

ORIGINAL ARTICLE

The genetic counseling profession in Austria: Stakeholders' perspectives

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Abstract

In contrast to most European countries, genetic counseling in Austria, Germany, and German-speaking Switzerland is exclusively carried out by medical doctors. In this study, we investigate the perspectives of key clinician stakeholders in Austrian genetics services regarding prerequisites, opportunities, and challenges of implementing master's trained genetic counselors. Semi-structured interviews with open-ended questions and thematic analysis were carried out with nine participants, mostly medical geneticists at different hierarchy levels from three Centers for Medical Genetics in Austria. Several Austrian medical geneticists strongly object to the implementation of non-physician genetic counselors, and representatives of 3/6 medical genetic centers declined to be interviewed. Semantic framing was identified as a critical factor: In German medical language, patient consultations carried out by medical geneticists are generally called 'Genetische Beratung' (genetic counseling), and many medical geneticists see themselves primarily as 'Genetische Berater' (genetic counselors). 'Genetic counseling' is specified as an exclusively medical task in Austrian law. There is apprehension that the introduction of non-physician genetic counselors could reduce quality and undermine the position of medical genetics as a clinical specialty. The situation in Austria resembles that in Germany. Our study highlights the need for a clear definition of roles, expertise, and scope of practice of different genetic professionals. The integration of genetic counselors into Austrian genetics services is most likely acceptable in multi-professional teams, closely affiliated with medical genetic services, and under the medico-legal oversight of medical geneticists.

KEYWORDS

education, genetic counseling, genetic counselor, genetics services, professional development

Abbreviations: ACMG, American College of Medical Genetics; BVDH, German Professional Association of Human Geneticists; EBMG, European Board of Medical Genetics; GfH, German Society of Human Genetics; GTG, Austrian Gene Technology Act; ÖGH, Austrian Society of Human Genetics.

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1 | INTRODUCTION

Rapid advances in laboratory genetics have sparked a surge in demand for genetic counseling that accompanies the genetic testing process. Globally, many countries employ non-physician genetic counselors (GCs) and medical geneticists to meet rising demands. GCs are healthcare professionals specifically educated in clinical genetics and counseling at master level (Skirton et al., 2013). The first graduate program in genetic counseling (GC) was inaugurated in the United States in 1969, and the profession has been an integral part of the Anglo-Saxon healthcare systems over the last 40–50 years. In Europe, the first GC graduate program was launched at Manchester University, UK, in 1992 and since then has spread across Europe (Table 1) (Abacan et al., 2019; Ormond et al., 2018; Paneque, Serra-Juhe, et al., 2017). In France, an evaluation of the medical workforce predicted a shortage of medical doctors. This triggered a governmental top-down initiative establishing a strong legal basis for the GC profession, a master training program, and the foundation of the French Association of Genetic Counselors in 2005 (Cordier et al., 2013; Voelckel, 2007). Cordier et al. (2016) investigated the view of French clinical and laboratory geneticists on GC employment, work responsibilities, and integration. The results show that French GCs manage a wide range of tasks independently but under the responsibility of medical geneticist (MGs). The study emphasizes that GCs are well recognized by physicians practicing within genetics services and that this mutual trust has been a key factor in the successful implementation of the GC profession.

The approaches to introduce GCs in European countries were quite diverse and often influenced by the setup of the healthcare system and legal boundaries. Given the significant variability of educational background and professional training of GCs all over Europe (Table 1), the European Board of Medical Genetics (EBMG) developed a core curriculum and regulatory framework regarding competencies and standards of practice to harmonize GC education and professional practice. Since 2013, European GCs are registered under the EBMG that also accredits two-year graduate programs that meet defined criteria. (Paneque et al., 2016; Paneque, Moldovan, et al., 2017; Skirton et al., 2010).

The concept of GCs has been discussed in Europe for several decades. In 1979, a symposium on the delivery of genetics services in Europe was held in Heidelberg, Germany. Experts from 15 European countries debated whether '*not all genetic counseling must be done by professional clinical geneticists*' and if '*genetic counseling could be considered a specialty in its own right*' (Passarge et al., 1980). While participants from the UK picked up on the American idea of implementing master's trained GCs, Austrian and German representatives did not embrace the concept at the time. This reluctance was partly due to the difficulties that medical genetics as a specialty faced in these countries. Compared to the Anglo-American world, the development of genetics services was delayed in Austria and Germany due to their difficult historical, societal, and rhetorical context (Petermann et al., 2017). Networks of doctors that were involved with the Nazi eugenics movement were not immediately destroyed after the fall of

What is known about this topic

The German-speaking countries have so far not implemented the genetic counseling profession, and many medical geneticists are apprehensive of an introduction.

