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# UNIVERSITY OF CALIFORNIA, IRVINE

Genetic Counseling Trainees' Experience of Cultural Sensitivity Training and Suggested Improvements

**THESIS** 

submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

Natasha Anjelic Go

Thesis Committee: Assistant Professor Suellen Hopfer, Chair Adjunct Professor Pamela Flodman Assistant Clinical Professor Meghan Blunt Assistant Professor Jennifer Young

## **DEDICATION**

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•	ı '~

Juvy Young and Herson Go for their eternally wise guidance

#### And

The UCI genetic counseling class of 2022 for their unwavering support through incredibly trying times

"One doesn't have to operate with great malice to do great harm. The absence of empathy and understanding are sufficient."

— Charles M. Blow

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Finally, to my parents, my brother, and my friends, it simply would not have been possible without you. You lifted me up and pushed me forward every time I felt I could not go on. Your importance to my success is immeasurable.

#### **ABSTRACT OF THE THESIS**

Genetic Counseling Trainees' Experience of Cultural Sensitivity Training and Suggested Improvements

by

Natasha Anjelic Go

Master of Science in Genetic Counseling
University of California, Irvine, 2022
Assistant Professor Suellen Hopfer, Chair

The racial demographic of the genetic counseling profession continues to be dominated by White practitioners. Per the 2021 professional status survey of genetic counselors, 90% of the profession is White. This stands in sharp contrast to the increasing racial and ethnic diversity of patients that receive genetic counseling. It is therefore critical that genetic counseling trainees receive education on cultural sensitivity and how to provide high quality care to patients of different racial, ethnic, and cultural background. Often a key step in cultural sensitivity training is to address personal implicit biases. While this process can build awareness of one's own internalized stereotypes, it can also raise emotional barriers known as "rebound effect" which may limit the trainee's ability to effectively engage in cultural sensitivity training. Little research has been done on the effectiveness of current cultural sensitivity training within genetic counseling programs.

Through this exploratory qualitative research study, 21 current and recently graduated genetic counseling trainees from across the country shared their perspectives on the state of cultural sensitivity training today. Five semi-structured focus groups were conducted via the

Zoom teleconferencing platform. Transcript data was analyzed via an inductive grounded theory model through two coding cycles.

Major findings indicate that GC trainees want more opportunities to learn from medical interpreters and gain insight directly from the minority perspective. Trainees also reported on problematic aspects of current training. This included taking the implicit association test (IAT) without being provided guided debrief after the activity, observing supervisor behavior that did not align with culturally sensitive teachings, and experiencing minority burden. Trainees felt that a critical aspect of cultural sensitivity training was engaging in open discussions on topics related to culture such as current events. Concurrently, trainees emphasized the importance of holding these discussions in a safe space, especially to alleviate minority trainee burden. Participants hypothesized that having a facilitator who is well trained in moderating sensitive conversations, adjusting timing and formatting of discussions, and following up with those negatively impacted by conversation can contribute to fostering a safe space. These findings can inform GC programs' cultural sensitivity training approach.

#### I. INTRODUCTION

#### 1. Genetic Counselors - Defined

## 1a. Roles and responsibilities

Genetic Counselors (GCs) are critical members of a comprehensive healthcare team. GCs serve as a liaison between patients and genetic testing laboratories, as well as physicians and the rest of the medical community. The profession plays a key part in advancing understanding of the genetic basis for disease which has, can, and will continue to lead to disease prevention, treatments, and cures. Common duties of a GC involve educating patients on the benefits and limitations of genetic testing and helping patients make complex health decisions that, due to the nature of genetics, involve not only themselves but often their families. Classic specialties in which GCs work are prenatal, pediatrics, and cancer. As time progresses, the field is expanding into other specialties such as cardiology, ophthalmology, and psychiatry. Relatively new and expanded roles include product design for industry companies, managerial roles within larger hospital or corporate entities, and variant interpretation. The roles and responsibilities of GCs have grown exponentially over the past several decades, and with the rapid growth of genetic testing technologies, GC expertise is becoming even more critical.

According to the 2021 professional status survey moderated by the National Society of Genetic Counselors (NSGC), "Genetic counselors work in a variety of settings, including but not limited to university medical centers, private and public hospitals/medical facilities, diagnostic laboratories, health maintenance organizations, not-for-profit organizations, and government organizations and agencies." While the list of settings in which GCs work is broad, it is known that GCs providing direct patient care primarily work in centers that more easily cater to those of higher socioeconomic status. This includes institutions such as university medical centers and

private hospitals. Fewer GCs work in outreach clinic settings as their primary mode of patient care. (National Society of Genetic Counselors Professional Status Survey, 2021) This makes it difficult for GCs to service and learn about minority populations, such as Indigenous populations, who live outside of major city centers. With the expected growth of the field, so too grows racial/ethnic diversity of patients the field will serve. To ensure that GCs are trained to serve the increasingly diverse racial/ethnic makeup of patients and families, including marginalized and minority populations, cultural sensitivity training during graduate schooling remains critical and is expected to grow in importance.

#### 1b. Training

To become a genetic counselor, individuals must attain a master's degree from an accredited genetic counseling program. To be admitted, most programs require a bachelor's degree and completion of certain biological sciences and psychology courses at the undergraduate level. A typical genetic counseling training program is two years long and is comprised of academic classwork, rich clinical experiences, a final research project, and other external experiences, such as advocacy work. After degree completion, many genetic counselors go on to take the nationwide Board Exam by the American Board of Genetic Counseling (ABGC). Most job opportunities require that a qualified genetic counselor be board certified. Each state within the U.S. has their own licensure requirements, but most required a GC to be board certified by ABGC or have active candidacy status.

The training period for genetic counselors is a critical time when students develop clinical habits they may utilize for many years to come. The impact bias has on a provider's behavior may become more pronounced as the individual progresses through training and their career (Hall et al., 2015). Therefore, it is critical that we prioritize and evaluate the quality of

implicit bias and cultural sensitivity training within GC training programs. Doing so increases the chance that future genetic counselors will carry these positive habits forward and continue to practice with cultural sensitivity.

## 1c. Racial and Ethnic Demographic Status of the Genetic Counseling Workforce

Despite the growing number and responsibilities of GCs, the racial and ethnic make-up of the professional community has remained relatively the same over the past several decades. Per the 2021 professional status survey, 90% of the profession is White. A more specific breakdown of ethnicity demographics finds that 5% of GCs identify as East Asian, 3% identify as South Asian, 2% identify as Black/African American, 2% identify as West Asian/Middle Eastern/North African, 1% identify as Southeast Asian, and less than 1% identify as Native American or Native Hawaiian. This distribution is in stark contrast to the diverse populations which GCs serve in the various positions they hold. Per U.S. Census Bureau data from 2020, only 61.6% of the U.S. population identifies as White Alone, 12.4% identify as Black/African American Alone, and 6% identify as Asian Alone. This disparity in ethnic/racial representation of the GC workforce, in comparison to the U.S. patient population, may continue to grow as the diversity of the nation is increasing yearly.

It is important to note that while there is clearly a lack of racial and ethnic diversity within the GC workforce, there also remains a lack of diversity with regard to gender, sexual orientation, disability, languages spoken, and other categories of diversity as well. While these other categories also impact one's cultural identity, this study will focus on the concerns raised by lack of ethnic/racial diversity.

It is also important to note the dark history upon which the profession lies. The birth of the concept of "genetic counseling" stems from the eugenics movement in the early twentieth

century (Resta, 1992). While the profession has since removed itself as far as possible from the ideals of those times, the historical injustices are not so quickly forgotten by the minority communities impacted. This history may explain why some individuals, especially those of minority background, may perceive "genetic counseling" as a frightening or intimidating endeavor. Knowing this, it is even more critical that GCs are well trained to interact with marginalized communities in a way that will build trust between them and the medical community.

## 2. Representation Disparity in GC Workforce

The imbalance in representation between the GC workforce and the patients they serve is a key concern to quality health care. It is widely understood that patients and their families often have more positive experiences with healthcare when the provider belongs to their same sociocultural group (Saha et al., 2003; Saha & Beach, 2020; Shen et al., 2018). This sentiment holds true in the GC profession as well. This experience could be due to a variety of reasons, one of which is counselor affect and tone when interacting with patients of minority status. A 2015 study investigated the relationship between GC implicit association test (IAT) scores and client rating of the GC's affective demeanor, communication, and nonverbal effectiveness. The IAT is an online exercise where participants associate certain images with either positive or negative words. The test "measures the strength of associations between concepts (e.g., black people, gay people) and evaluations (e.g., good, bad) or stereotypes (e.g., athletic, clumsy)" and provides a "score" of bias at the end of the exercise (Project Implicit). Clients of the 2015 study were either White, African American, or Hispanic. The study found that pro-White biased GCs were more verbally dominant and showed less positive affect to minority clients (Schaa, et al., 2015). While this study was conducted several years ago, if these findings hold true then White GCs

inadequately trained in cultural sensitivity may be providing subpar counseling services to non-White patients.

Inadequate cultural sensitivity training does not only place undue stress on the patients but the counselor as well. A 2020 study further analyzed the data used in the 2015 study using Linguistic Inquiry Word Count (LIWC) analysis. When analysis was extrapolated to the greater GC dataset, the study found that GCs tended to use more "partnership statements" when counseling minority clients. Partnership statements "are statements that convey the GC's willingness to work with the patient to provide help, support, decision-making, or development of the therapeutic plan." It was discussed that perhaps these "partnership statements" were used to compensate when the GC felt a lack of initial rapport with the minority individual (Lowe, et al.). A key to success in genetic counseling sessions is building natural rapport with patients. Learning to do so efficiently, with patients from a variety of backgrounds, will greatly improve the effectiveness of counseling services. Both studies indicate a relationship between implicit bias and the effectiveness of care administered to a patient based on the patient's ethnicity.

#### 3. Definitions

### 3a. Implicit racial bias - Defined

The National Society of Genetic Counselors has defined implicit bias as "The attitudes or stereotypes that unconsciously affect our understanding, actions, and decisions. These biases, which can be favorable or unfavorable, are activated involuntarily and without our awareness or intentional control." Implicit bias occurs due to a need for the human brain to take "cognitive shortcuts" in an overstimulating world. Researchers believe the main brain centers responsible for implicit bias are the hippocampus and amygdala. The hippocampus plays a major role in

learning and memory, and the amygdala is often described as the "fight or flight" response center. The neurological processes that lead to implicit bias are the same processes that allow us to make quick decisions in our daily lives (Peek et al., 2020).

Racial implicit bias is a subcategory of implicit bias describing the phenomenon of unconscious bias, either in favor of or against an individual, simply due to their presumed race. Implicit racial bias, just like broader implicit bias, can cause an individual to overtly act discriminatorily. This does not indicate that the individual is outwardly racist; rather these biases are perceptions formed through a lifetime of that individual's experiences (Maryfield 2018).

#### 3b. Implicit racial bias in healthcare

The Agency for Healthcare Research and Quality publishes a report each year documenting racial disparities in healthcare outcomes in the United States. The most recent report from 2019 found that Blacks, American Indians, and Alaska Natives received worse care than Whites for 40% of quality measures. Hispanics received worse care than Whites for a little over 30% of quality measures, and Asians and Native Hawaiians/Pacific Islanders received worse care than Whites for 30% of quality measures. From this report, it is clear that health care quality between different racial groups persist strongly in the United States, although the difference has been lessening since the year 2000. There are various factors that play into these differences. The World Health Organization defines social determinants of health as "the conditions in which people are born, grow, live, work, and age." Factors ranging from quality of school system to housing and transportation infrastructure to food availability impact an individual's healthcare outcomes. One element contributing to the racial disparity in health care today is culturally and linguistically lacking healthcare services.

