Racial and Ethnic Diversity in Genetic Counseling: Engaging with Undergraduate Students

by

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Genetic counseling remains one of the least racially and ethnically diverse allied health professions, with nearly 90% of practicing genetic counselors identifying as White. Further, racial and ethnic minorities (REMs) experience inequity in all aspects of the genetic counseling process as a result of implicit bias and underrepresentation. Though the National Society of Genetic Counselors is committed to increasing the number of REM applicants, there has not been a significant increase of diverse applicants in recent years. A diverse healthcare workforce is necessary to achieve health equity; it has been shown to reduce health inequities, implicit bias, and increase positive health outcomes. As the patient population continues to grow more diverse, the field of genetic counseling must make direct efforts to recruit diverse applicants.

To support diverse recruitment, this study created and performed an educational seminar about genetic counseling for REM undergraduate students. This seminar was hosted by the McNair Scholars Program at St. Mary's University; the goal of this federally funded program is to promote equity in science, technology, engineering, and mathematics (STEM) graduate degree attainment among underrepresented minorities. The seminar was performed using video-conferencing technology and included a PowerPoint presentation about the profession, including information about the role of genetic counselors, specialty areas, job growth and salary, and inequities related to genetic counseling. Participants completed a pre- and post-survey to assess their awareness, knowledge, and interest of the genetic counseling profession. Most study participants (77%) were enrolled in the McNair Scholars Program and self-identified as Hispanic or Latinx (86%). Pre- and

post-survey analysis identified an increased level of interest in the profession after the seminar and a statistically significant increase in knowledge about key aspects of the profession ($p = 0.005$). To our knowledge, this study is the first to provide an educational seminar about genetic counseling among primarily Hispanic or Latinx undergraduate students. This study and its materials can be utilized as a framework for future outreach to increase the number of diverse genetic counseling applicants. Intentional and scalable community-based efforts such as this are critical to promoting public health and equity for diverse populations.

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Preface

I would like to thank Dr. Andrea L. Durst, Dr. Sarah E. Krier, and Jodie M. Vento for their thoughtful contributions and support throughout this study. Each of you have been instrumental in my growth as a student and my skills as a genetic counselor, for which I am so appreciative. A special thanks to Jodie for her guidance throughout this effort, both personal and professional. Your kind approach to mentorship has had a lasting impact on me. To Dr. Zwahr-Castro, Program Director of the McNair Scholars Program at St. Mary's University, thank you for embracing this effort and welcoming me back to where this journey to become a genetic counselor began. To my family, friends, and classmates, thank you for your love and support throughout my academic career. Finally, thank you to Teddy, my dog, who kept me company as I wrote every page.

1.0 Introduction

The need to increase racial and ethnic diversity in genetic counseling is well established. The National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS) of 2022 reported that 89% of all practicing genetic counselors identified as White; 9% of practicing genetic counselors identified as Asian, 3% identified as Hispanic or Latinx, 1% identified as Black or African American, 3% identified as Middle Eastern or North African, and less than 1% identified as Native or Indigenous (NSGC PSS, 2022). Historically, racial and ethnic minorities (REMs) are less likely to be aware of genetic counseling and less likely to be referred to a genetic counselor for genetic testing, even when meeting clinical criteria (Cragun et al., 2019). Research suggests this is due to racial and ethnic biases. As health inequities continue to widen in genetic medicine, our field must make direct efforts to recruit diverse applicants, which is part of the foundation moving towards more equitable healthcare.

Though NSGC has committed to diversity and inclusion as an area of strategic focus and made efforts to increase the number of REM applicants, there has not been a significant increase according to the National Matching Service, an online ranking system for genetic counseling applicants and genetic counseling programs. The National Matching Service has not reported a significant increase in the percentage of self-identified REM applicants since 2018, which is when this demographic data was initially reported. Of all registered applicants from 2018 to 2021, an average of 12.75% identified as Asian (including Eastern, Southeast, and South Asian), 11.50% identified as Hispanic or Latinx, 3% identified as Black or African American, 2% identified as Middle Eastern or North African, and 0% identified as Native or Indigenous. 2021 accounted an overall lower percentage of diverse applicants, at 25%, compared to the 2018-2020 average of

28.67%. In 2021, the National Matching Service did report some improvement in the total percentage of REMs who matched to a genetic counseling program, at 30% in 2021 compared to 19% in 2020 (National Matching Service, 2021). To contribute to the effort of increasing the number of diverse applicants, I aim to provide an educational seminar about genetic counseling that includes a pre- and post-survey to assess the awareness, knowledge, and interest of the genetic counseling profession among REM undergraduates. In 2020, Erica Price et al. (Price et al., 2020) published results using a similar approach at Historically Black Serving Institutions. Price reported difficulties in reaching Black undergraduate students and recommended investigating additional strategies to inform how to recruit more REMs into the profession.

I plan to address this engagement barrier by partnering with the McNair Scholars Program, a federal TRIO program funded by the United States Department of Education. This program is active across 187 universities in the United States and Puerto Rico, including a presence at Historically Black Serving Institutions and Historically Hispanic Serving Institutions; it was designed to support and prepare undergraduate students from underrepresented backgrounds for graduate-level education, with the ultimate goal of diversifying the science, technology, engineering, and mathematics (STEM) workforce (McNair Scholars Program, 2022). Engaging directly with McNair Programs may serve as an opportunity to recruit diverse applicants into the profession through targeted outreach and create an active network across McNair campuses.

2.0 Literature Review

2.1 Racial and Ethnic Diversity in Clinical Genetics and Genetic Counseling

Since the establishment of the first genetic counseling graduate program in 1969, the field of genetic counseling and our knowledge of human genome has continued to grow. However, the racial and ethnic makeup of genetics providers, genomic data, and the patients referred to and benefiting from genetic counseling remains largely homogenous (Channaoui et al., 2020). The genetic counseling profession is comprised mostly of individuals who identify as White—89% (NSGC PSS, 2022). In a 2019 study that investigated the racial and ethnic demographics of allied health professions (genetic counselors, physicians, physician associates, nurses, occupational therapists, social workers, psychical therapists, and clinical lab technicians) genetic counseling ranked the least diverse (Channaoui et al., 2020). Similarly, genomic data gathered for research and the reference databases used to inform the genetic health of patients is derived from non-Hispanic White populations (Eggington et al., 2013; Sirugo et al., 2019). This, including the historic biases that REMs face in healthcare, leads to various levels of inequity in genetic counseling and testing.

2.1.1 Implicate Bias

In 2002, the Institute of Medicine confirmed that racial and ethnic disparities in healthcare are not explained by other factors, such as access to healthcare or patient preferences. This groundbreaking report asserted that inequities stem from institutional prejudice and bias towards

underrepresented populations by healthcare providers (Nelson et al., 2002). Since that time, additional studies have identified bias in provider referral of REMs to genetic counseling and testing (Cragun et al., 2019). It is likely due to implicit bias of physicians whose duty is to refer eligible patients for genetic counseling (Cragun et al., 2019; Muller et al., 2018).

Multiple studies have identified that REMs, particularly Hispanic and Black individuals, are less likely to be referred for cancer genetic counseling and testing than non-Hispanic Whites, even when meeting National Comprehensive Cancer Network criteria (Ademuyiwa et al., 2021; Cragun et al., 2019; Muller et al., 2018). A patient's race and ethnicity has also been determined to be independent from other factors such as stage of disease and insurance status with respect to physician referrals (Peterson et al., 2020). A 2015 study of practicing genetic counselors using a Race Implicit Association Test identified that genetic counselors showed moderate to strong pro-White bias. The study also revealed an association with lower levels of positive affect and emotionally responsive communication when counseling non-White patients (Shaa et al., 2015). Not only does this continued bias of physicians and genetic counselors reduce the quality of a patient's immediate care, such as treatment options, shared decision making, and future management recommendations, it removes their right to make informed decisions about their healthcare and provide accurate risk information to family members.

2.1.2 Underrepresentation and Reduced Diagnostic Utility

When referred for genetic counseling and testing, REMs also face inequity in the utility of their genetic test results. REMs are more likely to receive a variant of uncertain significance (VUS) compared to non-Hispanic Whites. This is likely due to underrepresentation in the reference databases used to classify genetic variants, exasperated by lower rates of referrals for genetic

counseling and testing for REMs. Using hereditary cancer panels, Caswell-Jin et. al identified that the VUS rate for non-Whites was 36% compared to 27% for Whites (Caswell-Jin et al., 2017), consistent with previous studies. It is well documented that genetic testing has less diagnostic utility for minority populations across disease spectrums including hereditary cancer syndromes, cardiomyopathies, and chronic kidney disorders (Florentine et al., 2021). Apart from reduced diagnostic utility, higher rates of uncertain results cause undue stress and anxiety for REM patients and may affect their perception of genetic testing.

Though understudied, research has identified deleterious mutations unique to REMs. In 2013, a study by Weitzel et. al identified the first *BRCA1* founder mutation in individuals of Mexican origin, *BRCA1* ex9-12del (Gallardo-Rincón et al., 2020; Weitzel et al., 2013). This large rearrangement has been identified in several studies involving Hispanic females with breast and ovarian cancer in North America, Latin America, and Europe (Fernández-Lopez et al., 2019; Villarreal-Garza et al., 2015). Continued research is especially critical in cancer genetics, as minority populations present with more advanced disease at younger ages (Liu et al., 2013; Zavala et al., 2021). Florentine et. al identified novel genes and deleterious variants associated with sensorineural hearing loss in Hispanic and Black pediatric patients (Florentine et al., 2021) which are being further investigated to establish a definitive diagnosis. We can hypothesize that there are many other deleterious variants across disease spectrums for REMs yet to be discovered and established in clinical genetic testing. Creating a genetic counseling workforce that reflects the diverse communities served is key to reducing implicit bias and provide equitable healthcare during referral, genetic counseling sessions, and genetic diagnosis.