What this paper adds to the topic

Here we report the results of an interview study exploring the objections against non-physician genetic counselors. Reasons for apprehension include the late development of Medical Genetics as a specialty closely linked to genetic counseling needs, and semantic framing as many Austrian and German medical geneticists use the term 'Genetische Beratung' (genetic counseling) for their core clinical activities.

the regime (Petermann et al., 2017). Whereas the European Society of Human Genetics was founded in 1967, it took until 2000 and 1987 to instigate the Austrian Society of Human Genetics (ÖGH) and the Western German Society of Human Genetics (GfH), respectively. The Eastern German Society of Human Genetics was founded in 1978 and combined with the GfH in 1991 (Passarge et al., 2020).

The introduction of medical genetics in Austria was linked to the availability of postnatal and prenatal cytogenetic analyses and the recognized need of genetic counseling in this context. In Austria, the first 'Genetische Beratungsstellen', that is, 'Genetic Counseling Centers', emerged alongside the legalization of termination of pregnancy in 1974 in Vienna and Graz; the University of Innsbruck followed in 1981 (Mayer et al., 2009; Petermann et al., 2017). These centers were not part of the hospital services but belonged to University Institutes of Medical Biology primarily dedicated to teaching and research. The focus of patient-oriented services was the provision of diagnostic genetic tests and related genetic counseling by medical doctors who were officially specialized in 'Medical Biology' and who regarded themselves primarily as 'Genetische Berater' (genetic counselors). Clinical genetic skills such as dysmorphology expertise were provided at children's hospitals rather than the genetic institutes, and medical genetics was made available as an additional qualification ('Zusatzbezeichnung') to other specialists such as pediatricians and gynecologists until the early 2000s. In Austria, the specialty of Medical Biology was only renamed Medical Genetics in 2007 (ÄAO, 2006).

The situation in Germany is comparable. In (Western) Germany, the medical specialist qualification in Human Genetics was introduced after the reunification in 1991. At present, Germany has 366 active MGs, 209 above the age of 50, which equals approximately 4 per million inhabitants (Bundesärztekammer, 2019; Scholz, 2018). In Austria, there are 30 fully qualified MGs who serve a population of 8.8 million citizens. Nearly half of MGs in Austria will reach retirement age in the coming decade, and many of them were recruited abroad. In-house training has only recently become a major aim but is hampered by

TABLE 1 European distribution of genetic counselors

European countries with practicing genetic counselors	Belgium, Cyprus, Denmark, Finland, France, Iceland, Ireland, Italy, the Netherlands, Norway, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, Turkey, UK
Accredited MSc programs in Genetic Counseling (accreditation board)	Cardiff University, UK (GCRB and EBMG) University of Glasgow, UK (GCRB) University of Manchester, UK (GCRB and EBMG) (integrated into the NHS Scientist Training Program) Université de la Méditerranée - Aix Marseille II, France (EBMG) Universidade do Porto, Portugal (EBMG) Universitat Pompeu Fabra Barcelona, Spain (EBMG) Babes-Bolyai University, Romania (EBMG)
New MSc programs in Genetic Counseling	Università di Siena, Italy 2018 Medical University of Innsbruck, Austria 2019 Linköping University, Sweden 2021

Note: Distribution of genetic counselors and genetic counseling education across Europe (Abacan et al., 2019; Ormond et al., 2018; Paneque, Serra-Juhe, et al., 2017). European Board of Medical Genetics (EBMG); UK Genetic Counsellor Registration Board (GCRB).

non-competitive salary regulations and uncertain career prospects in Austria. Considering the rapid expansion of genetic analyses in medical care, there are insufficient resources for providing counseling services in the medical genetic context both in Austria and Germany.

Neither Austria nor Germany has an independent GC profession and the legislature stipulates that genetic counseling must be provided by medical doctors. In 2011, the GfH performed a questionnaire study to investigate the opinions on 'genetic counseling by non-physician staff' (Zerres, 2013). The analysis showed that 78% of participating academic non-physician members of the GfH were interested in providing genetic counseling and 88% were willing to acquire additional qualification to do so. A strong majority of 93% of academic non-physician GfH members were in favor of opening genetic counseling to non-physician professionals, compared to 51% of MGs who were open to sharing this task. In 2019, the German Professional Association of Human Geneticists (BVDH) together with the GfH entered an official statement to the German Ministry of Health to request the introduction of GCs (GfH & BVDH, 2019), that for legal reasons will be working in a team with MGs who retain primary responsibility for genetic consultations.

