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“*I am* a Genetic Counselor”: A Qualitative Exploration of Field Leaders’ Perceptions of the Title “Genetic Counselor”

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Abstract

The genetic counseling profession is 50 years old, and is growing and diversifying. Despite this evolving context, no studies have formally explored the continuing relevance or appropriateness of the title “genetic counselor.” We used a qualitative research methodology (interpretive description) to explore this concept among thought leaders within the genetic counseling profession. We conducted 12 semi-structured telephone interviews, which ranged in length from 18 to 50 minutes, and transcribed them verbatim. Analysis and data collection unfolded in parallel. The following themes regarding participants' perceptions of the title “genetic counselor” emerged from the data: 1) others misunderstand “genetic counselor”; 2) the term “counselor” in our title produces complex and conflicting emotions; 3) risks of changing our title outweigh the benefit; 4) we need to own the narrative surrounding our title. Despite recognition that the title “genetic counselor” may not capture the full range of diverse roles members of the profession play, our data reveal overall support for the continued relevance and appropriateness of the title, for the value of the strength that comes from unity within the profession, and for efforts to highlight that which unites us across roles, disciplines and specialties.

Key words: genetic counseling, title, professional issues, narrative, history, thought leaders, genetic counselors, workforce

Introduction

Sarah Lawrence College was the first institution to provide a training program in Genetic Counseling. Its founding in 1969 ushered in the era of the modern-day genetic counseling profession (Stern, 2009). Since then, however, there have been major advances in understanding of gene-disease relationships, access to testing and genetic technology ; the development of the DNA microarray in the late 1990s/early 2000s, completion of The Human Genome Project in 2003, genome sequencing, and development of non-invasive prenatal testing (NIPT) in 2012 (Bumgarner, 2013; Moraes & Góes, 2016; Chitty et al., 2012). As of 2017, roughly 12 million individuals have purchased some type of direct-to-consumer (DTC) genetic test from the more than 200 companies currently on the market (Regalado, 2018; Hogarth & Saukko, 2017). With the growth and reach of genetic testing and technology today, genetic counselors' roles are expanding as well.

Today genetic counselors work in a variety of settings, including policy, research, administration, pharmacogenetics, laboratory support, public health, and more (NSGC Professional Status Survey, 2018). Between 2002 and 2018, workforce analyses have revealed trends that correlate with shifts in genetic knowledge and available genetic testing. For example, the discovery of genes related to cardiac conditions have led to a six-fold increase (from 2% to 12%) in the proportion of genetic counselors working in the cardiology specialty in 10 years. In addition, there has been a tripling (from 6% to 18%) in the proportion of genetic counselors working in a diagnostic laboratory between 2002 and 2018 (NSGC Professional Status Survey, 2002; 2008; 2018). Genetic counseling training programs, and the profession at large, are under constant pressure to adapt training and practice to position genetic counselors to fill these ever-expanding roles (Riconda et al., 2018).

Though the definition of the process of genetic counseling has evolved over time (Reed, 1974; ASHG, 1975; Resta et al., 2006), and despite the growth and diversification of the field, the issue of whether or not the title itself continues to fit our profession in the evolving landscape has, to our knowledge, not been formally explored. Initial debates about the title for the profession occurred in the 1970s during a time when genetic counselors were first organizing a professional society. Titles suggested included “genetic counselor” and “genetic associate.” At the time the title “genetic associate” was felt to imply an assistant or aid rather than a standalone healthcare professional. Physicians at that time were resistant to “genetic counselor” because they believed the process of genetic counseling could be done by various healthcare providers, preferably those with a medical background (Heimler, 1997). However, the title “genetic counselor” was ultimately decided on, and has remained. Thus, we aimed to explore perceptions of thought leaders within the field of genetic counseling regarding the continued appropriateness and relevance of the title “genetic counselor.”

<Insert Box 1 about here>>

Methods Overview

We conducted an interpretive description study, for which data were collected using qualitative, semi-structured telephone interviews. The study was approved by the Institutional Review Board at Boston University (H-37937).

