DIVERSITY IN THE GENETIC COUNSELING PROFESSION – PERSPECTIVES ON BARRIERS AND MOTIVATIONS

By

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ABSTRACT OF THE THESIS

Diversity in the Genetic Counseling Profession – Perspectives on Barriers and Motivations

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Genetic counselors are providing care for an increasingly diverse patient population with a workforce demographic that does not necessarily reflect the shifting global community. Although the genetic counseling profession is becoming more diverse over time, methods of diversification through recruitment and graduate-level training are still being explored. 34 current genetic counseling students and genetic counselors who identify as underrepresented individuals participated in an online, qualitative survey that assessed the career barriers and motivations they faced in entering the genetic counseling field, their experiences in graduate training programs and clinical settings, and their suggestions for expanding diversity in the profession. The term "underrepresented" could be used to describe any person who identifies as a minority, not limited to gender or ethnicity. Demographic factors participants identified with include ethnicity, sexual orientation, being a member of the disability community, international status, gender, religious/spiritual beliefs, and age upon entering the field. Several perceived barriers (e.g. late introduction to the field, financial factors) and motivations (e.g. family support, relationships with peers and mentors) were highlighted. Participants generally felt

supported and accepted in graduate training programs and in their practice, but occasionally experienced instances of subtle or unintentional discrimination. Current perspectives from underrepresented individuals in the field demonstrate that it is necessary to preserve and encourage diversity in the genetic counseling profession. Suggested methods to diversify the field include increased community outreach at earlier ages and in diverse communities, more accessibility to training programs, and improved cultural competency training in graduate programs.

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Introduction

Genetic counselors are providing care to patients who are from increasingly diverse populations; however, the workforce itself does not reflect the changing demographic of the United States. According to the Professional Status Survey of 2019, which assessed current genetic counselors in the workforce, 95% of respondents identify as female while 5% identify as male, and 90% of respondents identify as being White or Caucasian (*Professional Status Survey 2019: Demographics & Methodology*, 2019). Although the population of ethnic minorities in the United States is projected to increase through 2050, ethnic minorities are subject to receiving lower quality healthcare due to factors such as differences in language, geography, and cultural familiarity, even after health insurance status and income are controlled (Day, 1996; Institute of Medicine, 2003). Individuals from ethnic minority groups are less likely to use genetic counseling services due to lack of awareness of such services, limited access, socioeconomic factors, and distrust of how genetic information is used (Saulsberry & Terry, 2013). These lower rates of uptake also have an impact on the clinical utility of genetic testing for ethnic minorities because research data will be limited for the reclassification of certain genetic test results, such as a variant of unknown significance (Saulsberry & Terry, 2013). Reliable information about genetic variation among underrepresented minority populations is important for the accessibility of precision medicine; therefore, the benefit of precision medicine requires incorporation of patient-centered genetic counseling practices that are focused on patient understanding with respect to culturally-sensitive lifestyle and behavioral changes (Halbert & Harrison, 2018).

Diversity in the field of healthcare will strengthen cultural competence, which in turn will allow healthcare providers to better assist patients of various backgrounds (Sullivan, 2004). Cultural competence consists of knowledge, skills, attitudes, and behaviors practitioners must adopt in order to provide adequate healthcare services to diverse populations (Cohen, Gabriel, & Terrell, 2002). The timeframe to develop one's cultural competence can begin in the training and education stage. It is suggested that diversity in the educational setting, such as universities, allows students to prepare for integration into a diverse society (Cohen, Gabriel, & Terrell, 2002). In addition to fueling greater cultural competence in the genetic counseling field, expanding diversity in the workforce will also allow underserved communities to access healthcare services due to greater representation of minorities in the field, broaden research goals to reflect interests of diverse members of society, and expand diversity in related fields that are involved in public policy-making and healthcare management on the governmental level (Cohen, Gabriel, & Terrell, 2002). It becomes evident that efforts to increase diversity in the genetic counseling profession should be developed further.

Previous qualitative studies have primarily been interview-based and have explored perspectives of ethnic and gender minorities. Late and/or accidental introduction to the field of genetic counseling, difficulty obtaining information about the field, and the connotation that genetic counseling is a female career choice are factors that are viewed as possible career barriers for underrepresented individuals (Schoonveld, Veach, & LeRoy, 2007). How these perspectives have changed over time with the advancement of the genetic counseling profession has not been evaluated.

Diversity may also encompass backgrounds not limited to ethnicity and gender differences. Although not an exhaustive list, religious or spiritual affiliation, sexual orientation, involvement in the disability community, international status, and age upon entering a genetic counseling graduate program are a few other factors that may influence the training process and practice of a genetic counselor. Recruitment of students who belong to various social groups and inclusion of interactions with members of these groups in graduate-level training have previously been suggested for improved training, particularly in regards to disability and LGBTQ communities (Madeo, Biesecker, Brasington, Erby, & Peters, 2011; Glessner, VandenLangenberg, Veach, & LeRoy, 2010). Therefore, assessing perspectives of those who identify as underrepresented in the broader sense in the existing genetic counseling profession may shed light on possible approaches to diversifying the field and maximizing career support.

The purpose of this study is to assess the current experiences of genetic counseling students and genetic counselors who identify as underrepresented, and specifically assess their perceived barriers to and motivations for entering the field of genetic counseling, undergoing training at a graduate program, and working in a clinical setting. The study also explores the suggestions underrepresented individuals have for increasing diversity in the genetic counseling field. In the context of this study, the term "underrepresented individual" is used to describe any person who identifies as a member of a community that is not part of the majority.

Based on interview questions developed by Schoonveld et al. (2007), we conducted a qualitative survey that was distributed to genetic counseling students and genetic counselors who graduated or will graduate from an ACGC-accredited genetic

counseling graduate program in the years of 2016 to 2020. 34 respondents identified as underrepresented and completed the study survey. 15 respondents reported they were current students and 19 respondents reported they were current genetic counselors. 4 respondents identified as male and 30 respondents identified as female. Respondents' ages ranged from 18 to 69-years old. Respondents who practiced genetic counseling reported that they worked in adult, pediatric, cancer, prenatal, and laboratory settings. Demographic factors underrepresented in the genetic counseling profession that the respondents identified with include ethnicity, sexual orientation, member of the disability community, international status, gender, religious/spiritual beliefs, and age upon entering the field. 19 respondents identified with one underrepresented group while 15 respondents identified with two or more underrepresented groups.

A total of 16 domains were formed from evaluating participants' perspectives on barriers, motivations, and general experiences encountered in entering the genetic counseling field, training in a graduate program, and practicing in a clinical setting. Participants' suggestions for expanding diversity in the genetic counseling field and reasons for this expansion were also assessed in this study.

Methods

Instrumentation:

A 27-question qualitative survey was distributed to genetic counselors and genetic counseling students who graduated from an ABGC-accredited genetic counseling graduate program in the years of 2016-2020. The survey was hosted on Qualtrics and contained multiple choice and open-response questions about demographic information, introduction to the genetic counseling field, sources of support for and barriers to entering the field, training, clinical work, and suggestions for incorporating more diversity in the profession. The survey questions were adapted and modified from interview questions used in the study by Schoonveld et al. (2007), which explored ethnic and gender diversity in the genetic counseling field (See Appendix A). Survey questions were displayed in the same order on Qualtrics and took approximately 25-30 minutes to complete. Participants were allowed to complete the survey in more than one sitting. Survey responses were collected anonymously.