2.2 Diverse Workforce and Improved Health Outcomes

By 2045, the United States Census projects that non-Hispanic Whites will no longer make up the majority of the United States population. The 2021 Census reported the following population estimates: non-Hispanic Whites 60.1%, Hispanic or Latinx 18.5%, Black or African American 13.4%, Asian 5.9%, Indigenous 1.5%, and Two or More Races 2.8% (United States Census Bureau, 2021). The fastest growing racial and ethnic groups in the United States are Two or more Races, followed by Asians and Hispanics (United States Census Bureau, 2020). This highlights the urgency to achieve a diverse healthcare workforce.

A diverse healthcare workforce aids in reducing racial and ethnic health inequities and is associated with positive health outcomes, like patient satisfaction, compliance, cultural competency, and patient-provider partnership (Gomez et al. 2019). Studies have shown that both Hispanic and Black individuals seek out racially and ethnically concordant healthcare providers. In studies examining racial and ethnic-concordant vs. discordant patient-provider interactions, patients rated concordant providers as more participatory, reported higher feelings of respect from their provider, and had increased overall satisfaction (Cooper et al., 2006). Though genetic counselors have extensive training in providing respectful and patient-centered care, our impact can be strengthened by increasing our ability to provide racially and ethnically concordant care, particularly for areas with large Hispanic and Black populations.

2.2.1 Increased Practice in Minority Communities

There is evidence to show that REM healthcare providers are more likely to establish practice in minority communities, where access to healthcare providers like genetic counselors is

limited. In addition, these studies have repeatedly demonstrated that Hispanic and Black healthcare providers choose areas to practice that have large Hispanic and/or Black populations compared to non-Hispanic White healthcare providers (Gomez et al. 2019; Komaromy et al., 1996; Marrast et al., 2014). This may be reflective of personal, cultural, or community experiences and values unique to REMs. Similarly, diverse healthcare providers might be able to connect to the shared experiences of minority communities, further facilitating the genetic counseling process and reducing aforementioned gaps in equity.

2.2.2 Increasing Access to Underserved Regions

Genetic counselors are most concentrated in urban areas, typically associated with university medical centers and genetic counseling graduate programs (Villegas et al., 2019). Currently, there are approximately 5,629 practicing genetic counselors in the United States (NSGC PSS, 2021). The shortage of genetic counselors disproportionality affects rural areas, which comprises nearly half of the Southern United States (United States Census Bureau, 2016). These regions lack proximity to academic medical centers and rely on community-based healthcare. Medically underserved regions are more likely to have a lower socioeconomic status, poorer health status, and higher morbidity (McMaughan et al., 2020).

There are currently 52 genetic counseling graduate programs, only 14 of them are in the Southern United States (ACGC, 2022). Establishing additional genetic counseling programs in the Southern United States is critical, as the most populated states, Texas and Florida, have 0.43 and 0.26 genetic counselors per 100,000 people, respectively (Villegas et al., 2019). Overall, the Southern United States is racially and ethnically diverse; it has the highest percentage of Black individuals and a significant Hispanic population in Texas and Florida (OMH, 2021). Texas has

two genetic counseling graduate programs and Florida has one (ACGC, 2022). All are located in large metropolitan areas (Houston and Tampa). It has been proposed that establishing genetic counseling programs in the Southern United States could increase the future number of practicing genetic counselors there. Research suggests the likelihood of healthcare providers establishing practice in the same state they received their training is anywhere from 38-44% (AAMC et al., 2015; Koehler et al., 2016). Beyond the ability of reaching more patients in underserved regions through the establishment of genetic counseling programs in the Southern United States, it may also increase the number of REM applicants from the region through visibility and access.

2.3 Previous Efforts to Engage with Potential REM Applicants

To date, there have been few direct efforts to engage with REMs about the genetic counseling profession, specifically for Hispanic and Black populations. In a large 2019 study focused on undergraduate students, the demographics of respondents were predominantly White. It identified that REMs, particularly Hispanic and Black individuals, have a higher interest level in genetic counseling than non-Hispanic Whites (Gerard et al., 2018), supporting previous studies (Mittman et al., 2008; Oh et al., 2005; Wolfe et al., 2009). However, there remains a gap in awareness about the profession among REMs in high school students and undergraduate students (Kumaravel et al., 2011; Oh et al., 2005; Schoonveld et al., 2007). Undergraduate academic advisors are often involved in the process of identifying potential career options for students; when surveyed about their awareness of the profession and level of comfort in discussing genetic counseling with advisees, only 10% reported that they felt “extremely or very confident” (Carroll, 2017). Research also suggests that undergraduate students who first learn of genetic counseling

from an academic advisor are more likely to report lack of familiarity compared to those who first learned of the profession from someone they knew, a personal experience, or during coursework (Gerard et al., 2018). When investigating minority paths to becoming a genetic counselor, many genetic counselors and genetic counselor trainees indicated they learned about the career by chance during their undergraduate studies (Alvarado-Wing et al., 2021; Schoonveld et al., 2007). Participants also remarked that additional recruitment efforts need to be focused on universities with a significant proportion of REMs, such as Historically Black Serving Institutions and Historically Hispanic Serving Institutions (Alvarado-Wing et al., 2021).

Price's 2020 study focused on Historically Black Serving Institutions, Price et al. employed a pilot study to determine the effectiveness of strategies for participation and recruitment methods for undergraduate students, which included a presentation by a second-year genetic counselor trainee about the profession or a brochure detailing the same information (Price et al., 2020). Each group had the opportunity to complete an online survey evaluating their knowledge about the profession. Price noted that the seminar generated higher rates of survey completion compared to the brochure group, suggesting greater engagement through live methods. A barrier for this effort was lack of response or interest in recruitment sites, therefore the team recommends investigating additional strategies to inform how to attract more REMs into the profession, such as creating partnerships with STEM recruitment programs. An unexplored area for the genetic counseling profession in recruiting diverse applicants is partnering with the federally funded McNair Scholars Program.

2.3.1 The McNair Scholars Program

The Ronald E. McNair Post-Baccalaureate Achievement Program, also known as the McNair Scholars Program, was established in 1986 by the United States Department of Education to honor Dr. Ronald E. McNair, an astronaut who died in the Challenger explosion. The goal of this TRIO outreach program is to promote equity in STEM graduate degree attainment among underrepresented minorities, including REMs, first-generation students, and individuals with lower socioeconomic status. To be eligible to become a McNair Scholar, students must express interest in pursuing a graduate level degree. The McNair Program is active across 187 universities in the United States and Puerto Rico (McNair Scholars Program, 2022).

To prepare students for graduate level education, McNair Programs provide personal, social, and academic support; opportunities often include: defining research and career interests, funded research and internships, academic support and counseling, McNair regional conferences, educational seminars focused on graduate school studies and preparedness, faculty mentorship, and financial support for graduate school applications (McNair Scholars Program, 2022). A meta-analysis of graduate school enrollment of McNair Scholars determined that McNair Scholars who identified as a REMs were up to 12 times more likely to enroll in graduate school compared to REM students who were not enrolled (Renbarger et al., 2020). Indicating that the participation in the McNair Program can aid in REMs overcoming traditional barriers to graduate level education in STEM fields. To date, there is no active partnership between a McNair Scholar Program and the genetic counseling profession. Cultivating this partnership could be a sustainable way to recruit REMs interested in STEM careers and create an active network across McNair campuses.

3.0 Specific Aims

1. Assess the awareness, knowledge, and interest of the genetic counseling profession among undergraduate students at universities with an active McNair Scholars Program.

   a. Perform a virtual educational seminar about genetic counseling using video-conferencing technology, hosted by the McNair Program, which will be available to all undergraduate students

   b. Distribute a pre- and-post seminar survey to participants

2. Assess the number of total genetic counseling applicants and graduates within the McNair Scholars Program in the last 10 years.

4.0 Manuscript

4.1 Background

The need to increase racial and ethnic diversity in the field of genetic counseling is well established. This extends to genetic counseling program applicants, genetic counselor trainees, practicing genetic counselors, and genomic reference databases used to inform patient care. In 2019, genetic counseling ranked as one of the least racially and ethnically diverse allied health professions (Channaoui et al., 2020). This is highlighted by the 2022 National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS) which reported 89% of all practicing genetic counselors identified as White; 9% of practicing genetic counselors identified as Asian, 3% identified as Hispanic or Latinx, 1% identified as Black or African American, 3% identified as Middle Eastern or North African, and less than 1% identified as Native or Indigenous (NSGC PSS, 2022). Racial and ethnic minorities (REMs) continue to experience health inequities in nearly all aspects of the genetic counseling process because of implicit bias and underrepresentation—including reduced referral rates and access to genetic counseling and testing, reduced diagnostic utility, and the ability to seek out a racially and ethnically concordant healthcare provider (Cragun et al., 2019; Cooper et al., 2006; Florentine et al., 2021). As health inequities continue to widen in genetic medicine, the field of genetic counseling must make direct efforts to recruit diverse applicants, which is part of the foundation of moving towards more equitable healthcare.

Multiple studies have identified that REMs, particularly Hispanic and Black individuals, are less likely to be referred for genetic counseling and testing than non-Hispanic Whites, even when meeting criteria (Ademuyiwa et al., 2021; Cragun et al., 2019; Muller et al., 2018). A

patient's race and ethnicity has also been determined to be independent from other factors such as stage of disease and insurance status with respect to physician referrals (Peterson et al., 2020). When referred for genetic counseling and testing, REMs might experience racial and ethnic bias from their genetic counselor. A 2015 study of practicing genetic counselors using a Race Implicit Association Test identified that genetic counselors showed moderate to strong pro-White bias. In addition, lower levels of positive affect and emotionally responsive communication was identified when counseling non-White patients (Shaa et al., 2015). Inherent bias is also present in the genomic reference databases used to classify genetic variants and establish diagnoses. These reference databases are reflective of non-Hispanic White populations (Eggington et al., 2013; Sirugo et al., 2019). As such, REMs are more likely to receive a variant of uncertain significance (VUS) compared to non-Hispanic Whites (Caswell-Jin et al., 2017). Reduced diagnostic utility for minority populations is well documented across disease spectrums including hereditary cancer syndromes, cardiomyopathies, and chronic kidney disorders (Florentine et al., 2021).