In order to serve the rapidly growing demand for genetic counseling and to introduce the concept of specialized GCs as part of the medical genetic team in the German language countries, the Medical University of Innsbruck inaugurated the first German-taught graduate program in Genetic and Genomic Counselling in October 2019. The primary aim of this study was to explore the perspectives of key clinician stakeholders in Austrian genetics centers regarding prerequisites, opportunities, and challenges of implementing master's trained GCs.

2 | METHODS

2.1 | Study design

A qualitative research paradigm was considered most appropriate as it was crucial to understand the perceptions of a small stakeholder

group in an area that is new in the Austrian context and therefore not well studied. The six-step model by Braun and Clarke (2006), described in detail below, was used as the methodological approach to data analysis. Semi-structured interviews were conducted face-to-face, guided by a catalogue of topics. Ethical approval for the study was granted by the Cardiff University School of Medicine Research Ethics Committee.

2.2 | Target population

Currently, there are 30 registered MGs in Austria of which about 2/3 are employed in the six Centres for Medical Genetics serving a total population of 8.8 million people. Therefore, the group of professionals in this field in Austria is very small. A purposeful sampling technique was applied (Palinkas et al., 2015) to reach data saturation which was affirmed when themes were repeatedly observed in the different interviews (Saunders et al., 2018). The goal was a thorough understanding of stakeholders' opinions and attitudes toward the contribution that master's trained GCs can make to clinical genetics services in Austria. Recruitment included MGs at the Austrian genetics centres, with the clear aim to interview MGs at different hierarchy levels and from all parts of Austria and policy makers at universities and professional committees in human genetics, to gain insight into relevant policies.

2.3 | Procedures of data collection and treatment

Semi-structured interviews were conducted face-to-face by the primary investigator visiting the participants in their workplace. The interviews were guided by a catalogue of topics that emerged from a review of the international literature on the introduction of the GC profession and GC education. The interviews included the participants professional role, their knowledge about the genetic counseling profession in other countries, the diverging

development of the Austrian and Anglo-Saxon genetic centers, the advantages and disadvantages of introducing GCs in Austria, the demand and prerequisites for the introduction of GCs, and the possible professional role of GCs in Austria. Open-ended questions were used to elicit the interviewees' opinions and attitudes on the subjects and to reach data saturation. The audio-recorded interviews took an average of 28 min. Verbatim transcription was performed by the primary researcher. Identifiable information was removed from all transcripts. The text-files were anonymized and stored on a password-protected computer for the time of analysis. Field notes taken throughout the research process were also part of the analysis.

All interviews were performed in German; therefore, the optimal timing for translation was carefully considered to avoid the loss of cultural and possibly emotional subtleties. Literature on cross-language qualitative research advises to use a common first language and to use the interview language for as long as possible (Nes et al., 2010). Hence, the translation of codes from German to English was performed at the very end of the data analysis. The extracted themes were reviewed with both a German and English native speaker to ensure validity.

2.4 | Data analysis

The six-step model by Braun and Clarke (2006) provided the methodological approach to data analysis. Transcripts were coded in the Alfasoft NVivo software, text data were assigned codes, and then these were collated into emerging initial themes. Recurring themes were identified from the data through the reiterative reading of transcripts, resulting in the extraction of patterns informative of the research question. Codes and themes were regularly discussed among the first and second author to ensure coherence. The analysis resulted in six main themes grouped around one central theme. Thematic analysis provided a reliable method for a data-driven approach with an open outcome to extract original and possibly diverging opinions of the research participants (Braun & Clarke, 2006, 2013).

2.5 | Reflection on the methods used

When performing the research study, it was most crucial to consider personal characteristics of the primary author as the first Austrian studying GC at Cardiff University, and being part of the development team for a graduate program aiming at the introduction of the GC profession in Austria. The interviewer overtly stated that they had a vested interest in the development of the GC profession in Austria.

