ORIGINAL ARTICLE



Exploring racial and ethnic minority individuals' journey to becoming genetic counselors: Mapping paths to diversifying the genetic counseling profession

Tatiana E. Alvarado-Wing | Jennifer Marshall | Alicia Best | Joanne Gomez | Deborah Cragun

College of Public Health, University of South Florida, Tampa, FL, USA

Correspondence

Tatiana E. Alvarado-Wing, College of Public Health, University of South Florida, Tampa, FL, USA.

Email: tealvarado@usf.edu

Abstract

Reasons for limited ethnic and racial diversity among genetic counselors in the United States may be elucidated through better understanding the experiences of individuals from racial/ethnic minority backgrounds who are enrolled in genetic counseling graduate programs as well as recent graduates. Semi-structured interviews were conducted with racial/ethnic minority participants using Journey Mapping to elicit touchpoints that positively or negatively impact success at varying points along the path to becoming genetic counselors. Negative impacts observed at various touchpoints included the following: late awareness of the profession; observing lack of diversity in the field; financial burden of the application process; and microaggressions from peers, program leadership, and clinical supervisors. Positive impacts observed at various touchpoints included the following: group or personal mentors; opportunities to interact with practicing genetic counselors; opportunities to perform 'mock' admissions interviews; program interviews with a conversational interview style; and attending programs in cities with racially/ethnically diverse patient populations. Findings from this research suggest the lack of adequate infrastructure necessary to recruit and support racial/ethnic minority students is a critical systemic issue impeding progress toward diversifying the genetic counseling field. As such, this study reinforces the need for development, adaptation, and implementation of evidence-based strategies to optimize experiences of racial and ethnic minority individuals throughout the entire process of becoming a genetic counselor.

KEYWORDS

cultural competence, diversity, genetic counselors, lived experiences, underrepresented populations

1 | INTRODUCTION

According to the National Society of Genetic Counselors (NSGC), 90% of professionals practicing in the field of genetic counseling in the United States (U.S.) identify as non-Hispanic White (NSGC, 2019b). In contrast, approximately 40% of the U.S. population is comprised of people from diverse racial/ethnic backgrounds,

including those who identify as Black or African American, Hispanic or Latinx, American Indian, Asian, Native Hawaiian or Alaskan, or two or more races (U.S. Census Bureau, 2018). This lack of racial/ethnic minority representation among genetic counselors represents an important problem given that lack of representation has been well documented as contributing to health disparities (i.e., differences in health outcomes between groups) across a

variety of health-related disciplines (Kehoe et al., 2003; LaVeist et al., 2009; Schoenthaler et al., 2014). Specifically, research has revealed strong associations between racial/ethnic concordance, cultural competence, and institutional trust on outcomes such as medication adherence, healthcare utilization, as well as access to and perceived quality of healthcare among racial/ethnic minority populations (Kehoe et al., 2003; LaVeist et al., 2009; Schoenthaler et al., 2014; Sullivan, 2004).

Barriers to and facilitators of racial/ethnic minority student representation in secondary education and graduate degree programs that feed into health-related professions have also been well documented and are fairly consistent across healthcare professions such as medicine, nursing, dentistry, speech pathology, and genetic counseling (Cohen et al., 2002; Mittman & Downs, 2008; Saenz, 2000; Schoonveld et al., 2007). Common barriers include tuition costs, overall poorer performance on standardized tests and costs of testing, visual lack of representation, in some cases late awareness, and lack of social support. Common facilitators include early outreach, small cohorts that allow for individualized attention, post-baccalaureate preparation for graduate education, financial assistance, and mentorship relationships (Cohen et al., 2002; Mittman & Downs, 2008; Saenz, 2000; Schoonveld et al., 2007).

National Society of Genetic Counselors began implementing initiatives to increase racial/ethnic diversity among genetic counselors in 1992, but diverse representation still remains much lower than other health professions such as nursing and medicine (Mittman & Downs, 2008). Ethnic and racial diversity in the genetic counseling (GC) profession has remained stagnant with no notable increases in proportions from diverse groups (Channaoui et al., 2020). The first effort included a conference for program directors of genetic counseling graduate programs on Ethnocultural Issues in GC Recruitment. Other initiatives have included minority targeted outreach via recruitment posters, strategic planning and other meetings, various diversity task forces and working groups, diversity special interest groups, and increasing community engagement (Channaoui, Bui, et al., 2020). NSGC recently formed a Diversity and Inclusion task force that first convened in February 2019 and published a 'Statement of Diversity, Equity, and Inclusion' (NSGC, 2019a). This NSGC task force has also published a number of recommendations, including the need to further explore career pipeline barriers and potential solutions (Channaoui, Khan, et al., 2020).

To help identify potential solutions to increase diversity in the GC profession, we sought to better understand recent experiences of individuals from underrepresented racial and ethnic groups using a unique approach called Journey Mapping. Journey Mapping is an evaluation tool that has been previously used in social and behavioral sciences, education, and customer-service interactions to create a holistic picture surrounding a particular process of interest along with the role of various stakeholders in that process (Crunkilton, 2009). This study used the Journey Mapping approach to describe how students from diverse racial/ethnic backgrounds become aware, apply to, and graduate from genetic counseling graduate programs.

2 | METHODS

The Journey Mapping approach does not specify a particular research method, as it focuses more on understanding the processes within a system. For this study, in-depth qualitative interviews were conducted to identify key factors impacting individuals' journeys to becoming a genetic counselor and their perceptions of how race/ethnicity influenced their journeys.