A diverse genetic counseling workforce is essential to reducing implicit bias and achieving equity in genetic counseling referrals, genetic counseling sessions, and diagnostic utility of genetic tests. By 2045, the United States Census projects that non-Hispanic Whites will no longer make up the majority of the United States population. Evidence supports that a racially and ethnically diverse healthcare workforce is associated with positive health outcomes, like increased patient satisfaction, compliance, cultural competency, and patient-provider partnership (Gomez et al. 2019). This is especially relevant to Hispanic and Black populations, which have been shown to seek out racially and ethnically concordant healthcare providers and report increased feelings of respect and satisfaction from concordant patient-provider interactions (Cooper et al., 2006). REM healthcare providers are also more likely to establish practice in minority communities, where

access to healthcare providers like genetic counselors is limited (Gomez et al. 2019; Komaromy et al., 1996; Marrast et al., 2014).

Though NSGC has committed to diversity and inclusion as an area of strategic focus and made efforts to increase the number of REM applicants, there has not been a significant increase according to the National Matching Service, an online ranking system for genetic counseling applicants and genetic counseling programs. The National Matching Service has not reported a significant increase in the percentage of self-identified REM applicants since 2018, which is when this demographic data was initially reported. Of all registered applicants from 2018 to 2021, an average of 12.75% identified as Asian (including Eastern, Southeast, and South Asian), 11.50% identified as Hispanic or Latinx, 3% identified as Black or African American, 2% identified as Middle Eastern or North African, and 0% identified as Native or Indigenous. 2021 accounted an overall lower percentage of diverse applicants, at 25%, compared to the 2018-2020 average of 28.67%. In 2021, the National Matching Service did report some improvement in the total percentage of REMs who matched to a genetic counseling program, at 30% in 2021 compared to 19% in 2020 (National Matching Service, 2021).

To contribute to the effort of increasing the number of diverse applicants, I aim to provide an educational seminar about genetic counseling that includes a pre- and-post survey to assess the awareness, knowledge, and interest of the genetic counseling profession among REM undergraduates. In 2020, Erica Price et al. (Price et al., 2020) published results using a similar approach at Historically Black Serving Institutions. Price reported difficulties in reaching Black undergraduate students and recommended investigating additional strategies to inform how to recruit more REMs into the profession. I plan to address this engagement barrier by partnering with the McNair Scholars Program, a federal TRIO program funded by the United States

Department of Education. This program is active across 187 universities in the United States and Puerto Rico, including a presence at Historically Black Serving Institutions and Historically Hispanic Serving Institutions; it was designed to support and prepare undergraduate students from underrepresented backgrounds for graduate-level education, with the ultimate goal of diversifying the science, technology, engineering, and mathematics (STEM) workforce (McNair Scholars Program, 2022). Engaging directly with McNair Programs may serve as an opportunity to recruit diverse applicants into the profession through targeted outreach and create an active network across McNair campuses.

4.2 Materials and Methods

4.2.1 Participants

This study and seminar materials, including a PowerPoint and pre- and post-survey, were approved by the University of Pittsburgh Institutional Review Board (IRB), which can be reviewed in the Appendix (Appendix A). The participants of this study consisted of undergraduate students at St. Mary's University, a Historically Hispanic Serving Institution located in San Antonio, Texas. Though students enrolled in the McNair Scholars Program are required to attend weekly seminars such as this one, not all students in attendance completed the pre- and post-survey.

4.2.2 Seminar and Survey Design

A PowerPoint presentation (Appendix B) was designed to facilitate the seminar and included information about the genetic counseling profession, such as the role of genetic counselors, specialty areas, and job growth and salary; the PowerPoint also included a case example to illustrate inequities in genetic counseling related to race and ethnicity, demographic information about practicing genetic counselors, the application process, and resources for additional information. The pre- and post-survey were generated using Qualtrics (Appendix C) and accessed by participants using a quick response (QR) code at the beginning and end of the PowerPoint presentation.

Survey questions were designed to assess awareness, knowledge, and interest of the genetic counseling profession before and after the seminar; pre- and post-surveys were linked using a unique 4-digit code generated by Qualtrics. The general content of each survey can be viewed below in Table 1. The pre-survey included 24 questions and collected demographic information, undergraduate major and career interests, exposure to genetic counseling, and knowledge and interest-based questions about genetic counseling. Open text questions were also provided in the pre-survey to assess knowledge of the role of a genetic counselor and concerns about the profession. The post-survey included 11 questions and assessed knowledge and interest. The knowledge questions in the post-survey were identical to the pre-survey questions; an open text question was provided to assess concerns after the educational seminar.

Table 1 Pre- and Post-Survey Information

Pre-Survey	Post-Survey
Demographics Racial and ethnic identity Primary spoken language Gender identity Disability status Generational status (including United States and College)	**Knowledge-Based Questions** **Identical to pre-survey* Education requirements Average salary Career growth Physician genetics training Demographics of genetic counselors Inequity related to genetic testing Ability to access information
Major and Career Interests Undergraduate Major Year of Study McNair Scholars Program enrollment Careers of interest Interest scale for genetic counseling	**Interest** Interest scale for genetic counseling Should academic advisors present genetic counseling as a career option?
Exposure to Genetic Counseling Self or family member Coursework Academic advisor	
Knowledge-Based Questions Education requirements Average salary Career growth Physician genetics training Demographics of genetic counselors Inequity related to genetic testing Ability to access information	**Open Text Response** Concerns about the profession
Open Text Response Role of a genetic counselor	

Concerns about the profession	

4.2.3 Seminar Recruitment and Distribution

Recruitment of university sites was conducted through email. Program Directors at universities with an active McNair Scholars Program in San Antonio were informed of the study and invited to participate. In total, 7 universities were contacted and 3 responded with interest and scheduled a seminar. Due to the COVID-19 pandemic, all seminars had to be rescheduled and transferred to video-conferencing technology. As a result of scheduling conflicts, only St. Mary's University could accommodate the seminar. Recruitment of study participants was facilitated through coordination with the Program Director of the St. Mary's McNair Scholars Program. Program staff distributed two university-wide emails about the genetic counseling seminar. The McNair Scholars Program allocated space for participants to attend the seminar which was delivered using video-conferencing technology. This seminar was performed live and not recorded; at the beginning of the seminar, attendees were informed of the purpose of this study and that their participation and completion of the pre- and post-survey was optional. Before the PowerPoint presentation, 10 minutes were provided to complete the pre-survey. The educational portion was approximately 20 minutes and included audience participation and questions; 10 minutes were provided to complete the post-survey before an opportunity for participants to ask additional questions. During the open-ended discussion, electronic notes were taken by the presenter.

4.2.4 Data Analysis

Data from the pre- and post-survey was analyzed using descriptive statistics generated in Qualtrics and Microsoft Excel. All images were generated in Qualtrics using the Advanced-Reports Visualizations feature; tables were generated in Microsoft Word. Open text responses were individually reviewed. To determine the number of genetic counseling applicants and graduates within the McNair Scholars Program, the St. Mary's Program Director, who tracks McNair Scholars for at least 10 years after graduation, provided this information upon request.

4.3 Results

4.3.1 Demographics

A total of 13 participants completed the pre-survey, of which 10 (77%) were enrolled in the McNair Scholars Program. The majority of participants (86%) self-identified their race and ethnicity as Hispanic or Latinx (Figure 1) and their gender identity as female (77%) (Figure 2). Of all pre-survey participants, 23% reported that they have a disability. This demographic information is summarized in Figure 1 and Figure 2.