Participants:

Participants were recruited by two methods. For the first method, a letter of invitation to take the study survey was emailed to program directors of genetic counseling graduate programs, which was then circulated among genetic counseling students currently enrolled in graduate programs. For the second method of recruitment, the letter of invitation for the study survey was published in a weekly digest sent to all registered NSGC members as part of the NSGC Student Research Survey Program. A follow-up notification of the study survey was posted in the subsequent week's digest.

The letter invited genetic counselors and genetic counseling students who self-identified as underrepresented to participate in the study. The final sample of participants consisted of 15 current genetic counseling students and 19 current practicing genetic counselors.

Data Analysis:

Results from the survey responses were manually analyzed using a modified Consensual Qualitative Research (CQR) method (Hill et al, 1997). This method was originally used for analyzing topics that naturally arise from interview transcripts without consideration of the protocol for the interview. In this study, the researcher first assessed responses for each survey question independently and created domain names to fit the major topics addressed. The researcher then continued to use and build upon these domains when analyzing subsequent survey responses. A total of 16 domains arose from the data. After initial data analysis to identify domain names, the researcher assessed the survey responses again to confirm that the domains were stable and applicable to the data collected. The domain list was also reviewed by other members of the research team for clarity.

After the identification of domain names, the researcher coded survey responses into each domain. The coding process assigned survey responses to certain domains depending on specific phrasing used in the responses. To conduct a cross-case analysis for the survey responses, the researcher formed categories, which were summaries of each survey response, within each domain. The research team members independently reviewed the grouping of survey responses into each domain and category. The final results from the survey yielded 16 domains total.

Results

Demographic Information:

A total of 34 participants completed the study survey, which was accessed online through Qualtrics. 80 incomplete surveys were not considered for final data analysis. Participants were composed of 4 males and 30 females. 19 participants were current practicing genetic counselors and 15 participants were current students. 19 participants identified with one underrepresented demographic factor while 15 participants identified with two or more underrepresented demographic factors. Demographic factors include ethnicity, gender, sexual orientation, religious and/or spiritual beliefs, socioeconomic status, international status, being a member of the disability community, and age upon entering the genetic counseling field. The participants' ages ranged from 18 to 69-years old. To preserve anonymity, participants identified with an age range of a specific decade. The sample of participants represented genetic counseling students and practicing genetic counselors nation-wide who graduated from genetic counseling graduate programs 2016-2020. Table 1 outlines the percentages of the demographic composition of the sample.

Table 1: Demographic Information of Participants ($N = 34$)

Category	**Prevalence (*n*)**	**Percentage**
Males	4	11.8%
Females	30	88.2%
Current Students	15	44.1%
Current Genetic Counselors	19	55.9%
Demographic Factors		
Participants Who Identify with Two or More Underrepresented Groups	15	44.1%

Participants Who Identify with One Underrepresented Group	19	55.9%
Ethnicity	20	58.8%
Sexual Orientation	9	26.5%
Religious and/or Spiritual Beliefs	4	11.8%
Gender	4	11.8%
International Status	4	11.8%
Disability Community	3	8.8%
Age Upon Entering the GC Field	2	5.9%
Socioeconomic Status	1	2.9%

Participants' Introduction to the Genetic Counseling Field:

The majority of participants were introduced to the genetic counseling field in college rather than in high school or in earlier stages of education. Participants were also exposed to genetic counseling through online research. Introduction to the field in education settings consisted of lectures given by genetic counselors or genetic counseling students, mention of genetic counseling as a career option by professors or advisors, and general discussions about STEM careers. Courses in college or high school that bring up genetic counseling as a profession tended to be biology and human genetics courses. The remaining responses attribute introduction to the field to exposure from a family, friend, or acquaintance in healthcare and previous exposure to non-genetic counseling. Table 2 highlights the prevalence of each mode of introduction to the genetic counseling field.

Table 2: Introduction to the Field ($N = 34$)

Category	**Prevalence (*n*)**	**Percentage**

College	14	41.2%
Online research	7	20.6%
Previous Exposure to GC (Patient/Family or Work)	5	14.7%
High School	4	11.8%
Friend, Family, or Acquaintance in Healthcare	3	8.8%
Previous Exposure to Counseling	1	2.9%

Perceived Support and Barriers for Entering the Field:

Survey responses assessing participants' perceived support and barriers to entering the field of genetic counseling fall into three domains—career support, career barriers, and family support and barriers. Table 3 illustrates the different categories that fall into each domain, the prevalence of each category in survey responses, and the percentages of each category in comparison to total distinct responses. This method of calculating percentages was implemented because most survey responses per individual contained more than one distinct category.

Domain 1: Career Support

The career support domain contains 15 different categories. The majority of participants cited that the combination of science and counseling in genetic counseling was a factor that drew them to the field. The interactive nature of the profession in relation to patients and other healthcare providers and heavy involvement of genetics in the field are two factors that were also frequently mentioned. Some of the other factors that arose in responses include opportunities to educate others, opportunities to help

patients, previous education in genetics, biology, or psychology, the salary of a job as a genetic counselor, and the relatively short two-year training period in graduate school.

Domain 2: Career Barriers

The career barriers domain contains six categories that reflect participants' perceived hesitation towards entering the genetic counseling field. The majority of participants had no reservations towards entering the field. Other barriers mentioned include lack of diversity as a career barrier, lack of career growth, cost of treatment, perceived respect and/or treatment from other healthcare providers, the newness of the field, lack of confidence, and burnout.

Domain 3: Family Support and Barriers

Assessment of family attitudes towards entering the genetic counseling field yielded three categories—encouragement, limited knowledge of the field, and mixed support. Most participants expressed that they felt that their families were supportive and encouraging towards their endeavors to pursue genetic counseling as a career. A smaller proportion of participants expressed that their families lacked knowledge of the field of genetic counseling, which could have hindered their initial support for them; however, most participants who cited lack of knowledge as a factor also noted that their family members were open to increasing their understanding of the field. One participant mentioned feeling mixed support from their families when they made decisions to enter the field. Similarly, the participant mentioned their family's lack of knowledge of the profession contributed to mixed support.

Table 3: Career Support and Barriers

Category	Prevalence (*n*)	Percentage
Domain: Career Support	*N* = 69	
Combines Science and Counseling	19	27.5%
Interactive	12	17.4%
Field in Genetics	10	14.5%
Opportunities to Educate	6	8.7%
Helps Others	3	4.4%
Previous Education	3	4.4%
Salary	3	4.4%
Two-Year Graduate Program	3	4.4%
Evolving Field with Continuous Learning Opportunities	3	4.4%
Personal Experience in Healthcare Field	2	2.9%
Flexibility within Field	2	2.9%
Job Opportunities	2	2.9%
Good Work-Life Balance	2	2.9%
Personal Experience with Health Conditions	2	2.9%
Other	3	4.4%
Domain: Carrier Barriers	*N* = 21	
No Reservations	7	33.3%
Lack of Diversity	4	19.1%
Lack of Career Growth	2	9.5%
Cost of Training	2	9.5%
Treatment by Other Healthcare Providers	2	9.5%
Other	4	19.1%
Domain: Family Support and Barriers	*N* = 49	
Encouragement	30	61.2%
Limited Knowledge of Field	18	36.7%

Mixed Support	1	2.0%

Note: Singular, distinct responses that did not fall into any predetermined categories were collected under "Other."