This study was reviewed and approved by the University of South Florida's Institutional Review Board. Data were collected from November 2019-January 2020 using semi-structured interviews with current genetic counseling students and practicing genetic counselors. The first author, a Mexican American second-year GC master's student, conducted the interviews and data analysis. A second coder with a bachelor's degree in public health who has qualitative research experience and who identifies as an underrepresented minority, aided in data analysis. Both women (interviewer and second coder) have a personal and professional interest in the topic of institutional racism and its impact on health disparities.

2.1 | Participant Recruitment

Participants were selected based on the following inclusion criteria: (a) self-identifies as part of a racial/ethnic minority group (definition open to participants' own interpretation); (b) age 18 years or older; (c) currently enrolled in an accredited genetic counseling program, or a practicing genetic counselor who has graduated from an accredited genetic counseling program within the last three years. These criteria were selected in order to provide a more current snapshot of the journey of genetic counselors, in hopes of capturing differences in recent experiences as compared to experiences over 10 years ago.

To recruit participants, we sent an introductory email through the NSGC listserv. We also sent an email to the Association for Genetic Counseling Program Director listserv asking program leadership to forward the introductory email to any current or former students who might meet inclusion criteria. Individuals who were interested in the study followed a link to the consent form and were asked to complete an eligibility survey which obtained demographic (gender, age student/professional status, program enrolled in, region, and racial/ethnic identity) and contact information if they agreed to participate. Individuals who met inclusion criteria were sent a follow-up email with instructions to schedule an interview.

2.2 | Procedure

Interviews were scheduled via email at a time that was convenient for the participant and the researcher. One week prior to the scheduled interview, an email was sent to the participant as a reminder of the interview time and date along with the interview guide so that the interviewee had time to review questions that they would be asked. All interviews were conducted privately over the telephone.

Prior to beginning each interview, participants were reminded that they may stop the interview or skip a question at any time and for any reason. Participants were also given the opportunity to ask questions pertaining to the study or interview guide prior to starting the interview. Participants were informed that no identifying information would be shared. Verbal permission was obtained from each participant to record the interview. Interviews took approximately 30–60 min to complete.

2.3 | Instrumentation

Interview questions were developed using the Success Case Method (Brinkerhoff, 2003) to elicit individuals' thoughts, feelings, barriers, and opportunities at different touchpoints on their journey to entering a GC program and becoming a genetic counselor. Journey Mapping provides a way to collect and display these collective stories by identifying touchpoints in the process. Touchpoints are key or pivotal interactions with various persons, institutions, or experiences that have a positive or negative impact on the individual's path toward a particular outcome. To this end, interview guestions were designed to elicit the participants' lived experiences and were generally divided into eight sections representing chronological landmarks along the individual's path. These sections included the following: (a) gaining awareness of the GC profession; (b) deciding to apply to a graduate program; (c) selecting programs of interest; (d) applying to programs; (e) interviewing for programs; (f) attending a GC program; (g) taking the board examination; and (h) participants views on racial/ethnic considerations that may have influenced their experiences spanning across the stages of their journey to becoming a genetic counselor (cross-cutting). The interview guide began with an open-ended question for each section, and additional planned and spontaneous probes were included in several sections to obtain further detail about each individual's experience. For example, section one (i.e., gaining awareness) included the following opening question: 'Would you please describe how you first heard about genetic counseling?' Additional probes under this question included 'When was this?', 'What information were you given?', 'What did you first think about the profession?', and 'What interested you the most?' Each participant was asked questions up to the current point in their journey. The interview guide, which is available as an File S1, was developed by the research team and piloted with a GC student who was not a participant in the study.

2.4 | Data analysis

After each interview was conducted, field notes were recorded. The first author then listened to the recording and used a modified version of the interview guide to list touchpoints associated with each question within each section of the journey. The touchpoints were then put into a participant-specific summary that contained all eight sections listed above and categorized according to whether the

touchpoint was deemed positive or negative, and whether racial/ ethnic considerations were perceived to influence that touchpoint. Participant-suggested improvements were also noted to provide data about potential action steps. A second coder was assigned to independently analyze each recording following the same instructions in the summary sheet described above. The two coders compiled a master table containing all touchpoints and assigned categories. When discrepancies in coding or categorization were identified, the coders listened to the respective recording together to come to consensus. From the master table, the most common themes were identified and reported. These common themes were used by the first author to create a Journey Map describing several shared experiences of racial/ethnic minority participants as they journeyed through processes on the path toward the GC profession. Critical areas where processes and systems require improvement were identified as well.

3 | RESULTS

Sixteen individuals responded to the invitation and participated in an interview; none dropped out of the study or declined to answer any questions (Table 1). These participants represented 11 different genetic counseling graduate programs from all five U.S. regions as defined by the U.S. Census Bureau. Six participants were practicing genetic counselors while the remaining ten were first- or second-year graduate students. Results are organized by sections that represent the chronological progression throughout their journeys with additional considerations that span the journey described at the

TABLE 1 Participant self-reported identifiers

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Participant characteristics	n = 16
Females	14
Males	2
Age Range	24 - 34
1st-year GC Student	5
2nd-year GC Student	5
Practicing GC	6
GC Programs Represented	11
U.S. Regions Represented	
Northeast	3
Mid-West	6
South	4
West	3
Racial and/or ethnic identity Demographics	
Asian	6
Black or African American	3
Hispanic or Latino	5
Jewish	1
Multiple Race/Ethnicities	1