Participants

We used purposive sampling to identify potential study participants whose positions as thought leaders across diverse areas of the field of genetic counseling made their perspectives of particular interest (Etikan et al., 2016). Inclusion criteria were as follows: at least 10 years of related work experience in genetic counseling, leadership experience in the genetic counseling field, and ability to converse in English. For the purpose of the study, leadership experience was defined as elected positions within National Society of Genetic Counselors (NSGC), American Board of Genetic Counseling (ABGC) and/or Accreditation Counsel for Genetic Counseling (ACGC), and/or within genetic counseling training programs, and/or thought leadership as evidenced by academic contributions. To ensure that practice areas reported in the 2018 Professional Status Survey were represented among participants in the study, we recruited genetic counselor leaders in industry/lab settings, research, policy, clinical settings (pediatric, prenatal, cancer, specialty) and training programs, in both the United States and internationally (NSGC Professional Status Survey, 2018). To recruit subjects, the investigator contacted participants via an email address obtained from public domains to request participation in the study.

Procedures

We designed a semi-structured interview guide to explore participants' thoughts, perceptions, reflections and experiences regarding the title "genetic counselor." CM, JA, and KBS contributed to the creation of the interview guide. At the time of the study, CM was a genetic counseling graduate student, JA (PhD, CGC) was a full time academic research professor, who has worked in research since graduating from genetic counseling training in 2003, and held leadership roles in professional genetic counseling associations, KBS (MS, MPH, CGC) has worked in clinical settings, advocacy, research, and industry settings since entering the field in

2000 and was a genetic counseling program director at the time of this study. A list of core questions was asked of all participants, with further probing questions based on participant response (see supplemental material). All interviews were conducted by telephone with the same investigator (CM) and were recorded and transcribed verbatim and checked for accuracy.

Data Analysis

An interpretive description approach was used as this allows for the generation of “a coherent conceptual description that taps thematic patterns and commonalities believed to characterize the phenomenon that is being studied and also accounts for the inevitable individual variations within them” (Thorne et al., 2004). Data collection and analysis were performed concurrently to allow for constant examination of patterns and relationships among data. The ongoing examination also aided in interview guide revisions throughout the data collection process. In interpretive description, analysis is inductive, and begins with immersion in the accumulating data, and coding transcripts at the individual concept level. Two interviews were coded independently by CM and KBS, who then discussed until codes were agreed upon, these were then applied to the remaining 10 interviews. Reflexive memos and linkages were generated iteratively, throughout the process to allow for synthesis and contextualization of ideas, and the theorizing about their relationships within and between participants (Thorne et al., 1997). Developing concepts were discussed by the whole team throughout analysis to organize thoughts about these relationships and emerging themes.

Results

Thirteen individuals were contacted, and 12 of those individuals agreed to participate.

Demographic information was drawn from publicly available sources and characteristics are shown in Table 1.

<<Insert Table 1 about here>>

We identified four key themes within the interviews: 1) others misunderstand “genetic counselor”; 2) the term “counselor” in our title produces complex and conflicting emotions; 3) risks of changing our title outweigh the benefit; 4) we need to own the narrative surrounding our title.

Theme 1: others misunderstand “genetic counselor”

All participants commented on perceiving or experiencing some form of misconception or misunderstanding from those outside of the profession (both the public and/or other healthcare professionals) regarding the role of genetic counselors, for example:

The thing that I always hear is oh, wow. Counseling genes, how does that work? -

Participant #10

They were expecting a sort of Freudian, come and lie on this couch and all be counseled. -

Participant #9

So, I would see it as potentially reacting to the term genetics, oh you're just trying to make the perfect person. -Participant #11

These misconceptions did not appear to associate with any sort of substantive emotional response for participants. Rather, the existence of misconceptions was generally accepted as something to be managed, for example:

There's an educational component for us to make sure that people are clear before they come for genetic counseling about what the process involves. -Participant #7

Once I've explained that that's not my role -- and that's why I think contracting and agenda setting is so important, because as long as you get on the same page early on in the session, then it doesn't take the train completely off the rails. -Participant #1

Theme 2: the term “counselor” in our title produces complex and conflicting emotions

The “counselor” component of the title "genetic counselor" was a topic of focus in the interviews. It was simultaneously associated with both pride and a certain sense of stigma or discomfort. Specifically, on one hand, many participants often reflected on the fact that, to them, it is the term “counselor” in our title that captures the unique value of genetic counselors and sets us apart from many other types of healthcare professionals.

