical, and psychological aspects of a genetic investigation.

Counseling should focus on ethical aspects and support autonomous and informed decisions (Marteau et al. 2001). To achieve this, communication skills are vital, as well as applying a holistic view on care for patients and relatives (Frazer 1974; National Society of Genetic Counselors' Definition Task et al. 2006). In order to meet this skillset and ensure patient safety (Skirton et al. 2012), access to genetic counseling education is necessary and therefore recommended by European organizations promoting clinical genetics

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(European Board of Medical Genetics 2018). A European-wide, voluntary certification system for genetic counselors, most of whom have a Master's in Genetic Counseling, was introduced in 2013 in order to assure the quality of care provided by genetic counselors (EuroGentest 2010; Paneque et al. 2016)

Educational programs for genetic counseling existed in Sweden (2003–2006), however none at Master's level. The programs covered medical genetics, counseling skills, communication skills, ethics, psychosocial aspects, and law and regulations regarding genetics in theory and practice. Currently, however, there is no Master's level education in genetic counseling in Sweden, despite European recommendations. The number of genetic counselors in Sweden is relatively low (Abacan et al. 2019), yet keeps increasing, resulting in varying quality of care due to lack of a standardized approach (Pestoff et al. 2016). To date, there are about 30–40 professionals working as genetic counselors in Sweden.

The Swedish higher educational system adheres to European guidelines (Bologna process) and the European Credit Transfer and Accumulation System (ECTS) in the EU (Swedish Council for Higher Education 2019). The system is divided into three cycles: the first is generally equivalent to the undergraduate (Bachelor's) level studies (180 credits), the second corresponds to Master's (graduate) level (240 credits), and the third corresponds to doctoral (Ph.D.) level (360 credits) (Ibid).

In order to provide safe and efficient care to an increasing group of patients, we believe there is a need to set up quality standards for genetic counselors (without a specific Master's program) in Sweden, similarly to the EBMG certification in Europe (Abacan et al. 2019; Paneque et al. 2016). Therefore, this report provides a suggested pathway for education, employment, and certification as a genetic counselor in Sweden. Furthermore, these guidelines could prove useful for other countries without a Master's level education for genetic counselors.

Approach The authors conducted a literature review and two workshops to determine the minimum professional requirements for genetic counselors in Sweden. This work was supported by the Swedish Society of Medical Genetics and Genomics (SFMG) and the Swedish Society of Genetic Counselors (SFGV). To reach skills and competences equivalent for graduates at Master's level programs in genetic counseling, international standards for genetic counseling were (European Board of Medical Genetics 2018; Ingvaldstad et al. 2016; Skirton et al. 2012, Skirton et al. 2013). The result is an pathway for certification as a genetic counselor in Sweden, which has been scrutinized and accepted by both professional societies at a board meeting in January 2017 and published on the official website (SFMG, 2017).

Recommended educational pathway for certification as a genetic counselor in Sweden — a document used for guidance for the employment of genetic counselors in Sweden

Individual plan The goal of the individual educational plan is to enable genetic counselors in Sweden to obtain the equivalent skills and competences to Master's level programs in genetic counseling in Europe. There are several paths that can lead to this goal: *theoretical education, clinical practice, field visits, supervision, reflection, participation in conferences*, and *working in a genetics clinic*. These are not mutually exclusive and each individual's prior experience and education will determine their necessary pathway. A description of these paths can be found in Table 1.

At the start of employment, each new employee to become a genetic counselor has an individual plan set up, based on Table 1. Accordingly, there are three possible levels of employment within the profession. New employees may enter at any level depending on their existing competence, as each level corresponds to previous education and responsibilities. Further specific training and education are required, in order to reach the next level of employment, in a step-wise manner. Clinical placements should take place at a clinical genetics clinic, under the supervision of a certified genetic counselor, whenever possible. For the certification, appropriate examiners (clinical geneticist and senior genetic counselor) are appointed by the board of SFMG.