Racial health disparity is due in part to lack of culturally sensitive and unbiased care. This is because even when insurance, severity of condition, income, and age are comparable, racial and ethnic minorities are dying from common conditions, such as cancer and heart disease, at a significantly higher rate than Whites (Nelson et al., 2003). One of the most frequently cited early studies found that physicians were 40% less like to refer African American patients for a health improving procedure, despite identical patient scripts and gestures used to describe their symptoms (Schulman et al., 1999). A cross sectional telephone survey of 6,299 White, African American, Hispanic, and Asian adults found that, when compared to Whites, minorities were more likely to feel they would receive better medical treatment if they belonged to a different racial group. Additionally, minorities felt healthcare providers judged them based on their race/ethnicity and that quality of care depended on how well they spoke English (Johnson et al., 2004). Given this history, it is clear that the racial/ethnic disparity seen in healthcare today is due in part to the implicit biases of healthcare providers.

#### 3c. Cultural Sensitivity - Defined

Cultural sensitivity from a clinical perspective is defined as a practitioner's ability to "be aware of the importance of cultural factors, be aware of how cultural factors impact the practitioner-client relationship and be aware of their own biases" (Benuto, et al., 2020).

Additionally, a clinician should be able to integrate cultural factors into caregiving and practice idiographic sensitivity, or the ability to view the client as a unique individual. All these skills are useful tools for GCs in providing effective counseling to patients.

The term cultural sensitivity has been intentionally chosen over the popular term cultural competency. Cultural competency implies that an individual can become "competent" in culture, either their own or others, and frequently propels stereotypes (Krisnan et al., 2019). Culture is an

incredibly complex and interwoven "collection of beliefs, values, customs, ways of thinking, communicating, and behaving specific to a group" (Center for Disease Control and Prevention [CDC] 2021). Individuals belong to a variety of groups, which may include but is not limited to a unique combination of age, gender, socioeconomic, ethnic, and geographic groups. To believe that any one person can become "competent" or "all-knowing" about any other person's culture would assume an overly simplistic view of the human experience. It is more appropriate to expect healthcare providers to be "sensitive" to a patient's cultural background and work to provide care that aligns with an individual's rich and complex cultural identity.

#### 4. Training

#### 4a. Cultural Sensitivity – Training

Beyond a mere desire to do better by patients, it is known that a core competency requirement of graduating GCs is the ability to "apply genetic counseling skills in a culturally responsive and respectful manner to all clients" (Accreditation Council for Genetic Counseling, 2019a, p. 5). There is then not only a need, but an expectation for currently training and licensed GCs to hone their skills in cultural sensitivity to best serve the current patient demographic.

Despite the essential nature of adequate cultural sensitivity training, a 2020 study of focus groups comprised of non-White minority GC trainees found that cultural competency/sensitivity training across the country is often inadequate and not uniform. Some "participants felt like cultural competency was not a priority for their program, but rather done to 'check off a box'." Other participants felt that cultural competency training consisted of being told to memorize a list of stereotypes, a list that they either questioned the legitimacy of, or knew to be "downright incorrect." Some of the techniques used to teach cultural sensitivity include lectures, readings, discussions surrounding topics that arise in clinical cases, and role plays. While efforts were

appreciated by most of the minority trainees, there was clear desire for more effective training (Carmichael, et al. 2020).

## 4b. Implicit bias – Training

Frequently, a key first step in cultural sensitivity training is learning to acknowledge and address one's own implicit biases. Implicit bias is defined by NSGC as "the attitudes or stereotypes that unconsciously affect our understanding, actions, and decisions. These biases, which can be favorable or unfavorable, are activated involuntarily and without our awareness or intentional control" (National Society of Genetic Counselors). Implicit bias is best viewed as a learned internalized attitude towards others that then influence behavior. Seeing implicit bias as a learned phenomenon removes the stigma that implicit bias represents an individual's true state and moves the focus onto an actionable change (Houwer 2019). In genetic counseling specifically, the primary mode of patient service is communication. Communication behaviors are generally believed to be alterable and may lessen or potentially eliminate the impact of provider bias on patient experience (Hagiwara et al., 2019).

Several genetic counseling programs utilize the IAT to spark self-recognition of biases. Beyond taking the IAT, trainees have an opportunity to also cognitively process their newfound recognition in discussion-based settings. It is the combination of taking the IAT and participating in discussion that leads to increased self-recognition (Thompson et al., 2010). Beyond self-recognition, trainees need frequent practice facing and acting against their implicit biases for change to last. Just as implicit biases have been formed through a lifetime of existing within certain societal structures, implicit biases can only be combatted through frequent thought practice against these second-nature emotions (Wong and Vinsky, 2021). A common way to engage trainees in this thought process is through simulation. Simulations, such as role plays,

allow trainees to see problematic behaviors while being in a protected environment to learn from these mistakes and pinpoint actionable change (Vora et al., 2021).

While recognition and practice to combat personal implicit bias is critical to the larger goal of gaining cultural sensitivity ability, it may be accompanied by negative emotional reactions. These "rebound effects" can hinder an individual's ability to continue with the process of learning about cultural sensitivity. A common "rebound effect" is known as racial anxiety, which is the fear that an interracial interaction will go poorly. For White individuals specifically, it is the fear that one will be perceived as racist. Another common "rebound effect" is known as stereotype threat. This is when an individual, typically one of minority status, fears performing in a way that confirms a stereotype about their presumed group. Both fears, racial anxiety, and stereotype threat, can cloud the thoughts of individuals engaging in intercultural interactions and therefore produce abnormal behavior on either side. This abnormal behavior often then serves as confirmation to both parties that intercultural interactions are uncomfortable and unnatural. These experiences can frustrate learners and serve as roadblocks to future attempts at intercultural interaction (Godsil et al., 2014).

#### 5. Transtheoretical (Stage of Change) Model of Behavior Change

The framework for this study is the transtheoretical model of behavior change. Initially, this theory was formulated to describe health behavior change, such as quitting smoking. This model describes behavior change as occurring in a cyclical six stage process. The stages are named pre-contemplation, contemplation, preparation, action, maintenance, and relapse. Individuals engaging in behavior change work through this cycle, with every round moving them in an upward direction towards "better" behavior, and every trip through the cycle providing learned experience.

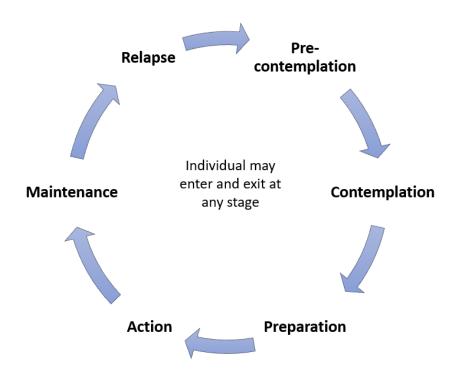


Figure 1: Six stages of Transtheoretical Model of Behavior Change (Based on work of Prochaska and Velicer, 1997)

Knowing in which stage an individual is within the cycle allows for targeted activities to keep an individual moving toward change. These activities, or processes of change, include interactions such as Consciousness Raising, Dramatic Relief, Environmental Revaluation, and Helping Relationships. The ultimate goal of these processes and this model is to empower individuals to a point of "self-efficacy", where an individual carries confidence they will not relapse to a previous negative behavior pattern given a certain situation (Prochaska and Velicer, 1997).

Although initially formulated to describe the phenomenon of health behavior change, the transtheoretical model applies well to the concept of recognizing and working to reduce impact of implicit bias on healthcare. Just as the model describes change as a constant cycle of improvement, so too is the work of addressing one's own implicit biases and working towards

more culturally sensitive healthcare. Our study will investigate if processes of change are already being used to move trainees along the cycle of behavior improvement and whether further use of these processes would be seen as useful for more effective cultural sensitivity training.

## 6. Creating quality curriculum

To combat implicit bias and the associated negative reactions, previous literature has suggested a variety of tactics. Some strategies are relatively simple personal thought practices such as Counter-Stereotypic Imaging or Perspective Taking. In Counter-Stereotypic Imaging, an individual recalls a notable person in his or her own life that represents the opposite of a stereotype from that notable individual's presumed group membership. In Perspective Taking, an individual assumes a first-person perspective of a member of a stereotyped group to try and better understand another viewpoint (Godsil et al., 2014). These tactics can also be used in activities such as simulations where, for example, a Black patient has an occupation and personal characteristics that are not typically associated with this race. Doing so reduces the risk of perpetuating stereotypes in learning (Vora et al., 2021). Genetic counseling programs could add this to their curriculum by having trainees participate in various role-playing activities.

Other tactics require more outgoing activity. Individuation is the act of obtaining more information about specific individuals of a stereotyped group to avoid viewing members as homogenous. Increasing Opportunities for Contact is self-explanatory and is the active choice to interact with diverse individuals to become more comfortable with intergroup interactions (Godsil et al., 2014). Together, these tactics support the "contact hypothesis" under which it is believed that repeated positive encounters with outgroup members results in lowered "stereotyping, prejudice, and discrimination" (Hagiwara et al., 2019). Genetic counseling

curriculum could integrate these tactics by having trainees interact with more minority patients during clinical rotations as well as visit various community centers such as support groups.

These tactics would work well to combat the findings from another 2020 study that looked at counselor IAT scores and their relation to counseling outcome. The study's results indicated that Pro-White biased GCs may provide less individualized care to minority patients. Pro-White biased GCs may unconsciously see minority patients as "outgroup" individuals and therefore lump minority patients as "all the same." This results in poorer rapport building between counselor and patient, less facilitation and activation statements, and less disclosure about psychosocial and lifestyle information from the patient (Lowe et al., 2020). Overall, the quality of the counseling session between Pro-White biased GCs and minority patients is reduced and could be aided by the above-mentioned tactics.

## 7. Creating a safe space for learning

The ability for a trainee to engage in cultural sensitivity training is heavily dependent not only on the curriculum, but also on the emotional space created by leadership in which the training is taking place. The topic of race in medicine is a critical subject to cover when looking to acknowledge and reduce racial implicit biases. Unfortunately, the topic of race in medicine can also create feelings of unease as well as touch upon traumatic experiences for some students. As mentioned with rebound effects, discussing race can also elicit a high level of self-consciousness that may hinder a student's willingness to engage in learning.

There has been extensive research amongst medical students into how a safe space can be created to foster discussion about race in medicine. These strategies can be applied for genetic counseling trainees as well. A key first step is prefacing these discussions with why race needs to be discussed in medicine, both at the academic level and within the clinical setting. Giving

students a holistic perspective on how race impacts healthcare frames the importance of the topic and fosters engagement (Mosley et al., 2020). It is important to emphasize an expectation for civil discourse and reward students that engage in honest, compassionate dialogue. Ensuring that terminology is precise and consistent throughout the discussion also aids in keeping the learning sphere a psychologically safe space. Instructors should lead sessions with stories rather than stating numerical facts. This will help engage students in the conversation and may prompt more open discussion. Another key element to creating a positive environment is discussing not only how race exists at the individual, institutional, and structural level, but to also teach about solutions that may empower students to make changes in their own immediate world moving forward (Peek et al., 2020).