Factors for Choosing a Graduate Program:

Participants specified their factors for choosing a graduate program, their satisfaction with their program, and whether or not diversity was an influencing factor for attendance. For the top factors taken into account when choosing a graduate program (N = 123), 23% of responses mentioned the importance of location, 15% of responses mentioned the impact of tuition cost and financial benefits on decision-making, and 9% of responses mentioned the importance of program structure and curriculum. The majority of participants believed their graduate program met or exceeded their expectations (N = 40), making up a total of 65% of responses. Those who did not think that their program met their expectations cited reasons such as needing to feel better integrated into the class and improved cultural awareness. When assessing whether or not diversity had an impact on attendance of a graduate program (N = 34), the majority of participants agreed that diversity was or would have been an influencing factor, making up approximately 60% of the responses; however, several of these participants also noted that diversity was a factor they would consider after other factors, such as program location and cost of tuition. The competitive nature of matching to a program due to limited spots in each graduate program also made diversity less pressing of a factor to consider when evaluating programs for attendance.

Experiences Within Genetic Counseling Graduate Programs:

A total of 13 domains emerged from assessment of participants' experiences within genetic counseling graduate programs. These domains examined barriers and support systems in training programs, differences in treatment with respect to background, and attitudes towards feeling accepted by members of graduate programs. These domains are listed in Table 4 with their corresponding prevalence and percentage.

Domain 4: Barriers in Training Programs

When assessing barriers participants encountered in their graduate training programs, 8 categories emerged. The top perceived barriers faced within training programs consist of cost and factors related to admissions and prerequisites. A portion of participants did not believe there were any barriers within training programs. Other perceived barriers included personal health problems, lack of openness towards a student's underrepresented background, lack of support, and distance from home. Participants noted that they had financial concerns in the interview process due to travel expenses, application fees, and fees to enter the matching process. Another concern was the cost of tuition without additional financial aid. Barriers related to admissions and obtaining prerequisites was another prominent theme in this domain. Participants frequently mentioned that access to genetic counseling shadowing opportunities and volunteering experience was limited depending on geographic region and time constraints.

Domain 5: Support Systems for Duration of Program

When evaluating support systems participants had during their time in their graduate programs, 10 categories emerged. Support from family and friends were most frequently mentioned. Some of the other sources of support participants received include classmates in graduate school, professional networks and mentors, faculty in graduate programs, colleagues, and counselors and/or therapists. Several participants specified that they sought support from individuals in professional networks and mentors with whom they share a similar underrepresented background.

Domain 6: Different Treatment in Interviews and in Graduate Program

Three categories arose from examining participants' perceptions of differences in treatment during the graduate program interview process and during their time in graduate programs—there was no different treatment, there was different treatment, or there was occasionally different treatment. The majority of participants answered that they felt no difference in treatment in both interviews and in their graduate program. Some participants felt that they were treated differently in both settings. A few participants felt occasional differences in treatment. Male participants experienced direct mention of their gender in both interviews and in the classroom setting when they were directly asked questions about counseling approaches from a male point of view. Many participants who had differences in ethnic background and/or international status cited that they felt the need to be a representative or spokesperson of the demographic group they belong to because they were asked questions about their respective group. "Invisible" factors, such as sexual orientation and having a disability that is not apparent upon a first impression, allowed some participants to feel that they were treated more or

less the same as their peers in graduate programs and in interviews. Overall, most participants noted that differences in treatment they received were subtle and not overt in nature; however, they were still perceptible.

Domain 7: Seeking Out Classmates with Similar Backgrounds

When assessing participants' experiences seeking out classmates within their graduate program who share the same background as them, three categories emerged—classmates with similar backgrounds were sought out over others, classmates with similar backgrounds were not sought out over others, and no classmates shared a similar background. The majority of participants did not purposely seek out classmates who shared the same background as them. Some participants who expressed they did not seek out students with similar backgrounds emphasized that no classmates in their class shared a similar background, while other participants reported that a similar background would not compel them to seek out certain classmates over others.

Domain 8: Impact of Background on Relationships Within Training Program

Four categories surfaced from examining participants' perceived impact their background had on relationships forged within training programs. These categories consist of no impact, neutral impact, generally positive impact, and generally negative impact. The majority of participants reported feeling no impact on their relationships within graduate programs. A portion of participants believed their background had a neutral impact on their relationships. Neutral impact reported by participants entails equal treatment from classmates and faculty, yet having fewer commonalities to discuss in a

conversational setting. The same proportion of responses reported feelings of a generally positive impact and a generally negative impact on relationships formed within programs.

Domain 9: Feeling a Part of the Training Program

When asked if they felt that they were a part of their graduate training programs, the majority of participants replied that they did indeed feel that they were a part of their programs. On the other hand, several participants felt partially integrated into their graduate program, and a smaller proportion of participants felt that they were not a part of their graduate program. Participants who felt well-integrated into their graduate programs felt supported by faculty and classmates. Some of these participants also mentioned that greater diversity in their class contributed to feelings of belonging to the graduate program. Those who felt partially integrated or not integrated into their programs reported feeling a disconnect due to differences in background or perspectives with peers and program faculty.

Domain 10: Times of Feeling Accepted vs. Othered

When comparing participants' instances of acceptance to instances of otherness in training programs, the majority of participants felt accepted sometimes. A smaller proportion of the responses reflect that some participants have always felt accepted within their programs. Another portion of responses suggest that some participants had never felt accepted in their training programs. Participants generally felt most accepted by classmates and program faculty, but would sometimes experience "tokenization" where they were expected to speak up on behalf of their underrepresented group. Several

participants who reported feeling othered noted that this feeling arose during clinical rotations or in group discussions with classmates, during which participants experienced microaggressions and/or believed that their opinions would not be respected by their peers.

Domain 11: Level of Knowledge of Background Within Training Program

Three categories emerged when assessing what participants believed was the level of knowledge people within their graduate program had of their underrepresented background—a limited understanding, a good level of understanding, and no understanding. The majority of participants reported that classmates and faculty had a limited understanding of their background. Although level of knowledge was limited, some participants also reported that their classmates and faculty made an effort to learn about cultural differences and similarities from underrepresented individuals and their level of understanding improved over time. Other participants noted their classmates and faculty members had a basic understanding or their background, but this level of knowledge did not seem to change over time. Another proportion of responses suggests that several participants believed their classmates and program faculty had a good understanding of their background already. A few participants believed their classmates and faculty had no understanding of their background. Participants who believed understanding of their background was lacking reported feeling obligated to teach others about their own background and/or felt that education should be sought on a personal level and not expected of an underrepresented individual to deliver.

Domain 12: Factors to Consider for Improved Understanding of Background

Factors to be considered for improved understanding of an underrepresented background yielded six categories—no recommendations, awareness of one's background, consideration that a background may not be visible, one's level of comfort in sharing information about their background, feelings of isolation, and other. The majority of participants reported they had no recommendations for improved understanding of students' backgrounds within graduate programs. Better awareness of one's background encompassed a smaller proportion of responses. Participants also reported the need to acknowledge the invisibility of certain backgrounds. Factors such as a disability or sexual orientation are not readily apparent. Participants who identified with these factors believed assumptions made based on their appearance, such as assumptions about health or being straight or cisgender, should be tailored to be more inclusive.