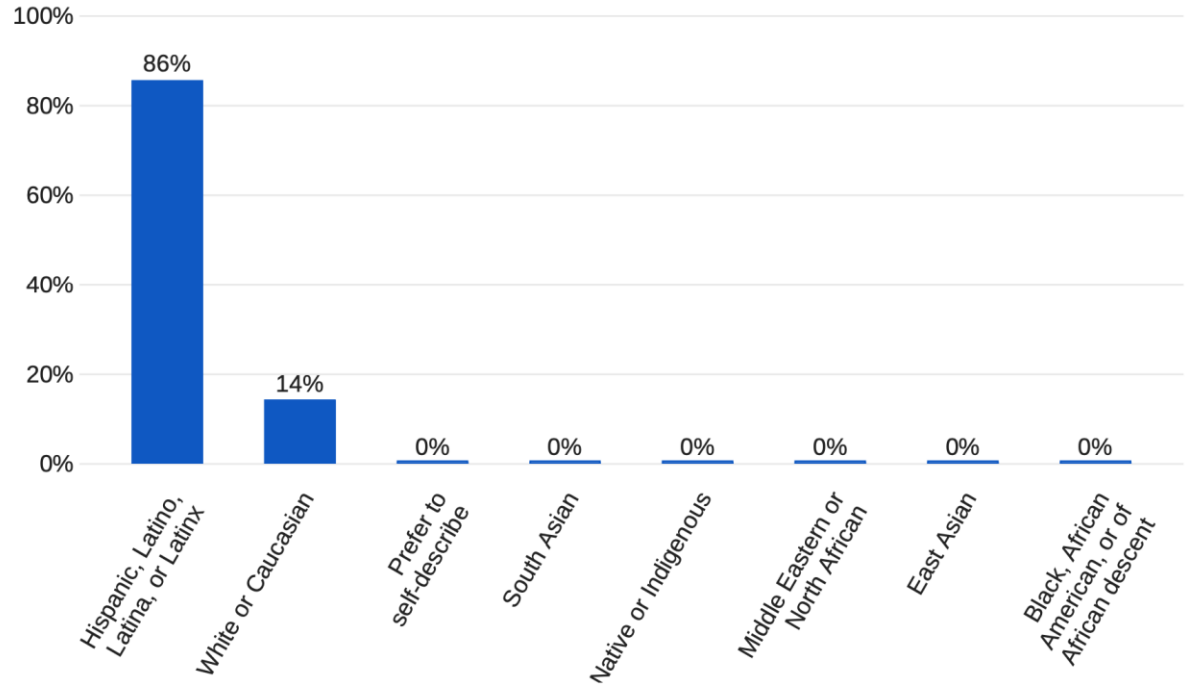


Figure 1 Racial and Ethnic Identity

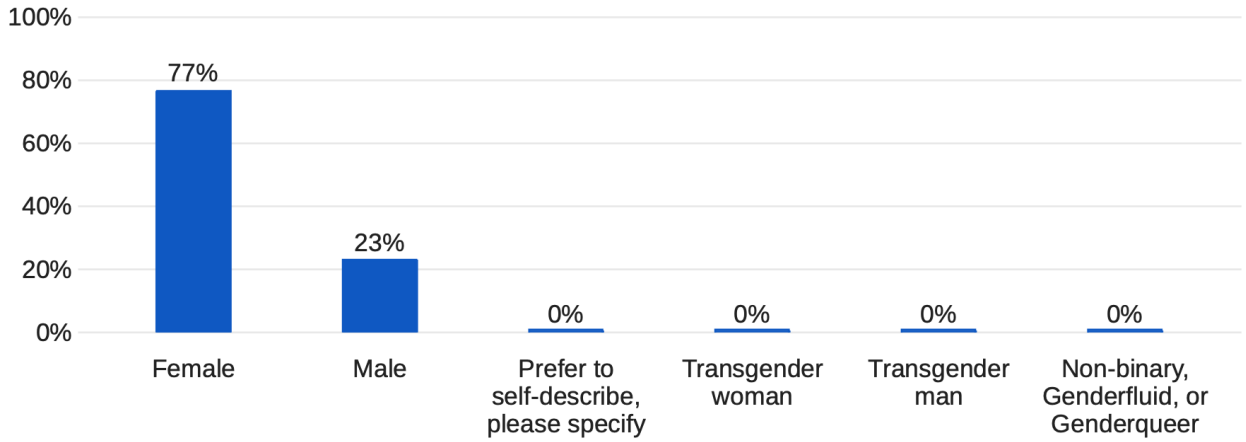


Figure 2 Gender Identity

Thirty-one percent of participants reported that they were a first generation American (referring to someone born in a country outside of the United States), 23% of participants reported

they were a second generation American, (referring to someone that has at least one foreign-born parent) and 38% reported they were at least a third generation American (referring to someone whose parents were both born in the United States) (Figure 3). Seventy-seven percent of participants reported that they were first-generation college students (Figure 3). All participants reported their primary spoken language as English.

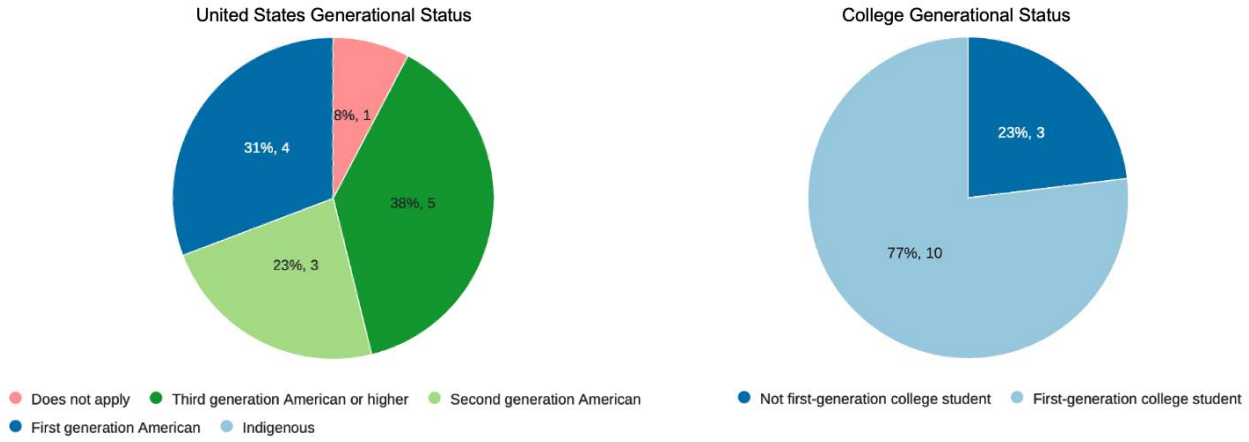


Figure 3 Generational Status and First-Generation College Students

4.3.2 Undergraduate Major and Career Interests

Participants were asked to report their year of undergraduate study and major in the pre-survey. Most participants were seniors (42%), followed by juniors (33%), freshman (17%), and sophomores (8%). The majority of participants were enrolled in a STEM major (75%). 5 of these participants reported that genetic counseling had been discussed in some of their major's curriculum, including general biology (3 participants), genetics (1 participant), and introduction to psychology (1 participant). Details about the undergraduate majors of participants can be appreciated in Figure 4 and Table 2.

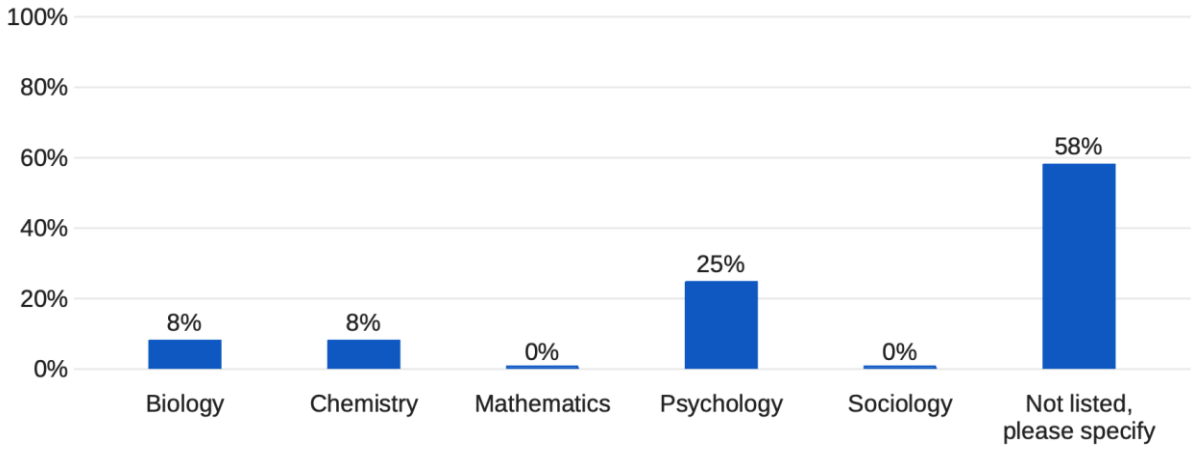


Figure 4 Undergraduate Major

Table 2 Undergraduate Major Open Text Entry Response

Selected Not Listed, Please Specify	
Open Text Responses	Computer engineering (1)
	Computer science (1)
	Bioinformatics (1)
	Forensic science chemistry (1)
	History (2)
	Communication (1)

Participants were also asked about their career interests in the pre-survey, including an opportunity for an open text response. None selected genetic counseling as a potential area of career interest. Most participants, 42%, selected research as a career interest, 25% selected an interest in psychology or mental healthcare, 25% selected that they are undecided, and 8% selected public health. Only 1 participant reported their academic advisor had presented genetic counseling as a potential career option. These results are illustrated in Figure 5.

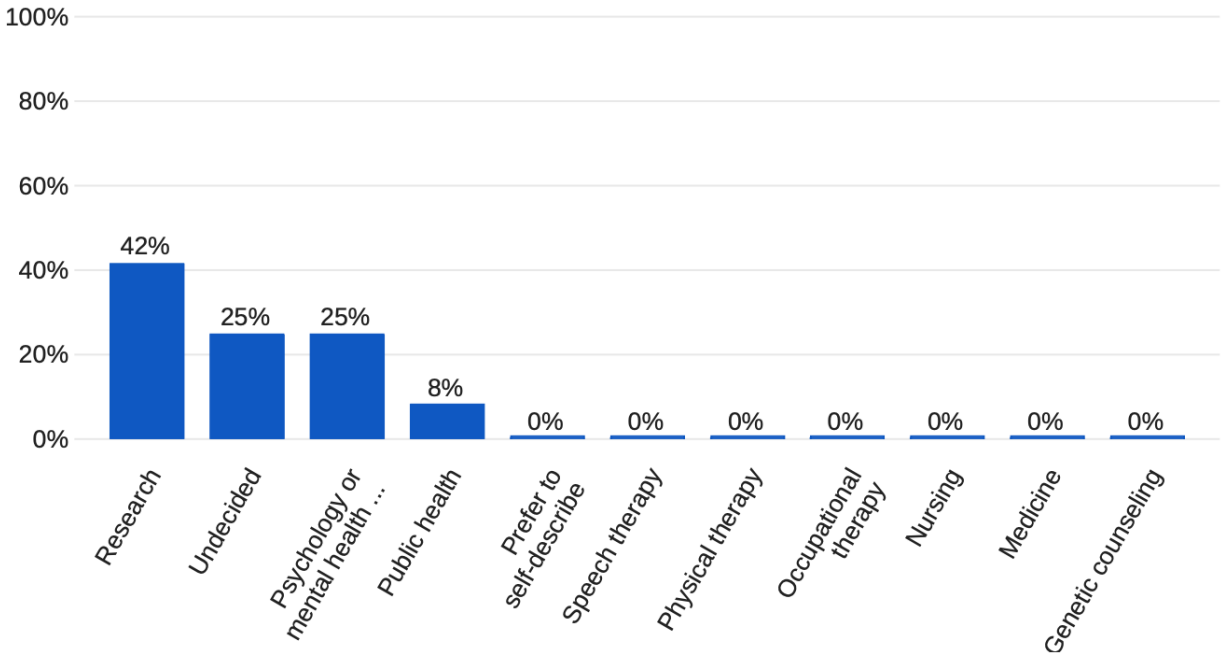


Figure 5 Career Interests

The pre- and post-survey also assessed if participants knew where to access more information about the genetic counseling profession or application process. A total of 9 participants completed the post-survey. Figure 6 illustrates the increase in the ability of these participants to access said information after the seminar, from 13% of participants selecting yes in the pre-survey and 88% of participants selecting yes in the post-survey.