So, if you look at ‘counselor’ as maybe being a term that encompasses or emphasizes the importance of the fact that it's a two-way interaction, that there's some feeling part of it involved and not just medical information. And so I guess I'd like to see us still retain some way of communicating that our field is not just about providing the genetic part of it but there's also the counselor part of it in terms of really taking into account how our

information is going to impact the patient and their family and that we stay attuned to ascertaining that and to making sure patients have supportive resources, because they have to leave our clinics and go out and live with these conditions or living with being at risk for these conditions. And I think that makes us different from other areas of medicine. -

Participant #11

....if we didn't do that part of it [counseling], then we would just be scientists or just master's people that can help interpret genetic reports but I think it's probably the counseling that makes us able to translate that into something that the patients can make decisions about and understand. So probably the counseling bit is a small part of it but maybe it's the bit that makes us different as well. -Participant #10

The genetics bit, that expertise, in terms of variant interpretation or phenotype management or risk assessment, an algorithm can do that at some point in the future. But what an algorithm couldn't do is walk for a moment in somebody else's shoes and support them as they make very difficult decisions to end a pregnancy or to tell a sister that they've got a risk of breast cancer or whatever, that kind of human element. -Participant #9

However, on the other hand, multiple participants also commented that the term "counselor" results in hesitation from those outside of the profession. There was a sense of perceived stigma attached to the concept of counseling.

I just found that people tend to have either an adverse reaction or -- there is a lot better way to put it, get a little squeamish about the concept of counseling. And obviously depending on somebody's personal experience or where they're coming from or their gender or other demographic backgrounds, people often say, well, I don't need counseling, right? -

Participant #6

I think there's people who just either don't believe in the concept of counseling, thinking about it more as a mental health construct and who don't believe it counseling period or don't think they personally need it. They might say, oh, that's fine for other people but I don't need to see a counselor. -Participant #3

I think the term counselor has a bit of a stigma to it and has the potential to evoke a response from people that may make some less inclined to follow through on a visit to a genetic counselor. -Participant #10

Overall, participants believe that it is critical to maintain the “counselor” part of the professional title, while also acknowledging that they perceived there was a certain stigma attached to the word from those outside of the profession.

Theme 3: risks of changing our title outweigh the benefit

Participants spoke to the idea that “genetic counselor” may not be the “best” title, and they varied in how much they believed it captures what we do. However, regardless of where they fell on this spectrum, none of the participants actively thought the title needed changing, and indeed

most thought that the title should *not* be changed. Part of this was driven by the perception of there being increasing recognition and awareness of genetic counselors and genetic counseling, for example:

So, I find it's not terribly descriptive. It doesn't say exactly what we do. And also, it's misleading. However, I wouldn't want it to be anything else now because it's internationally known. It's established. It would be harder to move to something else at this point, I think, because of all the work that genetic counselors have done over the last 50 years in establishing professional competencies to the title. -Participant #9

So, it's always a plus or minus situation and we are also gaining traction and more and more—like [...] years ago when I got my degree—you'd say “genetic counselor” and people would say “what?” but now you say it and people have a starting base. So, it's one of those things that, maybe it doesn't describe me perfectly, but people at least understand what I do, so that's helpful. -Participant #2

Some considered the term “genomic” as a possible alternative to “genetic,” but this was perceived to be without clear benefit:

I guess the only alternative these days would be “genomic counselor” but I think there would be risk in doing that because it's not a very lay language friendly term. And I think more people these days recognize what genetic means even if just vaguely -Participant #8

Overall, there was a sense from participants that the risk associated with changing the genetic counseling title would outweigh any potential benefit, and that such a move may damage the reputation and awareness that does currently exist.

I think we've worked incredibly hard over the last 50 years to place ourselves into the healthcare sphere as an important contributing partner. And I think our name and title has been a big part of that journey and I do fear that if we were to consider changing the title, it would bring into question the purpose and long-term sustainability of what we do. -

Participant #1

I think we've grown into genetic counselor and I don't want to be feeling that we have to keep adjusting our name to fit the technology. -Participant #11

If we change our title, I think it will cause even more confusion, even if there is current confusion [...] it would compound any confusion that did exist... -Participant #7

I think at this point, whether the name fits or not, you know, the effort has gone into it so it's like we just need to embrace it. -Participant #10

Theme 4: we need to own the narrative surrounding our title

Many participants remarked about the need to embrace the title given the progress of efforts to date to increase respect, awareness, and recognition of the profession.