Abbreviation: GC, genetic counseling

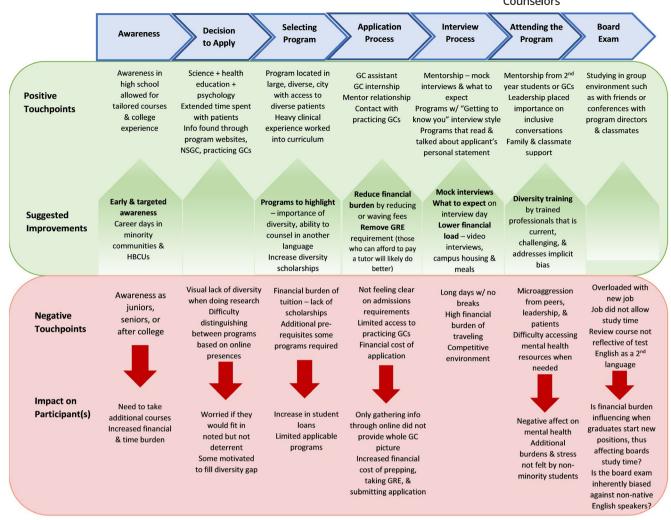


FIGURE 1 Journey map of the most frequently reported participant touchpoints along their journeys to becoming a genetic counselor. Participant-suggested improvements are included, when applicable, for each step in the journey

end. Each chronological category describes the positive and negative touchpoints that were common to several participants. When applicable to a particular section, the touchpoints are followed by participants' suggested improvements. The Journey Map can be found in Figure 1.

3.1 | Gaining awareness of the genetic counseling profession

All but one of the participants were introduced to genetic counseling during or after their undergraduate studies. The one participant who was exposed to the profession in high school commented that this allowed her to tailor her college courses to GC program prerequisites. This touchpoint was labeled to have a positive impact.

My mom happened to be reading...an article written by a genetic counselor who is Jewish, just like I am, and she was talking about how she works with Jewish communities and how she finds her profession really validating and it sounded like everything that I wanted to do. That was about 8 years ago... So, I went into college thinking this is what I'm going to do, um, and so I tailored my courses to that to get there.

- Participant 4, Positive touchpoint

Most participants gained awareness of genetic counseling as juniors or seniors in college or after graduation. This touchpoint was labeled to have a negative impact as these participants were often already working full-time jobs, several had to take additional courses as non-degree seeking students to meet admissions requirements, and they often had to pay out-of-state tuition or did not qualify for financial aid. They also had less time to develop relationships with people in the profession as illustrated below.

It feels like a game of catch-up with people that have known about this since high school and me changing from premed a couple years ago and deciding I want to pursue this now and still not having solidified a robust support system with people that are in the field.

- Participant 8, Negative touchpoint

Improvements suggested by nearly all participants were for genetic counseling programs to increase awareness of the field in minority communities, with an emphasis on reaching students as early as possible (i.e., in high school or undergraduate programs). Another suggestion was to extend outreach to students at Historically Black Colleges and Universities (HBCUs).

3.2 | Deciding to apply to a graduate program

Once participants became aware of the profession and began their research to find further information, most participants spoke to the combination of science, health education, and psychology and the ability to spend extended time with patients as the aspects that most attracted them to the field. Most participants listed online resources as their main source for information. These included the NSGC and graduate program websites. Additionally, many participants reached out to practicing genetic counselors for informational interviews. These were all labeled as positive touchpoints.

It was nice to hear about something other than just medicine, like being a doctor, and one thing that she (practicing GC) did say that really stuck with me was that it was the application of science, education, healthcare, and ethics all combined in this profession and that was nice.

- Participant 2, Positive touchpoint

Some negative touchpoints involved the perceived lack of diversity in the field and the difficultly in distinguishing the difference between programs based on their online information. Nine participants mentioned the lack of racial/ethnic diversity when doing research about genetic counseling. These participants mentioned finding a lack of diversity in the profession's demographic statistics, staff and student pictures on program websites, as well as pictures on other professional websites. This lack of representation was a motivator for three prospective students, as they saw the need to fill that gap in their communities. For the majority, it made them question if they would fit in or how being the only racial/ethnic minority student in a program would affect them once they got in.

The first thing I noticed was, wow, everyone is White female. It really made me kind of wonder why that was the case. Especially because the city I was in was very diverse and definitely our patient populations there were very diverse, so it just struck me

as strange because we saw a lot of diversity in other medical positions so why not genetic counseling.

- Participant 16, Negative touchpoint

3.3 | Selecting programs of interest

There were many characteristics that participants looked for when selecting GC graduate programs of interest. The most common positive touchpoints expressed were programs located in a larger, metropolitan areas with diverse patient populations and those that had clinical rotations in the first year and second year.

I actually looked up the demographics of each city to ensure there was some level of diversity, that I would feel like people like me lived in that city, so there wasn't, I guess that much a culture shock. I also looked to see if their website mentioned diversity, at least once, and I put an extra check if they had diversity scholarships.

- Participant 5, Positive touchpoint

Almost all participants listed cost as the other major consideration, and this was labeled as a negative touchpoint due to the lack of scholarships available. Other participants mentioned that they were limited in the programs they could apply to due to the additional pre-requisite courses that some programs require.

Finances was definitely a big factor for me, I guess like concern-wise but also when we talk about my deciding factors for the programs. Just because I don't come from a rich background or anything like that, so I need to be practical. So, I think that was one of my biggest concerns going in.

