

Title: 40 Years and Beyond for the National Society of Genetic Counselors: Reflections on Genetic Counseling Practice

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Running Head: 40 Years and Beyond for the NSGC

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1002/JGC4.1301](https://doi.org/10.1002/JGC4.1301)

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Abstract

The National Society of Genetic Counselors (NSGC) was established in 1979 and has grown from a small dedicated group of genetic counselors to over 5000 certified genetic counselors in 2019. During this time period, there have been tremendous advances in the practice of genetic counseling, the availability of genetic testing, and the use of technology. These advances have significantly changed our roles and responsibilities and have contributed to the expansion and diversification of our field in clinical and non-clinical work settings. The launch of genetic counseling services in prenatal, pediatric and adult genetics clinics has expanded to many medical specialties. Genetic counselors are also working in industry, public health, policy, education, research and other work settings. With growth into new areas and the significant increase in the number of practitioners, genetic counselors have established themselves professionally and created opportunities where they can not only contribute to the delivery of quality genetic services, but lead the way. The counseling skills that are a core part of training as genetic counselors will continue to have broad application in diverse work settings and roles. Looking to the future, genetic counselors need to proactively consider tasks that artificial intelligence and other technologies can accomplish so that genetic counselors have the bandwidth to use their expertise to successfully and efficiently meet the growing demands for genetic counseling services. During the 40th anniversary celebration at the 2019 NSGC Annual Conference, three of NSGC's past presidents reflected on the early years of NSGC and clinical practice, recognized key accomplishments and where the profession stands today, and shared thoughts about the future of genetic counseling. Videos of the actual talks can be accessed by internet search "NSGC Celebrates 40 Years" (<https://www.nsgc.org/p/bl/et/blogid=53&blogaid=1162>).

Key words: Genetic counselors, genetic counseling, National Society of Genetic Counselors, history, 40th Anniversary

“The Past” - Wendy R. Uhlmann, MS, CGC

Happy 40th NSGC [National Society of Genetic Counselors]! It is with great pride that I say: I-am-a-genetic counselor! I will be talking about our past – yes, I am representing the 5% of our membership that is the dashes in the Professional Status Survey (National Society of Genetic Counselors Professional Status Survey, 2019a). We are so few in number that our salaries are identifiable.

We are the generation that when you said you were a genetic counselor, the reply was genetic what? Perhaps we still hear that sometimes, but not as often. We were not consistently called genetic counselors; 23% were still using the title “genetic associate” in 1984 (Collins and Begleiter, 1984). Generally, clinical geneticists considered themselves genetic counselors and thought those with Master’s Degrees should be genetic associates (Heimler, 1997). According to Joan Marks, MS, early and longtime director of the genetic counseling program at Sarah Lawrence College (Marks, 1989): “Many leaders in the medical community felt strongly that the most appropriate candidates for training as counselors should be mature women who were parents as well. There was serious doubt that non-physician counselors could be trusted to know their limitations. There was open skepticism that dealing with the emotional component of genetic disease was either necessary or constructive” (Marks, 1989). Clearly, all of this was disproven!

Clinical Practice

What did clinical practice look like? Our generation began practicing when computers were either non-existent or newly in use. There were no fax machines, cell phones or internet. For case prep, we used books. When needed, we walked to libraries, both ways in the snow, and used a card catalog to find journals.

We had to figure out and define our roles for ourselves, the physicians we worked with and our patients. In the early years, mostly we took family histories and drew pedigrees with our plastic

templates of circles and squares, which we carried everywhere. We did inheritance and psychosocial counseling.

Clinic visits were often an hour or more. Genetic testing? Mostly we replied “not available.” The upside—we didn’t have to deal with insurance issues! More time was spent counseling and addressing psychosocial issues.

We mostly ordered karyotypes, if any testing was done. Single gene tests became more available in the 1990s. How did you find genetic testing labs? Some labs were well established. Some genetic tests were found by calling the authors of journal articles. In 1991, NSGC published a list of genetic testing labs in our newsletter, *Perspectives* (“Survey of clinical DNA diagnostic laboratories,” 1991, p. 7-10), which became a key resource.

Generally, we worked with clinical geneticists and mostly in pediatric or prenatal genetics’ clinics (Walker, 2009). We were not viewed as autonomous service providers. How did we advance our roles? By demonstrating our knowledge, value and asking to do more. With humor but meaning every single word, I had a 50% rule – if the doctor talked for more than 50% of the visit, I would not write the clinic visit letter. Over time, my role increased and so did the letters I had to write.