Domain 13: Methods of Diversity Inclusion in Training Programs

When evaluating methods of diversity inclusion implemented by graduate training programs, 10 categories emerged. Most participants were unaware of any methods used specifically for diversity inclusion in their graduate program. Many participants reported that there were no diversity inclusion methods implemented by their program. Of the participants who noted that their graduate programs did use methods geared towards diversity inclusion, several reported that their programs included verbal statements on diversity and inclusion in interviews. Some programs had a diversity grant or scholarship built into their admissions process. Other programs held community outreach events to promote themselves. While some programs were reported to use methods to increase

recruitment of students from diverse populations, the majority of participants seemed to not know of their programs' diversity inclusion efforts.

Table 4: Experiences in Graduate Training Programs

Category	Prevalence (*n*)	Percentage
Domain: Barriers in Training Program	*N* = 42	
Cost	14	33.3%
Admissions and Prerequisites	8	19.1%
No Barriers	6	14.3%
Health	3	7.1%
Lack of Openness Towards Underrepresented Status	3	7.1%
Lack of Inside and/or Outside Support	2	4.8%
Distance from Home	2	4.8%
Other	4	9.5%
Domain: Support Systems	*N* = 85	
Family	23	27.1%
Friends	18	21.2%
Classmates	10	11.8%
Professional Networks and Mentors	9	10.6%
Faculty	8	9.4%
Colleagues	6	7.1%
Counselors/Therapists	6	7.1%
Financial Support	2	2.4%
No Support Sought	2	2.4%
Support Groups	1	1.2%
Domain: Different Treatment in Interviews and in Graduate Program	*N* = 34	
No	21	61.8%
Yes	9	26.5%
Occasionally	4	11.8%

Domain: Seeking Out Classmates with Similar Backgrounds	*N* = 44	
No	22	50.0%
No Classmates with Similar Background	12	27.3%
Yes	10	22.7%
Domain: Impact of Background on Relationships Within Training Program	*N* = 34	
No Impact	13	38.2%
Neutral Impact	11	32.4%
Generally Positive Impact	5	14.7%
Generally Negative Impact	5	14.7%
Domain: Feeling a Part of the Training Program	*N* = 34	
Yes	23	67.6%
Partially	7	20.6%
No	4	11.8%
Domain: Times of Feeling Accepted vs. Othered	*N* = 34	
Sometimes Felt Accepted	18	52.9%
Always Felt Accepted	9	26.5%
Never Felt Accepted	7	20.6%
Domain: Level of Knowledge of Background Within Training Program	*N* = 34	
Limited Understanding	18	52.9%
Good Understanding	10	29.4%
No Understanding	6	17.7%
Domain: Factors to Consider for Improved Understanding of Background	*N* = 36	
No Recommendations	14	38.9%
Awareness of Background	13	36.1%
Background is not Necessarily Visible	3	8.0%

Level of Comfort Sharing Information	2	5.6%
Feelings of Isolation	2	5.6%
Other	2	5.6%
Domain: Methods of Diversity Inclusion in Training Programs	*N* = 38	
Unknown	13	34.2%
None	5	13.2%
Verbal Statement on Diversity and Inclusion	4	10.5%
Many Methods But Not Specified	4	10.5%
Diversity Grant or Scholarship	3	7.9%
Promotion of Program for Community Outreach	2	5.3%
Cultural Awareness Training	2	5.3%
Diversity and Inclusion Task Force	2	5.3%
Limited Methods	2	5.3%
Language Skills	1	2.6%

Diversity in Background and Clinical Performance:

The domain examining the impact of an underrepresented background on clinical performance yielded seven categories (Figure 1). The majority of participants reported that their backgrounds assisted them in having greater cultural awareness when interacting with different patient populations, making up 46% of responses. Participants who responded that their backgrounds had a positive impact on greater cultural awareness noted that their personal experiences as an underrepresented individual gave them a deeper capacity to empathize with patients, fostered open-mindedness, and benefited

building rapport and trust with patients. Other impacts of background on clinical performance include one's background being a barrier in contracting and rapport-building with certain patients, one's background being a barrier in overall job performance, some impact, or no impact at all. Participants who noted that their backgrounds had a negative impact on their clinical performance often identified with having an invisible disability that hindered their ability to work at their optimal state in either clinical rotations or in the workplace after graduation. Male participants also noted that they experienced more resistance from certain patients due to patients' level of comfort and perceptions of male vs. female healthcare providers.

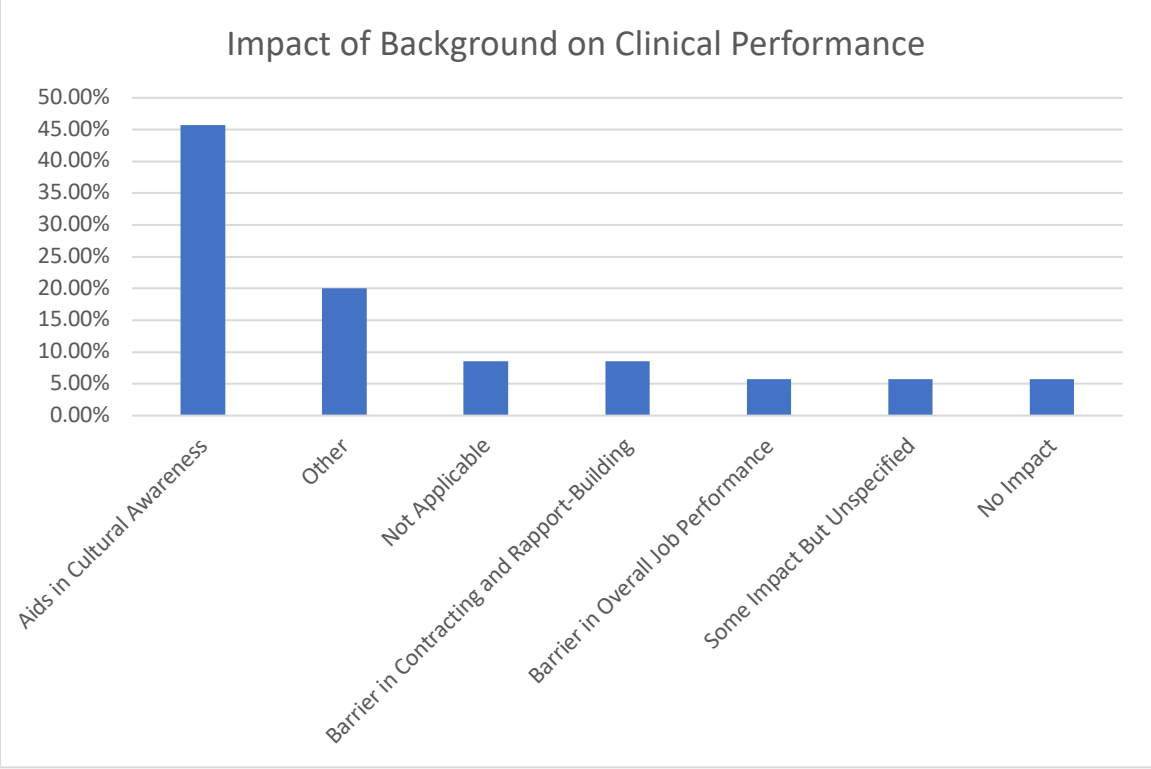

Figure 1: Participants' Perceived Impact of Background on Clinical Performance

Opinions on Diversity Inclusion in the Genetic Counseling Field:

The domain of perceived factors that cause a lack of diversity in the genetic counseling field yielded seven categories (Figure 2). The majority of participants believed lack of financial support was a reason for lack of diversity, which encompassed 30% of responses. Lack of awareness of genetic counseling as a career option made up 28% of responses. The current lack of diversity in the genetic counseling profession encompassed 20% of responses. Other proposed reasons include lack of access to prerequisite training prior to applying to graduate programs, socialization of females as counselors in the traditional sense, paucity of training programs, lack of cultural awareness training, limited access to genetic counseling services, and difficulty fulfilling admissions criteria and prerequisites. Many participants noted introduction to the genetic counseling field occurs later in education, such as during college or during one's working years, making genetic counseling a niche career path in comparison to other highlighted careers in medicine. Several participants also noted that lack of diversity could be attributed to a systemic issue, in which minorities from disadvantaged communities do not have the financial or social opportunities to pursue post-secondary education. Several participants also emphasized the lack of outreach to diverse communities to inform them of genetic counseling as a possible career path.

The domain of suggestions participants had to expand diversity in the genetic counseling field yielded eight categories (Figure 3). Most participants proposed that increasing community outreach to raise awareness of genetic counseling in different populations was a method that could expand diversity in the field, making up 41% of responses. Along with more outreach efforts, participants also proposed introducing people earlier to genetic counseling at earlier ages before college. Increasing financial

and social resources for those interested in pursuing genetic counseling as a career was mentioned in 27% of responses. Other suggestions include increasing diversity in program faculty, improving cultural awareness education in the graduate program curriculum, factoring in diversity in admissions, using flexible interview modalities for applicants who are unable to travel, having a broader acceptance of diversity as a whole, and highlighting the need for diversity in genetic information.

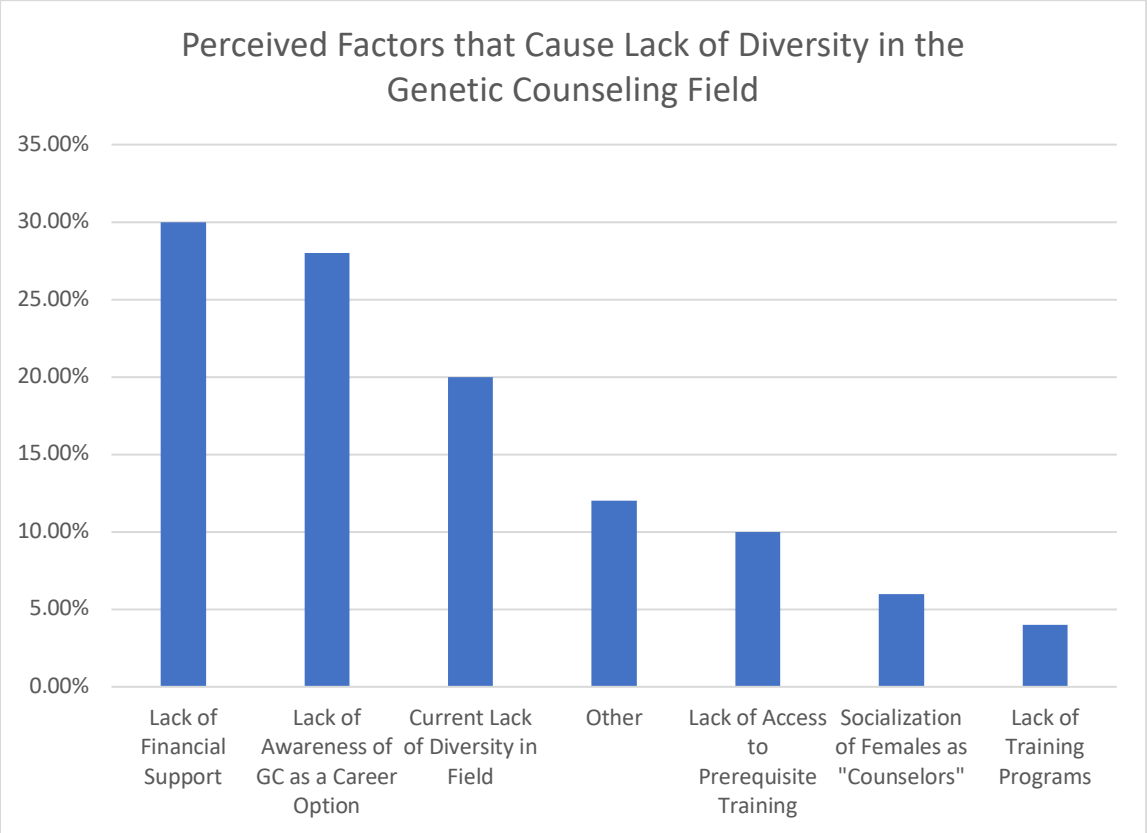

Figure 2: Perceived Factors Causing a Lack of Diversity in the Genetic Counseling Field

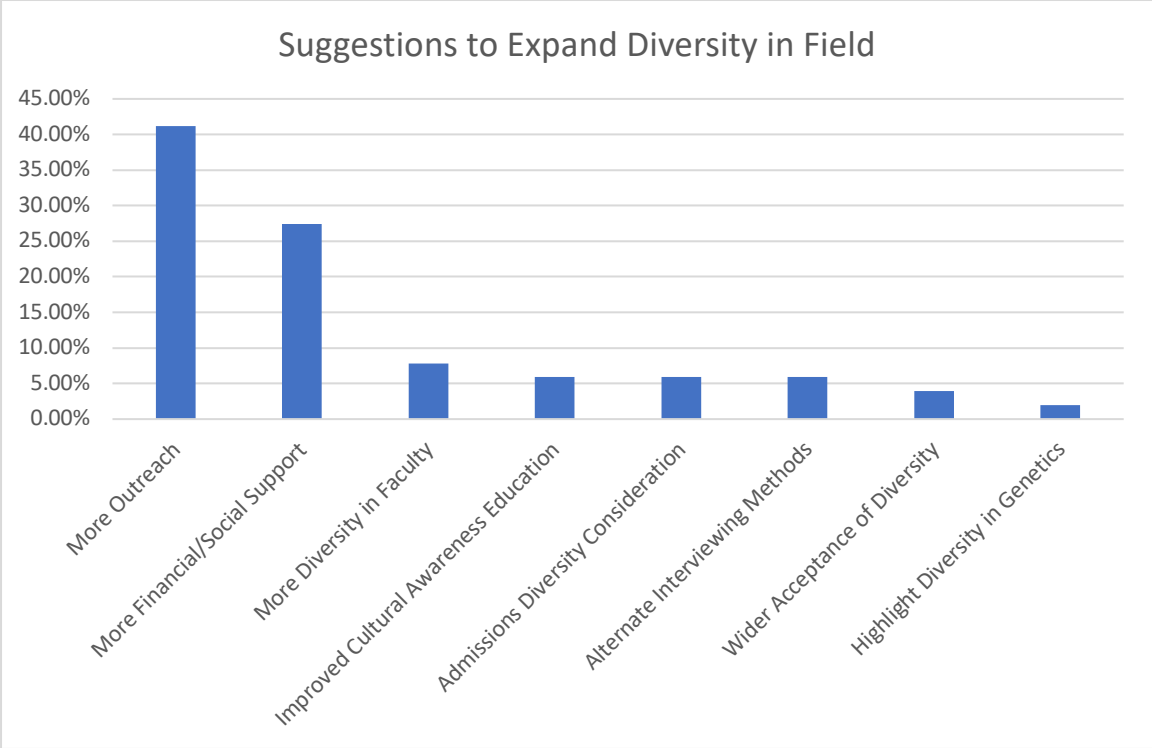

Figure 3: Participants' Suggestions for Expanding Diversity in the Genetic Counseling Field