- Participant 3, Negative touchpoint

Positive racial and ethnic considerations specifically mentioned in this section included programs that promoted the opportunity for students to counsel in another language, if fluent, and programs that explicitly mentioned the importance of diversity on their websites. Improvements suggested by participants were to offer diversity scholarships to individuals who meet the high standard of admission to their preferred institutions but would struggle financially, so that the cost would not be a barrier to attending.

3.4 | Applying to programs

This section included the path participants took to build their resumes and gain the needed experience to submit applications to accredited GC programs. There were many common touchpoints listed here, such as volunteering at a crisis hotline and shadowing

a genetic counselor in clinic. The most impactful touchpoints—mentioned by several participants—were hands-on experiences that included a mentoring relationship, such as participating in a genetic counseling internship or working as a genetic counseling assistant. During these experiences, they were exposed to what genetic counselors do in and out of clinic daily, including participation in institutional grand rounds, tumor boards, and research projects.

I did an internship. So, I was volunteering at a local hospital every week and I did that for about a year and a half before I got into the program... So, I volunteered at two sites, one was a Spanish speaking site and the other one was just a regular cancer center, so both cancer. I was able to shadow at least two cases every time I came in and then I also did pedigree intake and then I would do case conference, tumor board, and some smaller projects.

- Participant 1, Positive touchpoint

The practicing genetic counselors who participants shadowed through these experiences also provided guidance to them about writing their personal statements and preparing for the interview process. Furthermore, it was perceived that when mentors and applicants shared a similar racial or ethnic identity, the positive impact seemed to be even stronger. Some participants noted that shared minority status with their mentor resulted in a more personal or trusting relationship. The ability for minority mentors to give advice on how to navigate the path to becoming a genetic counselor as a minority was also valued.

The negative touchpoints expressed included a feeling of not fully understanding the qualifications that were expected of GC programs, or the competitiveness of getting into a program. The process could be intimidating, and most of these participants explained that they were only able to gather information through online resources and had limited in-person access to practicing genetic counselors in their own personal or professional networks. Another major negative touchpoint during the application process was the cost. Submission of applications can cost around 100 dollars per program in addition to GRE preparation and testing fees.

Ideas participants gave for improving the application process mostly involved waiving application fees for individuals who meet household income requirements or potentially refunding fees for applicants who receive a subsequent interview. Removing the GRE as a requirement was also mentioned as a way to reduce costs. A participant noted that individuals who can pay for prep courses and tutors may do better on the examination.

3.5 | Interviewing for programs

This section focused on experiences participants had while going through the admissions interview process and how they prepared for this process. Mentorship, again, was found to be a major positive touchpoint for those who had access to this kind of relationship. Mentors provided applicants with ideas of what to expect and conducted mock interviews with them. Twelve of the participants mentioned that they were drawn to programs where the interview was set up as a 'getting to know you' process that felt more conversational. In addition, participants mentioned that when programs made an effort to talk about aspects of their personal statement this relayed the message that the program appreciated the applicant as an individual.

Some did take a more personalized approach... I just felt individuals took so much time to write their personal statements and I'm assuming a lot of them were so vulnerable in their personal statements, and I kinda wanted to feel more than just a series of numbers and a GPA and the school I went to didn't make me feel like that.

- Participant 5, Positive touchpoint

Negative touchpoints included long days with multiple interviews and no breaks, a lot of traveling that meant a high financial burden, and an unexpected level of competitiveness in certain environments.

It also ended up being more costly than I was anticipating. Especially since the programs are so competitive, I guess when you're applying to programs it seems like this very competitive thing. So, for me, I applied to as many as I could and then when the interviews came back, I think it was more than I was anticipating so it was more expensive than I had initially budgeted for.

- Participants 4, Negative touchpoint

Suggested improvements to the preparation and interview process included an opportunity to practice mock interviews with experienced individuals, that programs should be fostered a 'conversational' environment that does not focus on the competitive nature of the process, and ways to lower the financial burden overall. Ideas mentioned that might lower cost included allowing applicants to interview over video conference or having a 'diversity day' where all applicants of racial/ethnic minority backgrounds are all interviewed on the same day. Others suggested that programs offer applicants financial reimbursement for their travel or stay, such as housing on campus with meals included.

3.6 | Attending a genetic counseling program

There were many important touchpoints that influenced participants' experiences while completing their programs. Throughout their programs, positive touchpoints included mentorship from second-year students or practicing genetic counselors to help navigate assignments and clinical rotations, programs with diverse cohorts, and leadership that placed specific value in having inclusive and sometimes challenging conversations surrounding implicit

biases (i.e., attitudes or stereotypes that affect our understanding, actions, and decisions in an unconscious manner (Ohio State University, 2015)). Participants who attended a program as part of a diverse cohort said this positively impacted their experience in that they were around others with similar life experiences, made friends easier and faster, and appreciated the general feeling of not being the only minority in the program. Other valuable sources of support mentioned by participants came from their classmates and families.

One of my favorite things about my program is that cultural competency is worked into every part of the program. It's not just a buzzword or one lecture, it's worked into most of the curriculum.

- Participant 7, Positive touchpoint

We have a mentor program... I have a second year and I have a genetic counselor who is pretty present in the program so she's really accessible if I needed her and my second year is really incredible.

- Participant 14, Positive touchpoint

Negative touchpoints while completing their programs included a variety of 'microaggressions' from classmates, leadership, and patients. Dr. Sue (2010) defines microaggressions as 'verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, which communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group membership'. Many participants expressed feeling like they were expected to be the spokesperson for the racial/ethnic minority community to which they identified. Although not all participants saw this as an added or unfair burden, many participants felt this added to their stress and negatively impacted their mental health throughout the program.