### 8. Research Questions and Study Aims

This study aims to explore ways to improve cultural sensitivity training in GC training programs. The main research questions are as follows:

RQ1: Describe the helpful cultural sensitivity training strategies that trainees experienced RQ2: Describe the aspects of current cultural sensitivity training that trainees found to be problematic

RQ3: What suggestions do trainees have to foster discussions relating to cultural sensitivity in a safe space

#### II. RESEARCH DESIGN AND METHODS

This study utilized purposeful sampling via a recruitment survey to gather participants for semi-structured focused groups. The data collection modality of focus groups was chosen over interviews since previous literature has shown that discussion between participants can generate more novel themes and shift power from the facilitator to the informants. Transcripts from the focus groups were cleaned, de-identified, and then analyzed using a modified grounded theory to discover novel themes.

## 1. IRB approval

This research study was reviewed by the University of California, Irvine, Institutional Review Board under HS#2021-6905. The research protocol was reviewed under the "expedited" category due to entailing "no more than minimal risk" to participant subjects. The application (eAPP number 16563) was submitted on July 16th, 2021. Final approval was granted on October 8th, 2021. IRB approval letter can be found in appendix E.

#### 2. Recruitment Protocols

Genetic counseling graduates or currently enrolled students were purposively sampled to enlist their experiences and reactions to the cultural sensitivity training they had during their 2-year training program. An online survey (Appendix A) was distributed via a program director listserv as well as various social media platforms (Facebook, LinkedIn, Slack, Discord, and Twitter) to recruit recent GC graduates and currently enrolled GC students. The online Qualtrics screening survey was available only in English. Prior to taking the survey, participants were asked to read through the study information sheet (Appendix B) and consent by selecting "I agree." The survey required potential participants to disclose the following: name, contact information, genetic counseling trainee status, and program attending or attended. Participants

were given the option to disclose the following: age, gender, pronouns, time zone, ethnicity/race, and cultural and religious upbringing/background. Branching logic was utilized to obtain information specific to an individual's trainee status. All information was used solely for the purpose of selecting and scheduling a diverse set of participants. No compensation was offered to participants.

**Table 1**Demographics of Participants

Pseudonym	Trainee Status	Gender	Age Group	Minority w/in GC	Ethnicity and Background as reported by participant
Belle	1st year	Female	25-34	Yes	American, Chinese, Peruvian
Cora	1st year	Female	25-34	Yes	Filipino
Elle	1st year	Female	18-24	Yes	Pakistani America, Muslim
Ori	1st year	Female	25-34	No	English, Scottish, Irish, Hungarian, French, German, Welsh, Ashkenazi Jewish
Page	1st year	Female	18-24	Yes	Black American
Quinn	1st year	Female	18-24	No	Italian, Greek, Turkish, English
Rose	1st year	Female	18-24	No	Hungarian and Irish ancestry
Ava	2nd year	Female	18-24	Yes	4th/5th generation Japanese American
Demi	2nd year	Female	18-24	No	German, French

Gigi	2nd year	Female	18-24	No	Polish, French Canadian
Hera	2nd year	Female	18-24	No	Irish and Polish
Thea	2nd year	Female	25-34	No	Irish, Italian, French, Dutch
Maya	2nd year	Female	18-24	Yes	Brazilian, White, Black
Nora	2nd year	Female	18-24	Yes	German, English, Swiss, French, and Asian Indian
Ida	Class of 2021	Female	25-34	No	Eastern European, English
Kyle	Class of 2021	Male	25-34	Yes	Hispanic/Latino/Latinx, Mexican American
Leah	Class of 2021	Female	25-34	Yes	Black, Vietnamese
Faith	Class of 2021	Female	25-34	Yes	Nepali; Asian American
Umar	Class of 2021	Male	25-34	Yes	Chinese
Jon	Class of 2020	Male	25-34	Yes	Chinese American
Sara	Class of 2020	Female	25-34	Yes	Native American, Mexican, Scottish

## 3. Participant Eligibility

Participants were eligible to be part of the study if they were enrolled at the time of the study or graduated in 2020 or 2021 from an accredited genetic counseling program within the

United States. This eligibility criteria were set in order to increase the likelihood that participants would be able to accurately recall training received. Participants had to report some degree of exposure on the topics of cultural sensitivity and/or implicit bias during their time in a training program. Additionally, new programs are established yearly and existing programs often change curriculum. Due to constant changes, recent participation in a training program is critical to providing as accurate a perspective on the current state of genetic counseling training as possible. Since cultural sensitivity and implicit bias as phenomena are heavily influenced by the surrounding sociopolitical landscape these likely vary in other countries, participants must have attended a program within the United States.

Participants were also required to be over 18 years of age, be fluent in English, and have the technological capacity to participate in an online focus group via the Zoom teleconferencing platform. Individuals were required to be fluent in English as they had to communicate with not only myself, but also other participants to provide rich data about their training experiences.

Focus groups were held via Zoom to eliminate exposure risks of COVID-19 and to allow participants from various parts of the country to participate without having to physically relocate.

### 4. Focus Groups

Participants were assigned to specific focus groups based on time zone, year in training, and program attended. Individuals were informed of their selection via text or email correspondence. They were asked to share their schedule availability via the online survey tool When2Meet. Focus groups were scheduled based on participant availability. Some sessions occurred on weekdays in the late afternoon/evenings and some on weekend afternoons.

I facilitated each focus group discussion as well as monitored timing, audio quality, transcription accuracy and took notes of each session. I captured both video and audio recording of the entire focus group session. Live close-captioned transcription was used as a first-line transcription service for data collection. Using the IRB approved focus group guide I would pose a question to the group, give examples of answer types I was looking for, and allowed the participants to answer the question in whichever order they preferred. If I noticed a particular participant was not being given the space to speak, I would specifically ask that participant for their opinion on any given question. Questions were also placed within the Zoom chat so that participants could look at the question as other individuals were speaking. At the very end of the session participants were given the opportunity to provide feedback on their experience and mention anything they had not been able to share yet. I did not record or fully transcribe these "feedback" sections to allow participants to feel more open about the feedback they wanted to share.

Table 2

Focus Group Composition and Timing

Focus Group	Participants			Length of
Number	(Pseudonyms)	Trainee Status	When	Session
			Sunday 11/21/2021; 1pn	n 1 hour 28
1	Ava	2nd year	PT	minutes
	Belle	1st year		
	Cora	1st year		
	Demi	2nd year		
	Ella	1st year		
			Tuesday 11/30/2021; 4p	m1 hour 40
2	Faith	Class of 2021	PT	minutes
	Gigi	2nd year		
	Hera	2nd year		
			Wednesday 12/1/2021;	1 hour 15
3	Ida	Class of 2021	5pm PT	minutes
	Jon	Class of 2020		
	Kyle	Class of 2021		

	Leah Maya	Class of 2021 2nd year		
			Friday 2/4/2022; 12:30pn	n 1 hour 23
4	Nora	2nd year	PT	minutes
	Ori	1st year		
	Page	1st year		
	Quinn	1st year		
	Rose	1st year		
			Saturday 2/5/2021; 1pm	1 hour 0
5	Sara	Class of 2020	PT	minutes
	Thea	2nd year		
	Umar	Class of 2021		

## **5. Focus Group Guide Development**

The focus group guide (Appendix C) was developed to elicit participants' experiences and attitudes towards their program's cultural sensitivity and implicit bias training. The focus group guide was pilot tested with two recently graduated GCs to ensure it would elicit the appropriate data content. The guide was grouped into three parts. The first part explored trainee cultural sensitivity overall, the activities used to learn cultural sensitivity as well as the physical and emotional reactions to this training. An example question from part 1 is below.

"My first question for you all is to please describe your experience with cultural sensitivity/ competency training in your program. Please describe what stood out most to you about your training experience and share in as much detail as you can remember, specific examples such as classes, role plays, or presentations that your program used to teach these skills."

The second part of the focus group guide focused specifically on implicit bias training and reactions to that training. Questions aimed to discover participant relationship with the discovery of their own implicit bias. A sample question is below.

"After doing the implicit bias training, what was one emotion that you felt? Can you say more about that emotion?"

The last portion of the focus group guide focused on the impact implicit bias had on cultural sensitivity training. Questions aimed to discover participant's mindset moving forward after working with the concept of implicit bias for a bit of time. A sample question is below.

"What methods do you find yourself relying on when serving patients from other cultural backgrounds than your own?"

### 6. Data Analysis

Data were audio recorded and transcribed via Zoom's live closed-captioning feature. Data was prepared by removing time stamps and replacing all identifiers (participant names, program names, healthcare institutions) with pseudonyms. Analysis was guided by the core tenets of grounded theory which involved conceptual development, category development, theoretical integration, and contextualizing findings in literature (Brennan 2021). After data immersion, I tagged segments of the data that reflected ideas that participants shared and generated descriptive codes (primary cycle descriptive coding). Example codes included describing training activities that were shared by participants such as "counseling class" or participant emotion such as "feeling guilty."

Subsequently, I developed a codebook (example sections located in Appendix D) in which I grouped and organized the descriptive codes into higher order interpretive themes keeping in mind the research via questions I had and how these themes may answer the research questions. The first excel data sheet comprised the primary codes and the second excel data sheet contained secondary codes based on groupings of the primary codes. For example, I grouped all primary codes relating to acknowledging and working with a unique population under the secondary code "diverse others." I provided transcript examples for each secondary code to root my further analysis. Lastly, depending on the research question, I either grouped the secondary

codes into even broader categories, for example "least to most helpful learning strategies", or in a process order.

## 7. Data Rigor

An audit trail of the data collection process includes verbatim transcriptions of the data for accuracy, a codebook, and a theory guided focus group discussion guide of the questions (see Appendix). The steps lend both credibility and transparency of the data collection and analysis process.

#### 8. Positionality

I recognize that as a young adult Asian American GC Trainee, I hold certain viewpoints that frame how I facilitate focus groups and analyze the data elicited. Due to my previous experience in the medical field, I view the cultural sensitivity skills of a GC to be of high importance. This drives me to look for ways that current training lacks and can be improved. As a racial minority in the profession, some participants may be wary of expressing certain viewpoints about cultural disparity to me, while other minority participants may feel a connection and be more open. My current trainee status allows licensed GC participants to feel they are experts when talking to me and allows trainee participants to not feel intimidated about sharing their experiences.

#### III. FINDINGS

A total of 24 valid responses were collected between November 1<sup>st</sup>, 2021, and January 4<sup>th</sup>, 2022. After review of responses, 21 participants were contacted and scheduled for an online focus group. The findings below emerged after multi-level coding analysis and review the present state of cultural sensitivity training as experienced by current and recent genetic counseling trainees. We explore the aspects of current training methodologies that trainees believe are most valuable and would like to see expanded, as well as discover which aspects of training methodologies are not perceived as useful and genetic counseling trainees' suggestions for how to create safe spaces for discussions on the topic of cultural sensitivity.

### RQ1: Describe the helpful cultural sensitivity training strategies that trainees experienced

#### **THEME 1: Learning from medical interpreters**

Trainees found that learning from medical interpreters, typically by listening to one give a lecture or interacting with an interpreter as a guest speaker, to be an incredibly valuable aspect of cultural sensitivity training. A current trainee reported:

"We had an interpretation lecture that has come in handy, a lot. A lot of families here speak Spanish, but also since we're doing telemedicine, we're reaching people all over the place. And so, I think back to that one the most." (Hera)

Hera shared that the interpretation lecture is one she refers to often in the clinical setting. This lecture is even more critical now that telehealth is a regular part of genetic counseling practice and genetic counselors are reaching a broader set of patients whose first language may not be English.