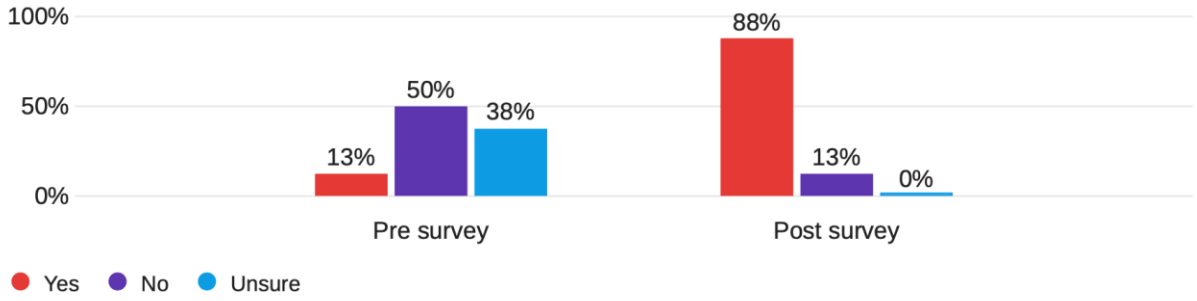


Figure 6 Accessing Information about Genetic Counseling

4.3.3 Open Text Response and Knowledge-Based Questions

The pre-survey included an open text response question to assess understanding of the role of a genetic counselor. 6 pre-survey participants did not enter text, 2 reported they were unsure, and 4 participants stated the following:

"A person who listens to what a person has which [is caused by their genetics]."

"A genetic counselor meets with people, usually people planning to conceive a child, to discuss their genetics & genetic compatibility."

"Scanning through DNA for ancestry or genetic disorders."

"Someone who listens to a person."

All participants reported that they or someone they know had not seen a genetic counselor before. Another open text response question was used in the pre-survey to assess concerns about the genetic counseling profession. No participants expressed concerns, however 2 participants expressed interest in learning about genetic counseling. Another participant, a psychology major, stated:

"I want to see how biology and psychology interplay."

A set of 6 knowledge-based multiple choice questions were used to assess participant knowledge of the genetic counseling profession before and after the seminar. Table 3 compares the frequency and percent of correct responses for each knowledge question before and after the seminar. When calculating the percent increase for each question, all questions were found to have a significant percent increase in correct responses ($p = 0.005$). Frequency and percent of correct responses for each participant can be appreciated in Table 4. The overall mean percent of correct responses for all knowledge-based questions in the pre-survey was 31.44% compared to 81.44% in the post-survey, an overall percent increase of 159.01% ($p = 0.005$) (Table 5). These questions

and corresponding values can be reviewed below. Questions are numbered according to their order in the post-survey.

Table 3 Frequency and Percent of Correct Responses by Question

Question	*Pre-Survey*		*Post-Survey*		
	Frequency	Percent	Frequency	Percent	Percent Increase
5. What type of education is required to practice as a genetic counselor? (Master's degree)	3	33%	9	100%	200%
6. What is the average salary of a genetic counselor in 2021? ($97,000)	2	22%	7	78%	250%
7. The U.S. Department of Labor estimates genetic counseling will grow how much through 2029? (21%)	0	0%	8	89%	89%
8. Most physicians have advanced training in genetics, true or false? (False)	4	44%	6	67%	50%
9. Someone who identifies as a racial or ethnic minority is (more/less/equally) as likely to be offered genetic counseling and testing as someone who is White or Caucasian. (Less)	5	56%	9	100%	80%
10. What percentage of practicing genetic counselors identify as a racial or ethnic minority? (15%)	3	33%	5	56%	67%

Table 4 Frequency and Percent of Correct Responses by Participant

Participant	*Pre-Survey*		*Post-Survey*	
	Frequency	Percent	Frequency	Percent
A	0	0%	5	83%
B	3	50%	5	83%
C	0	0%	4	67%
D	0	0%	5	83%
E	5	83%	5	83%
F	4	67%	4	67%
J	0	0%	5	83%
H	2	33%	5	83%
I	3	50%	6	100%

Table 5 Overall Mean Frequency and Percent of Correct Responses

	Mean Frequency	**SD**	**Mean Percentage**	**95% Confidence Interval**		**p-value**
				Lower CI	**Upper CI**	
Pre-Survey	2.83	1.72	31.44%	1.03	4.64	0.005
Post-Survey	7.33	1.63	81.44%	5.62	9.95	

4.3.4 Interest in Genetic Counseling

Interest in the genetic counseling field was assessed using a scale of 1 to 5, 1 being not interested, and 5 being interested. The pre-survey responses averaged a mean interest of 2.80 and post-survey responses averaged a mean interest of 3.71 ($p = 0.06$) (Table 6).

Table 6 Interest in Genetic Counseling Pre- and Post-Survey

	Min	Max	Mean	SD	Variance	p-value
Pre-Survey	2.00	4.00	2.80	0.60	0.36	0.06
Post-Survey	3.00	5.00	3.71	0.88	0.78	

All participants agreed that undergraduate academic advisors should present genetic counseling as a potential career option in the post-survey. When asked about concerns about the genetic counseling profession in the post-survey, 7 participants responded. 6 reported that they did not have concerns and 1 participant stated:

"The science aspect [of genetic counseling] scares me because I haven't dived too deep into it since I claimed my psychology degree."

This participant also selected 5 as their level of interest in the genetic counseling profession.

4.3.5 McNair Scholars Program Genetic Counseling Applicants

In review of their records, the Program Director for the St. Mary's McNair Scholars Program reported that there has only been a single genetic counseling applicant and matriculated genetic counselor trainee in the last 10 years. Generally, each McNair Program graduates at least 15 students per year.

4.4 Discussion

4.4.1 Study Population

To our knowledge, this is the first study to provide insight regarding the awareness, knowledge, and interest of the genetic counseling profession among Hispanic or Latinx undergraduate students, which consisted of 86% of the study participants. Given that most of the participants (77%) were enrolled in the McNair Scholars Program, it is unsurprising that this study's demographics largely reflect the criteria to eligible for the program, including identifying as an underrepresented minority, being a first-generation college student, and having an interest in pursuing a STEM graduate degree. Seventy-seven percent of participants reported that they were first-generation college students. This percentage is higher than the national average for Hispanics or Latinxs (44%), but consistent with previous research that indicates Hispanics or Latinxs are more likely to be first-generation college students compared to other racial and ethnic groups (Excelencia in Education, 2019). The reported generational status of participants is also consistent with previous research of the Hispanic or Latinx population as most participants reported that they were a second or third-generation American (Excelencia in Education, 2019).

4.4.2 Awareness and Knowledge of Genetic Counseling

The pre-survey identified that participants were either not aware of genetic counseling or had not considered it as a career, as no participants selected genetic counseling as a potential area of career interest. Considering that most of the study participants identified as a REM, reduced awareness of and exposure to the profession was anticipated because of previous research

(Kumaravel et al., 2011; Oh et al., 2005; Schoonveld et al., 2007). Only one student reported that their academic advisor had discussed genetic counseling as a potential career option, consistent with studies that surveyed academic advisors about their frequency and confidence of discussing the profession with advisees (Oh et al., 2005; Schoonveld et al., 2007). Several participants reported the profession had been discussed in their general biology course or another course in the pre-survey.

During the discussion with participants after the post-survey, an open-ended question was posed to determine if what they had learned about genetic counseling in their course(s) was similar or different to what was discussed in the seminar. Participants stated that their understanding of genetic counseling was different from what was discussed in the seminar and that the material covered in their course was not discussed in detail. These participants also noted that they did not have a complete understanding prior to the seminar. This finding agrees with an earlier investigation which determined that though undergraduates might have heard of the profession at some point, few report to be 'very familiar' with the profession (Gerard et al. 2018). Additionally, research of REM genetic counselors has identified that most learned about the profession by chance during their undergraduate studies (Alvarado-Wing et al., 2021; Schoonveld et al., 2007). There may be value in practicing genetic counselor or genetic counselor trainee involvement in general biology lectures within their community to increase visibility, awareness, and understanding of the field. It is important to acknowledge that a limitation for such involvement is access to genetic counselors, especially in certain regions that lack proximity to genetic counseling programs.

Comparison of the pre- and post-survey knowledge questions revealed that participants were able to achieve a higher percent of correct responses after the seminar. In reviewing each

knowledge question, a statistically significant increase ($p = 0.005$) in the ability to answer correctly was identified. Question 6, the average salary of a genetic counselor in 2021, had the highest percent increase at 250%. All participants underestimated the average salary of a genetic counselor, with 75% selecting $87,000 and 25% selecting $77,000. There were two knowledge questions that had less than 70% of correct responses in the post-survey, questions 8 and 10. Question 8, a true or false question about the level of genetics training among physicians, had a 67% correct response rate in the post-survey. Question 10, the percentage of practicing genetic counselors who identify as REM, had a 56% correct response rate in the post-survey. It is possible that rephrasing information for these questions in a more direct or simplified manner could be more effective. When looking at the overall percent of correct responses, the mean percent increase was also found to be statistically significant. These findings suggest that live presentations are successful in increasing participant knowledge of the genetic counseling profession.