National Society of Genetic Counselors (NSGC)

NSGC provided us with a community of genetic counselors and facilitated our professional development. We shared our successes and challenges with each other. Through our meetings, networking and publications, we learned what other genetic counselors were doing and were inspired to take on new roles and expand into new areas, like cancer genetics.

How did NSGC start? I refer you to the *Journal of Genetic Counseling* article written by NSGC’s first president, Audrey Heimler, MS (Heimler, 1997). Of note, Sarah Lawrence College’s genetic counseling program, including students, played a major leadership role in launching the discussions about a professional society (Heimler, 1997). Nationally, there was heated debate about whether to establish a professional society. Key issues were defining the profession and the professional, the name of the society, membership criteria and national representation (Heimler, 1997).

When NSGC started in 1979 – there were 233 members (“Report of 1979 Business Meeting,” 1979, p.1). Membership dues? \$20 for full members, \$5 for students (Smith, 1982) - and in the bank, \$772.68 (Heimler, 1997; “Report of 1979 Business Meeting,” 1979, p.1). Number of jobs listed in our newsletter, *Perspectives in Genetic Counseling*? 4 (“Positions Available,” 1979, p. 4). The first Professional Status Survey was conducted in 1980 - Median salary for new graduates? \$16,000. Five years of experience? \$18,700 (Begleiter et al., 1981).

The first Annual Education Conference was held in 1981 in San Diego with 182 attendees (Heimler, 1997). Six years later, I attended my first NSGC meeting when I was a second-year genetic counseling student at the University of Michigan. The University of Michigan genetic counseling program is also celebrating 40 years (University of Michigan Medical School, Human Genetics website, n.d.) – Go Blue! My whole class came to the meeting and we all roomed together – all two of us.

NSGC meetings were held with the March of Dimes until 1985 (Heimler, 1997; “NSGC News,” 1984, p. 3) and the American Society of Human Genetics until 2000 (Petersen and Soliday, 1998/1999; Soliday, 1998a; Soliday, 1998b; Uhlmann, 2000). This meant that you were gone a week if you attended both meetings. To call work or home, you waited in a long line to use the pay phone. You did not need to make meal plans in advance – we were all in the same meeting room and stayed at the same hotel.

There were few exhibitors at the NSGC meetings and most were cardboard standups. You made sure to get to the exhibitors early to obtain brochures on as many genetic conditions as possible. Clinics had limited budgets so copying these brochures was how we provided resources to our patients.

Initially, NSGC had no paid staff (Heimler, 1997). You volunteered for NSGC because you were NSGC and that was the only way conferences, publications and other resources could happen. The *Journal of Genetic Counseling* was launched in 1992 (Heimler, 1997), which facilitated and enhanced our field’s recognition. The NSGC listserv was launched in 1997 (Keiles, 1996/1997; Keiles, 1997). Due to our newness using this technology, we sometimes unintentionally sent personal emails to the entire NSGC listserv!

Twenty years ago, I served as President of NSGC (Uhlmann, 2000). Genetic testing was a key policy issue. Still is today. I had the honor of representing NSGC when President Clinton issued an executive order banning genetic discrimination in the federal workplace (Clinton Whitehouse Archives, 2000; Pear, 2000; Uhlmann, 2012) and represented NSGC at the White House ceremony when the draft of the human genome was announced (Clinton Whitehouse Archives, 2000; Uhlmann, 2012). Back when I had to answer the question, you are a genetic what? I would not have imagined representing NSGC in the presence of the President of the United States.

Boards

Let's talk about Boards. The American Board of Genetic Counseling was established in 1993 (American Board of Genetic Counseling, Mission and History, n.d.; Heimler, 1997). Prior to 1993, clinical geneticists and genetic counselors took the same American Board of Medical Genetics exam (American Board of Genetic Counseling, Mission and History, n.d.; Walker, 2009). That's right – you sat next to the clinical geneticists who authored the chapters you studied from and often were the luminaries in the field. You traveled to one of the few cities where Boards were offered with your sharpened number 2 pencils to fill in the dots on the paper exam. The Boards were offered every three years in June and you waited until October, usually timed with the meetings, to get your scores. A list of those who passed boards was published in the *American Journal of Human Genetics* – and you wanted to be on that list.