I think it's really, really strategic for us to embrace the fact that we now have an identity and respect and a place in the larger medical community that is independent of physicians. And that's something to behold and treasure and maximize, not challenge. -Participant #8

Several participants commented on how the title "genetic counselor" is an important part of the narrative of the profession, for example:

We have a story and that story contains one name and that's helpful for publicity and building a reputation. -Participant #2

Because participants perceived a need for acceptance of the title, they offered potential solutions to address issues surrounding the title.

We have a responsibility for future generations to really shout out loud about what it is that we do and what skills we have, because with genomic medicine going everywhere and anybody can get a genetic test now, we need to take ownership of the part we play in that patient journey. And as a profession, we have not been terribly good at that. We've been quite understated. And we've not really had a big marketing campaign about what we actually do and can deliver. So it's up to -- the lead is in our profession. -Participant #9

I think it's all how we promote ourselves and our knowledge and our expertise. And I think as much as we can be out there giving talks and writing, offering articles, all that is going to continue to increase the respect that other healthcare providers are going to have for our

field. -Participant #11

Some participants commented that beyond simply accepting the title, they felt proud of it, and of how they have expanded the scope of its meaning:

It's a term that I'm very proud of, to call myself a genetic counselor. -Participant #11

That "genetic counselor" term is one I'm very, very proud of but it's because of a base and a core that I was trained on and I've applied that in new and interesting ways." - Participant #2

Discussion

This study was the first formal attempt since the 1970s - of which we are aware - to explore the continued relevance and appropriateness of the title "genetic counselor." Our interviews with leaders of the genetic counseling profession across three continents revealed strong overall support for the title "genetic counselor," and commitment to owning and proactively directing the narrative around it.

Although most participants believed that the title "genetic counselor" should remain unchanged, some participants – especially those who were not engaged in direct patient care - talked about how the title may not fit all genetic counselors' roles. They also spoke however, about how there may not be a "perfect" title that would encompass the wide array of roles of genetic counselors today, and thus even for these participants, the general feeling was acceptance of the title – with the caveat that the profession must continue to take charge of the narrative surrounding the genetic counseling title and what it represents.

Many participants remarked that the “counselor” component of the title was important in describing genetic counselors’ unique value that sets them apart from many other healthcare providers. Given the anticipation that in the future, the education component of genetic counselors’ roles may be performed by chatbots, algorithms, web-based videos, or other service delivery models (Stoll et al., 2018), counseling skills may become even more prominent as the most valued and important aspect of the genetic counselor’s unique skill set.

However, at the same time, participants reported perceiving stigmatizing attitudes from others in relation to the term “counselor”. This has not – to our knowledge – been previously reported in relation to the genetic counseling profession, but given that the term “counselor” is often associated with professionals who treat individuals with mental health problems, it is perhaps unsurprising. “Associative stigma” is well described as a phenomenon in which there exists stigmatization of those who have relationships with individuals with mental illness, such as mental health professionals (Ebsworth & Foster, 2017; Gaebel et al., 2015; Ben Natan et al., 2015). Participants’ comments suggest that the same phenomenon may apply in the context of genetic counseling. Identifying strategies to overcome any discomfort or hesitation among genetic counselors due to this perceived stigma is important, in order to further allow genetic counselors to confidently promote our profession and our value as counselors. Engaging with the media has been suggested as a strategy for combating associative stigma from the public, with practice -oriented seminars proposed as an approach to tackling stigma from other healthcare professionals (Sartorius et al., 2010).

Every participant commented on perceiving that those external to the profession had misunderstandings or misconceptions about the role of genetic counselors and/or the process of genetic counseling. This perception is corroborated by studies that have shown relatively low

awareness of genetic counseling among the general population (69% had never heard of genetic counseling among the general population in Canada (Maio et al., 2013) and 46.4% had never heard of genetic counseling among residents of a Midwestern rural area (Riesgraf et al., 2014)), and among other healthcare providers (Godino et al., 2013).

Participants often talked about how genetic counselors should be proud of and embrace their title given the importance of connection to the history of the profession (Stern, 2009), and the progress that has been made under this banner. There was broad support for the value of the strength that comes from unity within the profession, and for efforts to highlight that which unites us across roles and disciplines and specialties, such as the “#IamAGeneticCounselor” initiative that was launched in the United States in 2017.