I was shadowing a genetic counselor who trying to explain dysmorphology to me and, I know they didn't mean it this way, but I think it's a good example of how trainees and potential trainees are more susceptible or sensitive to these things. She was talking about dysmorphology and she was giving examples and she said... Oh for example they used to call, like a term we wouldn't use anymore, like a mongoloid feature, or whatever, and the way that she talked about it wasn't sensitive...and then she pointed at my eye because I'm Asian and she said for example your eyes, that doesn't mean you're dysmorphic but you know, you have that feature.

- Participant 16, Negative touchpoint

The one class I was really interested in was supposed to be multicultural counseling. The way the program

described it, you know, it would be more than one class, but in reality, it was like two hours and maybe not even in a class day that they focused on it. It was taught by a Caucasian woman, just your normal typical genetic counselor, and when someone of minority and myself brought up a point that we disagreed with in the teaching, um, we were just dismissed. So that was really challenging because, like, you're teaching a class on multicultural counseling but you're actually dismissing some of the people who could tell you more about it.

- Participant 15, Negative touchpoint

When this participant was asked if the instructor had any specific training that made her qualified to teach a multicultural counseling class, she replied,

Not that I know of, and in fact I think there are better people to teach that class, um, I don't know if it was a scheduling thing or that was just not considered, but I thought there were better people to teach that class than the genetic counselor that ended up teaching it.

- Participant 15, Negative touchpoint

Improvements mentioned specifically for this section included providing diversity training for program leadership and students that is up to date and challenges individuals to recognize and address their implicit biases. Many participants felt that this training should be taught by those who identify with the community that is being discussed, whether that is a racial/ethnic minority group, members of the LGBTQ + community, or persons with disabilities. A few participants mentioned that having genetic counselor mentors who were outside of their program would have been beneficial in helping them navigate sensitive topics when program leadership or clinical supervisors were involved. This would have provided a safe place to discuss their concerns without fear of retribution.

3.7 | Taking the board examination

Practicing genetic counselors were asked about their process for studying and taking the American Board of Genetic Counseling (ABGC) Certification Exam, which genetic counselors must pass upon completion of their training in order to practice as a genetic counselor. Positive touchpoints in this section included studying in group environments such as with friends, or case conferences with program directors.

As far as prep for the boards went, in my program, our entire second year we would meet once a week with our program director and basically have a mini case conference where we would go through different conditions. Each student would be assigned

a different one and we would make like a two page word doc on the ins and outs... and that was nice because when it came time to study seriously in the summer I was able to go at my own pace and rereview those...

- Participant 12, Positive touchpoint

Negative touchpoints included being overwhelmed starting a new job and trying to study for board examinations. Some expressed that their new positions did not allow time during the work week to study. Two out of the five participants who mentioned this touchpoint expressed that they did not think the review course they paid for reflected the questions asked on the examination. Another two failed the board examination on their first attempt. Both of these participants did not speak English as their first language and felt that this contributed to them being unsuccessful in their attempts.

There's a genetic counselor that I interact with here [in her city], she's also involved in leadership... She's been very supportive of my career and she feels terrible that I've gone through this and she wishes there was more that the profession could do for people like me. She told me once that they tried to get data on the passing percentage of people who English is their second language or are of an ethnic background where their upbringing is different compared to the typical Caucasian student and ABGC denied publishing that information, so they don't want to share that information. Her theory is that the numbers just don't look good enough and they claim that the exam has gone through that rigorous process, same as the medical boards, to make sure there is no bias, um, but she seems to think that there will always be a bias and that they don't want to share that information.

- Participant 13, Negative touchpoint

3.8 | Racial/ethnic considerations spanning across the journey to becoming a genetic counselor (cross-cutting)

While touchpoints listed above were connected to specific stages in the process of becoming a genetic counselor, some considerations were salient to the experience overall. This section includes thoughts and feelings noted to cross various touchpoints related to the overall experiences of participants as racial/ethnic minorities in their process of becoming a genetic counselor.

The following four quotes illustrate the feelings participants had regarding diversity issues within the GC field overall. Specifically, participants felt that implicit biases and inexperience with inclusion and diversity efforts may be preventing the

profession from effectively identifying and addressing barriers for minority applicants.

There's almost like this white savior complex of like 'oh we can fix it, I'm passionate about racial/ethnic minority health so I can do this.' And like yeah that's great, we definitely need allies in this process, but we also just need minority genetic counselors.

- Participant 8

NSGC or affluent people talk about diversity but they don't really know what diversity is, they don't really think about what happens after you admit them (diverse students), so they really want us there but they don't know what to do with us after the fact.

- Participant 9

I'm still trying to navigate what it means to be a minority in the field of genetic counseling but also a male in this field. Just trying to figure out that in terms of myself but also in terms of how I interact with supervision has really been a struggle. I've just been trying to navigate what that actually looks like successfully because I feel like what I come in and offer is different from what past students that are White females look like and offer so I feel like there has to be a sort of flexibility or almost a give and take or willingness to learn from both sides. I need to have the freedom to be myself in a clinical space but I also want to learn what they have to offer but I can't be them because I'm me ... sort of thing.

- Participant 8

Before we push for more diversity we need to address these issues and make sure we 100% know that we have the infrastructure there for the diverse group that is coming into the field and be able to set them up for success, not for failure.