#### A recent graduate reported:

"translators actually come out from Hospital A, and do a bit, not only on how to utilize a translator, but also just different cultural pieces to be aware of when speaking to different

families. It was really nice to get the translators' inputs as well. To help just make sessions go easier for both the counselor and the families that we're talking to, also just little keynotes to be aware of. I thought that was really, really helpful." (Sara)

Sara recalled her interaction with a medical interpreter as insightful not just from a logistical aspect of learning how to effectively work with an interpreter, but also from a cultural standpoint. The interpreter shared cultural points to be cognizant of when interacting with patients that speak certain languages. Sara believed this information improved clinical care and fostered clearer communication between the practitioner, patient, and family.

#### **THEME 2:** Learning directly from the minority perspective

Trainees reported that learning from the minority perspective was an eye-opening part of their cultural sensitivity training. In our analysis, trainees highlighted three ways in which they engaged with the minority perspective. The first method was reading books written from the minority perspective. Ida, a current trainee, read the book The Spirit Catches You and You Fall Down. This book is about a Hmong child and her interaction with the American medical system from the perspective of the Hmong family. Ida recollected her class:

"[We] also read <u>The Spirit Catches You When You Fall Down</u>, which is a really great book, and if you haven't read it, I recommend. But that was a really meaningful way to think about how people understand disease and how culture really impacts that." (Ida)

Reading this book allowed Ida the opportunity to reflect upon how disease and cultural perspective interact. Another current trainee read the book The Social Life of DNA.

"The one that I read was called <u>The Social Life of DNA</u> which specifically... talks about the Black community and ancestry testing and how identity, ancestry, genetic testing, all culminate in a very intricate social life of genetics." (Hera)

This book, which was written by a Black professor, explores how the concept of genetics intersects with race, especially within the Black community. Through her reading, Hera was able to examine the field of genetics from a Black perspective.

A second way trainees learned from the minority perspective was through listening to guest speakers. Umar, a recent graduate, shared his hope that:

"if the program has access, [having a space] where we can have either guest speakers or patients who... [are] from a certain cultural background, share their experience in areas of "oh this is a time where I feel I had been heard", or "Oh I feel like the MDs or the GC was very insensitive about my concern because of the color of my skin" or whatever. I think just having different ways to incorporate the information not just through lectures and textbook, but also hearing it from individuals and listening to their stories. I think it can also be another way to enrich our understanding and learning." (Umar)

Umar felt that hearing directly from minority patients about their experience with the healthcare system, especially their interactions with GCs, is a great way to inform trainees how to provide more culturally sensitive care. He hopes that programs will incorporate guest speaker series into the curriculum, to augment learning alongside traditional lecture and textbook readings. Beyond learning about the clinical experience of minority individuals, trainees also expressed how valuable it is to learn about their lives from a more holistic viewpoint. A current trainee named Belle shared what her program arranged:

"They're kind of sessions that they get where people prepared talks and they talk about different... especially marginalized or underrepresented groups of people, and talk about different aspects of their lives and some of those sort of challenges and things that they might face that maybe most of us don't think about." (Belle)

Belle admitted that these talks exposed her to aspects of a minority individual's life she and others did not frequently consider.

The third way trainees learned from the minority perspective is through one-on-one interactions with individuals. Some commonly mentioned ways this was conducted include support group visits or events such as Rare Disease Day. Rose recalls:

"We have another part of our program where we each met with a child or adult who has Down syndrome. And so, I met with a 12-year-old who also lives in City A, and I got to kind of experience what it was like with... living with Down syndrome and I got to talk to her mom. And that was really enlightening for me too." (Rose)

Rose had the opportunity to speak one-on-one with a child with Down syndrome and her mother. Through this interaction, she gained first-hand insight into living with down syndrome and caring for a child with the condition. She felt that the experience was extremely valuable and increased her ability to be more culturally sensitive. Page, who attended a neighboring program, recalls attending an event known as rare disease day. She described the experience:

"They do this thing called rare disease day... it's really nice because we invite all the children and their families so it's like a mix of cultures and then a mix of the rare disease, to learn more about disease and just have them experience life at a hospital without being... like "hospital care"... I've talked to some of them, and it was just like [they were] super eager to tell me about their stuff and it was just really nice because they even talked about different culture experiences and how back in their home countries this wouldn't have happened and all that stuff so it was really nice." (Page)

Page describes a unique opportunity where she was able to interact with a diverse set of individuals, both in terms of ethnicity and rare disease. During the focus group, she explained that the rare disease day included playing games with patients and learning to see them beyond their diagnosis. The experience allowed her to not only learn about rare diseases and discover how this impacted patients beyond the healthcare setting, but also discuss how culture has impacted these families' experiences.

THEME 3: Open discussions on topics related to cultural sensitivity, such as current events

An additional commonly mentioned method to improve cultural sensitivity training was having

open discussions on current events and other topics surrounding cultural sensitivity. Demi shared
why she believes these discussions would be helpful:

"Maybe [we need] more connection between the real world and these abstract concepts because the things that are going on in the news are impacting the patients who we are working with and are part of where they're coming from.... just something that I wish was more explicitly addressed." (Demi)

Demi expressed her desire for programs dedicate more time to discussing current events because she recognized that these events are impacting the patients she is seeing in clinic. She felt that having the opportunity to discuss this impact with colleagues would improve her ability to be culturally sensitive. This type of conversation did happen for Nora, and she reflected on that experience.

"I mean I really enjoyed it. It was such a shift in power dynamic to see some of the faculty really letting their emotions fly with it [the discussion] and explaining their personal stories and actually having a chance to speak was a nice shift, but not be forced to say anything you didn't want to. Just to hear stories, and the, I think, the most ironic part about it is it wasn't planned at all by any of the faculty. It wasn't intentionally supposed to be a diversity training, but I think I learned the most from that talk." (Nora)

Nora shared that this discussion on current events allowed her to see the more human side of her faculty and supervisors. She learned more about their personal lives and can now better understand why they hold the viewpoints that they do. She appreciated finally having a space to speak without feeling like what she would say would be "graded" or "critiqued" as so often happens in other settings. At the same time, she appreciated that no one was forced to share their experiences if they did not feel comfortable speaking. Despite how helpful the conversation was, she noted that the discourse only occurred because of student direction. The conversation was not framed as "diversity training" but ultimately was extremely valuable to her own learning process of what it means to be more culturally sensitive. For other students, these types of discussions improved their cultural sensitivity training by acting as motivators for change.

"Talking about that I felt really uplifted [me] because I got to bounce ideas off of other students and I think that's really important. We were looking through some of the Journal of genetic counseling stuff and bouncing ideas off of each other and talking about... one person was really into Twitter, so they were talking about things that get brought up on Twitter a lot so I thought that was really great. And to kind of feel like maybe there are things that we can do." (Rose)

Rose described her feelings after having an open discussion on current events with her classmates. She noted that the conversation was a space to work together and brainstorm ways to address real-life issues they observed within the field. Ultimately, the conversation was uplifting for this counselor and served as a motivator to keep pushing for more culturally sensitive care.

### RQ2: Describe the aspects of current cultural sensitivity training that trainees found to be problematic

#### THEME 4: Taking the Implicit Association Test without debrief

Nearly every participant recalled taking the implicit association test (IAT) as a first step activity in recognizing their own implicit biases. While some trainees were given the opportunity to discuss those test results with their program leadership, several trainees were not afforded the same courtesy which led to various long-lasting negative emotions. A recently graduated counselor stated:

"Unfortunately, we weren't able to discuss this so that feeling was never resolved. [I] feel like, oh man, I'm a terrible person, I can't believe I'm unable to distinguish X versus Y." (Umar)

Umar, like many other trainees, came away from the IAT feeling guilty about his results. He shared that since there was no debrief after the exercise, he continues to feel terrible about those results to this day. While Umar felt guilty, Quinn reported feeling helpless.

"I have felt a little bit helpless. Because I am aware that I have implicit biases and taking the test kind of just told me that I had implicit biases but not exactly what those were or how to fix them. And so, from that, and personal experience, I then walked away and said, 'Okay, I have problems. I don't know how to fix it'" (Quinn)

Quinn felt the IAT informed her that she has biases, but in no way did it help her pinpoint how to counteract them. Since she did not have the opportunity to discuss the results with experienced program leaders, she was left in a frustrating position of recognizing a problem with no solution.

#### **THEME 5: Discrepancies between classroom training and clinical experiences**

Another way in which trainees felt cultural sensitivity training was problematic was when they would encounter supervisors or other faculty not acting in accordance with the cultural sensitivity training they were receiving. Gigi described a situation where this occurred:

"If a patient needs an interpreter, it should never be a family member, and that's just the rule of thumb I was always taught. And I've worked with so many counselors who were, 'well... let's ask the patient' [if they want an interpreter], and I have so many issues with that because now you're putting it on the patient to be 'do you need me to go out of my way to help you?'...So I'm always placed in an awkward supervisor-supervisee weird dynamic of trying to navigate that." (Gigi)

Gigi knew that a professional medical interpreter should be provided to all non-English speaking patients, regardless of who accompanies them to the appointment. Unfortunately, Gigi observed her supervisors bypassing this rule and instead placing the responsibility to ask for an interpreter on the patient. Seeing this discordance between what would be helpful to leading a culturally sensitive session and what care was actually provided was disheartening to Gigi. On top of that, she felt that her trainee status meant she could not easily speak to her supervisor about the matter, which led to feelings of frustration as well. In another situation where interpretation was needed. Faith described:

"There was this one session where we had a Hispanic couple, and the amount of information given to them was maybe 15 minutes of what would have been given to an English-speaking couple. And that was just not acceptable to me, but as a student, I'm not going to be 'What are you doing? You've got to do more than that'" (Faith)

Like Gigi, Faith observed clinical care being provided that did not align with culturally sensitive care. She felt that the supervisor's behavior was unacceptable, but at the same time did not feel she could comment on the behavior due to her trainee status. For some trainees, observing these moments was not only frustrating, but downright traumatic. Leah, a recently graduated minority counselor felt:

"It's really terrible when it's your own supervisor. And if you're observing a session where your supervisor is not only saying things that are offensive to you, [but] you're [also] seeing how it affects the patient and you're not in a position to change it? PTSD. I hated it." (Leah)

Leah explicitly stated that she hated having to listen to supervisors counsel in a way that was offensive to minority patients, especially as a minority individual herself. A specifically

problematic aspect of the situation was being forced to observe the negative effects on the patient but not being able to change the situation due to her trainee status.

#### **THEME 6: Minority trainee burden**

A frequently mentioned and significantly problematic aspect of current cultural sensitivity training was the unequal emotional burden that minority trainees reported feeling when the topic of minority cultures arose during discussions. During Elle's experience of classroom-wide discussion on culture she reported:

"The emotional burden if you're the only person of color in your class. Having to constantly tell your narrative like that." (Elle)

As the only minority trainee within her class, Elle felt obligated to share her personal story when the topic of the minority experience was raised Another minority trainee shared a similar sentiment about his experience during these types of discussions.

"You're in a room and you don't see any other minorities, it's kind of intimidating and you feel pressure to say something." (Kyle)

Kyle also reported feeling an expectation to speak alongside feeling intimidated by the situation. Notably, these feelings of obligation to share were not mentioned by trainees that identified as White only. Ava shared another reason for why she believed these discussions to place an unequal emotional burden on minority trainees.

