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# Studying the Needles in the Haystack: A Qualitative Study of African-American and Latino Genetic Counselors

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Experiences of the Minority

Studying the Needles in the Haystack: A Qualitative Study of African-American and Latino  
Genetic Counselors

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# Experiences of the Minority

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**Abstract**

The field of genetic counseling as a whole significantly lacks ethnic diversity within the ranks of their prospective students and trained professionals. This article describes the importance of understanding underrepresented minorities' (URM's) experiences and how their stories can be used to better implement recruitment techniques. In this qualitative study, five practicing genetic counselors and three genetic counseling students who identified as African-American and/or Latino participated in a structured phone interview. These interviews were aimed at better understanding their introduction into the field, their experiences in their training program, and their experiences in the profession. Themes that were explored include: learning about genetic counseling, barriers experienced, being an URM in a training program, motivating factors, and family support/mentors. Introduction to the field was often later in college. Majority of the participants expressed unconditional family support when pursuing genetic counseling as a career. As an URM, participants often experienced feelings of isolation due to their minority status. None of the participants had access to a role model/mentor/advisor of the same ethnic background and several expressed a desire to have a role model from the same or similar background. Participants also reported some instances of feeling misunderstood by faculty due to stereotypes related to race. Possible URM recruitment initiatives involving biographies featured on a website are discussed.

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### **Introduction**

The lack of diversity within the healthcare profession, specifically genetic counseling, is a well-recognized issue (Mittman *et al.*, 2008). According to the most recent census, the non-Caucasian population is growing more rapidly than the total population, and by 2050 minority groups (defined as populations represented in lesser numbers) are projected to become the majority population (U.S. Census Bureau, 2012). Despite this fact, the field of genetic counseling continues to see a significant lack of diversity within its practicing genetic counselors and prospective students. This growing gap between the number of minority genetic counselors and the increasing minority population presents a unique challenge. According to Smedley and Mittman (2011), studies show that when minority patients are able to select a healthcare provider, they are more likely to choose someone of their own ethnic background. Additionally, these relationships between patients and physicians of the same ethnic background promote higher levels of trust and respect. For these reasons, it is crucial that this lack of diversity within the field of genetic counseling is addressed to provide patients from all backgrounds with the best possible care. The present study was designed to explore the experiences and barriers faced by practicing genetic counselors as well as genetic counseling students who identify as an underrepresented minority (URM). Particularly, the study focuses on the experiences of African American and Latino genetic counselors and students, as these two groups remain highly unrepresented in the genetic counseling profession.

### **Literature Review / Background**

#### *Importance of URM Role Model Accessibility*

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A successful career outlook requires three things: access to information, support, and feedback (Knouse, 1992). Mentoring and access to role models can provide each of these things for prospective students, however, minority groups often lack access to informal networks and information that would allow them to be successful in an academic environment in which they are underrepresented (Thomas *et al.*, 2007). In addition, minority students often experience more feelings of isolation and less access to mentors and role models than their non-minority peers (Girves *et al.*, 2005).

In addition, it appears as though cultural differences between mentors and mentees seem to play a role in the expectation, attainment, and experience of mentoring (Liang & West, 2007). Linda Jucovy is a writer, whose expertise comes from working in programs for at risk youth, being involved in education reform efforts, and teaching at colleges in the New York and Philadelphia area. In her book, *Same-Race and Cross-Race Matching* (2002), Jucovy gives three main reasons why same-race mentoring programs work: Firstly, culture is deeply internalized, which provides racial groups with a sense of history, heritage, and continuity. Secondly, Jucovy states that matching mentees with mentors of a different ethnic background could send the message that there are not enough individuals from their own community that can serve as a positive role model. Thirdly, she believes that cross-race mentoring is an important way to strengthen the ties within a minority community. For these as well as other reasons, it is important that role models of similar backgrounds are accessible for URM students. If individuals from diverse backgrounds do not see genetic counselors that are of similar ethnic backgrounds to them, this may lead them to pursue other career options because they are less able to envision themselves within the field.

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### *Purpose of the Present Study*

This study is a continuation of work done by two former Sarah Lawrence College genetic counseling students. Their project was to create a recruitment website called “Become A Genetic Counselor”. This website aims to encourage and educate students while exploring the career path of genetic counseling (Anstett, K. & Chen, S., 2015). One section of the website called “Faces of Genetic Counseling” is devoted to sharing the stories of current genetic counselors from URM backgrounds. Since the launch of the website this past year, feedback has shown that the “Faces of Genetic Counseling” section has been the most popular thus far (Anstett and Chen, personal communication). This suggests the importance of role model visibility for prospective students. The purpose of the present study is to build off of the previous study by expanding the “Faces of Genetic Counseling” section of the website, while also determining common barriers and successes URM genetic counselors and genetic counseling students face.