Educational objectives There are four distinct educational goals with corresponding skills and competences: (1) *Counseling Skills*, (2) *Genetics*, (3) *Ethics and Law*, and (4) *Organization*, as shown in Table 2. These educational objectives strive to meet existing international guidelines for genetic counseling education (European Board of Medical Genetics 2018; Ingvaldstad et al. 2016; Skirton et al. 2013).

Suggested pathway to certification:

1. *Individual plan*: Created at the beginning of employment and based upon each individual's previous education and experience. This is arranged by the head of clinical genetics or an appointed supervisor together with the employee, in accordance with Table 1. The plan should sum up to a Master's level (minimum 240 credits), with at least 15 credits specifically related to genetic counseling.
2. *Training*: Additional necessary courses, lectures, conferences, and field visits, which provide practical skills and theoretical knowledge according to the educational objectives in Table 2.
3. *Master's thesis or equivalent*: (> 15 credits) within the student's main area of focus/education.

Table 1 Employment level and corresponding Title. *Background/basic level competence/education* and career development steps for genetic counselors in clinical operations in Sweden

Level—title	Background/basic level competence/ education	Responsibilities	Further education and for the next step career development
1. Basic profession, e.g., nurse, molecular biologist, social science worker etc.	Recommended minimum 180 credits (Basic Candidate Program in Nursing, Science, or Biology)	Document family history Draw pedigree Requisition of medical files Acquire consent from patients Manage samples	At least 15 credits in genetic counseling, which must include counseling/communication skills. Skills and competence within research methodology appropriate to achieve Master's thesis Participate in lectures, seminars, conferences, and other relevant educational opportunities
2. Assistant genetic counselor	Minimum 240 credits (corresponding to 4 years of full-time studies, equivalent to Master's level), with a focus on genetic counseling (minimum 15 credits)	Provide genetic counseling under supervision. Participate in reflection, individually, or in group Participate in clinical case discussions	Participate in training, education, and courses in genetics/nursing (individualized) Self-reflection at least 2 years of practice at a Clinical Genetics department Study visits Create a portfolio of cases (> 20 cases within speciality field) and career development (courses and educational opportunities) Regular meetings with mentor or supervisor
3. Eligible to be a certified genetic counselor (by SFMG)	Minimum 240 credits (corresponding to 4 years of full-time studies), with a focus on genetic counseling (minimum 15 credits) 2 years of clinical practice at Clinical Genetics department Certification possible according to the SFMG certification of a genetic counselor process	Provide genetic counseling independently Contribute to case discussions Take responsibility for educational programs/courses/-lectures within genetic counseling Contribute to research studies (as far as possible) Keep updated about research within the area and share this knowledge with colleagues Act as a mentor for an assistant genetic counselor	Supervision/mentorship training Participate in research and/or developmental work at the clinic Contribute to training and educational opportunities within the clinic and externally (to other healthcare professionals or society) <i>Continuing development:</i> acquire competence for certification as a genetic counselor within EBMG

Levels of employment for genetic counselors:

¹ The *first level* requires minimum an undergraduate level education (minimum 180 credits). It is recommended that the job title will be the same as the individual's *basic profession*, e.g., *nurse, scientist, biomedical analyst, midwife, social worker, or psychologist*. When necessary educational requirements are ascertained, individuals are assessed and advanced to the second level

² The *second level* is the Assistant Genetic Counselor and requires a Master's level education in the field of Nursing Science or Biomedical Sciences (minimum 240 credits). The training period in the clinical setting is a minimum of 2 years and a minimum of 15 credits specific for genetic counseling education. Their individual educational plan is assessed before advancement to the next level

³ The *third level* is eligible to become a *certified Genetic Counselor*, when fulfilling the requirements for certified genetic counselor according to SFMG-examination, including 2 years of practical experience at a Clinical Genetics department

4. *Work experience:* > 2 years in a clinical genetics clinic under the supervision of a certified genetic counselor (*whenever possible*).
5. *Supervision:* Continuous participation during clinical placements and education that could eventually evolve into a mentoring relationship.
6. *Documentation for certification:* Relevant courses, educational experiences, study visits, internship or other clinical practice and a patient case log (> 20 cases) and ethical reflections on counseling issues with three short,

reflective case-descriptions (*one especially good, one especially challenging, one ethically difficult*), as well as participation in supervision (both clinical and personal) (for further details, see Table 1).