"I was thinking about how a lot of these really difficult conversations don't only exist as one conversation. Oftentimes it's uncomfortable because people are living with this and are impacted by it for a really long time." (Ava)

Ava felt that because minority trainees often have to "deal with" the struggles they are sharing about outside of the classroom, the difficulty of the conversation heightens. Not only is the emotional toll heightened during discussion, but the emotional toll of these conversations might even extend beyond the discussion time.

## RQ3: What suggestions do trainees have to foster discussions relating to cultural sensitivity in a safe space

#### **THEME 7: Having a well-trained facilitator**

Trainees emphasized that having a trained facilitator is necessary to creating a safe space.

Minority trainee Elle boldly stated:

"It would be a disservice to have these conversations without people who are able to facilitate them...I think having a having a well-educated facilitator who is comfortable navigating these topics is extremely important" (Elle)

Facilitators are equipped to and enforce ground rules that protect all participants in the conversation. For example, Faith stated her desire that:

"There has to be some ground rules here. We're going to discuss things that are very sensitive, so people's feelings are going to be hurt. But [explaining] these kinds of things are okay to talk about and those kinds of things are not okay or... [emphasizing] free speech does not mean that hate speech is okay." (Faith)

During her time in the program, Faith witnessed one classmate using xenophobic comments, but program leadership did nothing to stop that individual. As expressed in the quote above, due to that negative experience she felt it is critical for a facilitator to clearly state the importance of everyone in the discussion using inclusive, non-offensive language. Another way in which a well-experienced facilitator could be helpful is if the facilitator is able to explain why sharing of perspectives is so important.

"I also think what has really helped me [in] feeling safe is understanding why I'm sharing...I feel like if my words have a purpose and have a meaning, and I know that it's actually helping others, then it's 'yes, I'll open the floodgates.'" (Cora)

Cora observed that once a discussion leader made it clear that sharing personal narratives is helpful to group learning, she became much more open to the idea of sharing her own story. Additionally, a well-trained facilitator is helpful is when the facilitator is able to exemplify vulnerability to the group before asking discussing participants to become vulnerable themselves. Ori elaborated on this idea:

"I think one of the things that could be utilized...and I'm sure there are other things...but having a professor say 'here's was what my implicit bias looks like' because nobody's implicit bias is perfect...So I think having the person who is technically in power, and it feels like is judging you, be vulnerable with you, can make it a really open space, which I think provides a lot more opportunity for growth." (Ori)

Ori hypothesized that having a facilitator admit their own faults before asking others to do so is a great way to create an open and safe space. It sets the precedent that it is okay to not be perfect and may make participants feel less like they are being judged by others. She further hypothesized that this assurance of a non-judgmental space could lead to a more productive space for trainees to grow in addressing their biases and furthering their cultural sensitivity.

#### THEME 8: Logistical approaches to support a safe space

Beyond having an experienced facilitator lead discussion, trainees shared several logistical suggestions to creating a safer space. Umar commented on the timing of discussions:

"I felt like if it was done in the second semester or even the beginning of second year, where we already have developed that really close relationship, then I think that could encourage us to be more open about, speaking our feelings, our insecurity, and having that safe space. Not feeling judged because we already know these colleagues and our classmates, a lot better than versus when we're doing this course at the beginning of first year right?" (Umar)

Umar stated his belief that the timing of these difficult discussions should be considered wisely. He speculated that having conversations later in the program is likely to increase how open discussion participants are with one another. He noted that having pre-established trust and respect for all the individuals in the conversation decreases fear of being judged and increases the safety of the space. Ida proposed another logistical way to create a safer space for discussion.

"Sometimes I felt like breaking up into smaller groups first, and having one or two people that are having a conversation first, and then moving to a bigger group, is sometimes when people feel more comfortable." (Ida)

Ida recalled that in her program trainees would break up into smaller groups first. This increased participant comfort since once individuals shared their ideas and stories with one or two others, they were more likely to share those thoughts with a larger group. Lastly, Leah shared a way in which her program tried to create a safer space.

"We had those google doc type discussions. We would have a due date of when we would need to reply to a certain prompt. So, in the beginning it's still kind of nerveracking, like who's going to make the first post, but you still at least have some time to think about it versus right after you hear something in class and having to scramble to reflect and form your response. I think it got a lot more out of people." (Leah)

In Leah's program, students would have discussions online using a live Google document.

Students were required to respond to a prompt and to each other by a certain time. She admitted that this process was still nerve-racking but provided students time to formulate and review their responses rather than being forced to come up with an answer on the spot. For Leah and her classmates, this format of discussion allowed for richer and more open conversation.

#### **THEME 9: Providing support to trainees post-conversation**

Some trainees felt that having post-conversation follow-up by program leadership to trainees negatively impacted by a discussion would help in creating a safe space. Ava, a minority trainee, explained:

"Something that we've been lacking is someone who can persistently and consistently follow up with that individual who is greatly impacted by that event or that conversation. I do think in order to create a safe space and bring up these important points, it's also important to have follow up so that the individual feels supported beyond that...because otherwise if you do go on and share something very openly, and then kind of feel left in the dust? I feel like that's even more detrimental than just creating a safe space in the moment." (Ava)

Ava had experienced sharing her story with her cohort and subsequently feeling as if no one cared about how much she had to give-up about herself in that moment. Ava shared her hope that programs organize a way for leadership to check up on those negatively impacted by discussion, even after the conversation has passed. Checking in on those that have already shared demonstrates appreciation for their efforts instead of leaving them to feel vulnerable and used. She stated her belief that without doing so, the experience for those "left in the dust" would be more negative than positive, even if the discussion was held in a safe space.

#### IV. DISCUSSION

I believe that a keyway to improve cultural sensitivity training in GC programs is to understand the trainee perspective and listen to trainee suggestions. Through these five semistructured focus groups, we explored three main questions relating to cultural sensitivity training across genetic counseling programs. All answers to the questions were from the GC trainee perspective. The first question focused on describing helpful cultural sensitivity training methodologies. The second question reviewed in what ways current cultural sensitivity training is problematic. The final question explored counselor's views on how a safe space for cultural sensitivity training can be developed. Overall, we found that trainees want more time dedicated to learning from medical interpreters, the minority perspective, and holding open discussions on current events. These methods were reported to be extremely beneficial to those that had the opportunity to participate in them and desired by trainees who were unable to experience them. On the other hand, trainees reported taking the IAT without post-test discussion, observing discordance between supervisor behavior and ideal culturally sensitive care, and minority trainee burden to be problematic aspects of current cultural sensitivity training. Trainees' perspectives emphasized the importance of creating safe environments to express and process the potential negative emotions that may accompany implicit bias processing. Additionally, trainees highlighted the importance for GC programs to consider bringing on board facilitators trained in leading implicit bias and cultural sensitivity discussions and debriefings effectively. Trainees also proposed several logistical adjustments to discussions as well as ensuring proper follow-up after discussions to create a safer space for discourse.

#### 1. Key Findings and Connection to Existing Literature

#### 1.1 HELPFUL LEARNING STRATEGIES

While there were many cultural sensitivity training techniques reviewed and an equal number of trainee suggestions on how to improve the learning experience, three prominent findings emerged. First, trainees found great value in learning from medical interpreters.

Language is a key component of cultural identity and serves as a major barrier to rapport building when patients have limited English proficiency (LEP). Medical interpreters report language and culture discrepancy between GCs and patients along with lack of cultural sensitivity to be a source of "culture bumps." Interpreters currently act as 'cultural brokers' to mediate these 'culture bumps' (Rosenbaum et al., 2020). When trainees learn directly from interpreters they learn not only how to effectively work with an interpreter, but also are provided 'tips' on how to become that 'cultural broker' to reduce 'culture bumps' within the patient session. Therefore, it is not surprising that trainees found learning directly from medical interpreters to be incredibly instrumental in improving their cultural sensitivity skills.

Trainees also reported learning directly from the minority perspective to be valuable to the cultural sensitivity training process. Trainees felt that everything from minority guest speaker sessions to reading literature written by minority individuals was perspective-widening and informative. The reported benefits of a personal perspective on the minority experience aligns with the characteristic methods of Critical Race Theory (CRT) writing and lecturing. CRT often utilizes "first person, storytelling, narrative, allegory" to present its position and has found long-lasting success in doing so (Bell, 1995). Another way in which trainees learned from the minority perspective was by interacting with minority individuals one-on-one. As stated in pre-existing literature, the "contact hypothesis" finds that as an individual has more positive

encounters with outgroup members, the "stereotyping, prejudice, and discrimination" that the individual carries against the group, is reduced (Hagiwara et al., 2019). The reported benefits of one-on-one interactions with individuals that identify as part of a minority group are likely trainee experience of this "contact hypothesis."

Most prominently, many trainees reported the positive effects of having time for open discussion on topics such as current events, race in medicine, and structural inequalities. Previous literature in fields outside of genetic counseling have found that intergroup dialogue can help individuals cope with racial discrimination and bias as well as foster a commitment to social actions (Gurin-Sands et al., 2012). Genetic counseling trainees described similar effects after engaging in program-wide discussions on these topics. Trainees also emphasized how discourse with supervisors was particularly valuable to future clinical interactions. This finding supports previous literature that found both supervisees and supervisors benefit from race-related dialogue. Dialogue was especially helpful for minority individuals in racially discordant supervisee-supervisor pairings (White-Davis et al., 2017).

From these findings, we can inform future program development of cultural sensitivity training. If program leadership must select only a few strategies to implement, choosing to dedicate more time to learning from medical interpreters, learning from the minority perspective, and holding open discussions on topics related to culture should be prioritized.

# 1.2 PROBLEMATIC TEACHING METHODS UTILIZED IN CULTURAL SENSITIVITY TRAINING

While trainees reported many helpful training methods that increased their cultural sensitivity skillset, they also shared many methods that they viewed as problematic. These activities resulted in various negative emotional reactions from trainees such as guilt, shame,

helplessness, frustration, and isolation. The first problematic activity was taking the implicit association test (IAT) without guided discussion afterwards. The IAT is not a perfect measure of an individual's automatic associations but is still considered one of the best ways to measure implicit bias within an individual (Vianello and Bar-Anan, 2020). Most trainees acknowledged the benefit of using the IAT to recognize bias, and several even endorsed its use across all programs. The issue with taking the IAT, however, is that without moderated self-reflection afterward, many trainees experience "rebound effects." Trainees reported feelings of guilt and shame that likely stemmed from the common "rebound effect" of racial anxiety. Being forced to recognize their implicit biases left trainees feeling ill-equipped to deal with intergroup interactions (Godsil et al., 2014). Other existing literature has clearly stated that the IAT is most effective when executed in conjunction with discussion (Thompson et al., 2010). Sukhera et al. urges "that regardless of how the IAT is used in education, curriculum designers and educators must consider...potential reactions from learners, and have a plan in place to address such reactions prior to delivering instruction." Discussions can be used to address these potential reactions to the IAT. The findings from this study, along with what is known in current literature, should serve as evidence for programs to include moderated discussion post-IAT as a regular part of cultural sensitivity training.