For the participants that responded to pre-survey question 13, an open text question about the role of a genetic counselor, there was a theme of listening from respondents. One participant appeared to have a more developed understanding of genetic counseling and referenced preconception genetic counseling. Surprisingly, only one participant reported concerns about the profession in an open text question provided in both the pre- and post-survey. Their concerns were related to their preparedness for science training at the graduate level without a biology major. Future efforts may benefit from posing more direct questions to explore if and how religious, cultural, or social factors relate to participant concerns, especially in underrepresented populations.

4.4.3 Interest in Genetic Counseling and Participant Discussion

Participant interest in genetic counseling increased after the seminar overall, though it was not a statistically significant finding ($p = 0.06$). This was measured using the pre- and post-survey scale and participant discussion after completion of the post-survey, where multiple students engaged in the discussion. Of the participants who selected 4 or 5 as their level of interest in the profession in the post-survey, 5 being very interested, none were STEM majors. Using the pre-survey data, two of these participants were determined as psychology majors with career interests in mental health counseling, and one participant was a history major with unspecified career interests. Earlier outreach and educational efforts have focused primarily on STEM majors and related departments (Gerard et al., 2018; Lega et al., 2005); however, it is possible that broadening the reach of educational seminars outside of STEM departments may attract applicants who might not have otherwise been exposed to the profession and who could bring valuable perspectives and skills to the field. In fact, a participant asked a question if applying to the field with a degree other than biology was acceptable.

An additional participant asked about the availability of local genetic counselors for shadowing and was encouraged to hear they welcome contact from students through the NSGC website. One male participant remarked that though they were interested in the profession, he had concerns about the low percentage of male genetic counselors, supporting the need to increase the visibility of male genetic counselors. Finally, a participant asked if there were any available undergraduate courses in genetic counseling, which prompted a discussion about the development of an introduction to genetic counseling course at several universities and potential course material. When the room of participants was asked if they would be interested in taking an introductory course about genetic counseling, it was received positively. Genetic counseling education at the

undergraduate level is an area of active development (Merchant et al., 2019; Neogi et al., 2020), including at the University of Pittsburgh. Offering an introductory course as an elective could be beneficial in attracting interest and allowing students to appreciate the dynamic role of genetic counselors. In areas with established genetic counseling programs, an undergraduate course could facilitate a stronger network between practicing genetic counselors, universities, and potential applicants.

4.4.4 Future Directions

Future efforts to assess awareness, knowledge, and interest of the genetic counseling profession among diverse populations should be continued. Future directions include creating successful partnerships with additional McNair Scholars Programs at Historically Hispanic Serving and Historically Black Serving Institutions to support recruitment efforts of diverse applicants using a similar framework to this study. Collaboration with professors that teach courses in biology, genetics, or psychology could be another avenue to explore in combination with the educational seminar. A classroom or laboratory activity about a genetic counseling case might illicit interest from additional students and aid in further understanding of the profession. Similarly, a discussion panel of practicing genetic counselors or genetic counselor trainees might be considered. It may also be beneficial to create a partnership with academic advisors or mentors within the McNair Scholars Program or similar programs that serve diverse populations, through study materials or inviting them to future seminars. Given the feedback during the discussion portion of the seminar, exploring the possibility of an introduction to genetic counseling course at St. Mary's University is also of interest.

4.4.5 Study Limitations

The ability of the present study's findings to be generalizable is limited due to the small sample size and high percentage of McNair Scholar Program participants, who benefit from personal, social, and academic support that is not accessible to all underrepresented populations. As such, this study population does not reflect the awareness, knowledge, and interest of the genetic counseling profession of all REM undergraduates. Regarding survey completion, though most participants completed survey questions in their entirety, some participants did not. Similarly, there was a reduced response rate for the post-survey, as 69% of participants completed both their pre- and post-survey. The evaluation of open text responses was limited due to most participants skipping open text responses or leaving them blank. Additional responses would have allowed for more robust qualitative analysis of the study population. University site recruitment was a significant barrier to university participation in this study, comparable to previous efforts (Price et al., 2020); retention of interested universities was also reduced due to the COVID-19 pandemic, which resulted in university closures and the inability to reschedule the educational seminar.

4.5 Conclusion

This study is one of many efforts needed to increase the number of diverse genetic counseling applicants. The preliminary data from this study is valuable to inform future outreach and highlights the benefits of creating partnerships with universities and federal programs like the McNair Scholars Program that serve REM communities. To our knowledge, this study is the first to provide an educational seminar about genetic counseling with majority Hispanic or Latinx

undergraduate students. This research, though limited in the number of participants, identified that there is an increased level of interest in the profession after an educational seminar and a significant increase in knowledge about key aspects of the profession. As Price et al. has shown, there is value in presenting seminars through live methods, such as in-person or through video-conferencing technology, as opposed to non-live methods like brochures or recorded lectures. It allows for discussion, feedback, and fosters a community between the genetic counseling profession, universities, and potential applicants. The impact of having such efforts lead by genetic counselors and genetic counselor trainees from diverse communities cannot be underestimated and are integral to achieving equity in all aspects of the practice of genetic counseling.

5.0 Relevance to Public Health and Genetic Counseling

5.1 Public Health

The Centers for Disease Control and Prevention's (CDC) framework for public health is centered on protecting and promoting the health of all people and achieving health equity. A diverse healthcare workforce is foundational to health equity and is the motivation for this study. With respect to the CDC's ten essential public health services, this study incorporates two essential services: (1) building and supporting a diverse and skilled workforce and (2) strengthening, supporting, and mobilizing communities and partnerships (CDC, 2021). These essential public health services were key in this study's application. These services were applied by engaging with underrepresented populations and building a partnership with the McNair Scholars Program through the educational seminar. Our hope is that this continued partnership will build a community between the genetic counseling profession and diverse applicants.

In recent years, there has been an increase in the attention to inequities experienced by REMs and how these inequities negatively impact public health. To achieve health equity for all persons, we must address the systemic and structural barriers that disproportionality affect REM populations. The CDC's Office for Minority Health is committed to integrating health equity in all aspects of public health practice. In their framework, strategies of partnership are highlighted, including efforts like ours that engage with diverse communities and promote the visibility of REMs in fields that they are not traditionally represented in (CDC, 2022). The framework also recommends the creation of infrastructure and student pipelines to further support the growth of diversity across all fields connected to public health, notably research and healthcare. Though this

approach is active in recruiting diverse applicants in medicine and biomedical sciences, there is no such pipeline for genetic counseling (Bouye et al., 2016). Given that the McNair Scholars Program is active throughout many minority serving institutions in the United States, continued partnership with the McNair Scholars Program should be utilized to promote this strategy in the genetic counseling field. Intentional and scalable community-based efforts such as this are critical to promoting public health and equity for diverse populations.

5.2 Genetic Counseling

In the NSGC 2022-2024 Strategic Plan, NSGC outlines strategies to promote justice, equity, diversity, and inclusion in the field of genetic counseling (NSGC, 2022). Part of this strategy includes recruiting and retaining diversity into the profession. As discussed in this manuscript, a diverse healthcare workforce is necessary to achieve equity at all levels of patient care. The knowledge gained from this study is valuable in the ongoing efforts to achieve a more equitable genetic counseling profession through diverse recruitment. This study and its materials can be utilized for subsequent outreach efforts by genetic counselor trainees, practicing genetic counselors, or program leadership. Considering that most genetic counseling curriculums require participation in community outreach, this might present an opportunity for genetic counselor trainees to fulfill this requirement by using this educational seminar materials—particularly in underserved regions and minority serving institutions.

Looking forward, the genetic counseling profession would certainly benefit from building infrastructure and recruitment pipelines to support diverse applicants, like those in medicine and biomedical science training programs. This might include establishing direct collaboration with

federally funded programs like the McNair Scholars Program that socially, academically, and financially support undergraduate students from underrepresented backgrounds in preparing for graduate level education. Increasing the availability and accessibility of genetic counseling internships for underrepresented persons should also be considered. Similarly, genetic counseling programs can bring greater attention to diversity efforts through their applications, interview processes, and scholarship opportunities. Several genetic counseling programs have made intentional efforts to highlight their commitment to diversity, such as including a diversity statement on the program website, establishing interview days for underrepresented applicants, and providing diversity scholarships. Together, these actions are critical to achieve diverse recruitment and retainment in the genetic counseling profession.

Appendix A IRB Approval

University of Pittsburgh | Institutional Review Board
Office of Research Protections

EXEMPT DETERMINATION

Date:	February 11, 2022
IRB:	STUDY21120025
PI:	Lauren Garcia
Title:	Racial and Ethnic Diversity in Genetic Counseling: Engaging with Undergraduate Students
Funding:	None

The Institutional Review Board reviewed and determined the above referenced study meets the regulatory requirements for exempt research under 45 CFR 46.104.