Practice implications

These data suggest that thought leaders in genetic counseling from three continents generally agree that changing the title of the profession should not be a high priority. Rather, participants spoke about the importance of efforts to increase awareness and reduce misconceptions of genetic counseling, and to own and direct the narrative about the profession and the diverse roles that we play.

Research recommendations

A large scale quantitative, international survey-based study of genetic counselors with diverse roles regarding their perceptions of the continued relevance and applicability of the title could be considered. Exploring perceptions among different groups of stakeholders (e.g. physicians) or genetic counselors with various roles, years of experience and/ or other more diverse demographics could also be valuable.

Limitations

Despite the size of the sample, we did in fact achieve saturation of main themes. However, because we did selectively recruit participants, we intentionally enriched for individuals who may have stronger feelings or opinions about the field and professional issues due to their leadership. By selecting individuals with long standing experience in the field, the views of those newer to the field are not necessarily reflected.

Conclusion

This study revealed experiences, opinions, and complex emotions of genetic counselors surrounding their title. Overall, participants generally agreed that there are potential issues and misconceptions related to the title “genetic counselor” that still need to be overcome. While some raised concerns about whether the title appropriately represents all professional roles, most participants believe the title should remain due to the progress made to date and the potential for adverse effects of a title change on the profession. Regardless of potential issues or barriers attributed to the title, the concept of unity aligning with the movement “I am a genetic counselor” was evident among the participants.

Author Contributions

CM: contributed substantially to the design of the work, acquisition of data, analysis and interpretation of the data, drafted the manuscript, approved the final version and agrees to be accountable for all aspects of the work

KBS: contributed substantially to the acquisition of data, analysis and interpretation of the data, revised the manuscript for important intellectual content, approved the final version and agrees to be accountable for all aspects of the work

AC: contributed substantially to the revision of the manuscript for important intellectual content, approved the final version and agrees to be accountable for all aspects of the work

JA: contributed substantially to the conception and design of the work, analysis and interpretation of the data, co-drafted the manuscript, approved the final version and agrees to be accountable for all aspects of the work

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Conflict of Interest Statement:

Chandler Means, Kathleen Berentsen Swenson, Allison Cirino, and Jehannine Austin declare that they have no conflict of interest.

Human studies and informed consent:

The study was approved by the Institutional Review Board at Boston University (H-37937). All participants gave their informed consent prior to their inclusion in the study.

Animal studies:

No non-human animal studies were carried out by the authors for this article

References

- ASHG—American Society of Human Genetics Ad Hoc Committee on Genetic Counseling (1975). Genetic counseling. *American Journal of Human Genetics*, 27, 240–242.
- Ben Natan, M., Drori, T., Hochman, O. (2015). Associative stigma related to psychiatric nursing within the nursing profession. *Archives of Psychiatric Nursing*, 29(6), 388–92. doi: 10.1016/j.apnu.2015.06.010.
- Bumgarner, R. (2013). DNA microarrays: types, applications and their future. *Current Protocols in Molecular Biology*, 101(1), 22.1.1-22.1.11. doi: 10.1002/0471142727.mb2201s101.
- Chitty, L.S., Hill, M., White, H., Wright, D., Morris, S. (2012). Noninvasive prenatal testing for aneuploidy-ready for prime time. *American Journal of Obstetrics and Gynecology*, 206(4), 269–75. doi: 10.1016/j.ajog.2012.02.021.
- Ebsworth, S.J., & Foster, J.L.H. (2017). Public perceptions of mental health professionals: stigma by association? *Journal of Mental Health*, 26(5), 431–41. doi: 10.1080/09638237.2016.1207228.
- Etikan, I., Musa S.A., Alkassim, R.S. (2016). Comparison of convenience sampling and purposive sampling. *American Journal of Theoretical and Applied Statistics*, 5(1), 1-4. doi: 10.11648/j.ajtas.20160501.11.
- Gaebel, W., Zäske, H., Zielasek, J., Cleveland, H.R., Samjeske, K., Stuart, H.,... Sartorius, N. (2015). Stigmatization of psychiatrists and general practitioners: results of an international survey. *European Archives of Psychiatry and Clinical Neuroscience*, 265(3), 189–97. doi: 10.1007/s00406-014-0530-8.
- Godino, L., Turchetti, D., Skirton H. (2013). Genetic counseling: a survey to explore knowledge and attitudes of Italian nurses and midwives. *Nursing & Health Sciences*, 15(1), 15–21. doi: 10.1111/j.1442-2018.2012.00708.x.
- Heimler, A. (1997). An oral history of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, 6(3), 315–324. doi: 10.1023/A:1025680306348.
- Hogarth, S., & Saukko, P. (2017). A market in the making: the past, present and future of direct-to-consumer genomics. *New Genetics and Society*, 36(3), 197–208. doi: 10.1080/14636778.2017.1354692.
- Maio, M., Carrion, P., Yaremco, E., Austin, J.C. (2013). Awareness of genetic counseling and perceptions of its purpose: a survey of the Canadian public. *Journal of Genetic Counseling*, 22(6) 762–70. doi: 10.1007/s10897-013-9633-z.