Jobs

You found out about jobs from your program director, the single job board at NSGC meetings and our newsletter, *Perspectives*. In other words, few genetic counselor jobs existed. Therefore, generally you would send your resume to every genetics clinic in the city where you hoped to live.

I graduated in 1987 after getting married between my two summer rotations. Thinking it was a good idea to continue living with my husband, I needed a job in Michigan. There were no genetic counselor jobs in Michigan. I continued working in the Cytogenetics Laboratory [University of Michigan], where I had been working prior to and during graduate school, analyzing chromosomes. Four months later, a prenatal genetic counselor job became available -

90 miles round-trip commuting each day from Ann Arbor to Detroit. I took it. Like other genetic counselors of my generation, I was just grateful to find a job as a genetic counselor.

And so 32 years later, I am the generation of dashes on the Professional Status Survey. The generation that saw the launch and early days of NSGC. NSGC became our professional home and community. We sought opportunities and continue to seek opportunities where the genetic counselor voice can significantly contribute. While I have talked about the past, I am very present in the present and look forward to an amazing future for our profession.

“The Present” - Jennifer Hoskovec

As I think about the history of our profession it is striking to realize how far we’ve come, supported by an organization that doesn’t just keep pace, but helps pave the way for our growth and successes. Over the years I’ve been challenged to think about my vision and hopes for the future of our profession. Whether it’s for an ice-breaker, education session or strategic planning – this question is one that I think we all should consider both critically and creatively, as we are in the driver’s seat. I recall during these many conversations always thinking of one seemingly simple answer – I want ‘genetic counselor’ to be a household name. For people to hear the term and immediately know what it means to them, a friend or a family member. So that takes me to my friend MaryAnn. MaryAnn and I met when she was one of my patients over 10 years ago. I saw her in two separate pregnancies and years later our paths crossed again in our neighborhood school. Now MaryAnn and I are neighbors and friends – far removed from the scenario that connected us many years ago. But, to this day, MaryAnn still introduces me to new people as “my genetic counselor and friend Jen”. Initially, this was strange to me – after all – I’m not really her genetic counselor anymore. However, the more I thought about it, this is what connected us and she cherishes. It doesn’t define our friendship but is part of our story and she shares that with anyone she can. MaryAnn is our advocate and for that I’m thankful.

I know that many genetic counselors are numbers people so I want to share a few numbers that will help illustrate where we are now as a profession and organization.

5,171 - the current number of certified genetic counselors (American Board of Genetic Counseling, n.d.). When I received the email from ABGC in September announcing that we have

surpassed 5,000 certified genetic counselors I felt incredibly proud. This is a celebration of every student, every mentor, every supervisor, every exam item writer, every employer, and the list goes on and on. Cheers to 5000 strong.

It's hard to do justice to the rapid expansion in clinical practice, roles and responsibilities of genetic counselors today. More and more, genetics is recognized as a subspecialty of every medical specialty. From cardiology to ophthalmology, genetic counselors have integrated themselves across the healthcare spectrum and forged new opportunities to make an impact in areas that didn't realize they needed us. Strength in numbers in industry continues to highlight our dynamic skill set (Bureau of Labor and Statistics, 2017; National Society of Genetic Counselors, 2019b). And to those genetic counselors taking their talents further outside the historical scope of genetic counseling practice – thank you. Each and every day genetic counselors have the opportunity to impact those around them whether it's healthcare providers, educators, patients, policy makers, insurers, students or lay public – and that, to me, is the incredible reach of 5000 strong.

47 – The number of Accredited Genetic Counseling Training Programs in the US. **4** in Canada (Accreditation Council for Genetic Counseling, n.d.). As we celebrate growth we also recognize the need to continue to recruit and train genetic counselors to meet the demand. Class sizes have increased, curriculum has evolved and the need for expanded clinical opportunities is clear. Program directors and their faculty are rising to the challenge to ensure students have exposure to the vast amount of information and experiences necessary to prepare them for our profession. While students today can access any journal article with the touch of a button, utilize incredible online resources for case preparation, and take their board exams and receive an instant score. One thing hasn't changed... the training our students receive translates into infinite opportunities and sets them apart from any other health professional. Sure, we are experts in many things genetic, but the communication and counseling skills we bring alongside our risk assessments and inheritance patterns is why we, and only we, are genetic counselors.