### **METHODS**

Interviews were conducted with 5 practicing genetic counselors and 3 genetic counseling students who all identified as an URM. Experiences and barriers were explored by focusing on three main areas: 1) Experience exploring the profession of genetic counseling, specifically when and how a career decision was made, family support, access to role models, and financial factors. 2) Experience in a genetic counseling training program, specifically addressing their status as a minority and how that impacted their overall experience. 3) Experience working in the field of genetic counseling, specifically focusing on interactions with colleagues, career challenges, and experiences working with patients of similar ethnic backgrounds. The aim is to use the

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information obtained in these interviews to not only create additional biographies for the website, but to further analyze the experiences of URM genetic counselors and genetic counseling students to further improve, create, and implement recruitment techniques.

### **Participants**

Participants were recruited through word of mouth by the authors of the current study. The inclusion criteria included individuals who self-identify as African American and/or Latino. The study received approval from a Sarah Lawrence College IRB. An invitation to participate was sent via email to a total of 15 practicing URM genetic counselors and genetic counseling students who had expressed interest in the study asking them to participate in a structured phone interview. This phone interview involved discussing how they learned about the genetic counseling profession, their experience in their training program, and experience within the genetic counseling profession. Participating individuals independently reviewed and returned a signed informed consent form via email and an interview was scheduled.

### **Structured Interview Development and Protocol**

A series of 33 open and closed-ended questions were developed for the structured phone interview (see appendix). These questions were based on previous research, which identified barriers entering health care professions and career path exploration tendencies seen in URM groups (Anstett, K. & Chen, S., 2015). The questions were targeted at revealing common barriers and successes experienced by genetic counselors or genetic counseling students from African American and/or Latino backgrounds. The interview was split up into three sections. The first section consisted of 14 open-ended questions focusing on career exploration and choosing genetic counseling as a profession. The



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second section consisted of six open-ended questions that focused on experiences within a training program and how identifying as an URM impacted that experience. The third section consisted of 13 open-ended questions regarding experiences as a practicing genetic counselor. This last section of questions was not used for participants who were current genetic counseling students. Participants were informed they could skip any questions they did not feel comfortable answering.

### **Procedure**

The study team conducted the telephone interviews. They were audio recorded and transcribed into a word document using a transcription service. The interviews ranged in length from 30-65 minutes. The interviewers asked the same questions in approximately the same order for each participant and included occasional prompts. Participant quotes used in this article were taken directly from the audio transcription.

### **Data Analysis**

We analyzed the interview transcript data independently using qualitative analysis where themes were allowed to develop freely from the interview data, rather than using a pre-existing coding scheme. After the interviews were transcribed, the first two authors analyzed the data to determine common themes. Once the content was analyzed and discussed, the authors developed content groups based upon the analysis process. These groups were each further divided into categories in which content was assigned. Each interview was coded using this coding scheme. On occasion, the categories within the groups were modified to more clearly represent the data. In addition, additional groups were added and removed to better reveal important themes. The coding scheme

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developed ultimately consisted of six groups with 26 total categories and six subcategories.

Each author coded the interview data separately. Upon completion of coding each individual interview, both authors compared how they coded the data to ensure consistency. The interview data was often coded identically approximately 90% of the time, however, on the occasion that discrepancies arose, the authors would discuss until consensus was reached. Finally, participants were all randomly assigned a number one through eight for the purpose of using anonymous verbatim quotes.

## **RESULTS**

### **Sample Characteristics**

A total of 10 genetic counselors and genetic counseling students responded who self-identified as an underrepresented minority. Two of the respondents did not meet the study criteria because they were not African American and/or Latino and were not included in the study. Five of the participants were practicing genetic counselors working in a clinical setting throughout the United States. Three of the participants were students enrolled in three different genetic counseling graduate programs located throughout the United States. One participant was previously a genetic counseling training program director. Their ethnic backgrounds included African American and Hispanic. See Table 1.

### **Common Theme: How Participants Learned about the Career and Barriers**

#### **Encountered**

Participants described a number of positive and negative experiences regarding being an URM in the genetic counseling field. Participants also discussed how they came to discover the genetic counseling career path and experiences they had throughout the

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process. These experiences allowed the authors to formulate an appropriate coding scheme that would encompass the overarching themes that were expressed by the participants. If a participant experienced none of the categories, they were coded as a negative depending on the group. The coding scheme, including groups, categories, and subcategories are described below. Frequency of responses and relevant participant quotes are listed in Table 2.