A surprising problematic aspect of cultural sensitivity training was the reported discrepancy between cultural sensitivity training in the classroom and observed supervisor behavior. Several trainees reported noticing supervisors exhibit behavior that did not align with culturally sensitive practice. Due to the pre-established trainee-supervisor relationship dynamic, these trainees did not feel able to comment on the problematic behavior. Instead of being able to alter the situation, students were forced to observe the negative effects their supervisor's

behavior had on patients. Ultimately these encounters left trainees feeling helpless, frustrated, and in some instances when supervisor behavior was particularly offensive, even traumatized. This phenomenon has not been extensively studied within the genetic counseling field and solutions to avoid this circumstance are also sparse. Participants from this study proposed requiring all program faculty to go through an equal level of cultural sensitivity training as their trainees do as a possible way to avoid supervisor-supervisee discordance. Future studies could work to thoroughly investigate this issue and research potential solutions.

A third aspect of present cultural sensitivity training that was reported to be problematic is the unequal emotion burden it places on minority trainees. The reported instances of minority burden in this study extend the findings of a previous study which focused specifically on the minority trainee experience in genetic counseling programs. The previous study found that "minority students, especially those in less-diverse class cohorts, felt obliged to contribute their perspectives in order to educate non-minority classmates about issues of race and ethnicity, leading to feelings of frustration and exhaustion" (Carmichael et al., 2020). In our study nearly every minority trainee also reported feeling obligated to educate non-minority classmates, but their resultant feelings were typically ones of nervousness and isolation. Knowing how frequently minority trainees report this phenomenon and the resultant negative effects, programs should work towards reducing minority trainee burden.

# 1.3 SUGGESTIONS TO FOSTER A SAFE SPACE FOR CULTURAL SENSITIVITY TRAINING

The results of this study have emphasized the importance of discussion in the cultural sensitivity training process. Alongside the importance of allotting sufficient time for discussion, trainees also expressed hope that discussions would be executed in a safe environment to protect

all trainees, especially minority trainees. A critical way to do this is by ensuring well-qualified facilitators are leading discussions that cover sensitive topics. Trainees found facilitators to be particularly crucial because they can explain the importance of the discussion in the first place. Giving students this holistic perspective has been reported to also be effective in other healthcare educational settings, such as medicine (Mosley et al., 2020). Facilitators are helpful when they are able to set and enforce ground rules that protect discussion participants from lasting psychological harm. Additionally, trainees felt there is great benefit when facilitators lead by example and share their own vulnerabilities before inviting discussion participants to do so. These two aspects of a well-trained facilitator have been proven effective to creating a safe space in other realms of healthcare education as well (Peek et al., 2020). Given the effectiveness of a well-qualified facilitator in other healthcare education settings, along with the predicted effectiveness within the genetic counseling setting, programs should work towards bringing on experienced facilitators to lead discussion aspects of cultural sensitivity training.

We acknowledge that finding well-qualified facilitators to guide cultural sensitivity discussions in programs and allocating the resources to adequately compensate those facilitators is a difficult task. To accompany that suggestion, trainees also shared various logistical ways in which discussions can be held in a safer space. Trainees suggested timing these discussions at a point when students are comfortable with each other and their faculty. Additional suggestions included having participants begin discussions in small groups before sharing with a larger group and having discussions be asynchronous to allow individuals the time to reflect upon their answers before sharing. These logistical suggestions have been previously found to be effective across other sectors of academia (Pfund et al., 2006) and should be relatively easy to implement.

Program leaders can incorporate these logistical suggestions to create a safer space for cultural sensitivity training.

A critically important reason to create a safe space is to alleviate the emotional burden that many minority trainees currently report occurs when discussing minority culture. While non-minority trainees report inter-group discussions on the topic of race, current events, and the lived experience of minority individuals to be beneficial to their learning, this is not always the case for minority trainees. Previous literature has reported an association between negative conversations about one's racial group with adverse mental health outcomes if the minority individual has experienced discrimination (DeLaney et al., 2021). This aligns with reports from this study where several minority trainees described feeling "left in the dust" and empty after sharing their narratives with classmates. Since negative feelings carry beyond the conversation timeframe, the suggestion to implement regular follow-up with individuals negatively impacted by a conversation should hopefully alleviate some of the detrimental emotions experienced by minority trainees.

#### 2. Future Implications

Cultural sensitivity training within genetic counseling training programs is a relatively new endeavor. There has been little research on the effectiveness of various teaching strategies. Through exploring the current trainee experience, this study has identified several effective cultural sensitivity training methodologies that program leadership can work to implement in their curricula. Programs can increase opportunities for students to learn from medical interpreters. Additionally, programs can emphasize learning from the minority perspective via providing literature written by minority individuals, inviting minority guest speakers, and having students interact with their local support groups, health care centers, and community at large.

Leadership can improve the training experience by providing more time for discussion, particularly on topics such as current events and after certain self-recognition exercises such as the IAT. These discussions not only enrich, but also complete the cultural sensitivity training experience by serving as a space for self and group reflection and finding the motivation to change behavior. The most impactful improvement that programs can make to the cultural sensitivity training process is by hiring well-qualified facilitators to guide discussions within cultural sensitivity training.

While many of the above suggestions may help alleviate some of the negative experiences that trainees reported experiencing during their training, some problematic aspects of training still need to be addressed. Supervisor-supervisee discordance in clinical rotations and the unequal emotional burden experienced by minority trainees are more complex issues to address moving forward. Grounded in the evidence collected through this analysis, programs have an opportunity to reflect on these two aspects of their curriculum and try various strategies to avoid them so that the training experience improves for all GC students.

Overall, if program leadership implement the suggested training methodologies and work to avoid problematic aspects of training, it is anticipated that effectiveness of current teaching can be improved on a program-wide scale. As trainees grow to become more culturally sensitive professional genetic counselors, the care of the profession will also increasingly improve for all patients, especially for minority patients.

#### 3. Limitations

While the focus groups conducted as part of this study led to many novel themes emerging, there are several limitations of the study that should be addressed.

Focus group participants were recruited through a voluntary recruitment survey.

Participants were not provided compensation in any form to participate in a focus group. This makes it highly likely that all participants held strong opinions about the current state of cultural sensitivity training prior to engaging in the study and may not accurately represent the sentiments of the genetic counseling trainee population as a whole. Informants represent a small timeframe of cultural sensitivity training. Given the rapid changes of the country's sociopolitical landscape, future trainees may have entirely different perspectives on cultural sensitivity training that could not be captured with this study.

All accounts of experience with cultural sensitivity training are self-reported by the trainee and must be accepted as presented. It is important to remember, however, that accounts may have been embellished or exaggerated, and key details may have been withheld. This could be due to a variety of factors including, but not limited to selective memory, feeling as if other focus group members or the researcher are looking for a particular story, or other personal circumstances that the researcher was not aware of at the time.

As the lead researcher, I approached this study aware of my own personal identity as a minority GC trainee. This identity may have impacted my relationship with focus group participants and how I analyzed my data. Due to time and manpower constraints, an independent coder was not feasible for this project. Efforts to correct for bias included a standardized focus group guide, use of modified grounded theory, and several iterations of the coding process.

Despite these efforts, personal bias may still have impacted data collection and analysis; repeat of this study with a different researcher perspective would be informative.

#### 4. Future Research

Given the prior limited research on cultural sensitivity training in genetic counseling programs and the exploratory nature of this study, there are many areas where future research will be valuable. First and foremost, this study involved hearing from 21 current and recently graduated trainees, a small fraction of the much larger population of genetic counselors overall. While several emergent themes repeated across groups, saturation of novel themes was not entirely met. More focus groups targeted at answering the same questions posed in this study may lead to more novel themes of ways that cultural sensitivity training can be improved and ways that discussions on the topic can be facilitated more effectively.

Another aspect that should be further studied is the minority trainee experience with cultural sensitivity training. This study had representation of both minority and majority trainees in each focus group. Minority trainees reported feeling more emotional burden and anxiety surrounding the topic than their majority trainee counterparts. A study dedicated to understanding the minority experience and how to improve it would be beneficial to current and future minority trainees. Improvement of their experience would also hopefully lead to a more inviting space to recruit minority individuals into the field. This will help close the demographic gap that currently exists between the profession and the population it serves.

Future qualitative and quantitative research studies can focus on effectiveness of particular training strategies such as role plays, listening to minority guest speakers, interacting with various minority communities, and open discussions. Having a clearer understanding of why certain training methods are more effective than others can inform future program development on cultural sensitivity training and improve the process overall.

Finally, based on literature review and analysis of data from this study, it is clear that there is a gap in explicit guidelines for what learning goals programs must achieve in the realm

of cultural sensitivity. The current standards of accreditation written by the Accreditation

Counsel for Genetic Counseling (ACGC) simply states that programs need to cover

"multicultural sensitivity and competency." While the practice-based competencies provide a

more detailed list of how this can be achieved, programs do not have a standardized objectives

available to ensure trainees are indeed culturally sensitive by the end of their training.

Furthermore, there is no standardized way to measure cultural sensitivity within a genetic

counselor. Future research should focus on establishing these more explicit goals and skill

measurements to aid in a standardized approach to cultural sensitivity training, just like so many

other aspects of training are standardized.

#### 5. Conclusion

This focus group study contributes novel findings on the current state of cultural sensitivity training and how it can be improved from the genetic counselor trainee perspective. Despite the importance of culturally sensitive genetic counselors in the workforce, there is limited existing literature on the effectiveness of cultural sensitivity training within programs. Through exploring trainee experience with cultural sensitivity and implicit bias training, three major themes emerged.

Trainees find that learning from medical interpreters and directly from the minority perspective to be some of the most effective learning strategies in cultural sensitivity training. Discussions are a critical part of the training experience, as they serve as a place for self and group reflection as well as emotional motivation to positively change behavior. Trainees also described unhelpful aspects of training which included taking the IAT without guided debrief afterwards, experiencing supervisor-trainee discordance in clinic, and either experiencing or witnessing minority trainee burden. Lastly, trainees provided suggestions on how to operate

cultural sensitivity training in a safer manner. They offered methods such as hiring well-qualified facilitators, altering logistical aspects of discussion time and format, and implementing regular follow-up with those negatively impacted by cultural sensitivity training activities.

In conclusion, through listening to the genetic counseling trainee perspective, several novel methods of improving the current state of cultural sensitivity training were discovered. As programs continue to improve their curriculum focused on cultural sensitivity, hopefully culturally sensitive care that genetic counselors provide will also advance and patients across the country will be able to experience higher quality care.

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#### **APPENDIX A: Recruitment Survey**

Do١	you consent to	partici	pating	in	this	research	study?

- Yes
- No

What is your name? Please answer LAST, FIRST (ex: Smith, Jane)

Which of the following is the best way to contact you to schedule you for a focus group?

- Text mobile number
- Call mobile number
- Email professional
- Email personal

Please enter your mobile number:

\_\_\_\_\_

Please enter your preferred e-mail address

\_\_\_\_\_

Do you have the technological capability to participate in a teleconferencing (Zoom) focus group?

- Yes
- No

#### What time zone do you work under?

- HT (Hawaiian Time)
- AKT (Alaska Time)
- PT (Pacific Time)
- MT (Mountain Time)
- CT (Central Time)
- ET (Eastern Time)

#### Are you currently a Genetic Counseling Trainee?

- Yes
- No

If you selected "yes", which program do you attend?

If you selected "yes", what year are you?

• 1<sup>st</sup> year

2<sup>nd</sup> year
3<sup>rd</sup> year
ou selected "

#### If you selected "no", which year did you graduate?

- 2020
- 2021
- Other

If you selected "no", which program did you attend?

