Journey Mapping the Minority Student’s Path Toward Genetic Counseling: A Holistic Picture

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Abstract

Reasons for limited ethnic and racial diversity among genetic counselors in the United States may be elucidated through better understanding the experiences of minority students who are attending genetic counseling graduate programs as well as recent graduates. Semi-structured interviews were conducted with minority participants using Journey Mapping to elicit touchpoints that positively or negatively impact success at varying points on the path to becoming a genetic counselor. Touchpoints with negative impacts include; late awareness of the profession, observing the lack of diversity in the field, the financial burden of the application process, and microaggressions from peers, program leadership, and clinical supervisors. Touchpoints with positive impacts include; group or personal mentors, opportunities to interact with practicing genetic counselors, the opportunity to perform mock interviews for the admissions process, program interviews with a conversational interview style, and attending programs in a diversity city with a diverse patient population. Results suggest that larger investments in mentorship programs for prospective students, lowering the financial burden, and addressing non-minority implicit bias would provide support, resources, and the safe spaces these students feel they need.
Introduction

In 2016, the United States Department of Education updated the demographic information on the field of genetic counseling, showing the profession is 88.1% non-Hispanic White (Department of Education, 2016). This highlights the lack of minority representation in the field, since about 25% of the U.S. population is of a diverse background, with estimates projecting up to 50% within the next 50 years (U.S. Census Bureau, 2018). The lack of minority representation and its negative effects on quality and access to healthcare have been well documented in various medical field professions (Smedley et al., 2003; Smith et al., 1993; Sullivan, 2004). Barriers and facilitators of diverse student populations to secondary education and graduate programs that feed into these professions have also been well documented and seem to be consistent across various medical professions (Looney, 1992; Saenz, 2000). The National Society of Genetic Counselors (NSGC) has been trying for decades to increase the ethnic and racial diversity of genetic counselors in the United States but numbers still remain far under that seen in other health professions (Mittman & Downs, 2008a). This suggests a unique part of the story, when it comes to genetic counseling, may still be missing from the literature. Journey mapping is an evaluation tool that has been previously used in social services, education, and customer-service interactions to create a holistic picture surrounding the process of interest and the impact different stakeholders have in that process (Crunkilton, 2009). This study used the journey
mapping approach to describe how students from diverse ethnic/racial backgrounds become aware, apply, and graduate from genetic counseling graduate programs.
Methods

The following study was reviewed and approved by the University of South Florida institutional review board. The first author, who is a female, second year genetic counseling master’s student, performed all the semi-structured interviews in this study after being trained in interviewing techniques. A second coder, who is female, carries a bachelor’s in public health, has qualitative analysis research experience, identifies as an underrepresented minority, and is trying to obtain admission into a graduate program of study herself, aided in data analysis. Both women have a personal and professional interest in the topic of institutional racism and its impact on health disparities.

Participant Recruitment

Individuals were recruited in order to gain insights from under-represented minority individuals with diverse racial and ethnic backgrounds, who were ages 18 and up who did not fully identify as Non-Hispanic White, Caucasian, or of European decent.

Participants consisted of current students in genetic counseling programs within the United States and practicing genetic counselors who graduated from an accredited genetic counseling program in the within the last three years. Recruitment involved sending an e-mail through the NSGC listserv and asking program leadership to forward an introductory email and a link to the consent form to any current or former students who might meet inclusion criteria.
Procedure

The study involved 30-60 minute semi-structured interviews with individuals who volunteered to participate. Emails describing the study asked individuals to review the consent form and complete a demographic survey if they meet inclusion criteria and were interested in being interviewed. The first author arranged and conducted all interviews using a semi-structured interview guide. A week before the agreed upon interview date, an email was sent to the participant as a reminder about the interview time and date and included the questions to be asked during the interview so that the interviewee had time to review the questions. All interviews were conducted over the phone. Prior to the 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 any questions pertaining to the study or interview guide prior to starting the interview. Verbal permission was obtained from each participant to record the interview.

The identity of the participants was matched to the chronological number of the interview so that the name of the participant was not audio recorded. The recordings of the interviews were stored securely.