### *Group 1: Learning about Genetic Counseling*

This group refers to how the participants learned about the career of genetic counseling.

This group is divided into 3 categories including:

- a) Through a course, teacher, advisor in high school
- b) Through a course, teacher, advisor in college
- c) Through the Internet

### *Group 2: Barriers*

This group concerns the barriers participants faced while pursuing a career in genetic counseling. This group contains 4 categories and 6 subcategories:

- a) Logistical/practical barriers, which include the following subcategories:
  - 1. Couldn't find information about genetic counseling
  - 2. Lack of exposure/knowledge of the field's existence
  - 3. Lack of shadowing opportunities
  - 4. Financial barriers either cost of tuition or earning potential
  - 5. Difficulty acquiring the appropriate prerequisites to apply to a genetic counseling program
  - 6. Struggle of balancing work and social life while in a graduate program.

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- b) Psychological barriers (thought to be attributed to race)
- c) Negative - no logistical/practical barriers were experienced
- d) Negative - no psychological barriers (thought to be attributed to race) were experienced

### *Group 3: Being an URM in a Training Program*

This group refers to being an URM in a training program and is further divided into the following 6 categories:

- a) Feeling alone and/or isolated
- b) Desire to have classmates from similar background
- c) Feeling the need to look outside the program to find students of similar backgrounds to interact with
- d) Being from a minority background allows for different perspectives
- e) At times feeling misunderstood by faculty members because of race
- f) Negative (no feelings of separation or being misunderstood because of race)

### **Common Theme: Family Support, Important Relationships, and Motivating Factors for Entering the Field**

Participants discussed the role that their family played on their decision to enter the field of genetic counseling. Additionally, they discussed the presence or absence of an important mentor-type role model, and whether or not these mentors shared a similar minority background. Participants also discussed their motivations for entering the field of genetic counseling. The coding scheme, including groups, categories, and subcategories are described below. Frequency of responses and relevant participant quotes are listed in Table 3.

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### *Group 4: Initial Family Support*

This group refers to the initial support offered by family members when choosing to pursue a career in genetic counseling. This group is divided into 3 categories including:

- a) Unconditional support
- b) Mixed support (encouraged idea of continued education but questioned genetic counseling as a career path)
- c) No support for genetic counseling career path

### *Group 5: Relationships; Important Others (excluding family)*

This group represents important individuals such as an advisor, mentor, or role model who supported participants in their journey to become a genetic counselor. This group is separated into 5 categories:

- a) Had a supportive advisor/mentor (not from the same race)
- b) Had a supportive advisor/mentor (from the same race)
- c) Had a desire to have a role model/mentor/advisor from the same ethnic background
- d) Shadowing was helpful/desired
- e) Negative - participants had no role models/mentors/advisors

### *Group 6: Rewards / Motivating Factors (for being in the genetic counseling field)*

This group refers to rewards and/or motivating factors for being in the field of genetic counseling. This group is divided into 5 categories including:

- a) Finds working with minority populations rewarding
- b) URM status facilitates building rapport/trust with minority patients
- c) Desire to blend science with helping people

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- d) Desire to be a female role model in the science field
- e) Desire to help patients understand complex topics

## **FINDINGS**

In the present study, 5 practicing genetic counselors and 3 genetic counseling students who all identified as African American and/or Latino were interviewed and discussed their entrance in the field, barriers they encountered, support and motivating factors for pursuing a career in genetic counseling. Common themes discovered through qualitative analysis are discussed below.

### **Introduction to the Field**

Of the eight participants, all of them learned about the field of genetic counseling while in college or shortly after graduating from college. Half of the participants learned about the field through a course, professor, or advisor in college, while the remaining learned about the profession through an Internet search. As one participant stated, “I kind of got tired of being by myself in the lab all the time so I was trying to find a career change and it’s just something that happened to pop up on the Internet.” Several of the participants were pursuing careers in medicine and other science fields. It was commonly expressed that something was missing from their original career path, and they wished they would have known of this profession earlier. When discussing career path exploration, one participant stated, “I wanted to be a doctor, but that doesn’t fit my personality. And so I was thinking, I don’t really know what to do because there’s nothing really else that I can do. I was basically saying what I want, who I am does not fit with being a doctor.” Knowing about the profession at a younger age could have prevented some of the barriers experienced, such as completing necessary course prerequisites, gaining shadowing experience, or pursuing career paths that were not an

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appropriate fit. Another participant explained an experience she had while considering entering the field. She discussed how a previous employer reacted to her desire to pursue a career in genetic counseling. She stated, “I knew for a very long time that I wanted to become a genetic counselor, and when I mentioned it he was like, ‘Oh you can’t get in...you need to be taller, you need to be blonde, and you need to have blue eyes.’”