The departure points of the study would likely have influenced the research outcomes, and therefore, the researchers' methodological grounding seemed pivotal during the investigation. The social constructivist paradigm was used to acknowledge

the researcher's departure points and helped to understand the research participants in their individual social and historical contexts, as it is open to multiple interpretations (Shannon-Baker, 2016). The researcher relies on the views of the interviewee, and meanings are not only discussed but historically and socially negotiated. Therefore, broad open-ended questions were chosen to facilitate the sharing of participants' views and to give them the opportunity to bring in as much of their own opinion as possible (Creswell, 2009). This process-oriented approach accounted for the investigators' dual role as part of the interaction with the study participants. Already at recruitment, the position of the primary author was clearly stated in the participant recruitment material and again at the start of the interview. Anonymity was assured to participants to create an open exchange of views as we expected there to be different views on the topic and hoped to explore attitudes and opinions as widely as possible. A personal reflective diary was used by the interviewer and also formed part of the field notes.

3 | RESULTS

3.1 | Participants

All six designated Centers for Medical Genetics in Austria employing approximately 20 MGs were approached for participation in the study. Three centers—represented by their directors—were willing to participate with 2–3 staff members each, while three centers declined participation. Conflicts around the introduction of the GC graduate program in Innsbruck and the dual role of the primary researcher as interviewer and part of the graduate program development team might have been reasons for people to turn down interview requests. A total of nine interviewees took part in the study: four consultant medical geneticists, three medical geneticists in training, one clinical laboratory geneticist, and one university official. The study included four women and five men with the following age range: 25–35 years (3); 35–45 years (1); 45–55 years (1); > 55 years (4). One MG and the university official were involved in setting up the recently inaugurated graduate program in Genetic and Genomic Counseling at the Medical University of Innsbruck. Participant numbers were removed from the quotes in the results section to ensure interviewee anonymity.

3.2 | Central theme - Apprehension

The thematic analysis resulted in six themes grouped around the central theme of 'apprehension' (Figure 1). This term best describes the degree of hesitation, worry, and nervousness, not only of individuals opposed to GCs but also of those who support the introduction of the profession in Austria. Apprehension was present in both a positive and negative spectrum ranging from expressions of concern to open opposition.

3.3 | Theme 1—'Genetics—a sensitive specialty'

Genetics is considered a sensitive specialty due to its consequences not only for individuals but for entire families. All participants were asked why they thought the Austrian healthcare system did not develop a GC profession similar to the Anglo-Saxon countries.

Because the non-medical professions in the UK are traditionally in a different role, they are more important than in the German-speaking region.

Maybe it's really because of the Nazi time strain. That you just say, genetics is so delicate, it's bad enough when a doctor does it. Under the guise of medical necessity you may still be able to accept it, but if there are any other professionals ... You may be particularly sensitive about this.

The historical context of eugenics was mentioned as one reason for the delayed development of genetics services in Austria. Additionally, the more hierarchical structure of the healthcare system and the late academization of healthcare professions compared to the Anglo-Saxon countries were attributed as major factors for the exclusion of GCs and the fact that GC is considered an exclusively medical activity.

3.4 | Theme 2—Awareness of the genetic counseling profession

Every participant was asked how familiar they were with the GC profession and whether they had ever worked or interacted with GCs.

Honestly not personally. In the sense that I would have spoken or encountered a GC - definitely not.

I was not fully aware of how GC is implemented in the Anglo-Saxon countries, like England. Not quite, I think not enough. Interviewer: At the European Society of Human Genetics conference, for example, are there no lectures from GCs that you might have attended?

Participant: Not that I am aware of, no. Are there lectures there [by GCs]? I'm not sure.

There was very little familiarity with GCs and the field of GC among the participants and a lack of awareness of the contribution of GCs at international meetings. Furthermore, participants pointed out that awareness about the GC profession has to be built through education of the medical field as well as the general public.

3.5 | Theme 3—Professional identities

The theme professional identities were the most content-rich due to the fact that the introduction of the new profession could potentially result in a restructuring and redefinition process for MGs. Therefore, the internal and external perception as well as the possible role of the GCs were specifically analyzed. The overlap of the professional competences might explain the declared apprehension toward the introduction of GCs apparent in the interviews.

3.5.1 | Professional identity of medical geneticists

Participants reported that the field of medical genetics has little external recognition even among physicians placing MGs into research or laboratory diagnostics.

I think that the visibility of medical genetics is far too poor. I don't think we're even a well-known specialty among other doctors.

I personally feel that [medical genetics] doesn't stand out very much to the outside. Actually, it is usually the case when I am somewhere with colleagues at a meeting, at a conference and I am asked what I do, and I say I am a doctor in medical genetics. Most say: Oh. Is there such a thing? The next question is usually the same: Does this mean that you work in research?