Discussion

In assessing the current perceived barriers and motivations underrepresented genetic counseling students and practicing genetic counselors have in pursuing genetic counseling as a profession, several themes arose. Across all demographic factors that contributed to an underrepresented status, participants generally viewed that barriers and/or motivations were prominent in the introduction to the genetic counseling field, experiences joining a graduate program and training in the program, and in clinical practice.

Barriers and Motivations in Entering the Genetic Counseling Field:

The timing of people's introduction to the genetic counseling field was a factor that influenced their decision to enter the field; timing seemed to impact all demographic groups in this study and was evidently also a decisive factor for represented individuals in a study led by Oh and Lewis (2005). Participants were generally introduced to the genetic counseling field in their college years or later through biology-related lectures and suggestions from family, friends, advisors, or colleagues. Several participants noted that they wished they had learned about genetic counseling as a career option earlier on in their education because obtaining shadowing experience and completing prerequisite requirements for graduate programs was more difficult to coordinate alongside work-related commitments. A few participants were introduced to the field in their high school years, which enabled them to solidify curriculum and extracurricular choices in higher education with genetic counseling as a career goal. A portion of participants mentioned finding out about genetic counseling through an online search first or performed more extensive research about the field online after learning about it from another source. With the integration of technology in career searching and increased discourse on social media platforms about developments in genetics, which covers topics like direct-to-consumer testing, it is possible that more and more prospective genetic counselors are learning about the field earlier on in their education (Roberts, Allen, & Andersen, 2019). However, these study findings suggest that promotion of genetic counseling as a career path in earlier education before college is less common than promotion of genetic counseling in higher education. In the study conducted by Schoonveld et al. (2007), ethnic and gender minority members of the field also reported that lack of information about the genetic counseling profession for interested individuals made entering the field

more challenging. While genetic counseling has gained traction over the years as an established STEM career path, awareness of genetic counseling in the general public and among students may still be lacking.

Regardless of factors contributing to underrepresented status, most participants chose to pursue genetic counseling as a career due to its combination of science and counseling, its degree of interaction with patients and healthcare providers, and its involvement in the rapidly-evolving field of genetics. This finding is in line with the Lega et al. (2005) study results suggesting that motivations for pursuing genetic counseling seemed to be similar across different ethnicities. Thus, differences in how one chooses to identify as underrepresented do not necessarily affect one's reasons for entering the genetic counseling field. However, while reasons for entering the field may not necessarily differ among underrepresented and non-underrepresented individuals, when participants were asked about factoring a graduate program's diversity into school decision-making, several responded that they would consider diversity as a beneficial reason to apply to a graduate program following other aspects, such as location of a program, cost, and program structure. Diversity in a graduate program—through the student body and faculty—is a feature that is currently sought after by underrepresented individuals and can serve as a motivation to enter the genetic counseling profession.

While most participants had no reservations when deciding to pursue genetic counseling as a career path, some participants responded that lack of diversity in the field, lack of career growth, cost of training, and genetic counselors' treatment by other providers were barriers. In past study findings, lack of diversity in the field, lack of career advancement opportunities, lack of autonomy, and financial concerns were also

highlighted as barriers to entering the field for ethnic and gender minority individuals (Schoonveld et al, 2007). However, the issue of salary, which emerged as a career barrier in the study by Schoonveld et al. (2007), was not mentioned by any participants as a current barrier. These findings emphasize that certain career barriers that existed when genetic counseling was a newer field, such as lower salary, are not as prominent present-day. Yet, other career barriers that influenced one's decision to enter the field, such as cost of enrolling in a training program, lack of diversity, and lack of upwards career mobility as a genetic counselor, are still as notable as they were several years ago.

The majority of participants indicated that their families were overall supportive of their pursuit of genetic counseling as a career. Family support tended to be positive, but many participants also reported that their families had limited knowledge of genetic counseling, which seems to correspond to a lack of awareness of the field as a whole. Some participants mentioned that their family members, who had mixed feelings about supporting their endeavors to pursue genetic counseling due to their uncertainty about the career, became more encouraging upon learning more about what the field entails. Aside from concern stemming from a lack of knowledge of genetic counseling, participants did not specify other concerns their family members had. Thus, increased awareness of genetic counseling benefits both individuals interested in exploring the field as a career path and their support systems.

Barriers, Motivations, and Perceptions Towards Underrepresented Backgrounds in Graduate Training Programs:

Notable barriers participants encountered during their experience in graduate training programs include financial concerns and admissions requirements. These were the most reported barriers across all demographic factors. Several participants expressed that their financial concerns included the cost of traveling for interviews, application fees, and tuition of a graduate training program. Due to the rising cost of higher education, graduate school training is becoming less and less obtainable (Hemelt & Marcotte, 2016). While financial concerns can be a burden for anyone regardless of their underrepresented or represented status, systemic oppression negatively impacts certain populations and prevents them from accessing higher education, which can typically be attributed to financial barriers and lack of opportunities in a given area. In addition to cost, participants also expressed that a lack of accessibility to genetic counseling training can also be attributed to strict admissions requirements. Several participants noted having access to shadowing and counseling opportunities is limited to geographic location. If there are no genetic counselors practicing in a certain region or genetic counselors are unable to give students opportunities to shadow, then individuals interested in the field are unable to benefit from in-person shadowing unless they travel to an area with more genetic counselors. Thus, financial constraints can also play a role in unfulfilled admissions requirements.

Across all demographic factors, top motivations participants had during their time in graduate training programs were support from family, friends, classmates, and professional networks and mentors. Overall, the majority of participants reported feeling a sense of belonging among their peers in training programs without considerable impact from their backgrounds, a finding consistent with past perspectives about the overall

supportive nature of these programs (Schoonveld et al, 2007). While some participants did not specifically seek out underrepresented individuals over others in their class due to lack of diversity in the class or feeling impartial towards their peers' backgrounds, several participants did connect with classmates or mentors who share the same background as them. These participants noted that these individuals have been sources of support for them throughout their training because of a mutual understanding of cultural differences. Access to support systems that enable underrepresented individuals to have their opinions heard and their perspectives on genetic counseling respected is an integral part of one's experience within a training program.