Experiences like this could potentially discourage minority populations from considering genetic counseling as a possible career path.

### **Important Relationships and Support Aid in Choosing to Pursue a Career in Genetic Counseling**

The majority of participants expressed having unconditional support from family members. One participant stated, “Whatever I chose, and whatever I decided, they were supportive. That was made clear from the beginning.” Two participants did have mixed support, meaning their family encouraged the idea of continued education, but questioned genetic counseling as an appropriate career path. One participant stated, “Everyone is always asking me, ‘So are you going to continue studying and are you going to be a doctor?’ And I’m like, no thank you. I like what I do very much right now.” When discussing family reactions to choosing to pursue a career in genetic counseling, another participant stated,

“It’s definitely the title genetic counselor. Once you put the counselor in it. I mean I don’t mind because that’s the field I’m going into but anyone who doesn’t understand what genetic counselors do automatically decreases the credibility of counselors especially in the minority community...because once you say counselor they’re like, oh, that’s not a great field like either a doctor or a lawyer or a nurse.”

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No participants expressed having no family support while pursuing the profession of genetic counseling. It was previously identified that family support is a factor when URM students are choosing a career path. It is encouraging that the majority of participants in this study expressed having unconditional family support, however, it was demonstrated that some participants have family support that is not entirely unalloyed, and could cause some to deter from pursuing entrance into this particular field.

The majority of participants had a supportive advisor or mentor while pursuing the genetic counseling career path. However, none of these advisors or mentors were of the same ethnic background as any of the participants. One participant stated, “My strategy was very much guided by an assistant director in particular. I actually was very fortunate to have that amazing mentor guiding the whole process.” Two participants articulated a strong desire to have a role model, mentor, and/or advisor from the same ethnic background. These participants wanted a role model, advisor, and/or mentor of the same ethnic background specifically because they wished to have someone who they could identify with and relate to in terms of barriers faced related to race. One participant stated, “I went to Google black genetic counselors because I was feeling like I wanted to find someone so I could just talk to them that was you know, like me...I just needed someone who I knew gets it.” This participant also went on to say, “There’s something that when you’re alone that it’s hard to be the only one...if you don’t have a role model, you will start to feel alone.” Another participant stated, “Even when I was going through the process, there really wasn’t anyone that had a similar background as me. It was a challenge trying to identify with someone.” Additionally, two participants stated that they did not have any role model, advisor, or mentor while exploring the profession of genetic



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counseling. This was exemplified when one participant stated, “I would say at that point it was really on my own. It definitely would have been helpful to have a mentor looking back now.” The small size of the field at the time of entrance was thought to be a contributing factor to not having a mentor or role model while exploring the field.

### **Commonly Experienced Barriers among URM Participants**

In the analysis of barriers experienced by participants, we split barriers into two broad sections: logistical/practical and psychological barriers. The most commonly experienced practical barriers involved financial concerns, work/social balance, and lack of exposure to the profession. These findings are consistent with what has already been established in our predecessors study (Anstett, K. & Chen, S., 2015). Their research found URM students make career decisions earlier than Caucasian students, and the current study shows that URM students were not exposed to the genetic counseling profession until college or later. As one participant stated, “I didn’t hear about genetic counseling until the summer before I got accepted into my program.” This barrier of lacking exposure most likely contributes to the issue of lacking diversity in the field since URM students generally make career decisions years before they have been introduced to genetic counseling. They also have fewer family and social influences that know about the profession, and are more likely to have financial barriers to higher education.

The psychological barriers included any barrier that was thought to be related to race. Several themes emerged from the data. Many participants specifically expressed feeling alone and/or isolated while exploring the career path and in a training program. As one participant stated, “It has something to do with being alone and feeling alone and realizing I’m the only one...it was actually quite depressing.” These participants often

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vocalized the desire to have classmates from a similar background. This led some to look outside of their training program to find other students of similar ethnic backgrounds that share the same cultural values and could provide the desired support. In regards to this barrier, one participant stated,

“So from the genetic counseling/student perspective I definitely had that support, but then you do have that other side of wanting that cultural support, being around people who are similar to you in other ways besides just academic. What I ended up doing was actively seeking out within the larger school...there was much more diversity within the school of public health, and that’s where I actually ended up garnering that other level of support that I needed.”