The lack of recognition for the specialty also influences the self-perception of MGs. Several participants expressed that the task of GC

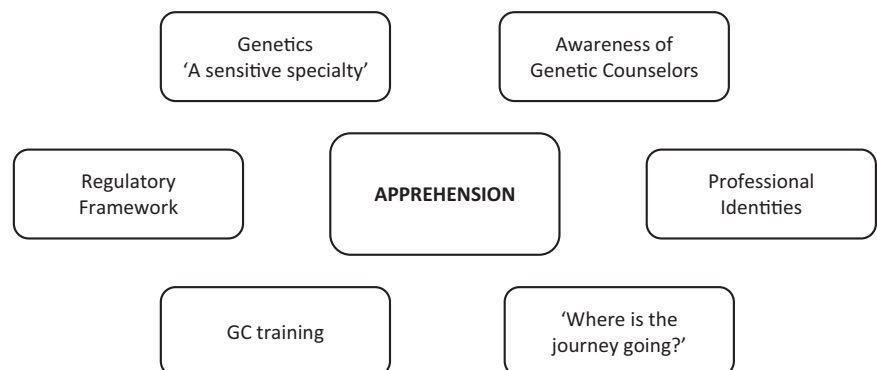


FIGURE 1 Themes. Thematic map with six major themes around the central theme apprehension

is strongly connected to the self-definition and therefore the professional identity of MGs.

For me, GC is the central task of the doctor. If I give it up as a doctor and delegate, I give up the specialty.

GC is our profession, we only define ourselves through GC and if we then enable others while we are already pressured by other medical specialties, we endanger our own future. We are sawing off the branch we're sitting on. That is why I believe that we should define our specialty differently for ourselves. We can pass on certain sub-areas to make work easier. We have to develop further.

[By introducing GCs] one can expand and broaden the specialty, increase resources and make the specialty more important and more noticeable. I think that's what many of my colleagues don't see as an opportunity at the moment.

Since MGs refer to themselves as genetic counselors—Genetische Berater—and consider the task of genetic counseling a core domain of MGs' clinical activity, it might not be easily shared with GCs or other professionals. Expanding medical genetics by employing GCs could be a possibility to strengthen the field but was not perceived in this way by several participants of the study.

3.5.2 | Professional identity of genetic counselors

All interviews discussed the professional opportunities for GCs. The participating geneticists confirmed a rise in consultations and a limited number of MGs as well as the difficulty to find young doctors to join the specialty.

The number and the waiting time are increasing at the moment. And I think there is a large unmet need for genetic consultation.

Because of the shortage of doctors, we have already discussed the question whether for example the drawing of family trees and repetitive content can also be taken over by non-doctors. ... At some point we won't be able to cope with the demand anymore.

There are not many posts for assistant doctors in medical genetics, that's correct. On the other hand, it is the case that they are not so easy to fill.

Yes, but we should be looking for ways to get more MGs and not to replace them or get help in the form of an assistant.

Opinions were diverse with regard to cost-effectiveness of GCs. Several participants recognized the advantage of using resources more efficiently. On the other hand, concerns were raised that the more economic employment of GCs could replace MGs.

We assume that it is cheaper. Then you get three GCs for two doctors.

Since the need will increase in the future and the doctors will not necessarily become many more, it is simply a time factor that you have someone who shortens the working time of a doctor per case from three hours to an hour and that therefore the doctor can take three patients. It's just a calculation.

The creation of posts for GCs was perceived as a minor obstacle as the healthcare system was considered flexible enough to engage new professions. Two major factors were stated as essential:

- GCs should only be working as part of a multidisciplinary team in a Center of Medical Genetics.
- Medico-legal responsibility must remain with MGs.

It was stated that patients should definitely always see a doctor in conjunction with the GC. The suggested sequence of the consultation was compared to the training of assistant doctors in which the resident first speaks with the patient and is joined by a consultant midway depending on the proficiency of the assistant and the complexity of the case.

I think we have good interdisciplinary teams, consisting primarily of gynecologists, but also surgeons, psychologists, specially trained nurses with a focus on oncology. And I think that in this setting the GC fits the team very well.

To put it positively, there is the fear that the quality could of course decrease to the extent that other specialties, i.e. gynecologists or other medical specialists, could get such a GC cheaply.

It was regarded a positive feature that GCs could contribute special expertise in counseling and communication since the genetic consultation is regarded a complex communication process.

It is extremely important to have a good admin or someone who is sensitive to the patients and is also available by phone. In this respect, I would appreciate someone who also knows what is going on administratively or simply understands the amount of agitation involved when it comes to hereditary diseases. ... And yes, I think that GC would have its place in its full form.