70 percent – the percentage of genetic counselors who are younger than NSGC (National Society of Genetic Counselors, 2019a). Our organization is primed for productivity and provides a place for collaboration, creativity, grassroots efforts, professional growth and friendship! NSGC has over 4000 members, with approximately 100 members holding a leadership position

(National Society of Genetic Counselors - NSGC Leadership, n.d.), including 25 formal liaison relationships with professional and governmental entities among others (Meghan Carey, NSGC Executive Director, personal communication, September 2019). Additionally, up to 75% of NSGC members belong to a special interest group and 25% volunteer in some capacity (Meghan Carey, NSGC Executive Director, personal communication, September 2019). The opportunity for genetic counselors to represent our profession and “have a seat at the table” has become the norm in 2019, but certainly not without perseverance and grit by those who first sat at the table and undoubtedly made their mark. NSGC has been nimble and proactive, allowing us to meet the needs of our members in a space that is unpredictable, unchartered and dynamic. With 55% of genetic counselors holding a state license (National Society of Genetic Counselors, 2019b), over 50% billing for services (National Society of Genetic Counselors, 2019b), and the introduction of the Access to the Genetic Counselors Services Act – we, as a member organization, continue to advocate for our profession and in turn those we serve.

Strategic Area of Focus 4 – With celebration and reflection also comes truth and humility. In the 2019-2021 NSGC Strategic Plan, the board outlined what is probably one of the most important initiatives in the history of the organization with an internal focus on diversity and inclusion (NSGC Diversity and Inclusion Task Force, 2019). These member-focused goals focused on promoting a culture of inclusivity and continuing to build community are essential to our success. I am proud to be a genetic counselor and I am proud to be a member of NSGC.

In celebration of the **40th** anniversary of NSGC, I encourage all genetic counselors to share their stories with each other about our profession, what they hold dear and what they are proud of. I hope all genetic counselors take time to connect with each other about their visions for our profession and organization in the next 40 years. But most importantly I want all genetic counselors to be present and take some time to enjoy where we are now because it’s pretty great.

“The Future” - Mary E. Freivogel, MS, CGC

Let’s play a game. I’m going to read a list of statements and I want all of you to guess what I’m describing. Are you ready? Here we go.

- Collects detailed personal and family history information

- Develops a differential diagnosis
- Provides informed consent
- Discloses genetic test results
- Provides a standard plan for medical management

Does everyone have a guess? Are you thinking about a genetic counselor? And if you are, you are incorrect. All the statements I read are describing a chatbot.

It's no secret that healthcare is shifting towards doing more with less. The demands are to see more patients in less time... for less money... with less human providers. Artificial intelligence (AI) is gaining traction as a way to meet these demands. Data shows that AI is superior to humans in consistency, comprehensiveness, and speed. Whether we like it or not, AI is here to stay.

So if we think about AI as our competition in a game of survival, how should we play the game? Should we attempt to "one up" it in areas where we have no chance of matching up? Probably not. Should we find things it can't do well and capitalize on those? Bingo. That's the secret to success.

So what does AI lack? It's simple: AI lacks heart. It cannot hear the fear in a patient's voice. It cannot see the hurt in a patient's eyes. It cannot sense the tension in a patient's body. But genetic counselors can. And when we do, we are uniquely positioned to support and guide that patient in a way that no one else... or nothing else... can.

Minouche Shafik recently said: "In the past jobs were about muscles, now they're about brains, but in the future they'll be about the heart" (Elkann, 2018).

Thankfully, as genetic counselors, we have been using our hearts for years. We have seen the future. We are ahead of the times. We are poised and ready to own the future, as long as we play our cards right.

Our profession has deep roots in counseling thanks to thought leaders like Carl Rogers and Seymour Kessler. However, over time, we've migrated away from a "counseling model" towards a "teaching model". We are prioritizing information-giving over the exploration of psychological concerns and family dynamics. In other words, we are the ones talking most of the time in our sessions, as we provide patients with information about diseases, inheritance patterns, and

genetic testing. Yet data shows that the less we talk, the more patients benefit. The counseling model is associated with higher patient satisfaction, not to mention better emotional and knowledge-based outcomes (Austin et al., 2014).

So why do we gravitate towards the teaching model? Maybe it's because it's more comfortable to follow a script in a session. Maybe it's because we feel pressure to be efficient and we worry about asking questions that will lead to a lengthy, intense conversation. Maybe it's because we've mistaken "non-directiveness" as something that limits us to being nothing more than an information provider. Maybe it's because we have imposter syndrome and think that true "counseling" is outside our scope and requires a referral to someone else (Austin et al. 2014).