The majority of participants expressed that they felt accepted and were treated equally by classmates and faculty in graduate training programs based on their underrepresented background. This equal treatment extends to the interview process and time spent in graduate programs. While participants generally reported equal treatment, several participants noted that there were subtle differences in treatment at times, particularly in the classroom discussion setting and in clinical rotations. Participants noted that they often felt the burden of acting as a "spokesperson" for their demographic group in class discussions and were expected to educate others in cultural competency. The study by Schoonveld et al. (2007) revealed similar reports about underrepresented individuals feeling that they were pressured to be "diversity experts" by peers, instructors, and colleagues. The issue with being given the position of a "spokesperson" is that it operates under the assumption that individuals with the same demographic factor also share the same experiences, which is not necessarily true. This expectation was not only applied to ethnic minorities. Male participants also expressed that they were

specifically asked about how their gender would impact their counseling techniques in the class discussion setting. In the study performed by Chen et al. (2017), similar findings were highlighted in which male genetic counselors reported feeling singled out and the target of microaggressions that bear the implication that gender has an impact on one's ability to perform as a genetic counselor. Microaggressions can be defined as "brief and commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile, derogatory, or negative prejudicial slights and insults towards any group, particularly culturally marginalized groups" (Sue, 2010). Therefore, fostering a safe environment where underrepresented students can share their experiences with peers without prior expectations is a goal that graduate training programs can continue to work towards. In clinical settings, participants expressed that the effect their diverse backgrounds had on their counseling methods were not always viewed in a positive light. One participant noted that a supervisor in their clinical rotation trained them to use a counseling style that did not match their cultural differences and values. A wider acceptance of counseling styles borne out of diverse experiences is thus another goal that graduate training programs can implement into their education. The visibility of people's underrepresented status also has an impact on whether or not they perceived differences in treatment. Participants who identified as members of the LGBTQ community or had an "invisible" disability proposed that the treatment they received from classmates and program faculty did not seem different because their underrepresented demographic factors were not readily apparent. It is evident from participants' responses that general acceptance of diverse backgrounds by members of graduate programs exists; however, improvements can be made in cultural competency

education and in the facilitation of class discussions to relieve the pressure underrepresented students face in feeling the need to speak up about topics of diversity as primary educators. Instead, an open environment that allows students to share their perspectives in a way that is comfortable for them may be more beneficial.

Perspectives Towards Underrepresented Backgrounds in Clinical Practice:

In clinical practice, the majority of participants reported that they believe their background aids in their own cultural awareness when working with patients, a perception that arose among ethnic and gender minorities in the study conducted by Schoonveld et al. (2007). This greater cultural awareness can manifest in a deeper sense of empathy, strengthened communication in rapport-building, and more trust in the provider-patient relationship. As cultural experiences can positively impact one's ability to tailor genetic counseling services to a variety of patient populations, it is apparent that diversity among genetic counselors is needed. On the other hand, a few participants expressed that their backgrounds hindered their ability to counsel patients effectively. One participant mentioned their disability prevented them from working at full capacity, but their supervisor and colleagues treated their situation with a limited understanding of the impact of a disability on job performance. Other participants who felt hindered noted these feelings stemmed from difficulty contracting and rapport-building due to gender or ethnic differences from their patients. The Schoonveld et al. (2007) study revealed that genetic counselors' conflicts with their bicultural identity can pose a challenge of acculturation when working with same-background patients who expect certain counseling behaviors; these genetic counselors were torn between using learned

counseling methods (e.g. nondirective counseling) and resorting to practices appropriate for the patient's cultural values. In contrast, while participants from this study did not express feeling the same sort of conflict, a few bicultural participants reported feeling "self-conscious" about their background and their patients' perception of it, which consequently affected rapport-building. Thus, it seems that increasing diversity in genetic counselors and normalizing differences in background in the clinical setting can further advance the profession.

A Need for Increased Awareness of the Genetic Counseling Field:

Several major suggestions to increase diversity in the genetic counseling field surfaced from participants' responses across all demographic factors. The most common suggestion is to provide an earlier introduction to the genetic counseling career to promote the profession alongside other well-known careers in healthcare. In addition, exposure to genetic counseling should also extend to diverse communities. Ethnic minorities and males have been shown to be less aware of genetic counseling, but are just as likely to pursue genetic counseling as a career compared to non-minorities (Oh & Lewis, 2005). Thus, community education about genetic counseling should not be restricted to the field's existing demographic. Mittman and Downs (2008) suggested that efforts made to explore reasons for lack of representation in the genetic counseling field have been focused on recruitment and training, but more attention should be concentrated on retention, the training experience, professional "climate," and professional issues, such as career advancement, job satisfaction, and mentoring. While these factors may be potential barriers or motivations later on in the genetic counseling career pathway

proposed by Oh and Lewis (2005), it is clear based on perspectives of individuals currently entering the field that efforts to increase community outreach to spread awareness of the existence of genetic counseling are still essential. Not only would increased awareness of the profession early on boost visibility of genetic counseling in the mainstream healthcare sphere, but it would also naturally attract a more diverse cohort of individuals interested in working in the field.

Another common suggestion is to improve accessibility to graduate training programs by providing financial aid, reducing fees, accommodating different interview methods in lieu of traveling, and judging admissions requirements on an individual basis if shadowing and counseling opportunities are limited. Participants expressed finances as a common consideration in choosing graduate programs, and it also acts as a barrier to entering the genetic counseling field.

The third suggestion put forth by participants is to promote open-mindedness and acceptance about how people's backgrounds can shape their counseling methods, which can be done through better cultural competency training in graduate programs among students, faculty, and clinical supervisors. While cultural competency training does exist in training programs, there is a need to hone in on various ways of cultural competency training in both the classroom and clinical setting that will allow students and other members of training programs to acknowledge personal biases and exchange opinions in a culturally-sensitive environment. Cultural competency training should also avoid relying on underrepresented students as experts of their demographic group. Biases people harbor may include preferred counseling techniques that are centered on Western medicine. The idea that there is no one-size-fits-all method of counseling is important to

uphold in order to respect genetic counselors' abilities to gauge the provider-patient dynamic and determine the best course of action based on prior cultural experiences. Implementing improved cultural competency training can assist students in feeling more prepared to work with a diverse workforce and patient population.

While the field of genetic counseling is becoming more diverse over time, means to facilitate this process starting with the recruitment stage are still being explored. Diversity within graduate programs, which can be reflected in a program's student body, faculty, and individuals holding leadership positions, has an impact on a student's level of comfort within a program and sense of belonging. Current perspectives from underrepresented individuals in the field demonstrate that it is necessary to preserve and encourage diversity in the genetic counseling profession. Proposed methods to diversify the field include making concerted efforts to improve early exposure to the genetic counseling career in diverse communities, expand accessibility to training programs, and refine cultural competency training among both faculty and students of training programs.

Study Limitations:

The study findings were obtained from recruitment of current genetic counseling students and practicing genetic counselors who identify as underrepresented, and open-response survey questions were used to extract an unrestricted amount of data about their opinions on pursuing the genetic counseling profession as minorities. However, since the criteria for participation in this study requires interested individuals to self-report their experiences as minorities in the field, it is possible that there is selection bias. Due to a

small sample size of 34 participants, responses from participants are not necessarily representative of the views of current students and practicing genetic counselors who identify with the same aforementioned demographic factors. The study survey also had a relatively low completion rate of approximately 30% in comparison to the total number of individuals who opened the survey. A total of six weeks was allotted to data collection and survey entries that did not answer all questions on the survey were excluded from data analysis. Therefore, the length of the study survey and nature of its questions that request descriptive responses could have had an impact on survey completion rate. The survey did not ask participants to rank their perceived barriers and motivations in the different stages of the genetic counseling career path. As a result, importance of barriers and motivations were determined by the prevalence of each barrier and motivation in participants' responses; however, ranking each factor would provide more numerical weight to the data obtained.