When discussing the GC process in detail, participants offered opinions on specific tasks that could be delegated to GCs. It became apparent that MGs are mostly used to administrative support and tend to place the GCs into this category.

The GC could sit in the real consultation with the MG and type the report like a secretary and put it into a first version.

In the end, it actually results from the information that something like this already exists in the Anglo-Saxon countries. I knew that, but of course not as we want it to be understood here.

The professional niche for GCs still needs definition. MGs may regard GCs as a sort of 'genetic-super-secretary', and the quote above implies that a professional role which differs from other countries might be sought. Regardless of their attitude toward GCs, each interviewee offered an opinion on the kind of tasks that could be performed by GCs: Preparation, follow-up, writing letters (explicitly mentioned by five participants); patient communication, psychosocial issues, 'a complex communication process in which there are goals other than just consent to a genetic test' (four participants); 'taking the medical history' (four participants) and 'drawing the family tree' (five participants); 'give the first explanations of biological relationships between inheritance and risk figures' (three participants); 'explain the consent' (two participants); take on 'simpler consultations, routine consultations that are carried out frequently' (three participants) like breast cancer consultations (five participants). 'With the GCs it could be handled similar to the assistant doctors. They lay a basis in the consultation and then the consultant comes in and answers questions that still arise' (two participants). 'Patients should then still have contact with a MG' to answer further questions and if a degree of complexity arises that needs the expertise of the doctor (four participants).

3.6 | Theme 4—Where is the journey going?

My fear is, I say it frankly, the fear especially for the younger MGs is...: where is the journey going?

Since genetic counseling was stated as a defining element for MGs, it was interesting to further analyze the interviews for evidence on a perceived competition for this task. Concerns about a growing insecurity arose especially among younger interviewees.

I think it is the strongest fear that one is pushed out of the GC process, from the direct contact with patients.

In principle there is pressure that a lot of GC is necessary, and this pressure enables us to either get more jobs, better pay, and maybe the private field opens up, similar to other countries. And the pressure is reduced if there are other professional groups that can help. It

is the question of whether that makes sense for us in this situation.

One participant pointed out that the increasing demand for genetic diagnoses could be used to improve the opportunities for MGs. The fear to be replaced by GCs was raised but was also put into perspective by considerations of the growing amount of genetic testing expected in the future.

I think we need both the GCs in our field and the outsourcing of advice to other fields. I think that the point when we will run out of work is very, very far away.

Some individuals voiced the concern that more and more competences would shift to technologies, academized GCs and doctors in other specialties.

Of course, there are certain things where one would say, now that makes sense if it were maybe done by other specialists and not by MGs. These are things like Factor V Leiden mutations ... actually, you are happy if they stay outside. With many other questions, it is even the other way around that we would have preferred the patients to be sent in.

The envisioned scenario in which GCs provide GC under the supervision of other clinical specialties, without involvement of trained MGs, caused major apprehension. Participants clearly stated that this would not just damage the field of medical genetics but would lead to a decrease in quality of patient care.

An important question is: can you ensure that the trained GCs actually work, basically in human genetics departments, in the medical genetic environment?

A regulatory reassurance that GCs will work in the context of a genetics department was expressed as a catalyst for the acceptance of the new profession.

3.7 | Theme 5—Genetic counseling training in Austria

The Medical University of Innsbruck and the University of Applied Sciences Tyrol decided to collaborate on the first German-taught graduate program in Genetic and Genomic Counseling in autumn 2018. The first student cohort was accepted for October 2019. These plans were briefly announced to the Board of the ÖGH at the annual meeting in October 2018 and controversially discussed in the Spring of 2019.

But in general, what I would also have liked to see, would have been that something is agreed on in the

ÖGH. Which is difficult, of course, there are different opinions.

And simply to call it a genetic counseling program. That could have been a problem or a mistake. Calling it genetic counseling assistant right from the start would have made it clearer.

The discussion on whether regulation of the profession or the education should have come first were also part of the interviews and were seen from two directions.

I would have wished that the prerequisites had been laid beforehand and that training had started afterward.

I think that's the famous chicken and egg problem. I think that it is faster to establish the graduate program than the job profile. I think very pragmatically, you study and then let the job profile develop based on the existing degree.

Interviewees largely agreed that the master's level of the profession was appropriate. Little awareness was present about the European effort to register GCs and accredit graduate programs in Genetic Counseling that follow a predefined core curriculum by the EBMG.