- Moraes, F. & Góes, A. (2016). A decade of Human Genome Project conclusion: scientific diffusion about our genome knowledge. *Biochemistry and Molecular Biology Education*, 44(3), 215–23. doi: 10.1002/bmb.20952.
- “National Society of Genetic Counselors: NSGC Professional Status Survey.” (2002, 2008, 2018). Accessed December 9, 2018.
- Reed, S.C. (1974). A short history of genetic counseling. *Social Biology*, 21(4), 332-339. doi: 10.1080/19485565.1974.9988131.
- Regalado, A. (2018, February 12). 2017 was the year consumer DNA testing blew up. *MIT Technology Review*. Retrieved February 7, 2019, from <https://www.technologyreview.com/s/610233/2017-was-the-year-consumer-dna-testing-blew-up/>
- Resta, R., Biesecker, B., Bennett, R., Blum, S., Hahn, S., Strecker, M., Williams, J. (2006). A new definition of genetic counseling: National Society of Genetic Counselors’ task force report. *Journal of Genetic Counseling*, 15(2), 77-83. doi: 10.1007/s10897-005-9014-3.
- Riconda, D., Grubs, R.E., Champion, M.W., Cragun, D. (2018). Genetic counselor training for the next generation: where do we go from here? *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics*, 178(1), 38–45. doi: 10.1002/ajmg.c.31598.
- Riesgraf, R.J., Veach P.M., MacFarlane, I.M., LeRoy, B.S. (2014). Perceptions and attitudes about genetic counseling among residents of a Midwestern Rural Area. *Journal of Genetic Counseling*, 24 (4), 565-579.
- Sartorius, N., Gaebel, W., Cleveland, H.R., Stuart, H., Akiyama, T., Arboleda-Florez, J.,... Tasman, A. (2010). WPA guidance on how to combat stigmatization of psychiatry and psychiatrists. *World Psychiatry*, 9(3), 131–44.
- Stern, A.M. (2009). A Quiet Revolution: The birth of the genetic counselor at Sarah Lawrence College, 1969. *Journal of Genetic Counseling*, 18(1), 1–11. doi: 10.1007/s10897-008-9186-8.
- Stoll, K., Kubendran, S., Cohen, S.A. (2018). The past, present and future of service delivery in genetic counseling: keeping up in the era of precision medicine. *American Journal of Medical Genetics Part C: Seminars in Medical Genetics*, 178(1), 24–37. doi: 10.1002/ajmg.c.31602.
- Thorne, S., Kirkham, S.R., MacDonald-Emes, J. (1997). Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169-77. doi: 10.1002/(SICI)1098-240X(199704)20:2<169::AID-NUR9>3.0.CO;2-I.
- Thorne, S., Kirkham, SR., O’Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1–11. doi: 10.1177/160940690400300101.

Box 1. The evolution of the definition of genetic counseling.

1974	1975	2006
A kind of genetic social work without the eugenic connotations (Reed, 1974).	A communication process which deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family (ASHG 1975).	The process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease (Resta et al., 2006).

Table 1. Participant demographics

	N (%) or mean (range)
Gender	
M	2 (16.7%)
F	10 (83.3%)
Country	
US	9 (75%)
Outside US	3 (25%)
Years since graduation	24.2 (12-38)*
Highest degree	
Master's degree (MS, MA, MSc)	6 (50%)
Doctoral degree (PhD, EdD)	6 (50%)

*Data from two participants were not publicly available