This shows the importance of recruiting a culturally diverse genetic counseling workforce in order to provide students and professionals with the appropriate support they want and need.

In addition, half of participants reported at times feeling misunderstood by faculty members (program faculty, rotation supervisors, course instructors) specifically because of race. These individuals expressed feeling that faculty members were more concerned about their academic abilities because of the stereotype that they may be more inclined to struggle with difficult course material. One participant stated, “I think it was an assumption being made that I would be struggling in classes and I’m not. You know, it’s little micro-aggressions like that.” Another participant stated that, “I feel that one of the instructors...we have to meet and debrief. She’s always worried about me I guess. That’s the only way I can put it, and I’m always like, ‘I’m fine.’ But she always wants to talk to me. I don’t know if it’s just me personally or if it’s because of my race.” Other

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participants discussed their negative experiences with rotation supervisors critiquing them based off of cultural characteristics. Specifically, some participants expressed supervisors' critiques involving language, and how they should introduce their sessions by stating that English is not their native language. Others reported that supervisors critiqued them for not being "professional" enough because they used "slang" in their sessions or spoke with an accent. This was exemplified when one participant stated,

"I was running into some issues with not all my supervisors but some supervisors. I had one supervisor say I used slang during the session. I had one supervisor not be able to tell me exactly why they felt like I needed to be more professional. You know, I felt like maybe there was something that really ended up being seeped in kind of a cultural misunderstanding."

These situations weighed heavily on the participants and had a negative impact on their overall experience.

## **Pursuing a Career in Genetic Counseling is Motivated by Various Factors**

Most of the participants reported that they found working with minority populations rewarding. One participant expressed, "As far as being a minority, I do enjoy providing genetic counseling to individuals or the minority, especially Spanish because I am able to connect a little bit more with those patients." In addition, majority of participants stated their URM status facilitated building rapport and trust with their minority patients and they expressed having a desire to help patients understand complex topics. One participant stated, "Sharing a cultural background definitely helps with rapport, that's for sure." Another participant shared, "I do know that having that shared experience and that shared language does give a certain level of trust and it gives, I think,

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some patients a certain level of freedom to ask the questions that they want to ask.”

Multiple participants reported that a main motivating factor for entering the field of genetic counseling was a desire to blend science with helping people, as well as the ability to be a female role model in the science field.

## **DISCUSSION**

The review of URM role model and mentor literature identified an important void. There is a gap in the current literature addressing the experiences had by an URM genetic counselors and genetic counseling students while entering, attending a program, and working in the field. There is also limited information regarding an URM individuals desire to have access to role models of similar backgrounds in the genetic counseling community. This study allowed for the exploration of experiences current genetic counselors and genetic counseling students encountered on their journey. Specifically, we aimed to better understand their thoughts regarding what barriers stood in their way, what they found rewarding, the impact of important relationships, and how race influenced all of these factors.

This study has allowed for the analysis of the commonly experienced barriers and successes of these eight participants who identify as URM genetic counselors and genetic counseling students. The themes that arose were consistent with the review of the literature, specifically, that URM students have limited access to role models, advisors, and/or mentors of a similar ethnic background. This creates a problem for students who are currently making career decisions, as they do not have adequate exposure to the field and role models of similar backgrounds. Several participants discussed how not having a role model of a similar ethnic background created a challenge because they were unable

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to connect with someone who shared not only their academic goals, but also their culture. Linda Jucovy (2002) states that one of the reasons why it is important to have same-race mentors or role models is because it allows students to see themselves in that particular role. This was a challenge considering the fact that none of the participants had a role model, mentor, or advisor from the same ethnic background. Additionally, since Caucasian females heavily dominate the field of genetic counseling, some participants discussed that being aware of this was important for understanding the differences they may be exposed to in the field. This further implies the need to make URM role models in the field of genetic counseling more visible to allow prospective students to envision themselves in the profession.

Majority of participants in this study reported having unconditional family support. Family members can influence career path decisions and deter minority individuals from pursuing certain careers depending on the level of support that is provided (Schoonveld *et al.*, 2007). It is important to note that the participants studied in this project were all successfully in the genetic counseling field, which aligns with the high level of family support that was received by participants. It's possible that if family support was low, their entrance into the field of genetic counseling may not have been as likely. Therefore, this finding correlates with what would be expected for these eight individuals.