In my eyes, a Master is of higher quality and good. Doctorate is not necessary.' Interviewer: 'The European Board of Medical Genetics has a Genetic Counseling Branch Board, that registers GCs and accredits GC university programs. Participant: I was not aware of this.

3.8 | Theme 6—Regulatory framework

Participants were asked about their opinion regarding regulatory requirements. The integration of GCs into existing organizational structures at Austrian Centers for Medical Genetics was not perceived as an obstacle.

I think this is a job that has to be arranged in the clinical genetic area. Supervised by the management of clinical genetics - supervised and controlled. There are no structural hurdles.

I think that is relatively easy to integrate at the moment. As soon as you stay in this medical environment, it is very easy to integrate. I don't see any problem there.

While the legal basis of the GC profession is frequently used as an argument against the introduction of the profession, the Austrian law was considered to be flexible by some participants of the study. The Austrian

BOX 1 Practice Implications

Summary of aspects regarded as crucial for a successful establishment of the Genetic Counseling profession in Austria.

- Clear definition of the professional role and scope of practice of genetic counselors in comparison to medical geneticists, in recognition of the special skill set of genetic counselors
- A linguistic framing for the profession that is in line with established medical and legal terminology in Austria
- Integration of genetic counselors into multidisciplinary teams under the medico-legal oversight of MGs in medical genetic centers
- Establishment of a legal regulatory framework and specified posts for genetic counselors; strengthening of medical genetics centers as important clinical service providers
- A MSc standard education including practical experience
- Acceptance and trust by patients

Gene Technology Act (GTG) was created in 1990 and updates in 2005 and is accompanied by a regularly publishes 'Gene Technology Book' that includes amendments by an advisory board (Gentechnikgesetz, 2018).

I know both sides. Some say that if you read the law literally it is not possible [for GCs to work]. Others say that when you see it interpretatively, it's actually not that problematic. ... Even if there was no scope, it would be possible in my eyes - you can adjust the law.

You can also change laws fundamentally. That may not be an absolute reason for exclusion.

Regulation for the GC profession is regarded mandatory by the MGs interviewed but is considered a manageable obstacle for the profession. The most crucial aspects of practice implication for the GC implementation process are summarized in Box 1.

4 | DISCUSSION

Establishment of the GC profession only has a chance to succeed if GCs are not perceived as a threat to existing medical genetic centers but rather as valued team members within the services (Shelton & Whitcomb, 2015). Therefore, the support by MGs is likely to be the most crucial catalyst for the introduction of GCs in the German-speaking countries. Our study confirms that the reluctance of some Austrian MGs to endorse the establishment of the GC profession is strongly influenced by the late introduction of medical genetics as a clinical specialty and the focus on genetic counseling as a

self-defining task of MGs. Some interviewees confirmed the assumption that the special characteristics of medical genetics in Austria and Germany are at least partly due to the history of eugenics and the crimes carried out in the Nazi period.

Clarifying the scope of practice of MGs and GCs is an ongoing challenge even in countries in which the GC profession is well established. In January 2020, the American College of Medical Genetics and Genomics (ACMG) published an open letter criticizing a legislative draft regarding access to genetic counselor services. It was argued that *'without appropriate scope of practice limitations, genetic counselors will receive reimbursement for carrying out activities that fall within the practice of medicine'*. (ACMG, 2020). The ACMG emphasized that *'optimal patient care requires that genetic counselors work with or under the direction of a medical geneticist or other physicians knowledgeable about the application of genetics and genomics information within their field'* (ACMG, 2020). The challenge of defining the professional role of GCs is thus not limited to the German-speaking countries.

Genetic counselors are trained in a unique set of skills, tailored to serve the specific needs of patients and their families at risk of a genetic condition, but they are not intended to replace MGs. They can complement multidisciplinary teams with their communicative, ethical, and psychosocial expertise (Pestoff et al., 2015). They support families in recognizing the implications of an inherited disease and help them adjust to the medical, psychological, and familial effects (Resta et al., 2006; Skirton et al., 2015). These qualities can enhance the complex communication process that facilitates patient decision-making and can form an important component of high-quality patient-centered care.