Instrumentation

Questions included in the interview guides were designed using the Success Case Method (Brinkerhoff, 2003) to elicit – thoughts, feelings, barriers, and opportunities at different touchpoints on the individual’s journey to becoming a genetic counselor. Touchpoints are interactions with various persons, institutions,
or experiences that have a positive or negative impact on the individual’s path to becoming a genetic counselor. The questions elicit the participants lived experience and reflection and were generally divided into 7 sections that represent chronological landmarks along the individual’s path. These sections begin with gaining awareness of the genetic counseling profession, then move to the decision to apply to a graduate program, factors in selecting the programs, the application and interview process, completing the program and beyond. Each section begins with an open-ended question and additional planned and spontaneous probes were included in several sections to obtain further detail about each individual’s experience. As an example, the opening question of “Would you please describe how you first heard about genetic counseling?” was asked. Additional probes under this question were “When was this?”, “What information were you given?”, “What did you first think about the profession?”, and “What interested you the most?”.

**Data Analysis**

All interviews were recorded with the participants’ permission. After each interview was conducted, the first author listened to the recording and used a modified version of the interview guide to list touchpoints that fell under each question. She then attached a label of positive or negative to each touchpoint indicating the overall impacts the experience had on the participant. The touchpoints were then put into a participant specific table that contained all seven sections listed above and whether the touchpoint fell into the following categories; positive, negative, racial/ethnic considerations, and ideas for improvement. Racial and ethnic considerations are defined as touchpoints or thoughts directly related to the racial or ethnic identity of a participant, do not necessarily fall into the other
categories, but are significant to their journey. A second coder was assigned to independently analyze each recording following the same instructions described above. The two coders compared touchpoints and the positive negative label assigned to each. They compiled a master table that contained all touchpoints and related categories. When the two coders did not find the same touchpoint or labeled a touchpoint within different categories, the coders, together, went back and re-listened to the respective recording and came to consensus. From the master table, the most common themes were identified and reported. These common themes were used to create a journey map that describe several shared experiences of minority individuals as they gain awareness of the genetic counseling profession and move through graduate school and beyond. Areas for systems improvement that were reported by participants were also compiled.
Results

Detailed characteristics of the 16 study participants can be found in Table 1 and Table 2. The participants represent 11 different genetic counseling programs from all five U.S. regions as defined by the U.S. Census Bureau. Six of the participants are practicing genetic counselors while the remaining ten are first or second year graduate students. Results are organized by sections that represent the chronological progression throughout the journeys with additional considerations described at the end. Each chronological category describes the main positive and negative touchpoints that were common to several participants. When applicable to a particular section, the touchpoints are followed by participants’ suggested improvements and/or reported positive aspects of racial/ethnic diversity.

Table 1: This table provides details about the participants’ characteristics

<table>
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<th>Participant Characteristics</th>
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<td>Mid-West</td>
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<td>West</td>
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Table 2: This table provides details about the participants’ racial and/or ethnic reported identities

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<td>Hispanic or Latino</td>
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<td>Jewish</td>
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<tr>
<td>Total</td>
<td>16</td>
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</tbody>
</table>

**Awareness**

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

"My mom happened to be reading a magazine and in it was 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, I can’t remember if I was a sophomore or junior in high school. 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

Of the remaining individuals, most gained awareness as juniors and seniors in college or after graduation. This late awareness sometimes resulted in the need to take additional courses as a non-degree seeking student to meet admissions requirements. This touchpoint was labeled to have a negative impact as these
individuals were often already working full-time jobs and had to take additional courses as non-degree seeking students and often had to pay out-of-state tuition or did not qualify for financial aid.

“It feels like a game of catchup 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 called for institutions to focus on increasing awareness in minority communities with an emphasis on the earlier the better and attending career days at Historically Black Colleges and Universities (HBCUs).

**Decision to Apply**

Once participants became aware of the profession and began their research to find further information, most individuals 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 include the NSGC and graduate program websites. Additionally, many participants reached out to practicing genetic counselors for informational interviews. All these aspects were 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 visual lack of diversity in the field and the difficulty in distinguishing the difference between programs based on their online information. At least five participants mentioned the lack of racial/ethnic diversity when doing research about genetic counseling. This lack of representation was a motivator for some prospective students, as they saw the need to fill that gap in their communities. For others it made them question if they would fit in or how being the only minority student in a program would affect them once they got in. Others noted the lack of diversity, but didn’t feel it was a deterrent for themselves.

“The first thing I noticed was, wow, everyone is White female. I didn’t feel that necessarily that was a deterrent for me, but 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 strange because we saw a lot of diversity in other medical positions so why not genetic counseling.” – Participant 16, Negative touchpoint

Selection of Programs for Application

There were many characteristics that individuals were looking for when selecting genetic counseling programs to apply to. The most common positive touchpoints expressed were programs located in a larger, diverse city with diverse patient populations and with heavy clinical experience worked into the curriculum.
“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 include the ability to counsel in another language and programs that explicitly mention the importance of diversity on their websites. Improvements mentioned involve providing diversity scholarships to individuals who meet the high standard of admission but would struggle financially.