- Participant 13

Although the majority of the participants felt that the pressure to represent their racial/ethnic group was an added burden, three of the participants saw this as a positive opening to provide further context and promote understanding about their communities to individuals that lacked the opportunity to interact with more diverse populations. In addition, one applicant expressed that he felt being a minority and a male gave him a competitive edge during the application process. Over a third of participants felt the internal pressure to be a representative for their minority community affected their mental health throughout their time in a GC program.

The most challenging aspect for me is coming into a field that is so homogeneous. I feel like it's always having to pave your own way or be the voice of your... because I'm Black, so I always feel I have to represent Black people well and I have to be the voice and I have to speak up about things and it's uncomfortable and a lot of extra stress on top of being a graduate student and doing something that difficult academically and personally and having to be a minority on top of that has been the biggest challenge.

- Participant 7, Negative touchpoint

Half of the participants who identified as Asian in this study explained that they felt negative cultural pressures from their families around the decision to become a genetic counselor, as opposed to a physician. They struggled with communicating this decision with their families because their families saw becoming a physician as a more prestigious goal or thought physicians could perform what was described as a genetic counselor's role.

Over a third of participants expressed a general frustration toward their classmates or the GC community, feeling that there is an academic understanding of racial disparities and their negative impact on healthcare delivery, but little effort has been made to address these problems internally as individuals, organizations, or as a system.

4 | DISCUSSION

Findings from this study suggest ongoing barriers and challenges faced by individuals from underrepresented racial and ethnic minority groups on their journeys to becoming genetic counselors within the last five years. The most common barriers reported across various touchpoints included the following: late awareness of the profession due to limited access to information within social, academic, and professional networks; financial burden of applying for and enrolling in a genetic counseling program; and microaggressions and implicit bias from peers and leadership based on racial/ethnic identity. There were also key facilitators identified that helped mitigate barriers including the following: personal/group mentors who shared similar racial, ethnic, and/or socio-cultural backgrounds; efforts to understand experiences of students from diverse backgrounds, such as a 'getting to know you' interview structure; and programs with access to racially/ethnically diverse patient populations.

Many of the experiences reported by participants in this study are not new. For example, Schoonveld et al., (2007) identified several barriers experienced by GC students and practicing genetic counselors from racial/ethnic minority backgrounds, including late awareness of the profession, microaggressions, pressure to be diversity representatives, and financial burden, which mirror several findings from this research. Additionally, recommendations made by participants in our study reflect best practices reported by Mittman and Downs (2008) for increasing racial and ethnic diversity in health

careers, including genetic counseling. As such, our findings reinforce the ongoing need for more deliberate efforts to offer a diverse pool of mentors, post-bachelor internships, financial assistance, and to create an inclusive environment for racial/ethnic minority students in predominately white institutions.

Progress has been made in genetic counseling to implement several practices that align with positive touchpoints and facilitators identified in this research (Channaoui, Bui, et al., 2020; Mann, 2020). However, many study participants were unaware of supports that were available to them, which indicates the need to raise awareness of currently available resources. For example, none of our study participants mentioned organizations that offer mentorship opportunities for prospective and current GC students and GC professionals from underrepresented populations such as the Minority Genetic Professionals Network (Mann, 2020), or the Boston Minority Genetic Counselors group (Berro et al., 2020). Other efforts to diversify the field of genetic counseling have included blogs, podcasts, speaking engagements, panel discussions of diverse counselors, in-person presentations, and development of targeted recruitment tools. However, limited data are available on the effectiveness of various efforts to raise awareness and recruit diverse candidates to the GC profession (Channaoui, Bui, et al., 2020; Price et al., 2020).

To improve interest in genetic counseling programs and increase the number of diverse applicants, participants from our study and prior research (Channaoui, Bui, et al., 2020) suggest promoting the profession among underrepresented populations at local high schools, career days at HBCUs (Price et al., 2020), or undergraduate events at each respective program's university. One recently published study suggested that in-person presentations may generate higher interest in GC among individuals from underrepresented minority groups compared to more passive strategies such as informational brochures (Price et al., 2020). Another recent effort included an elective undergraduate course to aid recruitment in India (Neogi et al., 2020). After taking the undergraduate course, over 75% of respondents agreed or strongly agreed the course increased their interest in the field, suggesting that undergraduate courses may hold promise in attracting diverse candidates. Similar to our findings, survey respondents who took the course reported lack of shadowing and limited interactions with practicing counselors as key barriers, and they suggested that case studies and observation of patient interactions to help with understanding genetic counselors' roles/ duties.

Programs with access to diverse patient populations and/or those that can allow their students to counsel in different languages may consider explicitly stating this on their websites. Diverse applicants in our study were also more attracted to programs that had a 'getting to know you' interview style; thus, programs seeking more diversity should consider revisiting the structure and dynamics of their interview processes considering perspectives of racial/ethnic minority applicants. Furthermore, some GC and public health graduate programs have already removed or are considering removing the GRE requirement for admissions (Millar, 2020). Although changing the GRE requirement could potentially have an impact on diversifying

the applicant pool, it is too early to know for certain. However, participants in our study cited the GRE as a barrier and it has been established that many racial/ethnic minority students, in general, do not do as well on standardized testing as their non-Hispanic White counterparts. Multiple studies have shown that GRE performance is not a good predictor of student success or graduation rates, and is in fact a barrier to increasing diversity in some professions (Miller & Stassun, 2014; Wolf, 2014). As more GC graduate programs remove the requirement of GRE for admissions, and as data are published looking at the correlation of GRE scores and ABGC board examination pass rates, programs should take this into account and consider whether retaining the GRE requirement is of value or not.