While several interviewees were apprehensive, they conceded that GCs could have a place in the Austrian genetics services as it expands the genetics workforce. Interviewed MGs reported difficulties in recruiting a sufficient number of young physicians to serve the rapidly rising number of complex genetic tests. Integrating GCs into a collaborative multi-professional team in medical genetic centers, and restructuring professional responsibilities, might help to meet these demands. Tasks suggested to be appropriate for GCs included preparation, follow-up, taking of family and medical history, patient communication, psychosocial attending, as well as *'simple'* or *'routine'* consultations. These findings are strongly coherent with the outcomes of the GfH survey (Zerres, 2013) that also identified tasks that could be delegated to non-physician staff members. The main duties listed were the collection of individual and family history, the advice on the possibilities and limits of genetic testing and the consultation of routine cases on recurrent abortions / fertility disorders and hereditary / family cancers (Zerres, 2013). Personal experience with GCs might be required to foster acceptance as the lack of familiarity with the profession clearly contributed to the hesitation of study participants to consider a complementarity of GCs and MGs. Interviewees highlighted the need for close ties of GCs to the medical genetic centers as a crucial prerequisite for the integration of the new profession in Austria.

The study participants voiced appreciation of the special training in counseling and communication skills and mentioned potential

economic benefits of employing GCs. However, only few saw an opportunity in introducing GCs to strengthen the specialty, which might relate to the self-definition of MGs, as several interviewees emphasized genetic counseling (Genetische Beratung) as the primary task of MGs. This dilemma was considered by the GfH when it coined the professional title 'Genetischer Beratungsassistent' (genetic counseling assistant) in the request for the introduction of the new profession to the German Ministry of Health (GfH & BVDH, 2019). This term may be unsatisfying for the GC community, and confusing in view of the role of genetic counseling assistants that support GCs, for example, in the UK and the USA (Hnatiuk et al., 2019) but reflects more a linguistic issue than an attempt to diminish the professional expertise of GCs.

4.1 | Study limitations

This study is the first to explore the opinions and attitudes of key stakeholders in Austrian genetics services toward the introduction of GCs. A qualitative approach was considered the appropriate tool to effectively gain insight in the individual views of members recruited from this small group of professionals. A limitation of the study was probably the time overlap of the interviews with the initiation phase of the GC graduate program in Innsbruck and the involvement of the research team with the setup of the program. The impartiality of the research group was questioned by at least one of the Austrian genetics centers.

5 | CONCLUSION

Medical Genetics in the European context may be best served by the establishment of regional centers which offer comprehensive clinical and laboratory services in close interaction with non-genetic colleagues (Great Britain Ministry of Health, 2003). This was also recognized in the Austrian Health Structure Plan (Österreichischer Strukturplan Gesundheit, 2017) which defines six Centers for Medical Genetics and highlights interdisciplinary and multi-professional collaboration as specific quality criteria. GCs can play a central role in the provision of optimal patient care in these teams, as has been shown in many countries worldwide (Pestoff et al., 2018). A clear definition of the scope of practice and mandatory affiliation with MG-led centers should help reduce apprehension toward the profession and encourage more support for GCs. The authors welcome an inclusive and open dialog regarding the future of a genetic counselor profession in Austria.

AUTHOR CONTRIBUTIONS

The primary investigator Gunda Schwaninger conceptualized and administered the study. She performed all interviews, analyzed, validated and curated the data, wrote the original draft of the article, and visualized the findings. Caroline Benjamin supervised the research project in aspects of conceptualization, methodology, data analysis, and validation. As an English native speaker, she reviewed

the translation of themes and the writing and editing process. Sabine Rudnik-Schöneborn contributed substantially to the study design and the critical revision of the manuscript. Johannes Zschocke supervised and supported the first author in the conceptualization, recruitment, and data analysis. He gave important intellectual input in the writing and editing of the manuscript and provided the necessary resources for the project. The authors confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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COMPLIANCE WITH ETHICS STANDARDS

CONFLICT OF INTEREST

Gunda Schwaninger, Sabine Rudnik-Schöneborn, and Johannes Zschocke have implemented the first German-taught graduate program in Genetic and Genomic Counselling at the Medical University of Innsbruck and support the introduction of the profession also in the German language countries. Caroline Benjamin declares no conflict of interest. No financial assistance was received in support of the study.

HUMAN STUDIES AND INFORMED CONSENT

This study was approved by and conducted according to the ethical standards of the Cardiff University School of Medicine Research Ethics Committee. All participants gave their informed consent prior to their inclusion in the study.

ANIMAL STUDIES

No non-human animal studies were performed by the authors for this study.

DATA AVAILABILITY STATEMENT

All interview recordings and transcripts are securely stored in accordance with the Cardiff University Records Retention Schedules. Full interview transcripts are not made available to protect anonymity of study participants.

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