Studies show that when minority patients are able to select a healthcare provider, they are more likely to choose someone of their own ethnic background (Smedley & Mittman, 2011). Additionally, studies have shown that minority healthcare professionals are more likely to treat minority populations (Sullivan, 2004). Since lacking minority

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representation within the genetic counseling field is well recognized, this further suggests that to provide patients with the best possible care, the genetic counseling field needs to be more diverse. Participants in the current study specifically expressed the desire to work with patients from similar backgrounds as it facilitates building rapport and/or trust. In addition, several participants expressed that they felt as though patients were more at ease and asked more questions when they shared a similar ethnic background, in turn likely leading to improved understanding and retention. The ability to build rapport and trust efficiently allows genetic counselors to provide better patient care to minority populations, in turn leading to a more constructive genetic counseling experience.

## **Study Strengths and Limitations**

By using a qualitative design, it was possible to generate a cohesive collection of participant experiences. However, it is important to note that qualitative data are not intended to generalize to the studied population.

We encountered challenges in developing the interview questions, specifically concerns regarding the content of the questions. The goal was to address specific barriers faced by URM's in the genetic counseling profession while still learning about their overall journey. Since an aspect of this study involves creating biographies of URM genetic counselors, it was necessary to develop interview questions that would allow us to create structured biographies to be featured on the website, while also allowing us to extensively explore the barriers and successes faced as an URM student and professional in the field of genetic counseling. After completing the interviews, it appears there were some questions that could have been explored further to aid in the analysis of role model barriers, such as asking further questions to determine how having a role model of a

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similar background could have enhanced their overall experience with exploring and entering the profession.

### **Future Implications for Recruitment Techniques and Initiatives**

With this information, one can see the benefits of implementing recruitment techniques that involve addressing the specific barriers experienced by URM genetic counselors and genetic counseling students. We believe the most pressing barrier is the lack of URM role model visibility and accessibility. This topic came up frequently throughout the interviews and impacted many of the participants in some way. This further implies that using these interviews to create biographies to be posted on the website is a valuable technique to aid in the recruitment of URM students into the genetic counseling profession, as it addresses several issues that were identified in this study. Looking ahead, we hope to eventually expand the “Faces of Genetic Counseling” section to include other under represented groups, such as men and Native Americans and the LGBTQ population.

### **CONCLUSIONS**

Despite the efforts of the genetic counseling profession to increase diversity within the field, African Americans, Hispanics, and American Indians represent only a small fraction of the genetic counselors and at a level much lower than that seen in other health care professions (Mittman *et al.*, 2008). This signifies that recruitment techniques must be further developed to address common barriers to move the genetic counseling profession forward and create a field that represents national ethnic and cultural diversity. “Become a Genetic Counselor”, specifically “The Faces of Genetic Counseling” is a step

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towards addressing these barriers and being a comprehensive resource for prospective URM students.

### **ACKNOWLEDGMENTS**

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**Table I.** Population Characteristics

	P1	P2	P3	P4	P5	P6	P7	P8
Current Student or Practicing GC	Practicing GC	Student	Student	Practicing GC	Student	Practicing GC	Practicing GC	Practicing GC
Gender	Female	Female	Female	Female	Female	Female	Female	Female
Ethnicity	Latino	AA	Latino	AA	AA	Latino	Latino	AA
Specialty	Pediatric	N/A	N/A	Lab/Prenatal	N/A	Cancer	Cancer	Prenatal
U.S. Region	North East	North East	North East	North East	South Central	North East	South East	North East
Years in Field	4 years	N/A	N/A	8 years	N/A	4 years	5 years	21 years

*Note.* P: Participant, GC: Genetic Counselor, AA: African American

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**Table II.** Discovering the Genetic Counseling Career and Barriers Encountered ( $N=8$ )