Given that mentorship opportunities served as a key positive touchpoint for many of our participants at every stage of their journey, the Minority Genetic Professionals Network may prove to be an effective approach for diversifying the profession as more individuals become aware of this organization (Mann, 2020). Furthermore, ABGC can promote mentoring programs by giving incentives to practicing GCs who participate in mentorship relationships, such as providing a professional activity credits that serve as credit toward ABGC board recertification. Mentorship relationships can be facilitated by individual counselors or on a program/institutional level (Schwartz et al., 2016). Second-year student mentors and professional GCs within and outside of graduate programs helped some of our participants navigate and understand the nuances of being admitted to and completing a GC program. These mentor relationships were described as even more impactful when sharing the same racial/ethnic identity; however, assumptions should not be made in this regard and individuals should have autonomy in choosing with whom they form mentoring relationships.

A recent article highlighting various diversity, inclusion, and equity initiatives in the field of genetic counseling suggested that efforts should go beyond simply recruiting individuals from underrepresented groups into the profession (Channaoui, Bui, et al., 2020). Our findings support the importance of focusing on minority experiences during graduate education as well as the need for more efforts to reduce microaggressions cause by implicit bias. Implicit bias can be defined as 'negative evaluation of one group and its members relative to another' which 'operates in an unintentional, even unconscious manner (Blair et al., 2011)'. It is imperative that GC students, practitioners, educators, and institutional leadership undergo additional training to become aware of implicit biases and structural barriers that may have unintended consequences for diverse populations pursuing GC careers. Many racial justice advocates and authors (Cargle, 2018; Saad, 2017) would argue that diversity training, and its various forms, does not go far enough in addressing the systemic barriers created by implicit bias and racism. Rather, implicit bias training is one necessary strategy to begin undoing societal programing and miseducation that has developed and persisted over time in a racialized society. If implicit biases and the systemic barriers they create are not recognized, understood, and ultimately dismantled, then inclusivity efforts could perpetuate the negative experiences students/genetic counselors experience within graduate

programs and professional spaces. Notably, there have been steps to address implicit bias and racism. The 2019 NSGC conference held a Confronting White Womanhood workshop led by Rhiannon Childs which challenged participants to identify how their privilege and implicit biases show up in daily interactions and how this could negatively impact people of color and other minority groups.

One important programmatic challenge is deciding the minimum diversity and inclusion training necessary for GC students and practicing counselors. Some of our study participants did not recall any specific lectures on diversity and inclusion offered in their programs, while others indicated these topics were woven throughout their curriculum. Some participants also suggested that genetic counselors should aim to adopt a public health lens in order to better understand health systems, population health, social determinants of health, and how institutional racism affects racial disparities and healthcare delivery (Ormond et al., 2018). It must additionally be acknowledged that healthcare as a whole, and the field of genetics specifically, has a history of racism and mistreatment of racial/ethnic minority populations. For example, lessons learned from eugenics initiatives and inappropriate research conducted on racial/ethnic minority populations must be acknowledged and understood by all genetic counselors (L. Cohen, 2020; Resta, 2019).

In addition to improvements in diversity education, building additional diversity infrastructure is of critical importance. Diversity infrastructure in this context refers to extended efforts and resources aimed at enhancing the experiences of individuals from underrepresented groups throughout the entire process of becoming a genetic counselor. Given the financial burden of graduate school, the diversity scholarships offered by 4 of 31 GC graduate programs who responded to a recent survey are an important key for improving diversity (Channaoui, Bui, et al., 2020). It is also promising that five more GC programs reported in the same survey that they were in the process of implementing diversity scholarships. Furthermore, the Association of Genetic Counseling Program Directors recently created an admissions match fee waiver for those who meet income requirements; however, this does not address the admissions fees charged by the GC programs' institutions to which they apply. Although participants in our study suggested refunding admissions fees to racial/ethnic minority students who receive an interview, this practice could introduce ethical challenges with regard to individuals who are not interviewed or others experiencing financial hardships. Nonetheless, additional infrastructure to recruit and support racial/ ethnic minority students is critical for substantial progress toward achieving diversity.

Given the variety of cost barriers noted in this study and others (Stoddard et al., 2021), identifying approaches to lower the financial burden at other touchpoints along the journey to becoming a genetic counselor is warranted. For example, allowing interviews to be conducted over video conference, or providing on-campus housing and meals for interviewees were suggestions provided by our study participants. Many programs conducted interviews remotely in 2020 due to the COVID-19 pandemic which provides an opportunity to assess the impact of remote interviewing, compared to costly

in-person interviewing, on increasing diversity in the genetic counseling field.

Diversity infrastructure must also include necessary support to optimize the ability of underrepresented individuals to successfully complete GC programs and attain positions in the GC profession (Bryant et al., 2014). Given that participants in our study reported challenges in passing the ABGC board examination, graduate programs should consider additional ways to support graduates. This is critical given that genetic counselors must pass the examination to gain or maintain employment in the GC field. Additional considerations related to the board examination illustrate the many interwoven factors to consider. As mentioned by a participant in our study, the ABGC has not released statistics on the pass rate for racial/ ethnic minority students, including those with English as a second language. However, ABGC board members have committed in their annual publication (ABGC, 2020) to hire an external reviewer to evaluate examination items and examination development processes for explicit bias, as well as provide more transparency about the examination, and host a forum for discussion around examinationrelated barriers faced by racial/ethnic minority genetic counselors. Although transparency is important, the potential for unintended consequences should be noted. For example, if substantial ethnic/ racial differences were found in ABGC board pass rates, then the revised Accreditation Council for Genetic Counseling (ACGC) standard that will soon require accredited GC programs to post board examination first time pass rates has the potential to negatively impact efforts to diversify the profession. Although there may be no published evidence of outright or intentional discrimination in GC program acceptance or completion rates, the experience of participants in our study and others indicates a need for GC programs, ACGC, and ABGC to evaluate their assessment and teaching practices to consider how these practices might differentially impact underrepresented groups.