Let's put this to rest today. Genetic counselors are well-positioned, well-educated and well-equipped to provide counseling to patients in the context of diseases that may or may not run in their family. We have the ability to go beyond the medical perspective of a risk assessment or a diagnosis. I ask each of you... are you doing this in your everyday practice?

Are you talking less than your patients?

Are you exploring what is holding them back from adhering to recommended treatments, screening, or lifestyle changes?

Are you proactively delving into family dynamics that may impact the ability for the patient to share genetic test results with relatives?

Are you forging longitudinal relationships and titrating clinical details over time in order to avoid information overload?

If you aren't doing these things, I would argue that you are not practicing at the top of your scope... and you are not capitalizing on what makes us unique... and you are not fulfilling your obligation to support our future.

I am a genetic counselor and I am so very proud to have the word "counselor" in my job title. Counseling is an innate part of my profession... so ingrained in it that the term is actually in the words that I used to describe myself on my business card. Counseling is something AI cannot do so let's leverage that skill to its maximum capacity. Just as our heart keeps us alive as human beings, it may also be what allows us to survive and flourish as a profession in the future.

But counseling takes time... and like other healthcare providers, we are feeling pressure to do more with less. We need to be efficient. So how do we do this while at the same time leveraging the counseling model and letting our patients do most of the talking?

If only there was someone... something... that could do some of the routine things in order to free up our time in the session so we can do more meaningful work with patients.

Do you see what I'm getting at here? Let's leverage AI. Let's allow it to help. But let's remain in the driver's seat and make it work for us, versus the other way around. If we fight AI, we run the risk of losing our position of power. Instead, let's embrace it and be the ones to determine its' scope and set its' boundaries.

And another thing... I bet you money that if we drive the appropriate use of AI and spend less time on rote tasks, we will derive greater professional satisfaction from our patient encounters. We will be challenged to a higher degree. We will have more varied experiences on a day-to-day basis. We may indeed see less genetic counselors leaving patient-facing roles because the monotony will give way to deeper connections and greater emotional fulfillment.

How will NSGC help us move into this new world? As our professional home, it will support us in practicing at the top of our scope. It will provide us with the encouragement, confidence, education, and tools to do something that scares us and let go of the teaching model that many of us are used to in order to embrace the counseling model that will ultimately elevate us, secure our unique position in healthcare, and bring us greater professional satisfaction. As we delve into these more complex interactions with patients, we may see the cognitive burden of our day-to-day work decrease but the emotional burden increase. NSGC will foster a connected community that we can turn to for support and strength.

We have the tools. We have the expertise. We have the training. We have the support. So let's stop hiding behind things that can be done by others. Can a chatbot do it? Then let it do it. Can a video do it? Then let it do it. Can another healthcare provider do it? Then welcome them with open arms, guide them, support them. Do something valuable with the time that you've saved. Do something that no one else can do but you.

As genetic counselors, we are not health educators... we are not providers of informed consent... we are not gatekeepers of genetic testing based on criteria decided by expert panels or insurance companies. We are genetic counselors and above all else, we use our hearts.

Author Contributions

Wendy Uhlmann, Jennifer Hoskovec and Mary Freivogel all made substantial contributions to the conception of the work, wrote and revised content and provided final approval of the version to be published. All agree to be accountable for all aspects of the paper.

Acknowledgement

This material was presented at the 2019 National Society of Genetic Counselors Annual Conference. We would like to acknowledge and express our appreciation for the work done by Debra Collins, MS, CGC and Linda Robinson, MS, CGC. On behalf of the NSGC Late Career Special Interest Group, they proposed this plenary session, created an NSGC timeline with exhibit from which we obtained historical dates and provided us with references for information as needed. Debra Collins, MS, CGC and Linda Robinson, MS, CGC, through their time, effort and hard work, have helped collect and document NSGC's history, which will benefit future generations.

Conflict of Interest declaration

Mary Freivogel: Employee and stockholder of Invitae; Consultant for HCA/Sarah Cannon

Jennifer Hoskovec: Member of two advisory boards: Coalition for Access to Prenatal Screening & Billion to One

Wendy Uhlmann: Receives book royalties from Wiley-Blackwell: John Wiley & Sons, Inc.

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