Categories	Prevalence (n)	Participant quotes
<i>Group: Learning about Genetic Counseling</i>		
a. HS course/teacher/advisor	0	
b. College course/teacher/advisor	5	P3: "I shadowed a GC that summer as part of a college course at school."
c. Internet	4	P5: "...it's just something that happened to pop up on the Internet." P7: "I actually found it through a Google search. I found it through NSGC."
<i>Group: Barriers</i>		
a. Logistical/Practical	8	
1. Couldn't find info	2	P7: "There's not a whole lot out there in terms of information."
2. Lack of exposure	4	P2: "I was like, oh my God, I never even knew this was a profession!"
3. Lack of shadowing	2	P5: "It was very difficult to get shadowing and that's at a place where there are numerous GC's."
4. Financial	6	P1: "Definitely money played a role in deciding schools." P3: "Could I realistically afford this school?"
5. Pre-requisites	1	P1: "I noticed that I do not have a good chunk of credits or background in more social aspects and the psychology."
6. Work/Social balance	5	P5: "It was very difficult for me to get back into student mode." P6: "I had to work. I wish I could have just been a student"
b. Psychological	6	P6: "Oh you can't get in. You need to be taller, you need to be blonde, and you need to have blue eyes." P2: "I think it was an assumption being made that I would be struggling in classes and I was not."
c. Negative (logistical)	0	
d. Negative (psychological)	2	P1: "Within the classroom we were all pretty much equal. The relationship was good."
<i>Group: Being an URM in Training Program</i>		
a. Feel alone/isolated	3	P2: "I think it had something to do with being alone and feeling alone and realizing I was the only one." P4: "It was good. I think when I look back I felt a little isolated at times." P8: "I definitely felt some level of isolation."
b. Desire classmates from similar background	3	P3: "It was a challenge trying identify with someone."
c. Look outside program...	3	P8: "There was much more diversity within the school of public health and that's where I actually ended up garnering that other level of support I needed."

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d. Being an URM allows for dif. perspectives	4	P7: "We were all very different. I think what made us very strong is that we acknowledged those difference." P3: "I can tell that some of these experiences that I have had have been very different because of my race and ethnic background."
e. Feel misunderstood by faculty b/c of race	4	P8: "I had one supervisor say I used slang during the session." P5: "I felt that one of the instructors...was always worried about me I guess." P8: "I had some supervisors not be able to tell me exactly why, but they felt like I needed to be more professional."
f. Negative (none of the above)	2	P1: "...I wouldn't say that I experienced any differences"

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*Note.* P: Participant, GC: Genetic counselor

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**Table III.** Support and Motivating Factors to Become a Genetic Counselor ( $N=8$ )

Categories	Prevalence (n)	Participant quotes
<i>Group: Initial Family Support</i>		
a. Unconditional support	6	P7: "They were very supportive and always very excited about a career in genetics." P4: "...whatever I decided they were supportive."
b. Mixed support	2	P1: "Everyone is always asking me, "So are you going to continue to study and be a doctor?" And I'm like, no thank you. I like what I do very much."
c. No support	0	
<i>Group: Relationships; Important Others</i>		
a. Supportive advisor/mentor (not from same race)	6	P7: "I actually was very fortunate to have that amazing mentor guiding the whole process."
b. Supportive advisor/mentor (from same race)	0	
c. Desire to have role model/mentor/advisor of same race	2	P2: "I went to Google black GC because I was feeling like I wanted to find someone so I can just talk to them that was you know, like me."
d. Shadowing was helpful/desired	4	P4: "...so I actually shadowed with a GC and...fell in love with it basically." P5: "I would definitely advocate for shadowing."
e. Negative (no role model/mentor/advisor)	2	P3: "Even when I was going through the process, there really wasn't anyone that had a similar background as me."
<i>Group: Rewards/Motivating Factors</i>		
a. Working with minority population is rewarding	7	P2: "If I could make a clinic or something in a minority neighborhood that would be ideal." P1: "I enjoy providing genetic counseling to individuals or the minority, especially Spanish..."
b. URM status facilitates rapport/trust w/ minority pt's	5	P6: "I feel they are more at ease with me when they notice I start speaking in Spanish." P7: "Sharing a cultural background definitely helps with rapport, that's for sure."
c. Blend of science and helping people	2	P1: "...the combination of medical information and being able to spend time with patients."
d. Being a female role model in science	2	P3: "...I could encourage other women in general, but also other women of URM backgrounds, to be in the sciences."
e. Helping patients understand complex science	5	P6: "I like that I can help people to understand." P1: "I just really love to be able to help the patients understand some of what's going on..."

*Note.* P: Participant, GC: Genetic counselor

## **APPENDIX: Interview Questions**

### **Background Information:**

- Name
- Program attended
- Graduation year
- Genetic Counseling Specialty
- How do you identify in terms of ethnic background or race?