While information reported by our participants provides a starting point for building or enhancing diversity infrastructure, additional formative research may be necessary to capture information relevant to a specific underrepresented group, region, and/or program. Furthermore, strategies to build diversity infrastructure should be supported by evidence, which is limited for the field of GC (Channaoui, Bui, et al., 2020). A 2018 review article (Simone et al., 2018) concluded that a multi-faceted approach may be more valuable rather than focusing on a single intervention. However, the most abundant evidence of success was among interventions targeting the admissions process, including the following key features: awarding points for underrepresented minority status; altered weighting of existing admissions criteria; and use of application assistance. Enrichment programs that included study skills/ time management and exposure to clinical or research experience, mentoring, application assistance, or standardized test preparation were also effective across most studies taking this approach. Notably, the authors of the review article were concerned that interventions to increase diversity have increased the competitiveness of underrepresented candidates but have not increased the pool of

underrepresented candidates by promoting interest in health professions, and they advised that more is needed to promote interest in health professions.

4.1 | Study limitations

As with all self-report research, it is possible that recall bias and social desirability bias could limit or influence participants' responses. However, every effort was made to ensure that participants felt comfortable sharing their experiences openly and without judgment. Additionally, we acknowledge that each individual who participated in this study is unique, and although we identified some common themes, the goal was not to generalize to all racial/ethnic minority groups or comprehensively represent the experiences of any one group. There were several unique experiences that continued to emerge during data analysis, but theoretical saturation was not necessary to gain valuable insights from the Journey Mapping approach. Nevertheless, we recognize that each of the themes identified across touchpoints warrants further study, and additional interviews are required to identify a more comprehensive list of barriers/facilitators and achieve full saturation. Finally, the results of this study reflect the experiences of those who successfully went through the process of applying to and were accepted into a genetic counseling program. Thus, findings may miss some very important barriers to application and/or enrollment faced by racial/ethnic minority individuals who were not admitted to a genetic counseling program.

4.2 | Study strengths

Notable strengths of this study included the use of two independent coders to increase reliability and trustworthiness of findings, as well as representation of individuals from programs across all regions of the country, and our focus on multiple touchpoints along the genetic counseling journey. To our knowledge, this is also the first study to use Journey Mapping in the context of genetic counseling as a process-specific and system-oriented method to identify multiple opportunities for improvement from the perspectives of those who are impacted by such processes and systems. This study is important in that it presents diverse views, confirms findings of prior studies, outlines suggestions that may help recruit and support racial/ethnic minority students, and, ultimately, contributes to the literature on increasing diversity within the genetic counseling field.

4.3 | Future research

Future survey-based research with a larger sample would be required to better delineate, understand, and compare variation in perceptions and experiences among individuals across diverse racial and ethnic groups. In particular, surveys could be developed and administered to

confirm barriers/facilitators identified at each touchpoint along the genetic counseling journey explored in this study. Additionally, findings from this study which reinforce those from previous research provide sufficient support for the need to develop and test interventions to address some persistent challenges to diversifying the genetic counseling field. Finally, although we acknowledge a broad definition of diversity, this study specifically focused on approaches to increase representation from underrepresented racial/ethnic minority groups. Ultimately, we anticipate that this research will lead to improved racial/ethnic and other diversity within the GC profession and translate to improvements in patient care (Biesecker, 2018).

AUTHOR CONTRIBUTIONS

Tatiana Alvarado-Wing, the first author, has made substantial contributions to the study conception and the acquisition and analysis of data for the work: she had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. She is responsible for drafting the work along with subsequent revisions for important intellectual content; gives final approval to the version being published; and agrees to be accountable for all aspects of the work in enduring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. She completed this work as to fulfill a degree requirement as part of her genetic counseling training. Deborah Cragun has made substantial contributions to the study conception; and revising it critically for important intellectual content; and gives final approval to the version being published; and agrees to be accountable for all aspects of the work in enduring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Alicia Best has made substantial contributions to the study conception; and revising it critically for important intellectual content; and gives final approval to the version being published; and agrees to be accountable for all aspects of the work in enduring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Jennifer Marshall has made substantial contributions to the study conception; and revising it critically for important intellectual content; and gives final approval to the version being published; and agrees to be accountable for all aspects of the work in enduring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Joanne Gomez has made substantial contributions to the analysis of data for the work; and revising it critically for important intellectual content; and gives final approval to the version being published; and agrees to be accountable for all aspects of the work in enduring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

All of the authors declare that they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

This study was reviewed and deemed exempt by the University of South Florida's Institutional Review Board. All participants provided informed consent before filling out a demographic survey for voluntary participation. Participants then provided verbal consent prior to each recorder interview. No identifiable information is reported in this study.

ANIMAL STUDIES

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

DATA AVAILABILITY STATEMENT

The data that support the findings of this study may be available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Tatiana E. Alvarado-Wing https://orcid.org/0000-0003-4986-3838

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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