Determination Documentation

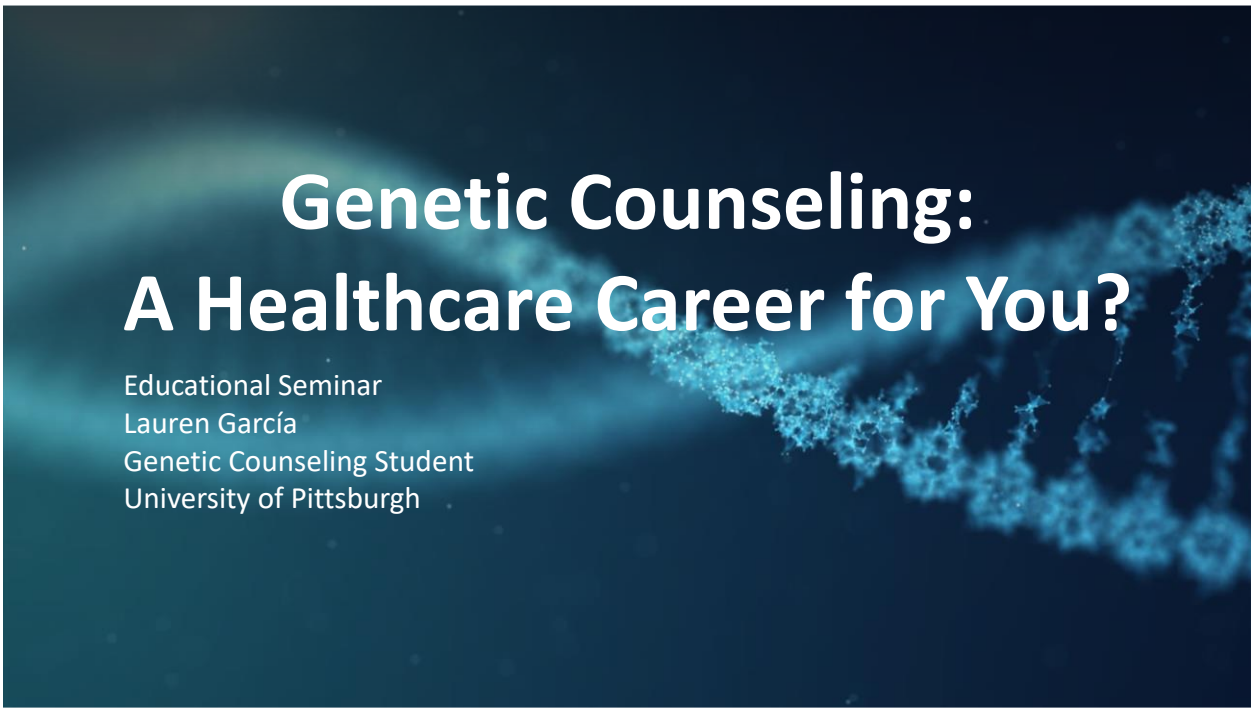
Determination Date:	2/11/2022
Exempt Category:	(1) Educational settings

Approved Documents:	• GC Post-Survey • GC Pre-Survey • Genetic Counseling Seminar • Recruitment email • Site Permission Letter - St. Mary's University

If you have any questions, please contact the University of Pittsburgh IRB Coordinator, Emily Bird.

Please take a moment to complete our Satisfaction Survey as we appreciate your feedback.

Appendix B PowerPoint Presentation



About Me:

Graduate student at the University of Pittsburgh	Studying Genetic Counseling
Ronald E. McNair Scholar (2018)	B.A. in Biology St. Mary's University, San Antonio, TX
Here to discuss genetic counseling as a potential career option as part of my graduate thesis!	

Survey 1

https://pitt.co1.qualtrics.com/jfe/form/SV_08RoDKl2QxscK4C

Cancer Genetics: Example

Question: Why was Patient B not offered genetic testing?

Patient A	Patient B
• **White female** • **Breast cancer diagnosed at age 32** • **Family history of breast cancer** • **Offered genetic testing** • Identified *BRCA1* gene mutation → Up to 87% lifetime risk of breast cancer → Up to 63% lifetime risk of ovarian cancer	• **Hispanic female** • **Breast cancer diagnosed at age 32** • **Family history of breast cancer** • **Not offered genetic testing**

Cancer Genetics: Background

- Certain types of cancer can be caused by a genetic change (mutation) that can be passed down in families (hereditary cancer syndrome)
- **Patient A's** *BRCA1* mutation causes Hereditary Breast and Ovarian Cancer Syndrome (HBOC)
  - Characterized by young age of diagnosis and strong family history of breast cancer
- Anyone diagnosed with breast cancer before age 45 should be referred to a **genetic counselor**
  - **A genetic counselor is a healthcare provider with specialized training in medical genetics, genetic testing, and counseling**
- Genetic test results may impact cancer treatment, future management, and the health of other family members
  - Targeted chemotherapy and surgery
  - Risk-reducing surgical options (i.e., mastectomy) and increased cancer surveillance (i.e., mammogram)
  - Identify other at-risk family members who might have the same mutation (close blood relatives are at a 50% chance of having the same mutation)

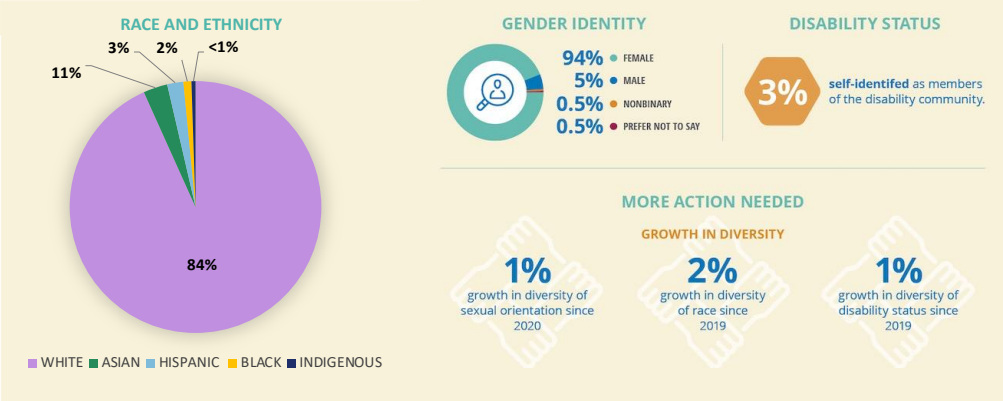
Cancer Genetics: Example Cont. Outcomes

Patient A	Patient B
• **White female** • **Breast cancer diagnosed at age 32** • **Family history of breast cancer** • **Offered genetic testing** • Informed healthcare decisions → Chemotherapy for *BRCA* mutations → Double mastectomy, reduces risk of breast cancer by 90% → Family members offered testing	• **Hispanic female** • **Breast cancer diagnosed at age 32** • **Family history of breast cancer** • **Not offered genetic testing** • Breast cancer recurred 2 years later

Why was Patient B not offered genetic testing?

- Even when meeting clinical genetic testing guidelines, racial and ethnic minorities are:
  - Less likely to be referred to a genetic counselor for genetic testing; research suggests this is a result of implicit bias
  - Less likely to be aware of genetic counseling and genetic testing
- Underrepresented persons are unlikely to see themselves reflected in their healthcare providers, including genetic counselors
- Studies show that both Hispanic and Black individuals seek out racially and ethnically concordant healthcare providers
  - Positively related to partnership, respect, communication, and patient satisfaction
  - Reduces racial and ethnic bias
  - Highlights the need for racial and ethnic diversity in genetic counseling

The Need for Diversity in Genetic Counseling



As the patient population becomes more diverse, increasing the number of genetic counselors from underrepresented backgrounds is a critical step in achieving health equity, reducing implicit bias, and improving health outcomes.

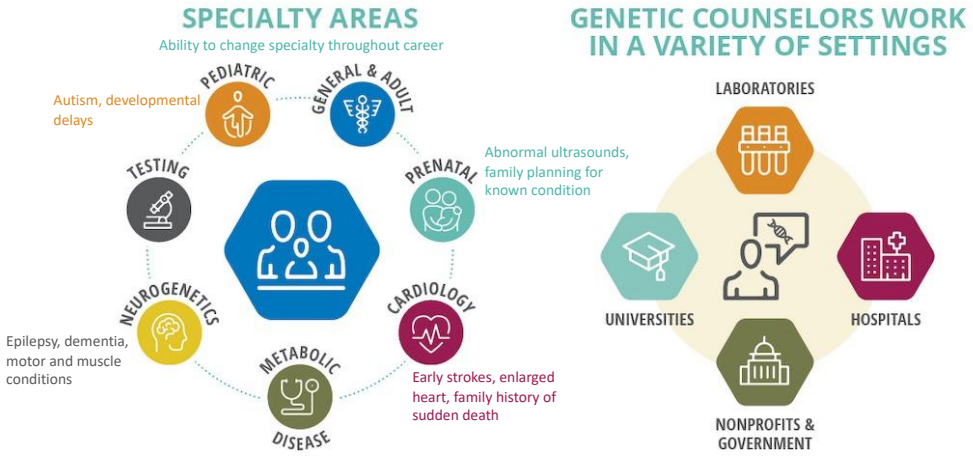
National Society of Genetic Counselors

The Role of Genetic Counselors

- Part of the healthcare team within clinics and hospitals
  - Most physicians do not have advanced training in genetics
- Genetic counselors serve as a translator for complex genetic information such as:
  - The risk of having a genetic condition based on family history and health information
  - How genetic testing works
  - What genetic test results mean
  - How to manage a genetic condition
- Genetic counseling sessions also involve counseling skills to facilitate decision making, provide emotional support, and advocate for patients
- The average genetic counseling session is about 60 minutes

Specialties and Employment

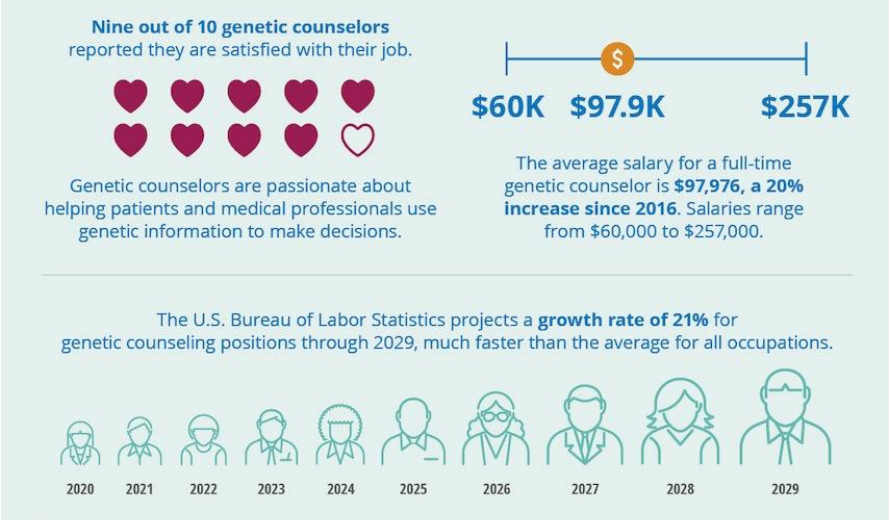
The largest primary specialty areas for genetic counselors are **cancer genetics (34%)**, **prenatal genetics (20%)** and **pediatric genetics (14%)**, but genetic counselors work in a variety of areas:



National Society of Genetic Counselors

Salary and Job Outlook

2021 National Society of Genetic Counselors Professional Status Survey



National Society of Genetic Counselors

Education Requirements to become a Genetic Counselor

- Earn a Master's Degree in Genetic Counseling
  - 2-year program
  - Specialized coursework in medical genetics, genetic testing, and counseling
  - Clinical rotations in core specialty areas
  - Master's Thesis or Capstone Project (clinical, laboratory, or social focus)
- Pass the American Board of Genetic Counseling Certification Exam

74%
of genetic counselors accepted a position before graduation, and seven out of 10 accepted their position one to three months before graduating.