\_\_\_\_\_

#### Did/does your program discuss/teach cultural sensitivity?

- Yes
- No

#### Did/does your program discuss implicit bias?

- Yes
- No

What is your age?

What best describes your gender?

- Male/Masculine
- Female/Feminine
- Non-binary
- Other
- Prefer not to answer

If you selected other, please specify

\_\_\_\_\_

#### What are your preferred pronouns?

- She/Her/Hers
- He/Him/His
- They/Them/Theirs
- Ze/Hir(Zir)/Hirs(Zirs)
- Other
- Prefer not to answer

If you selected other, please specify

\_\_\_\_\_

_				C			_		
1)A \	you identify	/ as a	nerson	Of His	nanıc	l atino	or S	nanish	Origin 2
00	you lucitiii	y us u	person	01 1113	puilic,	Latino,	0, 0	pariisii	Origin:

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican Am., Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin For example: Salvadoran, Dominican, Colombian, Guatemalan, Spaniard, Ecuadorian, etc.
- \_\_\_\_\_
- Prefer not to answer

#### What is your ethnicity/race?

- White specify, for example: German, Irish, English, Italian, Lebanese, Egyptian, etc.
- Black of African American specify, for example: *African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali etc.*
- American Indian or Alaska Native specify name of enrolled or principal tribe(s), for example:
   Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barro Inupiat Traditional
   Government, Nome Eskimo Community, etc.
- Chinese
- Filipino
- Vietnamese
- Native Hawaiian
- Korean
- Samoan
- Asian Indian
- Japanese
- Chamorro
- Other Asian specify, for example: Pakistani, Cambodian, Hmong, etc.
- Other Pacific Islander specify, for example: Tongan, Fijian, Marshallese, etc.
- Prefer not to answer

If you have a more specific understanding of your ancestry, please share here

Ex: Paternal family is Chinese, Maternal family is Puerto Rican

\_\_\_\_\_

Do you consider yourself an ethnic/racial minority within the genetic counseling profession?

- Yes
- No
- Unsure

Briefly describe what you believe to be your cultural and religious/spiritual (if applicable) upbringing:

Ex: Born and raised in Southern California, first generation immigrant family, Catholic, Chinese American

\_\_\_\_\_\_

Thank you for filling out this recruitment survey. You will receive either a text or email (depending on selected preference) with confirmation of receipt within the next week.

<u>If selected as a potential focus group participant</u>, scheduling details will be included within the confirmation of receipt email. All responses to this questionnaire are intended for informed recruitment purposes only and will be kept confidential.

<u>If not selected as a potential focus group participant</u>, all data collected in this survey will immediately be disposed of in a secure manner. You will be informed when answers to this questionnaire have been permanently deleted.

If you have any questions or concerns, please contact:

Natasha Go Genetic Counseling Trainee at the University of California, Irvine Nago@hs.uci.edu

#### **APPENDIX B: Study Information Sheet**

## University of California, Irvine Study Information Sheet

## Genetic Counseling Trainees Recognition of Implicit Bias and its Impact on Cultural Sensitivity Training

#### **Lead Researcher**

Natasha Go B.S., Genetic Counseling Graduate Student
Department of Pediatrics, University of California, Irvine School of Medicine
Mobile Contact: 714-829-0606
Email: nago@hs.uci.edu

#### **Faculty Sponsor**

Dr. Suellen Hopfer PhD., Assistant Professor Department of Health, Society & Behavior, Program in Public Health, University of California, Irvine

Email: Shopfer@hs.uci.edu

- Please read the information below and ask questions about anything that you do not understand. A researcher listed above will be available to answer your questions.
- You are being asked to participate in a research study. Participation in this study is voluntary. You may choose to skip a question or a study procedure. You may refuse to participate or discontinue your involvement at any time without penalty or loss of benefits. You are free to withdraw from this study at any time. If you decide to withdraw from this study you should notify the research team immediately.
- You are being asked to participate in a research study to investigate and describe the attitudes of how implicit bias may impact cultural sensitivity training among genetic counseling trainees.
- You are eligible to participate in this study if you are at least 18 years of age or older; are a current or recently graduated (class of 2020 or 2021) genetic counseling trainee from an accredited genetic counseling training program in the United States; speak English; are able to recall cultural sensitivity and implicit bias training; and have access to the internet, a computer, and microphone system.
- The **research procedures** involve a video-taped focus group discussion online via Zoom conferencing software. The focus group session will involve three to four participants having guided discussion on the topics of implicit bias and cultural sensitivity training. The entire session, including introductions and wrap-up, should last about 90 minutes.
- **Possible risks/discomforts** associated with the study are psychological distress from discussing emotionally charged topics, potential for other participants to share what was discussed during the focus group with those outside of the study, and

embarrassment/social stigma if participant shares views that other focus group participants do not align with.

- There are **no direct benefits** from participation in the study. However, this study may explain how to improve current cultural sensitivity training models for genetic counseling trainees across the nation.
- There are no alternative procedures available. The only alternative is not to participate in this study.
- You will not be compensated for your participation in this research study.
- There is no cost to you for participation in this study.
- All research data collected will be stored securely and confidentially. MP4 files and transcripts of the Zoom focus group session will be stored on the lead researcher's personal laptop that is password protected. MP4 files and transcripts will never be uploaded or shared to other devices or cloud storage options.
- The research team, authorized UCI personnel, the faculty sponsor, and regulatory entities, may have access to your study records to protect your safety and welfare.
- While the research team will make every effort to keep your personal information confidential, it is possible that an unauthorized person might see it. We cannot guarantee total privacy.
- If you have any comments, concerns, or questions regarding the conduct of this research please contact the researchers listed at the top of this form.
- Please contact the **UCI Institutional Review Board** by phone, (949) 824-6662, by e-mail at <u>IRB@research.uci.edu</u> or at 160 Aldrich Hall, Irvine, CA 92697-7600 if you are unable to reach the researchers listed at the top of the form and have general questions; have concerns or complaints about the research; have questions about your rights as a research subject; or have general comments or suggestions.

**What is an IRB?** An Institutional Review Board (IRB) is a committee made up of scientists and non-scientists. The IRB's role is to protect the rights and welfare of human subjects involved in research. The IRB also assures that the research complies with applicable regulations, laws, and institutional policies.

#### **APPENDIX C: Sample Focus Group Guide**

Written by Natasha Go, Edited by Dr. Suellen Hopfer and Dr. Jennifer Young
Last updated 11/15/2021

#### WARM UP /Explain purpose of study

Good morning/afternoon/evening everyone! Thank you so much for agreeing to participate in this focus group session on implicit bias and its impact on genetic counselor training. You are all experts in the genetic counseling trainee experience, and I am excited to learn from what you have to share today.

My name is Natasha Go. I am currently a second-year trainee at the University of California, Irvine's Masters in Genetic Counseling Program. I became interested in this topic after various talks and posters I listened to and viewed during the 2020 NSGC Conference. After taking some counseling courses during the first quarter of my time in the training program as well as after numerous political events that I am sure you are all aware of, I became even more invested in studying this phenomenon of cultural sensitivity training. What truly catapulted me to committing to this topic was my early start in clinic and desire to better serve our minority patients.

Before we begin, I have to get through a few logistical points. First, please keep all discussion that we have today confidential. As you all know, the genetic counseling world is very small and the best way for all of us to have rich discussion is if we can rely on each other to keep conversation content private. Please keep all language inclusive and respectful by actively listening and using "I" language. I want to keep this space safe for all participants to honestly share their views. There are no right or wrong answers. All your experiences are valuable and worthy of being shared. Lastly, please wait to speak after someone has completed talking sequentially. I know internet lag makes this more difficult, but as the moderator I will work to ensure that everyone has an opportunity to speak. My role today will be to pose questions to the group and keep the discussion on track. You may find that I move from topic to topic quicker than expected or that I ask additional clarifying questions to some participants. Other than these points, I hope that the bulk of today's dialogue will be filled with your valuable insights and reflections.

#### Ice Breaker

Let's start off by having each of you to share your name, the program you attended, and where you are currently located.

Great, thanks everyone for the introduction!

#### SECTION I: GC Cultural Sensitivity/Implicit Bias Training Experience

Many programs incorporate into their curriculum some type of training that provides future genetic counselors with the skills to effectively counsel individuals from all walks of life and

cultural backgrounds. Some programs may have termed this cultural competency training, cultural engagement training, or cultural sensitivity training.

**My first question** for you all is to please describe your experience with cultural sensitivity/ competency training in your program. Please describe what stood out most to you about your training experience and share in as much detail as you can remember, specific examples such as classes, role plays, or presentations that your program used to teach these skills.

**Probe:** How did this training prepare you to counsel patients that may come from a different cultural background than you. Please provide an example.

**Probe:** How did this training impact your counseling or approach to counseling for patients that may come from a different cultural background than you. Please provide an example.

Probe: [you could alternatively or additionally ask..] Tell me about your thoughts/reactions/feelings to this training in the immediate aftermath? In what ways did this training impact your approach/thoughts/feelings to counseling moving forward? [this probe actually gets at whether the training had an immediate impact moving forward or whether it may have "kicked" in years later down the road?]

[this gets counselor to elaborate about what they felt/thought was helpful not helpful about the training...if you want this data, I would ask this first and ask open-endedly to have counselors describe what about the training they felt was helpful/impactful/ what was not]: I would start open—ended....Tell me your thoughts about...

**Describe** what was most helpful about this training?

**Describe** what was least helpful about the training? What could be improved?

#### **SECTION 2: IMPLICIT BIAS TRAINING AND REACTIONS**

Oftentimes, the first step in effectively counseling a patient that comes from a different background is being aware of your own personal biases you might have towards the patient. This is so one can try and avoid acting or reacting to those hidden emotional reactions. These unconscious thoughts towards someone are known as implicit bias.

Right now, I'd like for everyone who had specific training on implicit bias to raise their hand. [count number of people]
Great, thank you!

[If there were people who did not raise their hand]: So it seems like [names], you all did not receive this training in your program? That's no problem. Some of the following questions may not be as relevant for you, but if you do have anything to say on the topic, please feel free to jump in at any time.

**Question:** At what point in your training did your program ask you to reflect on possible hidden biases you might hold?

**Prompt:** How did your program initiate this type of self-reflection? **Probe:** eg., writing reflection pieces, taking the IAT test, discuss biases with others

**Question 1:** After doing the implicit bias training, what was one emotion that you felt? Can you say more about that emotion?

**Question 2:** Now that it has been some time since the idea of implicit bias was first introduced in your program, how have your thoughts or feelings towards this concept of unconscious bias changed or evolved?

**Question 3:** What strategies did your program provide to guide you in "de-biasing" yourself? Please provide an example.

### SECTION 3: IMPLICIT BIAS'S IMPACT ON CULTURAL SENSITIVITY/ENGAGEMENT/COMPETENCY TRAINING

**Question 1:** Given our discussion about our own feeling towards our unconscious biases, how did these emotions show up in your broader cultural (sensitivity/competency/engagement) training?

What do you believe is necessary for creating a safe space?

Have you felt strong negative or positive emotions when having these conversations related to implicit bias or cultural sensitivity?

**FLEXIBLE Question 2:** When, for example, you were asked to \_\_\_\_\_\_ (role play, think from patient perspective, counsel) with a (real or actor) patient that comes from a different cultural background than you, how did these emotional reactions affect your performance? -can change the activity of interest to anything that the participants mentioned during section 1, question 1.