**Application Process**

This section includes the path individuals took to build their resumes and gain the needed experience to submit applications to accredited genetic counseling 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 seemed to include access to genetic counseling internships or working as a genetic counseling assistant. Individuals expressed how these experiences where built around a mentor relationship. During these experiences they were exposed to what genetic counselors do in and out of clinic daily, as well as exposure to institutional grand rounds, tumor boards, and research projects. The practicing genetic counselors who participated in these types of experiences also helped applicants in writing their personal statements and getting ready for the interview process. When mentors and applicants shared a similar minority status the impact seemed to be even stronger as a more personal relationship was established and advice on how to navigate this path as a minority was shared and valued.

“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 negative touchpoints expressed included a feeling of still not fully understanding the qualifications that were expected of genetic counseling programs as a whole or the competitiveness around getting into a program. Most of these individuals where only able to gather information through online resources and had limited in person access to practicing genetic counselors. Another major negative touchpoint during the application process was the cost. Submission of applications
can cost around one hundred dollar per program, which comes with no guarantee of further contact or feedback from said school.

*Participant:* "I talked to a couple program directors and they said my GRE score wasn’t high enough, so I took it two more times..."

*Researcher:* “Did you do anything differently to study for the GRE the second time around?”

*Participant:* “Yeah, there was this website called Magoosh, and they have GRE prep, so I paid for that (~$150+) the second time.”

*Researcher:* “and do you feel like that was helpful or made a difference for you?”

*Participant:* “Yeah, I guess so. Oddly enough, the second time I took the GRE I did worse than the first time and that’s why I had to take it the third time and the third time I did pretty good so I guess it helped, I’m not really sure”

– *Participant 6, Negative touchpoint. Estimate of at least $750 spent on GRE alone*

Ideas of improvement mostly involved waiving application fees for individuals that meet household income requirements or potentially refunding fees for applicants who receive a subsequent interview. Removing the GRE as a requirement was also mentioned. A participant noted that individuals who can pay for prep courses and tutors will do better on the exam.

**Interview Process**

This section focused on the lived experiences of individuals 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 often had been through this experience
themselves and could provide applicants with ideas of what to expect and practice mock interviews. Most participants claimed to gravitate toward programs where the interview process 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 read and 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 include an opportunity to practice mock interviews with experienced individuals, programs being more upfront about what to expect on interview days, and ways to lower the financial load of the entire
process. Ideas mentioned that might lower cost included allowing applicants to preform interviews over video conference, or having a diversity day where diverse applicants are all interviewed on the same day and are afforded financial reimbursement for their travel or stay, such as housing on campus with meals included.

**Completing the Program**

There were many touchpoints experienced by the participants while completing their programs. Through their duration in the program, positive touchpoints that were found include; mentorship from second year students or practicing genetic counselors to help navigate assignments and clinicals, programs with diverse leadership and cohorts, and leadership that placed specific value in having inclusive and sometimes challenging conversations surrounding implicit biases. Other valuable sources of support mentioned by participants was that form 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, you know, 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 microaggression from classmates, leadership, and patients. Most participants felt
that these microaggressions were based in ignorance and lack of awareness of how
to interact with individuals from different backgrounds. Many participants expressed
feeling like they were made to be the spokesperson for the minority community
they identified with and most, but not all, saw this as an added and unfair burden.
Many individuals felt this added stress to their mental health throughout the
program and mentioned knowing that there where resources available, but the
initiative was placed on them to navigate the logistics of finding those resources
instead of the path being clearly laid out.

“Well I can think of the negative one [most negative influence on her journey] right
off the bat and that happened before I even got into a program, this was when I
was shadowing. I was shadowing a GC who trying to explain dysmorphology to me
and, I know they didn’t mean it this was 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 taking 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 -microaggressions

Participant: “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.”

Researcher: "and was this a GC that worked within your program or was it a guest speaker?"

Participant: "It was someone that worked within the program."