Certification When the goals corresponding to the third level of employment in the individual's pathway have been met, the person is eligible to apply for certification as a genetic counselor. Applications are submitted to the SFMG secretary via

Table 2 Educational objectives for certified genetic counselors in Swedish practice. There are four distinct educational goals that should be assessed during certification: *Counseling Skills, Genetics, Ethics and Law*, and *Organization*. Here is the detailed information on the educational content which should lead to the required skills and competences of each goal

1. *Counseling skills*

- Knowledge of human psychological and social development.
- Ability to apply different communication and decision theories.
- Ability to guide people to make independent, well-informed decisions related to the genetic investigation.
- Ability to conduct a conversation and communicate about existential issues related to genetic issues.
- Ability to identify and respond to people in crisis.
- Ability to carry out a follow-up with people who received a difficult message.
- Ability to conduct family meetings in genetic counseling.
- Ability to communicate knowledge in genetic counseling to healthcare professionals and to the public.
- Ability to self-reflection in counseling situations.

2. *Genetics*

- Knowledge of medical genetics and its applications in health care, as well as consequences for the patient and the family.
- Knowledge of inheritance patterns and inherited diseases.
- Knowledge of genetic databases relevant to clinical work.
- Ability to understand and communicate genetic analysis results.
- Ability to evaluate and display critical and independent thinking in relation to current research within the field and critically review and evaluate scientific information on genetics and genetic counseling.

3. *Ethics and Law*

- Knowledge of ethical concepts and theories.
- Ability to understand, evaluate and take into account ethics for individuals and families from a genetic perspective.
- Knowledge of current laws, regulations, and guidelines that concern healthcare professionals and patients in regard to genetic investigations.
- Knowledge of medical-ethical assessments and considerations.

4. *Organization*

- Knowledge about health care and health care organizations.
- Knowledge of work improvement within the profession.
- Knowledge and understanding of genetic clinic organizations in Sweden.
- Ability to complete teaching at the undergraduate and postgraduate education level.
- Knowledge about the genetic laboratory functions and activities.

email. The application is assessed by two examiners appointed by SFMG (one clinical geneticist MD and one senior genetic counselor). Examiners are clinically active in Clinical Genetics departments and have substantial knowledge in genetic counseling.

Discussion and conclusion

We have described an alternative pathway for certification as a genetic counselor in Sweden, a country without a Master's level program in genetic counseling. The aim is for professionals to achieve necessary competences, equivalent to

Master's level, for safe and effective genetic counseling practice. To be eligible for certification according to this pathway, the applicant must have 240 credits, with a focus on genetic counseling, and a minimum of 2 years of clinical practice and fulfilled the goals of the individual's educational pathway.

Since quality assurance of genetic services is important, also of genetic counseling, we plan to validate this pathway after implementation in Sweden. This will be done by examining genetic counselors' career development opportunities, responsibilities, and experiences and, more importantly, by measuring patients' satisfaction and experiences using the genetic counseling services by means of validated instruments (patient related outcome measures).

In conclusion, we believe it is essential for genetic counselors to have access to continuing professional development and counseling supervision. Therefore, we hope that this suggested pathway can inspire and guide career development and certification for genetic counselors also in other countries that lack the recommended Master's education and where the profession is still emerging.

Acknowledgments We wish to acknowledge Heather Skirton for valuable input and support in the preparation of this manuscript.

Compliance with ethical standards This manuscript has been written in compliance with ethical guidelines and does not contain any studies of human or animal subjects.

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

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