**Question 3:** (FOR CURRENTLY PRACTICING GC'S AND ONLY IF I FEEL GOOD RAPPORT AND TRUST HAS BEEN ESTABLISHED) What methods do you find yourself relying on when serving patients from other cultural backgrounds than your own?

**Question 4:** What suggestions do you have for improving GC programs training in cultural sensitivity/competence or implicit bias?

**Question 5:** How important do you feel it is for incoming trainees to have that varied experience of interacting with a lot of people, or do you feel like a lot of that can be learned during their time in a training program?

#### **DEBRIEF**

**Question:** Is there anything else anyone would like to share that I haven't asked? **Question:** Since this is a pilot focus group session, what feedback do you all have on how this session went? Questions that you felt were insightful? Questions that maybe made you uncomfortable? Questions that could be worded better?

Thank you all for your time and energy today. I greatly appreciate all the insight, stories, and viewpoints you have shared. Please do not hesitate to contact me at my email (put email in chat) if you have any further questions or concerns. I hope to share the results of this focus group with you and the rest of the genetic counseling community soon!

### **APPENDIX D: Codebook Sample Pages**

QUESTION cultural sens		nees believe could help crea	ate a safe space for discussions related to implicit bias and
2nd level			
Code	1st level codes that fit under	Definition/Explanation	Examples
Definition	Authentic Self Safe Space	A safe space is one where an individual can be their authentic self without fear of judgement	"I feel like you know just having a space where people could just like voice their opinions and not be like they're going to be judged, and then not feel like they have to like watch what they say." FG4
	Safe Space Does Not Equal Comfort	A safe space does not mean that the conversation will be comfortable, it means that feeling uncomfortable is okay	"I think there might be like a false association between like a safe space not especially around the topics of like diversity race, ethnicity, bias and identities like I think people might associate safe space with the fact that like we're going to be able to talk about these things without being uncomfortable."
Ground Rules	Comfortable with Uncomforta ble	The first step to creating a safe space is for people to understand that the conversation will likely be uncomfortable	"Um, I would say for everyone in the room though, just being aware that it's going to get uncomfortable and being okay with that, and reminding everyone almost physically open your mind." FG5; "So you're all going to be uncomfortable together, and that's okay." FG5; "And I think one other thing is also having some basic ground rules like across the board." FG2
	Open Warning Statmement	This should be done by the facilitator clearly stating at the beginning of the session that being uncomfortable is okay and is likely to happen	"But I think having a statement at the beginning it's really helpful to recognize and acknowledge that people have varying levels of comfort, like you don't have to share if you don't want to, you can leave if you need to, like, just having that be an open environment for, and recognizing those differences." FG1
	Open Comfort Statement	Other ground rules the facilitator should set include: specifying difference between free speech and hate speech	"So, there has to be some ground, some ground rules here. We're going to discuss things that are very sensitive so people's feelings are going to be hurt. But these kind of things are okay to talk about and that kind of things are not okay or." FG2 "Free Speech does not mean that hate speech is okay." FG2
	Understand Purpose Share	Explaining the value in sharing experiences/viewpoints /etc.	"I also think that what has really helped me feeling safe is understanding why I'm sharing" FG1; "I feel like if my words have a purpose and have a meaning, and I know that it's actually helping others, then it's like yes, like I'll open the floodgates." FG1
	Comfortable with Others Different Biases	Explaining how to critcize each other in a respectful manner	"And kind of like creating a space that we're calling on and calling in is okay, and like calling out isn't. So I guess that could be a ground rule, where there is self correction but also correction coming from others, and that's okay too. To be corrected and to do the correcting. But part of that is creating those ground ground rules that allows someone to feel comfortable and safe to experience that and to do it. But I think like have if you're going to have a space that calling on and calling in on each other is definitely necessary." FG2

	Rapport with Everyone in Discussion	Trainees also felt that if participants come in acknowledging that one, their classmates may have different biases from themselves and two, they know to forgive themselves throughout the discussion	"And, you know still recognizing the person next to you even if they have different biases or different thoughts, y'know, just being aware that everyone is a little different and that's okay. Because everyone is going through the same thing you are and recognizing their own implicit biases." FG5  "Because you got to go in there with an open mind and just be able to forgive yourself for any implicit biases that you recognize. Just like I said I was very embarrassed by what I recognized in myself. Now looking back I wished I'd been a little kinder to myself during those conversations." FG5
	Desire Calling In NOT Calling Out	it would help in creating a safe space for everyone	during those conversations. Tes
Facilitator Abilities	No Facilitator Disservice	Reason for below section	"I think it would be kind of like a disservice to have these conversations, without people who are able to like facilitate them." FG1; "And so when you have professors who have biases that they don't recognize, or have never realized, or using problematic language because they haven't educated themselves. I don't think should be facilitating these kinds of conversations and unfortunately they do." FG2
	Allow Emotions	4	"I absolutely agree on the person in charge, like shifting that power dynamic. Because that's what made that anti-Asian hate unhappy hour thing so effective was like being able to see faculty cry over this, because that's not something that I feel like happens in cultural competency trainings, but it should. This stuff is really emotional so just trying to sap it of the emotion doesn't make a lot of sense to me." FG4
	Acknowledg e Lack Diverse Experiences Okay	5	"I do think one really important aspect too, now that you're mentioning this Quinn, that guilt that you keep talking about like not having the experience. I think is super important to bring up in a cultural competency class. Like if there was a formal class, I really hope that it wouldn't only focus on, like, the diversity of culture but also talking about how like some people may lack that diversity or that background and like, how do you cope with that because that's not often talked about and I think that is super important too." FG4
	Failitator Well Educated	1	"I think having like a having a well-educated facilitator who is comfortable navigating these, these topics is extremely important" FG1;
	Facilitator Aware Self Bias	2	"And I think one of the things that I think could be utilized, and I'm sure there are other things, but like having a professor having [them] saying like "here's was what my implicit bias look like" because nobody's implicit bias is perfectSo I think having the person who's technically in power and it feels like is judging you, kind of be vulnerable with you, can make it a really open space, which I think provides a lot more opportunity for growth." FG4

	Facilitator	3	"I think what really helps me be feel safe is like, I don't
		3	
	Initial Share		know if it needs to be a facilitator someone, who is able
			to share first." FG1
	Student Faculty	Reason for 6	"That that can be a barrier for a lot of people to you know be like "okay these people are going to be giving
	Relationship		me letters of recommendation" or like we'd like there's
	Impact		this you know kind of rapport that you're supposed to
	Safety		have and they're supposed to have a certain image of
			you, you know as a faculty- student relationship." FG5
	Outsource	6	"I feel like maybe they have to outsource because what I
	Training		tend to see here is obviously in the science community
			and especially in genetic counseling [because its] so
			small, there's not a diverse amount of people of color, or
			like sexual orientation or even with regards to
			disabilities." FG4; "I was almost thinking that you
			could have a facilitator that's not a part of the program
			and then have the students just discuss this with the
			facilitator and not have faculty, not included." FG5
Minority	Minority	A specific struggle for	"then also having like the emotional burden if you're like
Struggles	Emotional	minority trainees	the only person of color in your class, like having to
2 11 11 88-11	Labor	involved	constantly tell your narrative like that." FG1; "if you're
			in a room or you don't see any other minorities, it's kind
			of intimidating and you feel pressure to say something."
			FG3
	Avoid	Other trainees	"the emotional labor of like teaching about cultural
	Minority	acknowledge this	competency falling upon those who have marginalized
	Emotional	struggle and hope in	identity, I would like to see that change." FG1; "if
	Labor	future discussions this	there's also like a specific topic where one or two people
	Luboi	minority burden will be	in the room like either have that identity, hold that
		avoided	identity, something like that All of the responsibility
		avoided	should not be falling on their shoulders. They should not
			be the only educated person in the room on this
			experience." FG2
Logistical	Small to	A few logistical	"Sometimes I felt like breaking up into smaller groups
Improveme	Large Group	aspects of discussions	first, and kind of having y'know one or two people that
nts	Discussion	that can improve safety	are having a conversation with first and then moving to
1103	Discussion	of space: having	a bigger group, is sometimes when people feel more
		conversation in a	comfortable." FG3
		smaller group before	comfortable. 1'd5
		expanding out to a	
		larger group	
	Later	Having "heavy"	"I felt like if it was done in this, you know, the second
	Timing	discussions later in the	semester or even the beginning of second year, where
	Helpful	program, once students	we already have developed that really close relationship,
	Ticipiui	and faculty are more	then I think that could encourage us to be more open
		comfortable with each	about, you know, speaking our feelings, our insecurity,
		other	and having that safe space not feeling judged because
		outer	we already know these colleagues and our classmates, a
			lot better then versus when we're doing this course at the
			beginning of first year right." FG5
	Asynchrono	If conversations are	"We did so like the splitting into small groups but
	us	had earlier on in the	instead ours was like it was small group and it was also
	Discussion	program, doing them in	asynchronous when we had those google doc type
	Helpful	an asynchronous	discussions. And we would like have a due date of when
	Heibini		
		format	we would need to you know reply to a certain prompt.

			So in the beginning it's still like kind of nervous, like who's going to make the first post but you still at least have some time to think about it versus right after you hear something in class and like having to scramble to like reflect and form your response. I think it got a lot more out of people." FG3
At	ollow-up fter onversatio	If those that are negatively impacted are not followed-up with, they often feel "left behind" or taken advantage of in the conversation.	"And I do think something that we've been lacking is someone who can persistently and consistently follow up with that individual who is greatly impacted by that event or that conversation so I do think, in order to create a safe space and bring up these important points, it's also important to have follow up so that that individual feels supported beyond thatbecause otherwise if you do go on and share something very openly, and then kind of feel left in the dust? I feel like that's even more detrimental than just creating a safe space in the moment." FG1

#### **APPENDIX E: IRB Documentation**



OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD
PAGE 1 OF 3

October 8, 2021

Natasha Go DIVISION OF GENETIC AND GENOMIC MEDICINE

RE: UCI IRB #2021-6905 Genetic Counseling Trainees Recognition of Implicit Bias and its Impact on Cultural

Sensitivity Training

The above-referenced human-subjects research project has been approved by the University of California, Irvine Institutional Review Board (UCI IRB). This approval is limited to the activities described in the approved protocol and extends to the performance of these activities at each respective site identified. In accordance with this approval, the specific conditions for the conduct of this research are listed below, and informed consent from subjects must be obtained unless otherwise indicated below. Additional conditions for the general conduct of human-subjects research are detailed on the attached sheet.

NOTE: Approval by the Institutional Review Board does not, in and of itself, constitute approval for the implementation of this research. Other institutional clearances and approvals may be required. Research undertaken in conjunction with outside entities, such as drug or device companies, are typically contractual in nature and require an agreement between the University and the entity. Such agreements must be executed by an institutional official in Sponsored Projects, a division in the UCI Office of Research. The University is not obligated to legally defend or indemnify an employee who individually enters into these agreements and investigators are personally liable for contracts they sign. Accordingly, the project should not begin until all required approvals have been obtained.

Questions concerning the approval of this research project may be directed to the Office of Research, 160 Aldrich Hall, Irvine, CA 92697-7600; 949-824-6068, 949-824-2125, or 949-824-0665 (biomedical committee) or 949-824-6662 (social-behavioral committee).

Expedited Review: Category(ies) 6,7

Jessica Sheldon, CIP Assistant Director, Human Research Protections

Approval Issued: 10/8/2021 Expiration Date: 10/7/2024

UCI (FWA) 00004071, Approved: January 31, 2003