Researcher: “and do you know if she had any specific training that made her qualified to teach a multicultural counseling class?“

Participant: “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 GC that ended up teaching it." – Participant 15, Negative touchpoint

Improvements mentioned specifically for this section include having diversity training that is up to date and challenges individuals to address their implicit bias. Many participants felt that this training should be done by those who identify with the community that is being discussed, whether that is racial/ethnic minority group, members of the LGBTQ+ community, or persons with disabilities. A few participants mentioned that having GC mentors that where outside of their program would have been beneficial in helping them navigate sensitive topics when program leadership or clinical supervisors were involved.
**Board Exam**

Practicing genetic counselors were asked about their process for studying and taking the board exam. Positive touchpoints in this section include 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 re-review those...”

– Participant 12, Positive touchpoint

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

“There’s a GC that I interact with here [in her city], she also evolved 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 & thoughts about not passing the board exam

**Racial/Ethnic Considerations Spanning Across the Journey**

This section includes thoughts and touchpoints related to the lived experiences of participants as minority individuals that cut across multiple points in the journey. The first author felt these were specifically important to include to further progress the discussion about diversity and inclusion in the genetic counseling field.

“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 interviewees felt that the pressure to represent their minority community was an added burden, three of the participants saw this as a positive opening to provide further depth and context 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 felt a cultural pressure around the decision to become a genetic counselor, as opposed to a physician, and struggled with communicating this decision with their families because their families saw becoming a physician as a more prestigious goal or thought physicians would perform what was described as a genetic counselor’s role. Over a third of participants felt frustrations toward their classmates, and the genetic counseling community as a whole, as they felt there is an academic understanding of racial disparities and their negative impact on healthcare delivery but they made no further effort to address these problems in themselves or in outside interactions.
Discussion

Due to the overall lack of progress the genetic counseling field has made in diversifying its members, this study sought to find any unique information missing in the research when it comes to genetic counseling specifically. The novel approach of journey mapping was used to elicit the experiences of racial and ethnic minority individuals as they go through the process of becoming a genetic counselor. This research identified multiple barriers and facilitators experienced by these individuals but most of these experiences are not new to genetic counseling. Schoonveld et al., (2007) identified many of the same findings such as late awareness, microaggressions, pressure to be diversity representatives, and financial cost among genetic counseling students and practicing genetic counselors. Many of the recommendations identified by our study participants reflect best practices reported by Mittman & Downs (2008) for increasing racial and ethnic diversity in health careers, such as genetic counseling. These practices include mentors, post-bachelor internships, financial assistance, and creating an inclusive environment for minority students in predominately white institutions. Many of those same facilitators were found to be positive touchpoint in this research study.

So, the question now becomes, why has little changed in the last 10-12 years? The answer may be the ongoing lack of infrastructure to support diversity. Diversity infrastructure, in this context, refers to extended effort and resources that are supported by evidence found in this and past studies (Glazer et al., 2018;
Looney, 1992; Mittman & Downs, 2008b; Saenz, 2000) to bring these individuals in, and almost more importantly, set them up for success once they are here. This may look different from traditional approaches to the application and education model of higher education. Perhaps the best way to find solutions to this problem is to involve those we are trying to help in the process, or better yet, provide them with resources to lead the process. However, it is also imperative that we reflect inwards at our implicit biases that got us in this position in the first place. Many racial justice advocates and authors such as, Rachel Cargle and Layla Saad, would argue that diversity training, and its various forms, does not go far enough in addressing implicit bias. Instead, we must engage in racial justice training that is specifically anti-racist in order to fully come to terms with and undo the societal programing that, we didn’t necessary give permission to exist in ourselves, but is part of growing up in a society that was made by and for White people. Notably there have been steps in this direction. The 2019 NSGC conference held a Confronting White Womenhood workshop lead by Rhiannon Childs that challenged participants to identify how their privilege and implicit bias shows up in daily interaction and how that negatively impacts people of color and other minority groups.

There are changes that can be made at various levels from individual-level to institution-level that can begin to address this problem and many of them have been stated throughout the paper. Based on findings from this study, changes should include targeting education about the profession to minority communities for early awareness. This can be done by individual genetic counselors or by programs requiring students to participate in outreach and educational events at local high
schools, career days at HBCUs, or even the undergraduates at each respective program’s universities. Others mentioned finding ways to also reach a larger male audience and that targeting those in premed majors may be successful. Mentorship opportunities provided a key positive touchpoint for many of our participants and was found to be impactful at every stage of their journey. This type of relationship can be facilitated by individual counselors or on a program/institutional level.