Practical Implications and Recommendations:

Several possible methods for increasing diversity in the genetic counseling field emerged from the findings of this study. Increasing exposure to genetic counselor at earlier times, such as in high school or earlier, is a prominent theme. Expanding community outreach efforts can be smaller-scale projects involving graduate training programs and information sessions given by genetic counselors or students, or they can be larger-scale efforts through promotional events put on by professional organizations, such as the National Society of Genetic Counselors. To raise general awareness of genetic counseling as a profession, it should also be promoted alongside other well-

known careers in healthcare. In addition, outreach efforts should be aimed towards more diverse populations in order to address the issue of lack of diversity in the current field. Physical and virtual events introducing the genetic counseling field at no additional financial cost would allow students to learn about the profession even if genetic counseling resources are not necessarily available in their geographic region.

In terms of changes within graduate training programs, more effort can be made to bring in different avenues of cultural competency training. To challenge the stereotype that genetic counseling is a field for white, privileged female individuals, it is important for students to recognize their own biases, engage with members of diverse communities in the classroom setting and in clinical rotations, and have access to educators—faculty, supervisors, and mentors—who are also involved in diverse communities themselves. Implementing perspectives from diverse educators would alleviate the burden minority students face in educating others about their backgrounds. Resources such as the Minority Genetic Professionals Network, which was established in 2018, can serve as platforms for minority students and current practitioners in the genetics profession to interact and exchange support.

Remedying financial concerns also emerged as a common theme. By implementing financial aid in different steps of the genetic counseling career path, such as providing a waiver of the application fee, scholarships, teaching assistant opportunities, or remote interview methods that do not sacrifice one's performance in graduate school interviews, graduate programs may be able to appeal to a wider and more diverse group of prospective genetic counselors. Careful assessment of admissions requirements on a case-by-case basis may also allow applicants, who have limited

shadowing and counseling opportunities due to geographic location and/or financial burden, to still pursue this career path.

Future Directions:

Further research on effective methods of community outreach to promote earlier introduction to the field of genetic counseling is necessary. For example, exploration of the impact of small-scale and large-scale outreach events on students' openness to genetic counseling as a career path can be done to determine feasible modes of outreach. Since this study focused on common perspectives across numerous demographic factors, follow-up studies can also be performed to assess each demographic factor in more detail with respect to opinions about diversity in the field. Many studies assessing diversity in the genetic counseling field have been focused on minorities in ethnicity and gender, and there is a lack of available data reflecting perspectives from other underrepresented groups, such as people of low socioeconomic status, people with different spiritual and/or religious beliefs, people of the disability community, and others. To further establish a source of comparison on studies centered on diversity in the field, studies can be performed to distinguish between perceptions of non-minority and minority members of the genetic counseling field. The utility of mentorships, learning modules, different types of classroom discussion structures, and other methods of cultural competency training in clinical practice may also be assessed further. To evaluate the progress of diversification in the genetic counseling field, longitudinal studies following genetic counselors and/or graduate program directors who have seen the profession evolve in the past few years may also be conducted to extract their perspectives on specific strengths and weaknesses

of recruitment methods. Additional studies can also be performed to evaluate the retention of minority members in the genetic counseling field.

Conclusion

Over the years, diversity in the genetic counseling profession has become an important topic of interest, and various methods for better recruitment and retention have been proposed; however the efficacy of these proposed methods has yet to be validated (Lega et al, 2005; Schoonveld et al, 2007; Mittman & Downs, 2008). While the findings from this study suggest that the genetic counseling profession and its graduate training programs generally show acceptance of individuals of different backgrounds, the findings also highlight that past career barriers faced by underrepresented individuals interested in entering the field—such as financial burdens, lack of awareness of the genetic counseling profession, lack of pre-existing diversity, and lack of career mobility—are still influential factors today. There is a need to continue working towards effective recruitment and retention that fosters a professional climate that welcomes diversity in a workforce. Additional efforts can be made to improve the introduction of the genetic counseling field to interested individuals, the accessibility of training, and cultural competency education. Expanding on the diversity in the field will allow genetic counselors to provide services in a manner suitable for their increasingly diverse patient population.

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Appendix A: Qualtrics Survey Questions

Demographic Information:

1) What is your year of graduation from a genetic counseling graduate program?
    a. 2016
    b. 2017
    c. 2018
    d. 2019
    e. 2020
2) What is your gender?
    a. Male
    b. Female
    c. Other: _____
3) What is your age?
    a. 20-29
    b. 30-39
    c. 40-49
    d. 50-59
    e. 60-69
    f. 70 or older
4) What is your genetic counseling specialty?
    a. Cancer
    b. Pediatric
    c. Prenatal

   d. Other: _____
   e. Current student

5) How do you identify as an underrepresented individual in the genetic counseling field? You may select more than one option if multiple ones apply to you.
   a. Ethnicity
   b. Gender
   c. Sexual orientation
   d. Religious/Spiritual Beliefs
   e. Socioeconomic status
   f. International status
   g. Member of the disability community
   h. Age upon entering the field
   i. Other: _____
6) Would you like to elaborate on your selection for Question 5? If so, please use the space provided.

Questions adapted from "What Is It Like To Be in the Minority? Ethnic and Gender Diversity in the Genetic Counseling Profession" by K.C. Schoonveld (2007).

<u>Introduction to the Field:</u>

7) How and why did you find out about the field of genetic counseling?
8) When did you make this career choice (high school, college, work force, etc.)?

9) What attracted you to the field? Do you have any reservations about entering the field?
10) What factors did you consider while choosing your graduate program?
11) What expectations did you have for the program that you chose to attend and to what extent have these expectations been met?
12) Was/would your choice of which graduate school to attend have been influenced if you knew that your classmates would consist of diverse populations (i.e., was the presence of other minority students a factor in your graduate program selection)? Was/would your choice have been affected if you knew that one or more of your professors and/or supervisors would have a diverse background?
13) In your opinion, do you feel that you were treated differently than other students during the interview process? What about since you've been in your program?

Support/Barriers:

14) How did your family and friends initially respond to your choice to become a genetic counselor? How do they feel now?
15) What would you say was the biggest barrier you faced to entering graduate school, if any? Do you feel that there are currently barriers you face in school?
16) Who have you sought support from?
17) Have you joined groups or activities whose participants include a diverse array of individuals?

Training:

18) Do any of your classmates share the same or similar background as you? If yes, have you sought them out over your other classmates for support during graduate school?
19) Do you feel that your background has impacted your relationship with your classmates, instructors, and/or supervisors?
20) To what extent do you feel a part of your training program?
21) Have there been specific times that you felt accepted? Have there been specific times when you felt like an outsider?
22) In your opinion, how much did your classmates and supervisors know/understand about your background on a general level? How has this knowledge/understanding changed over time?
23) Are there any particular things that you wish that your classmates and/or supervisors knew about your background?
24) What does your graduate program have in place for diversity inclusion and recruitment?

Clinic:

25) What impact do you think your background has on your clinical performance?

Suggestions:

26) What is your perception as to why the genetic counseling field lacks diversity?
27) Do you have any suggestions for how we can better diversify our field?