- There are 56 accredited Genetic Counseling Programs across the United States and Canada (and growing!)
  - Each program accepts about 4-20 applicants each year in April

National Society of Genetic Counselors

What makes a competitive applicant?

- Undergraduate degree in any field with coursework in:
  - Genetics
  - Statistics
  - Psychology
  - Biochemistry
- Advocacy experience and volunteer work
- Genetic counseling field exposure
  - Shadowing, webinars, conferences, podcasts etc.
- Research experience

Application Resources and More Information

- My Gene Counsel
  Contains a Prospective Student Toolkit
  - Career information
  - Application Process
  - Where to connect with other students
- National Society of Genetic Counselors
  - Career information
  - Connect with a Genetic Counselor in your area
  - Simulated genetic counseling sessions

Additional Resources

- **Simulated Genetic Counseling Sessions:** Cardiovascular, Cancer, and Prenatal
  - The Master Genetic Counselor Series: https://www.nsgc.org/Education-and-Events/Online-Education-Center/Online-Education-Inventory/JEMF-Master-Genetic-Counselor-Series

- **Mentorship:**
  - The Minority Genetics Professionals Network (MGPN): https://mgpn.chronus.com/
  - The Genetics Opportunities, Learning, Development and Empowerment Network (GOLDEN): https://docs.google.com/forms/d/e/1FAIpQLScep1CbgAZPKwuT_Jq3D7FcnVLrDGCnk9FF_VPVMOnIznk59Q/viewform?vc=0&c=0&w=1&flr=0

Survey 2

https://pitt.co1.qualtrics.com/jfe/form/SV_1YQ904E9ZhODrBI

Questions?

For additional questions, please feel free to email me at:
LAG150@pitt.edu

Appendix C Pre- and Post-Survey

Appendix C.1 Pre-Survey

Genetic Counseling Pre-Survey

Start of Block: Demographic Information

Q1 Select your racial and ethnic identity. Select all that apply.
If you do not feel your racial or ethnic identity is reflected, please specify.

- ☐ Black, African American, or of African descent (1)
- ☐ East Asian (2)
- ☐ Hispanic, Latino, Latina, or Latinx (3)
- ☐ Middle Eastern or North African (4)
- ☐ Native or Indigenous (5)
- ☐ South Asian (6)
- ☐ White or Caucasian (7)
- ☐ Prefer to self-describe, please specify (8)

_____

Q2 Select your primary language

- English (1)
- Spanish (2)
- Chinese (3)
- French (4)
- Tagalog (5)
- Vietnamese (6)
- Not listed, please specify (7) _____

Q3 Select your gender identity

- Male (1)
- Female (2)
- Non-binary, Genderfluid, or Genderqueer (3)
- Transgender man (4)
- Transgender woman (5)
- Prefer to self-describe, please specify (6)

_____

Q4 Select your disability status

- Disability (1)
- No disability (2)
- Prefer to self-describe, please specify (3)

_____

Q5 Select your generational status
First generation refers to someone who is born in a country outside of the United States. Second

generation refers to someone that has at least one foreign-born parent. Third generation or higher refers to someone whose parents were both born in the United States.

- ○ Indigenous (1)
- ○ First generation American (2)
- ○ Second generation American (3)
- ○ Third generation American or higher (4)
- ○ Does not apply (5)

End of Block: Demographic Information

Start of Block: Education Information

Q6 Select your current major(s)

- [ ] Biology (1)
- [ ] Chemistry (2)
- [ ] Mathematics (3)
- [ ] Psychology (4)
- [ ] Sociology (5)
- [ ] Not listed, please specify (6)

_____

Q7 Select your current year of study

- ○ Freshman (1)
- ○ Sophomore (2)
- ○ Junior (3)
- ○ Senior (4)

Q8 Are you a first-generation college student?

- ○ Yes (1)
- ○ No (2)

Q9 Are you currently enrolled in the McNair Scholars Program?

- ○ Yes (1)
- ○ No (2)

Q10 Select which healthcare professions you have considered or are considering

- [ ] Genetic counseling (1)
- [ ] Medicine (2)
- [ ] Nursing (3)
- [ ] Occupational therapy (4)
- [ ] Physical therapy (5)
- [ ] Psychology or mental healthcare provider (6)
- [ ] Public health (7)
- [ ] Research (8)
- [ ] Speech therapy (9)
- [ ] Undecided (10)
- [ ] Prefer to self-describe, please specify (11)

_____

- [ ] None of the above (12)

Q11 On a scale of 1 to 5, 1 being not interested and 5 being very interested, how much does genetic counseling interest you as a potential career option?

	not interested			interested		
	1	2	3	3	4	5
Scale ()						

End of Block: Education Information

Start of Block: Genetic Counseling

Q12 Have you or someone you know seen a genetic counselor before?

- ○ Yes (1)
- ○ No (2)

Q13 What are the typical roles of a practicing genetic counselor?

_____

_____

_____

_____

_____

Q14 Do you have any concerns about the genetic counseling profession? If so, please specify.

_____

_____

_____

_____

_____

Q15 Has genetic counseling been discussed in any of your courses? If so, please indicate the general topic of that course.

- ☐ Embryology (1)
- ☐ Genetics (2)
- ☐ General Biology (3)
- ☐ Psychology (4)
- ☐ Not discussed in any courses (5)

Q16 Has an academic advisor ever presented genetic counseling as a career option?

- ○ Yes (1)
- ○ No (2)

Q17 Do you know where to find more information about genetic counseling or the application process?

- Yes (1)
- No (2)
- Unsure (3)

Q18 What type of education is required to practice as a genetic counselor?

- Bachelor's degree (1)
- Master's degree (2)
- PhD (3)

Q19 The U.S. Department of Labor estimates genetic counseling will grow how much through 2029?

- 1% (1)
- 11% (2)
- 21% (3)
- 31% (4)
- 51% (5)

Q20 What is the average salary of a genetic counselor in 2021?

- $67,000 (1)
- $77,000 (2)
- $87,000 (3)
- $97,000 (4)
- $107,000 (5)

Q21 Most physicians have advanced training in genetics, true or false?

- True (1)
- False (2)

Q22 Someone who identifies as a racial or ethnic minority is ____ to be offered genetic testing as someone who is White or Caucasian.

- Equally as likely (1)
- Less likely (2)
- More likely (3)

Q23 Approximately, what percentage of practicing genetic counselors identify as a racial or ethnic minority?

- 45% (1)
- 30% (2)
- 15% (3)
- 5% (4)

End of Block: Genetic Counseling

Start of Block: Block 3

Q25 Please enter your 4 digit ID below: ${e://Field/Random%20ID}
Please keep note of this ID, you will use it for the post survey, thank you!

_____

End of Block: Block 3

Appendix C.2 Post-Survey

Genetic Counseling Post-Survey

Start of Block: Block 1

Q12 Please enter your 4 digit ID:

_____

End of Block: Block 1

Start of Block: Default Question Block

Q1 On a scale of 1 to 5, 1 being not interested and 5 being very interested, how much does genetic counseling interest you as a potential career option?

	not interested			interested	
	1	2	3	4	5
Scale ()					

Q2 Do you have any concerns about the genetic counseling profession? If so, please specify

_____

_____

_____

_____

_____

Q3 Do you think academic advisors should present genetic counseling as a career option more often?

- Yes (1)
- No (2)

Q4 Do you know where to find more information about genetic counseling or the application process?

- Yes (1)
- No (2)
- Unsure (3)

Q5 What type of education is required to practice as a genetic counselor?

- Bachelor's degree (1)
- Master's degree (2)
- PhD (3)

Q6 What is the average salary of a genetic counselor in 2021?

- $67,000 (1)
- $77,000 (2)
- $88,000 (3)
- $97,000 (4)
- $107,000 (5)

Q7 The U.S. Department of Labor estimates genetic counseling will grow how much through 2029?

- 1% (1)
- 11% (2)
- 21% (3)
- 31% (4)
- 51% (5)

Q8 Most physicians have advanced training in genetics, true or false?

- True (1)
- False (2)

Q9 Someone who identifies as a racial or ethnic minority is ____ to be offered genetic testing as someone who is White or Caucasian.

- Equally as likely (1)
- Less likely (2)
- More likely (3)

Q10 What percentage of practicing genetic counselors identify as a racial or ethnic minority?

- 45% (1)
- 35% (2)
- 15% (3)
- 5% (4)

End of Block: Default Question Block

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