At a program level, those that have access to diverse patient populations or can allow their students to counsel in different languages should explicitly state this on their websites. Diverse applicants were much more attracted to programs that had a “getting to know you” interview style and programs seeking more diversity should look at the structure of their interview process to see what type of environment it is presenting. A few programs have already dropped or are considering dropping the GRE requirement for admissions. This could potentially have a huge impact on diversifying the applicant pool. Minority students statistically do not do as well on standardized testing as their White counterparts and multiple studies have shown that this is not a good predictor of student success or graduation rates and is a barrier to diversity (Miller & Stassun, 2014; Moneta-Koehler et al., 2017; Sampson & Boyer, 2001; Sealy et al., 2019; Wolf, 2014).

Second year student mentors and GC mentors within and outside of the program seem to be extremely helpful to these individuals in navigating and understanding the nuances of getting into and being successful in a GC program. These mentors were stated to be even more impactful when the mentor and mentee identified with the same minority group, though assumptions should not be made, and the individuals should have autonomy in choosing whom they form these relationships
with. ABCG can promote this by giving incentives to practicing GCs who participate in mentorship relationships such as providing a PACs that serve as credit toward board recertification or other such motivators.

Program and institutional issues include the need to decide what, as a profession, should be the minimal level of diversity and inclusion training for our students and members. Some of the participants recall their programs having no specific lectures on the topic while others work this into their everyday curriculum. It would be hard to argue these programs are molding genetic counselors who are equally equipped to engage with diverse patients. Some of our participants suggested that GCs take on a more public health lens to better understand how institutional racism affects racial disparities and healthcare delivery. That we must acknowledge that genetics and healthcare as a whole has a problematic past with communities of color and that instead of trying to brush this off as problems of old, the lessons learned must be understood by all genetic counselors so that we may humbly move forward.

Additionally, cost is another barrier that has been noted in this study and others. Suggested ways to address this include lowering the financial burden at various touchpoints such as, refunding application costs for students who receive interviews, allowing interviews to be done over video conference, providing on campus housing and meals for interviewees, and waiving the match fee for those who meet income requirements. As an example, if I had to take the GRE twice, pay for GRE prep, and apply to five schools, that would be an over one-thousand-dollar investment with no guarantee of any further contact or feedback from a genetic counseling program and costs of in-person interviews dramatically increase that
cost. Cost burdens may also come in the form of student loan repayment post-graduation as individual form some racial and ethnic minority groups will statistically make less than their White counter parts once in the workforce (*USUAL WEEKLY EARNINGS OF WAGE AND SALARY WORKERS-FOURTH QUARTER 2019*, n.d.), though NSGC does not current break down salary difference based on this information. Financial issues may also be a reason that graduates begin jobs earlier and take less time off to study for the board exam.

Additional considerations related to the board exam illustrate how complicated making change can be and the many interwoven factors to consider. A participant in this study mentioned that ABCG has not released statistics on the pass rate for minority students and students with English as a second language. The reason for this is unknown, but what if the numbers did not look good and they were released? Would programs be less likely to admit these students given the new requirement to display their first-time board pass rates on their websites to be in compliance with ACGC standards? Although ACGC created this standard to be in alignment with best practices outlined by the Council for Higher Education Accreditation, there is the potential for unintended consequences. This could especially impact diversity in smaller or newer programs and is something that will take careful thought as we consider how we evaluate ourselves, our programs and our education standards.

Individuals who participated in this study are all 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 nuances and experiences that continued to be
uncovered, but theoretical saturation need not be achieved to gain valuable insights from a journey mapping approach.

Strengths of this study include the use of two independent coders to add trustworthiness to the findings, representation of individuals from different programs across all regions of the country, and our focus on multiple points on the genetic counseling journey. This is also the first time journey mapping has been used in the context of genetic counseling. Despite our novel journey mapping approach and over 10 years since other studies published in the GC field about this topic, our findings suggest that limited progress has been made.

Future survey-based research with a larger sample would be required to better delineate and understand variation between racial/ethnic groups. A survey could be created focusing on touchpoints identified here. However, similarities found in this study and those of the past provide sufficient data to start taking action now that would likely help all racial/ethnic minority students and better diversify the field. Numerous ideas for improvement have been identified by multiple studies and what we need now is sustained action and commitment to change within ourselves and our institutions.
References


http://www.aspresolver.com/aspresolver.asp?BIZP;2359431


https://doi.org/10.1080/15228830902755879

Department of Education. (2016). Genetic Counseling. Data USA.

https://datausa.io/profile/cip/511509/#demographics


https://eric.ed.gov/?id=ED356696


https://doi.org/10.1038/nj7504-303a


https://doi.org/10.1007/s10897-008-9160-5


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