### **Interview Questions:**

#### Exploring the Career:

- As a child, did you know what you wanted to be when you grew up? Describe.
- How old were you when you seriously began to consider your career choice?
- How/when did you first hear about genetic counseling?
- What other careers did you consider?
- How did your family influence your decision-making about a career?
- How old were you when you decided on genetic counseling?
- What did you do to find out about genetic counseling?
- What was your approach when applying to graduate programs?
  - Did you have a mentor? Advisor? On your own? What were some of the challenges you faced with the application process? Did you tour a program?
- What role models, if any, did you have while exploring the field? How did they influence your decision to become a genetic counselor? If none: describe what was it like not to have a genetic counselor role model as you considered the field?
- What did your family think about your choice to become a genetic counselor?
- Were you able to meet/shadow a genetic counselor? If yes, how did this inform your decision to become a genetic counselor? If no, why not & do you feel it would have been helpful?
- How did financial factors (either the cost of education and/or earning potential as a GC) influence your decision to become a genetic counselor?
- Describe the importance of being able to “give back” to your community as a factor in your decision to become a genetic counselor?
- What else about your journey to becoming a genetic counselor would you like to share with interested URM students?

#### Experience in the Program:

- Describe your overall experience as a student in the genetic counseling program?
- What did you like the most about your training to become a genetic counselor? What was the biggest challenge?
- Do you have a favorite case that you remember from your training?
- Were you the only minority student in the program? If so, what was this like for you?

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- How would you describe your relationship with your classmates as an URM? With the program faculty?
- What advice do you have for URM students who are applying to programs about choosing a program, being a student in the program and the training process?

### Experience in the Profession:

- How long have you worked as a genetic counselor? If applicable, what are the different jobs you have had?
- Tell me about your current job (role, specialty, setting, types of patients seen, etc.)
- Can you describe a typical day you might have working as a genetic counselor?
- Who are some of your colleagues and how do you interact with them?
- What do you love most about your job?
- What are some of the challenges?
- Describe how and when you know you are really making a difference in your job?
- Tell us about any opportunities you've had to work with patients within your own community in your professional role. How important is this type of work to you?
- Do you think sharing a similar background with your patients helps you to provide better care for your patient, and if so, how? If not, why not?
- Describe any professional activities you are involved in (NSGC, research, teaching, etc.)
- Describe your identity as a genetic counselor (what does it mean for you to be a gc)?
- Describe your identity as a minority in the genetic counseling profession (what does it mean for you)? How important is this to you?
- Is there anything else you would like to share?

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### References:

- Anstett, K., Chen, S. (2015). Become a genetic counselor.org; A Website to Facilitate Recruitment of African Americans and Latinos into the Genetic Counseling Profession.
- Girves, J.E., Zepeda, Y., Gwathmey, J.K. (2005). Mentoring in a post-affirmative action world. *Journal of Social Issues*, Vol. 61 No. 3, pp. 449-80.
- Hess, F. M., & Leal, D. L. (1997). Minority teachers, minority students, and college matriculation: A new look at the role-modeling hypothesis. *Policy Studies Journal*, 25(2), 235-248.
- Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (2003). Washington, DC: National Academy Press; p.23.
- Jucovy, L. (2002). Same-race and cross-race matching. *Office of Juvenile Justice and Delinquency Prevention – Big Brothers Big Sisters of America*, 7, 1-29.
- Knouse, S. B. (1992). The mentoring process for hispanics. In S. B. Knouse, P. Rosenfeld, & A. L. Culbertson (Eds.), *Hispanics in the workplace*: 137-150. Newbury Park, CA: Sage.
- Liang, B., West, J. (2007). Youth mentoring: Do race and ethnicity really matter?. *Research In Action*, 9, 3-13.
- Mittman, I. S., & Downs, K. (2008). Diversity in genetic counseling: past, present and future. *Journal of Genetic Counseling*, 17, 301–313.
- Mondisa, J. (2014). Mentoring Minorities:Examining mentoring from a race and gender lens. *American Society for Engineering Education*.
- Schoonveld, K.C., McCarthy Veach, P., & LeRoy, B.S. (2007). What Is It Like To Be in the Minority? Ethnic and Gender Diversity in the Genetic Counseling Profession. *J Genet Counsel* 16, 53–69.
- Smedley, B.D., Mittman, I.S. (2011). The Diversity Benefit: How Does Diversity Among Health Professionals Address Public Needs. *Healthcare Disparities at the Crossroads with Healthcare Reform* (pp. 167-193). Springer US.
- Sullivan, Louis W (2004). *Missing Persons: Minorities in the Health Professions, A Report of the Sullivan Commission on Diversity in the Healthcare Workforce*.
- Thomas, K. M., Willis, L.A., Davis, J. (2007). Mentoring minority graduate students: issues and strategies for institutions, faculty, and students. *Equal Opportunities International*, 26, 178-192.
- U.S. Census Bureau (2012). Statistical abstract of the United States: 2012.

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<http://www.census.gov/compendia/statab/2012/tables/12s0005.pdf>